

A QUALITATIVE INTERVIEW EXPLORATION OF EXPERIENCES AND BELIEFS
AROUND RISKY HEALTH BEHAVIOURS IN A PAEDIATRIC AND AN ADULT
CYSTIC FIBROSIS POPULATION

By

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ABSTRACT

Smoking, excessive alcohol consumption and illicit drug use are prevalent within the Cystic Fibrosis population, with these behaviours having adverse health effects upon patients regardless of their treatment adherence. Previous quantitative research highlighting the incidence, prevalence and effects of these behaviours within the Cystic Fibrosis population demonstrates the need for more effective health promotion measures to be integrated into Cystic Fibrosis care. Therefore, attempting to reduce occurring risky health behaviours specifically within the Cystic Fibrosis population, this doctoral research aimed to identify influential factors associated with these behaviours. This research utilised qualitative methods to explore beliefs associated with risky health behaviours within the adult Cystic Fibrosis population. This first phase of data collection was followed by another qualitative study exploring Cystic Fibrosis adolescents' understanding of, and beliefs about risky health behaviours. Both phases of data collection highlight that a desire to be normal, acceptance of Cystic Fibrosis and awareness of risks are influential in initiation and engagement of risky health behaviours. Both adult and paediatric participants reported a lack of awareness regarding adverse health effects of risky behaviours, demonstrating the need for more effective health promotion and encouragement of healthier lifestyles. Accordingly, to create a corresponding intervention, the researcher has listened to how Cystic Fibrosis Specialist Nurses perceive the issue of risky health behaviours within the population, along with gaining Cystic Fibrosis health care professionals' views on what interventions are needed to reduce the occurrence of such behaviours. The researcher presently plans to collaborate with health care professionals to design an intervention, which would consist of continuous professional development for health care professionals to improve awareness on risky health behaviours within the Cystic Fibrosis population, and would inform patients regarding the Cystic Fibrosis-specific adverse effects of risky health behaviours via interdisciplinary collaboration and scholarship between psychology and technology. Overall this research has provided practical insight into policy change for the prevention and reduction of risky health behaviours within the Cystic Fibrosis population nationally and internationally by informing current advice and practice.

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CHAPTER ONE: INTRODUCTION TO CYSTIC FIBROSIS

Cystic Fibrosis (CF) is the United Kingdom's (UK) most common life-limiting genetic disease (Elborn, 2016; Jackson & Pencharz, 2003), caused by defects in a recessive gene (CFTR) located on chromosome seven (Abbott, Hart, Morton, Gee & Conway, 2008). The "faulty" CFTR gene mainly impairs the functioning of the respiratory tract and the pancreas by allowing too much salt and water into cells, increasing the production of mucus (Kerem et al., 1989; Stoltz, Meyerholtz & Welsh, 2015) which impacts upon the clearance of microorganisms, leading to recurrent infections, inflammation of the respiratory tract, lung damage and in severe cases fatal respiratory failure (Abbott et al., 2008; Elborn, 2016). In the pancreas, CF causes the pancreatic ducts to become blocked, preventing the production of digestive enzymes, leading to the maldigestion and malabsorption of nutrients (Abbott et al., 2008; Elborn, 2016; Sinaasappel et al., 2002). CF is also associated with complications such as chronic liver damage, pneumothorax, haemoptysis, osteoporosis (Abbott et al., 2008; Couce, O'Brien, Moran, Roche & Butler, 1996) and commonly CF related diabetes (CFRD), with nearly 20% of adolescents and 40-50% of adults with CF experiencing CFRD (The CF Trust, 2013a).

Symptomology for CF varies between individuals, with symptoms typically emerging during the first twelve months of an individual's life; however in milder forms symptoms may remain undetected until adolescence or even later (NHS, 2016a). Nationwide CF newborn screening began to be introduced in the UK in 2003 (Super, 2003), with all newborn babies in the UK since 2007 being offered a newborn blood spot test to help detect CF (The CF Trust, 2017a). Most cases of CF today are detected soon after birth, with babies receiving this screening between five to eight days after birth (NHS Choices, 2016). If screening suggests a baby has CF two main tests can be conducted to confirm a diagnosis, a sweat test, to measure the amount of salt in sweat; and a genetic test, where a blood or saliva sample is checked for the faulty gene which causes CF (NHS Choices, 2016).

The respiratory symptoms of CF can include breathing difficulties, shortness of breath, a chronic cough, which if untreated will produce thick mucus, frequent wheezing in the lungs and tightness of the chest (Bennett, Patrick, Lymp, Edwards, Goss, 2010; Gibson, Burns & Ramsey, 2003). In addition to the respiratory symptoms, a child may also present with pneumonia, poor growth, persistent diarrhoea and meconium ileus (an intestinal blockage due to mucus build-up); all of which would lead to the diagnosis of CF (NHS, 2016a). Individuals with CF often present with a fever and report feeling tired, due to both physical implications and emotional implications such as worry, depression and frustration, with these at times being co-existing symptoms not directly as a result from CF, but as a

consequence from having CF, which can impact upon an individual's ability to sleep (Goss, Edwards, Ramsey, Aitken & Patrick, 2009).

CF is a serious disease which at present is incurable and progressive; however there are several treatments which aim to reduce the severity of symptoms and slow down CF's progression, consequently improving an individual's quality of life (NHS, 2016b). CF daily medical regimens vary, with most CF treatments targeting the lungs, with an aim to reduce breathing obstructions resulting from frequent infectious exacerbations (Smyth, 2016; NHS, 2016b). These treatments commonly consist of chest physiotherapy and exercise to assist the clearance of excess mucus (Kriemler, Radtke, Christen, Kerstan-Huber & Hebestreit, 2016), oral and intravenous antibiotics to treat infectious exacerbations within an individual's respiratory system (Smyth, 2016); and nebulised therapies which are often used to administer antibiotics and Pulmozyne (an enzyme [DNase] which thins and breaks down mucus within the lungs, allowing the individual to remove the excess mucus easier), or Hypertonic saline (an alternative to DNase) (NHS, 2016b). However, as an individual's disease deteriorates the above treatments may no longer be as effective in preventing frequent infectious exacerbations, therefore lung transplantation may become a necessity for people with severe lung disease whose FEV₁ falls below 30% (The CF Trust, 2017b). Besides respiratory treatments, CF treatments also target the digestive system, with pancreatic insufficient patients often being prescribed pancreatic enzymes to aid with digestion, and vitamin supplements (typically vitamins A, D, E and K) due to the likely malabsorption of fat soluble vitamins (Elborn, 2016; NHS, 2016b).

CF treatments are continuously developing, there are currently numerous trials leading to the development of new drugs which promise to revolutionise CF care. CF care is entering a period of personalised medicine with the emergence of precision medicines. These new drugs target the underlying cause of CF by treating and correcting specific genetic mutations, with the drug an individual receives being dependent upon their genome (CF News Today, 2016; Fajac & De Boeck, 2017; Keyte et al., 2017a; The CF Trust, 2017c). These new drugs are targeted at only a few different CF mutations, and work is underway to create drugs targeted for other mutations, specific to the genome of individuals. Whilst these drugs aim to increase both the quality and quantity of individuals lives with CF, not all individuals with CF have access to these new medications, with there currently being issues in getting Orkambi licensed within the UK due to the cost of the drug (Keyte et al., 2017a; The CF Trust, 2016a).

The impact of the increasing life expectancy within the Cystic Fibrosis population

CF is associated with a reduced life expectancy, and therefore adds an emotional burden for people (McHugh, McFeeters, Boyda & O'Neill, 2016; Withers, 2012), with associated psychology sequelae which is well documented within the literature. Quittner et al (2014) report that symptoms of depression and anxiety are elevated within CF patients, with research suggesting that individuals with CF can have a preoccupation with death (Lawler, Nakielny & Wright, 1966). This is not just evident within adult patients; with research providing evidence of some paediatric patients also having a preoccupation with death (Lawler et al., 1966). Such preoccupation can be as a result of individuals with CF witnessing other CF patients experience health deteriorations, either at hospital visits or through friendships they have formed. Higham, Ahmed and Ahmed (2013) pointed out that when patients witness others with CF suffering, and passing away it is a frightening experience, with such individuals not only having to cope with the death of a loved one, they also have to deal with witnessing what their own death may entail, and the suffering they may encounter prior to death; as well as confronting their own mortality.

While CF is an incurable disease, recently the CF population has experienced an increase in its life expectancy. In the 1980s life expectancy for CF was fourteen years; in 2003 this increased to eighteen years (Pinkerton, 2013; Withers, 2012), and this has continued to increase recently, because of medical advances in managing respiratory infections and pancreatic insufficiency (Kettler, Sawyer, Winefield & Greville, 2002). CF is therefore no longer a paediatric entity, as many people are progressing well into adulthood, with most individuals with CF born during the 1990's being expected to survive to more than forty years of age (Elborn, 2016); the current medium predicted age of survival for CF in the UK is 48 years (The UK CF Conference, 2016).

This improvement in life expectancy has been coupled with an improvement in quality of life, with recent research suggesting there is no elevated risk for anxiety or depression amongst individuals with CF (Backström-Eriksson, Sorjonen, Bergsten-Brucefors, Hjelte & Melin, 2015). Götz and Götz (2000) reported that individuals with CF often lead "normal lives", with CF not appearing to be the major obstacle to school or work attendance. Nonetheless, CF is still an incurable and progressive disease (Gee, Abbott, Conway, Etherington & Webb, 2000), which does still provide individuals with emotional burdens (Abbott et al., 2008; McHugh et al., 2016), with the research evidence varying when reporting anxiety and depression within individuals with CF. Adults with CF often have to deal with a diminishing ability to engage in activities as they become older, due to their worsening health (Orenstein, 2004), which is difficult for usually active individuals to deal

with, and this is often coupled with serious health implications (Burker, Kazaukas & Williams, 2012).

In addition, whilst CF health care professionals (HCPs) are skilled in helping individuals with CF adjust to decreased health, HCPs may be less experienced in supporting people whose health has shown an improvement (Horky, 2014). A parent of a CF patient at the UK CF Conference (2016) explained how the discourse HCPs use is hard, with HCPs rarely discussing hope and inspiration, despite the parent reporting that CF's increasing life expectancy does provide patients and families with hope and inspiration. This parent believed that HCPs should focus on the here and now (e.g. the patient is well), rather than dwelling on potential future implications. With this increasing life expectancy it is acknowledged HCPs may overlook "new" issues that individuals with CF are now faced with, such as a vulnerability to engage in risky behaviours (Horky, 2014). As a consequence of the anticipated improvements in CF treatment in the upcoming years, allowing individuals with CF to lead a more "normal" life, it is essential for HCPs to become aware of these "new" challenges, to effectively help patients, especially with the CF population being a growing population (Horky, 2014; Owen, 2016).

With the increasing life expectancy it is acknowledged that there is a need for new approaches to health care within the changing CF population. Owen (2016) emphasised that today CF care needs to be individualised, with Cox (2015) illustrating at the UK CF Conference that from 2015 - 2020 the five year challenge for the CF population includes dealing with the growing CF population, and aiming to keep patients away from hospital due to the risk of cross infection and the emotional aspects of hospital visits, indicating that quality of life is sometimes a better measure than lung function. Cox (2015) and Owen (2016) both stated that in order to meet the needs of this growing population, both in terms of health and quality of life, research needs to be done to listen to the views of individuals with CF in terms of what it is like to live with CF. In an attempt to meet some of the five year challenges research is being conducted to investigate different ways healthcare could be delivered, for instance Cox (2015) states that HCPs could potentially do health checks on stable patients using technology e.g. via phone calls or the internet, rather than clinic visits (Bilton, 2015; Owen, 2016). This illustrates that the focus of CF care for clinicians and researchers alike, is not just on pharmacological care, with CF care heavily focusing upon quality of life and shifting towards a person-centred model of care (Owen, 2016).

Whilst CF care is a changing environment, a major focus that has not changed is adherence, as despite the improved life expectancy, individuals with CF still require daily "preventative management and symptomatic treatment" (Kettler et al., 2002, p. 459) to

manage their progressive disease. Therefore, the increasing life expectancy is creating a welcomed challenge for HCPs, in supporting adolescents as they become increasingly responsible for their own medical regimens, with research indicating that poor adherence is a major concern within the CF population (Bregnballe, Schiøtz, Boisen, Pressler & Thastum, 2011).

Poor adherence within the Cystic Fibrosis population

Due to CF's increasing life expectancy, more individuals with CF are entering adolescence and adulthood in comparison to previous generations, with this creating manifold challenges for patients in independently maintaining their complex and time-consuming treatment regimens (Barker, Driscoll, Modi, Light & Quittner, 2012). As a consequence of treatments complexity, coupled with CF's progressive nature, ongoing treatment adherence is a major concern (Horne, 2000; Quittner et al., 2014); with these medical regimens being essential as adults with CF encounter more health-related limitations and symptoms than they experienced during childhood and adolescence (Elborn, 2016; Orenstein, 2004). However, despite the necessity of these medical regimens, poor adherence is prevalent during adolescence, with 60% of CF adolescents agreeing that the three main barriers preventing their adherence are a "lack of time, forgetfulness and unwillingness to take medication in public" (Bregnballe et al., 2011, p.512). Furthermore Kettler et al (2002) stated that poor adherence within CF may be a result of individuals having to interpret and understand their complex regimen, and having to prioritise their prescribed treatments within their daily lives. However, Horne, Weinman, Barber, Elliott and Morgan (2006) concluded that treatment complexity is not the key determinant within non-adherence, but how well a particular treatment fits into an individual's routine.

In terms of CF, poor adherence is a significant predictor of pulmonary exacerbations during a 12-month period (Eakin, Bilderback, Boyle, Mogayzel & Riekert, 2011), with Quittner et al (2014) indicating through the use of medical progression ratios that poor adherence is associated with acute health-care use. Therefore, an obstacle HCPs have to overcome to successfully treat CF is poor adherence. Many HCPs do acknowledge their patients poor adherence, however they often underestimate the extent of this poor/non-adherence, with CF patients often reporting their adherence rates to be higher than the reality (Daniels et al., 2011). As a consequence HCPs often underestimate the extent of patients poor/non-adherence, with Wilderman (2015) stating that CF HCPs often work "under the lamppost" when treating CF. For instance, Wilderman (2015) states that it often the case that if an individual's lung function or BMI has declined, HCPs will prescribe additional medical regimens; however in doing this HCPs may not take non-adherence into

account. When patients are not open about their adherence efforts it does create challenges in successfully treating their individual condition, however it has to be acknowledged that the difficulty lies in how to communicate with patients in order for them to be able to be honest about their adherence efforts. Work is therefore needed to highlight how HCPs can work with patients in a patient centred way to facilitate open discussions about treatment regimens, specifically surrounding what patients find difficult to follow in terms of their treatments, and why.

Literature suggests that effort needs to be employed to improve treatment adherence within the CF population by creating new adherence interventions, therefore improving subsequent health outcomes (Eakin et al., 2011; Quittner et al., 2014). In order to create such interventions, factors associated with adherence need to be more clearly identified. There are a variety of research suggestions indicating what influences adherence within the CF population. Research by Kettler et al (2002) reported that individuals with CF receive little positive reinforcement for their adherence, as the health of an individual with CF will progressively deteriorate, regardless of adherence. Furthermore, research indicates that adherence within CF differs between treatment types, with individuals appearing to focus on short-term treatment benefits, without considerations for long-term benefits; with their adherence decisions being based on their immediate symptoms (Abbott, Dodd, Bilton & Webb, 1994; Keyte et al., 2017b).

Research has also explored the roles of psychological distress and disease severity as potential predictors of adherence. Kettler et al (2002) suggests that an increase in disease severity may be associated with a decrease in adherence, possibly due to a reduction in positive reinforcement as CF becomes more severe. However, Abbott et al (1994) demonstrated no association between disease severity and adherence in an earlier study, and this was confirmed by Daniels et al (2011) using electronic monitoring data. A concomitant increase in psychological distress as symptoms worsen may also account for a reduction in adherence (Kilbourne, 2005; Sundbom & Bingefors, 2013), with research concluding that higher depressive symptoms within individuals with CF is associated with less positive medication beliefs, which consequently is associated with lower medication adherence (Hillard, Eakin, Borrelli, Green & Riekert, 2015; Keyte et al., 2017b). Whilst depression has been linked to poor adherence, some individuals with CF who have concerns and potential anxieties towards CF remain motivated to adhere to their treatments (Keyte et al., 2017b). Such concerns surrounded CF's fatal nature, and the uncertain future this provides individuals with, with some people describing how health deteriorations can exacerbate their concerns (Keyte et al., 2017b).

Within the literature, the influence of a number of factors on adherence such as sex, age and time of day have been explored. Research has indicated sex differences in adherence within the CF population (Abbott, Havermans & Hart, 2009), with female adolescents displaying more non-adherent behaviours and feelings than male adolescents (Patterson, Wall, Berge & Milla, 2008). These findings may offer an explanation as to why the age of onset for progressive decline in pulmonary function is younger for females with CF (12-14 years) in comparison to males (19-20 years) (Cory, Edwards, Sevinson & Knowles, 1990; Harness-Brumley, Elliott, Rosenbluth, Raghavan & Jain, 2014; Rosenfield, Davis, Simmons, Pepe & Ramsey, 1997). Research indicates that the relative risk for survival is significantly lower for females than males with CF (Harness-Brumley et al., 2014; Kullich, Rosenfeld, Griss & Wilmott, 2003), potentially due to the sex differences within adherence affecting pulmonary function and nutritional status (Patterson et al., 2008).

Adherence rates differ by age group during a twenty four hour period, in one study (McNamara, McCormack, McDonald, Heaf & Southern, 2009) paediatric CF patients were more adherent in the evenings in comparison to the mornings; indicating that time-pressures in the mornings (for both parents and children) may adversely affect adherence (Latchford, Duff, Quinn, Conway & Conner, 2009; McNamara et al., 2009). Another study by Ball et al (2013) showed that adolescents were more adherent during weekdays in comparison to weekends, and during term-times in comparison to holidays. This supports Horne et al's (2006) observation around the importance of CF care being integrated into "structured, daily family schedules, which act to contain treatments" (Ball et al., 2013, p.442).

Keyte et al (2017c) investigated how adherence differs for CF adults during the weekend in comparison to weekdays, utilising a daily phone diary (DPD) methodology (Modi et al., 2006), whilst examining the roles of gender, anxiety, depression and lung function as predictors of adherence. In this study, adults with CF had higher reported adherence during the weekend in comparison to weekdays, particularly for female participants. These findings differed to those of Ball et al (2013) where adolescent adherence was higher during the weekdays, with Keyte et al's (2017c) findings supporting previous work (Kettler et al., 2002; Keyte et al., 2017b; Patterson et al., 2008), with sex, psychological distress and lung function predicting adherence.

Although Keyte et al's (2017c) research used a different method to Ball et al (2013) to record adherence rates, the difference in findings suggest a difference in the adherence relationship between adolescents and adults with CF. There are a variety of possible reasons for this change; adults may have more difficulty in independently integrating their daily treatments within their weekday lifestyle, alongside employment or study commitments.

For paediatric patients, daily treatments are more likely to be managed by parents or guardians, with it potentially being easier for parents to organise their child's daily treatments during the weekdays, as CF care would be integrated into structured, daily routines (e.g. school) (Ball et al., 2013, p.442).

CF adolescents and young adults may consciously choose to be non-adherent during the weekdays in an attempt to hide their illness identity from their peers. Individuals may believe their illness identity is on display when they have to engage in medical regimens, therefore some individuals with CF may consciously choose to be non-adherent to provide themselves with a degree of invisibility towards their illness, allowing them greater normalcy (Keyte et al., 2017b; Yates et al., 2010) and this was one of the findings in Keyte et al's (2017c) research.

The role of identity is one of the possible explanations for why the weekend / weekday difference in adherence was most prevalent within adult female CF patients (Keyte et al., 2017c), with females with CF often reporting experiencing embarrassment when their adherence behaviours are visible to their peers resulting in self-consciousness (Patterson et al., 2008). Therefore females with CF may have lower reported adherence during the weekdays due to their conscious efforts to avoid performing medical regimens in front of their peers (e.g. at work), in order to provide themselves with a degree of invisibility towards CF. Literature suggests that invisibility towards one's CF is often valued by patients. However whilst this may be associated with increasing one's quality of life, or having psychological benefits, such invisibility could have negative health implications if it is associated with avoiding medical regimens.

Risky health behaviours within the Cystic Fibrosis population

Research has recently started to view non-adherence in a different way, stressing that non-adherence should not be viewed just in terms of medical regimens. There are other damaging behaviours that some chronically-ill individuals engage in, which can be viewed as severe forms of non-adherence, such as "risky behaviours" (Huq et al., 2011; Mays, Streisand, Walker, Prokhorov & Tercyak, 2012; Withers, 2012). Risky behaviours are any behaviours that expose an individual to harm or significant risk, which will therefore prevent them in reaching their potential (Richmond, 2014). Researchers often view non-adherence and risky behaviours within the CF population as two separate entities. However the relationship between risky behaviours and non-adherence within chronic illnesses was suggested by Mays et al (2012), who stated that type 1 diabetic adolescents are presented with decisions regarding risky behaviours alongside their complex treatment regimen.

Adolescents' decisions surrounding risky behaviours and adherence are related, and are likely to be influenced by the same factors (Buller et al., 2003; Flay, 1999; Jamner et al., 2003; Solberg, Desai, O'Connor, Bishop & Develin, 2004; Tercyak, 2004; Tercyak et al., 2005; Tercyak, Britto, Hanna, Hollen, & Hudson, 2008; Tyas & Pederson, 1998); with risky behaviour engagement being associated with poor treatment adherence (Solberg et al., 2004).

Quantitative research has displayed that smoking, excessive alcohol consumption and illicit drug use are prevalent within the CF population, with these behaviours being a major concern for individuals with CF, as they are having adverse health effects on individuals regardless of their treatment adherence (Richmond, 2014).

Smoking and Cystic Fibrosis

Smoking within the general population is considered to be a risky behaviour, with it being reported that smoking is the primary cause of preventable illness resulting in premature death, accounting for 96,000 deaths a year in the UK (ASH, 2016a; Health & Social Care Information Centre, 2012). Smoking dramatically reduces both the quality of an individual's life and their life expectancy, having adverse health effects on the majority of organs within the body, and causing various health complications such as "lung cancer, respiratory disease and heart disease, as well as numerous cancers in other organs including mouth, throat and kidney" (ASH, 2016a, p. 2; Das, 2003). Despite these adverse health effects smoking is still prevalent within the general population (Verma, Clough, McKenna & Dodd, 2001), with the current prevalence of cigarette smoking being 19% in the UK (Borrelli, Bartlett, Tooley, Armitage & Wearden, 2015). Cigarette smoking prevalence amongst adults in the UK decreases with age, with there being more male smokers than female smokers within each age group (Office for National Statistics, 2013), however this sex gap in cigarette smoking prevalence has narrowed in recent years, with there being a decrease in cigarette smoking prevalence among adults in the UK since the early 1970's (Office for National Statistics, 2011; 2012). In terms of adolescents, the reduction in smoking prevalence among 11-15 year olds has been more gradual than in adults, plateauing in the early 2000s, but accelerating in 2007 (Amos & Hastings, 2009). Experimentation of smoking commonly begins during early to mid teens, with smoking prevalence and consumption increasing until the mid-twenties (Amos & Hastings, 2009).

Studies of the incidence, prevalence and effects of smoking within a CF population (Verma et al, 2001) identified that despite CF's respiratory difficulties, active smoking is prevalent (Huq et al., 2011; Smyth, O'Hea, Williams, Smyth & Heaf, 1994). McEwan,

Hodson and Simmonds (2012) reported that 46% of CF patients at Royal Brompton CF Unit had tried smoking, with 3% continuing to smoke regularly. Verma et al (2001) reported that 21% of CF patients at a Manchester Unit had tried smoking, with 11% continuing to smoke regularly.

The prevalence statistics within the CF population are less than the general population (in the case of McEwan et al., 2012: 3 vs 21%; $p < 0.001$), however the detrimental effects of smoking are well documented, and they present a particular and specific risk to those who have CF. Smoking decreases the lung function of individuals with CF, with their FEV₁ scores being reduced by 4% for every 10 cigarettes they smoke, and their FVC scores being reduced by 3% for every 10 cigarettes they smoke (Verma et al., 2001). This evidence shows a dose-dependent relationship between the number of cigarettes smoked and CF's severity. Smoking causes growth suppression, an increase in the frequency of infectious exacerbations, resulting in their being an increase in the need for intravenous antibiotics (Verma et al., 2001). Whilst there may be halt in spirometric deterioration when an individual stops smoking, the lungs are an organ that do not recover (Verma et al., 2001), therefore emphasis needs to be placed on reducing the number of individuals with CF who admit in this behaviour.

In addition, people who smoke will not be considered for lung transplantation (Aurora, Carby & Sweet, 2008; NHS, 2016b; Orens et al., 2006; The CF Trust, 2017b; Withers, 2012). Therefore, smokers are decreasing their lung function, needing lung transplantation quicker than predicted, but failing the assessment due to their smoking behaviour (Minai & Budev, 2005). Smoking also has adverse health effects on CFRD (Mays et al., 2012); with smoking resulting in poor blood glucose regulation, elevated haemoglobin, and hypoglycaemia (Haire-Joshu, Glasgow & Tibbs, 2004; Mays et al., 2012). Smoking can also accelerate the progression of diabetes-related micro-vascular complications, as well as various types of diabetes neuropathy (Daneman, 2006), nerve damage and kidney disease (Hofer et al., 2009; Mays et al., 2012; Wadwa, 2006).

Within the general population there are currently a variety of interventions to aid cessation (Aveyard & Raw, 2011; Lancaster, Stead, Silagy, & Sowden, 2000), which have had a degree of success, such as nicotine replacement therapies (Aveyard & Raw, 2011; Bollinger et al., 2000) (e.g. chewing gum, inhalers, nasal spray), and mass media campaigns. The mass media campaigns provide education about smoking's adverse health effects in an attempt to modify individuals' attitudes, to therefore increase cessation intentions and attempts (Lancaster et al., 2000). In addition to mass media campaigns the government has also implemented a number of smoking bans in an attempt to reduce the

occurrence of smoking within the general population. These bans include the smoke free law introduced in England on 1st July 2007, which banned smoking in workplaces and enclosed public spaces (Hawkins, Cole & Law, 2011); the illegalisation of smoking in cars and other vehicles with anyone present under the age of 18 years, introduced on 1st October 2015 (Department of Health, 2015a); and the launch of smoke free zones in major outdoor spaces (currently implemented within Nottingham and Bristol) (Abbott, 2011; BBC, 2016; The Telegraph, 2014). These bans aim to reduce the normalisation of smoking within the general population, protecting non-smokers from the adverse health effects of passive smoke (Department of Health, 2015a). In terms of CF, environmental tobacco smoke is associated with a decreased lung function, as well as lower weight (Ong et al., 2017). In addition to non-smokers, these bans aim to improve the health of smokers, and are associated with various health benefits. As a consequence of the smoke free law there have been 1200 fewer hospital admissions for heart attacks in England, and Scotland has experienced a 10% drop in premature births (Mackay, Nelson, Haw & Pell, 2012; Sims, Maxwell, Bauld & Gilmore, 2010). Whilst the current smoking bans have had some effect, further measures are required.

The use of electronic smoking devices as an aid to smoking cessation has increased in recent years, however they are not licensed as medicines (Department of Health 2015b). These devices are designed to deliver nicotine in a vapour form (ASH, 2016b), with it being reported that they are now the most popular smoking cessation aid (Smoking in England, 2016), which appear to be effective (Department of Health, 2015b). Whilst electronic cigarettes are addictive, they are considered to be less harmful than smoking (Ash, 2016b). However, due to electronic cigarettes being a new intervention there is an absence of comprehensive scientific studies (Giroud et al., 2015), and long-term health implications are currently unknown (Britton & Bogdanovica, 2014; Hajek, Etter, Benowitz, Eissenberg & McRobbie, 2014), with Pisinger and Døssing (2014) stating that although no firm conclusions can be drawn on the safety of electronic cigarettes, they can hardly be considered harmless. Furthermore the specific effects that electronic cigarette use has upon distinct populations, such as the CF population, again is unknown, with fears that such engagement could result in respiratory infections due to cleanliness of the devices, or natural fungi that exists within the substances used within electronic cigarettes (Reddit, 2015).

Due to the normalisation of electronic cigarettes, it is reported that they are not just used by individuals who wish to attempt smoking cessation, they are used by individuals who have never smoked (Tan, 2015), with Kamerow (2015) reporting that more young people "vape" electronic cigarettes than smoke conventional tobacco cigarettes, with adolescents who have used electronic cigarettes being more likely to then smoke

conventional tobacco cigarettes (McCarthy, 2015). In addition, electronic cigarettes are also providing marijuana users with a new method of inhaling cannabinoids, with the use of electronic cigarettes often resulting in less detection from others (Giroud et al., 2015). Giroud and colleagues (2015) therefore suggested that a consequence of the normalisation of electronic cigarettes may be that adolescents are being provided with an alternative gateway to marijuana and nicotine. With individuals with CF, it has been speculated that vaping marijuana could be associated with an increased risk of the development of aspergillus, which has very severe consequences upon the health of an individual with CF (Cystic Fibrosis, 2015). Consequently research is needed to investigate the incidence, prevalence and effects of electronic cigarettes (both in terms of nicotine and marijuana) within a CF population, to see whether this alongside smoking is an issue within individuals with CF.

Excessive alcohol consumption and Cystic Fibrosis

Excessive alcohol consumption and binge drinking are also seen to be risky behaviours within the general population, with the consequences of such behaviours being well documented. Excessive alcohol consumption and binge drinking impacts upon the whole body and plays a role in the development of numerous medical conditions, increasing an individual's risk of cancer, including mouth, oesophagus, throat, liver and breast (National Institute on Alcohol Abuse and Alcoholism, 2017; NHS, 2016c). Most commonly alcohol abuse can impact upon the heart, potentially resulting in cardiomyopathy, arrhythmias and high blood pressure; the liver, potentially resulting in cirrhosis, steatosis and alcoholic hepatitis; the pancreas resulting in pancreatitis; the immune system, potentially resulting in the body being vulnerable to pneumonia; and the brain, potentially resulting in Korsakoff's syndrome which is characterised by persistent memory and learning impairments (NHS, 2016c).

In terms of the prevalence of excessive alcohol consumption in England, it is reported that 29.9 million people (58% of the population) drink alcohol on a regular basis, with 38% of secondary school pupils reporting experimentation with alcohol (NHS Digital, 2016). Males are more likely to drink excessive amounts of alcohol (34% of men and 27% of women drank more than the recommended guidelines), with elder people tending to drink more frequently than younger people (1% of 16-25 year olds had drunk every day of the previous week compared with 13% of individuals aged 65 years and above), however younger people tend to drink more heavily on a single occasion than older people (6% of men and 2% of women aged 65 years and above had drunk heavily at least one day in the previous week, compared to 22% of men and 18% of women aged 16-24 years) (Office for National Statistics, 2011).

Alcohol use (particularly binge drinking) within individuals with CF is problematic because of the impact alcohol use as well as CF can have upon the liver, with CF liver disease being the third leading cause of death in CF (Sakiani et al., 2017); as well as the increased risk of developing pancreatitis (NHS, 2015; Withers, 2012), and the possibility of alcohol-induced hypoglycaemia within individuals who have CFRD (The CF Trust, 2013a). Symptoms of alcohol-induced hypoglycaemia include abdominal pain coupled with vomiting (Withers, 2012); therefore these symptoms are often mistaken for being drunk (The CF Trust, 2013a). Despite these adverse health effects, McEwan et al (2012) found that 94% of males with CF and 98% of females with CF at Royal Brompton Hospital had tried alcohol, with 83% continuing on to drink alcohol regularly. However, McEwan et al (2012) indicated that overall 79% of the CF patients they investigated did not drink alcohol, or they drank within the recommended guidelines, which is significantly more than the general population (77%; $p < 0.001$).

There are various legislations and mass media campaigns which aim to reduce the occurrence of alcohol abuse. These interventions can focus upon informing society about the adverse health effects of drinking excessive amounts of alcohol, providing tips on how to reduce the amount of alcohol people consume (Change4Life, 2017). In increasing societies awareness regarding excessive alcohol consumption, the alcohol industry provides on 80% of product labels the unit information of that product, the recommended drinking guidelines, and a warning regarding drinking during pregnancy (Department of Health, 2015c). To reduce the alcohol individuals consume, the government are trying to increase the price of the cheapest drinks by implementing a minimum price per unit of alcohol, and banning drink offers (e.g. 2-for-1 offers) (Department of Health, 2015c). The government are also currently working with the advertising standards authority and ofcom to stop alcohol advertisements appealing to young people, by stopping these adverts being aired during programmes that appeal to younger generations (Department of Health, 2015c).

The government have also implemented an alcohol risk assessment which is included within the NHS health check for adults between the ages of 40-75 years (Department of Health, 2016; NHS Health Check, 2017). In addition hospitals have alcohol liaison Nurses to assist individuals admitted with alcohol-related problems, to ensure they receive the appropriate treatment (e.g. treatment for alcohol dependence), with the government currently developing a model to specifically support young people admitted to hospital with alcohol-related problems (Department of Health, 2016). In addition to the government's efforts, within the UK there are also a number of contacts for individuals who feel they have an alcohol problem, such as "drinkline", "alcoholics anonymous" and "addactions". These contacts range from being a confidential helpline, right through to self

help groups and treatment agencies (Addactions, 2015; Alcoholics Anonymous, 2017; NHS, 2016d). Despite the success of these legislations and interventions, alcohol misuse is still prevalent within the UK; therefore new interventions are required.

Illicit drug use and Cystic Fibrosis

Illicit drug use impacts upon all anatomical lung compartments, producing morphological changes (Glassroth, Adams & Schnoll, 1987; Tashkin, 1990; Tomashefski, 2004). It is reported that 8.4% of adults in the UK aged between 16 - 69 years have taken an illicit drug, with 15% of pupils in the UK having experience with illicit drug use (Health and Social Care Information Centre, 2016). The prevalence of drug use increases with age amongst adolescents in the UK, with 6% of 11 years olds reporting that they have tried an illicit drug at least once, compared to 24% of 15 year olds (Health and Social Care Information, 2016). Common complications of drug use within the general population include lung infections, such as HIV, septic emboli and pneumonia (Tomashefski, 2004); all of which would increase the severity of an individual's lung disease with CF. Despite these pulmonary complications, McEwan et al (2012) found that 35% of CF patients at Royal Brompton Hospital had tried illicit drugs, with such drug use commonly compromising of cannabis (31%), cocaine (14%) and ecstasy (6%). These statistics are less than the general population (37%, $p < 0.001$).

There are a variety of legislations and interventions which aim to reduce the occurrence of this risky behaviour. The government aims to reduce the number of young people initiating in drug use by providing them with accurate information on drugs and alcohol through drug education (Department of Health, 2016) and the FRANK (2017) service, which is a website designed specifically for adolescents, to provide them with guidance if they feel under pressure to take drugs. The website also provides adolescents with contact details so they can receive confidential help about their drug use or thoughts on initiation (Frank, 2017). In addition, the government have recognised that drug use is multi-factorial, therefore the government aims to help young people who are drug dependent to get treatment and support, with this support being offered to many areas within their life (e.g. housing or mental health problems) so that the young person does not relapse as a way of coping with other problems within their life (Department of Health, 2016). Despite these legislations and interventions, again illicit drug use is still prevalent within the UK; therefore new interventions are required in order to further reduce the occurrence of drug use.

Addressing risky health behaviours in the Cystic Fibrosis population

While smoking, excessive alcohol consumption and illicit drug use are prevalent within the CF population, research clearly reports that prevalence for each of these risky behaviours is lower in the CF population than it is within the general population (McEwan et al., 2012). However, for each of these risky behaviours it is plausible that prevalence within the CF population may be higher than the data suggests, due to potential under-reporting by individuals with CF (Haire-Joshu et al., 2004). In addition, it is feared that risky behaviour prevalence within CF may increase as life expectancy also increases. Treatment advances within CF mean that individuals have an improved health status, consequently today individuals with CF are more susceptible to engaging in risky behaviours. The age of onset for risky behaviour initiation is commonly during adolescence (smoking initiation within CF is 13-14 years, alcohol initiation within CF is 16.3 years; illicit drug use initiation within CF is 19 years) (McEwan et al., 2012; Verma et al., 2001); in previous generations individuals with CF at that age would most likely have been too ill to consider engagement.

Despite the prevalence of risky behaviours within the CF population being reported to be less than the general population, the health consequences of engagement in such behaviours are far more detrimental for those with CF. Consequently information on prevention and cessation need to be specifically tailored to CF so individuals understand the CF-specific adverse health effects such behaviours can have, highlighting why individuals with CF should not engage in risky behaviours in order to prolong and protect their current and future health status. The need for interventions to be specifically tailored to CF is highlighted by individuals with CF, with individuals reporting that in addition to the interventions found within the general population to reduce the occurrence of risky behaviours, individuals also benefit from advice from their doctors, with generic self-help documents not being as helpful as personalised material (Aveyard & Raw, 2011; Lancaster et al., 2000; Verma et al., 2001). As risky behaviours are still prevalent within the CF population despite current attempts by HCPs, it suggests that more effective health promotion measures are required specifically within the CF population (McEwan et al., 2012). Metse et al (2014) indicates that whilst individuals who engage in risky behaviours within the general population are inpatients, they are surrounded by information (both verbal and written information) that outlines why they should not engage in such behaviours, which can impact upon an individual's motivation to attempt cessation. However without post-discharge support pre-admission risky behaviours often return (Metse et al., 2014). Consequently support to aid cessation should be extended into the community after discharge to reduce the prevalence of risky behaviours, and personalised information should

be provided to individuals with CF regarding how such behaviours can specifically impact upon their CF

Overall, the prevalence of risky behaviours within the CF population, and the specific detrimental consequences such behaviours can have upon an individual with CF, demonstrates the need for research-informed interventions to be developed to promote healthy lifestyles within the CF population, by reducing the occurrence of risky behaviours. In order to create such interventions it was essential for the researcher to understand how UK CF units approach the issue of risky behaviours, exploring what awareness is provided to patients in an attempt to prevent initiation, and which patients receive this awareness. Insight into current UK practice within the CF population was essential to understand how research can progress current interventions, to more effectively reduce the occurrence of risky behaviours, specifically within the CF population. The evaluation the researcher conducted to investigate how the issue of risky behaviours is currently addressed within CF care, provided a rationale for this doctoral research, highlighting the need for more effective health promotion measures.

CHAPTER TWO: TRANSITIONING FROM PAEDIATRIC TO ADULT CARE: AN EVALUATION ON MATERIAL AND INFORMATION PROVIDED TO INDIVIDUALS WITH CYSTIC FIBROSIS REGARDING RISKY HEALTH BEHAVIOURS

The problem of risky health behaviours and transitioning into a self-care model

The initiation of risky behaviours within the CF population, as in the wider population, commonly occurs during adolescence, therefore it is timely to discuss such issues during transition from paediatric to adult care. The timing of transition from paediatric to adult care does vary between individuals, with the majority of individuals transitioning to adult care between the ages of 16-18 years (Great Ormond Street Hospital for Children, 2017; NHS Choices, 2015; University Hospital Southampton, 2014). Transitioning from paediatric to adult care is significant not only for HCPs, but also for patients who transition from a model of care-from-others to a more independent model of self-care. Whilst many young adults continue to be monitored and guided by parents when outside the care of professionals, this is not the case for all individuals with CF, and even with the most engaged supportive parents or carers, risky behaviours may still be prevalent in young adults with CF. It can be reasonably assumed that a significant number of young adults with CF are behaving as any other young adult, and the time of transitioning into adult care is about the time where risky behaviours initiate and can become a problem in the CF population (McEwan et al., 2012).

The transition period is a time where individuals are expected to take on more responsibility (University Hospital of South Manchester, 2014), and have a more active involvement in treatment decisions (Barber, 1995). Research indicates that as the responsibility of regulating health behaviours shifts from the clinicians and family to the individual, risky behaviours within the CF population become prevalent (McEwan, et al., 2012). Risky behaviours result in adverse health effects upon patients regardless of their adherence to medical regimens (Mays et al., 2012; Withers 2012), therefore additional support during transition is key in increasing the health and wellbeing of individuals with CF. Huq et al (2011) emphasised the importance of risky behaviours being explored with patients at periodic reviews to identify those who are more vulnerable to initiate such behaviours. The transition period would be an appropriate time to discuss risky behaviours with patients, as clinicians often talk to patients without parents or guardians, and respect patient confidentiality (University Hospital of South Manchester, 2014).

Current material and information

The researcher conducted an evaluation on the information received by individuals with CF in the UK during their transition. All nineteen adult CF regional units in England (The CF Trust, 2017d) were contacted, and out of these sixteen units replied. Written information regarding risky behaviours during transition is currently provided by two CF units. These units administer the ready, steady, go questionnaires (University Hospital Southampton, 2014) to paediatric patients three times prior to transition, which assists the adult medical team in developing an individual treatment plan. Within this questionnaire there are two questions which relate to risky behaviours:

- 1) "I understand the risks of alcohol, drugs and smoking to my health"
- 2) "I know where and how I can access information about sexual health"

Answers are given by either ticking a "yes" or "no" box. Additional options exist, such as ticking a box "I would like some extra advice/help with this"; and there is the opportunity for individuals to write comments. When adolescents with CF are transferred to the adult unit, they receive the same questionnaire on three different occasions, enabling identification of changes in an individual's awareness of whether or not they understand the consequences of risky behaviours.

One further adult unit provides individuals with verbal information specifically on risky behaviours during transition, but they do not use generalised leaflets or written questionnaires, suggesting that all individuals are different and require support in different areas. It is recognised though that the consequences of risky behaviours are similarly detrimental for all individuals with CF. Consequently it has to be questioned whether standardised written information on the adverse health effects of risky behaviours should be incorporated, as a preventive method to the treatment of all individuals who are transitioning, regardless of their personal identification of being 'at risk' or not.

HCPs at this unit record such discussions with the use of a transition proforma. The transition proforma asks HCPs to tick "yes" or "no" to indicate whether or not smoking, recreational drugs and alcohol have been discussed with the CF patient, with HCPs having to document any concerns that were present prior to transferring. These actions are best practice, and understandably such discussions are not always fully undertaken due to competing clinical pressures. Informal communication (2015) with HCPs involved in CF care to inform this evaluation, suggest that discussions around risky behaviours are not prioritised for a number of reasons, including time pressures, other pressing clinical needs and an

unwillingness of young people to engage openly in such discussions. To overcome these issues, individuals with CF could be provided with a standardised questionnaire to attain rich and useful information about an individual's knowledge and attitudes towards risky behaviours, followed by a standardised leaflet outlining the consequences of risky behaviours specific to CF; this would complement any verbal information received. Individuals forget up to half of the information/advice that has been given within five minutes, and recall only 20% of the information (Entwistle & Watt, 1998; Little, Griffin, Kelly, Dickson & Sadler, 1998). Patient retention of information can be improved with supplemental written information (MacFarlane et al., 2002).

All twenty paediatric CF regional units in England (The CF Trust, 2017e) were contacted, and out of these twelve units replied. Written information regarding risky behaviours during transition is currently provided by two paediatric CF units. One unit provides individuals with a questionnaire (as previously discussed), and the other unit provides information to patients from health education about sexual health, drugs and alcohol. This information is not specific to CF, however it does provide information regarding the effects of these behaviours. This information could be improved further by outlining the effects of these behaviours upon CF, and certainly provides grounds for further investigations.

Issues with the current materials and information

This evaluation of current practice in providing information and materials indicated the need for standardised risky behaviour advice from HCPs, and the need for research informed practice, which is scant in the area of CF. Specifically, the evaluation indicated that services address risky behaviours in different ways, with many units not incorporating risky behaviours as a formal part of their transition process. The majority of units approach the issue of risky behaviours on an individualised basis, which may involve a referral to the psychosocial team; however this is focusing on aiding the cessation of an already established behaviour, rather than preventing initiation. It is well known that risky behaviours are much easier to prevent than terminate once initiated, and missed opportunities appear to be a common phenomenon in past and current practice (Jáen, Strange, Tumiel & Nutting, 1997).

Furthermore, despite the positive efforts of two adult units, where they acknowledge the occurrence of risky behaviours, the use of questionnaires to identify patient vulnerability may be problematic. If an individual has ticked the box to indicate that they are aware of the risks of such behaviours, the individual is merely indicating that they understand the risks,

but they may not necessarily disclose that they have engaged or are contemplating engaging in these behaviours. Additionally, due to social desirability bias, it may be that individuals respond in a positive way, in order to be viewed favourably by their new clinicians at the adult unit (Krumpal, 2013; Lippitt, Masterson, Sierra, Davis & White, 2014; Sanzone et al., 2013).

In conclusion, all the adult and paediatric CF units contacted do have procedures in place when an individual engages in a risky behaviour, but more emphasis should be placed on preventing initiation, and this should start when most of those risky behaviours start, that is, before and during transition. Therefore qualitative research is required to inform such interventions, by investigating individuals' beliefs and attitudes towards risky behaviours, which may provide an interpretive perspective. The main conclusion drawn from this evaluation is that the important transition into adult care is challenging for everyone involved; patients, parents, HCPs, and even researchers. The importance of investigating risky behaviours in the CF population, and putting in place an effective standardised format for providing information and support, may assist in the development and provision of health care at a crucial time for young people to make choices that have a long-term impact on their future health.

Such research is imperative within the adolescent CF population, as adolescence is a period associated with heightened risk-taking behaviours, with adolescents being less likely than adults to perceive situations as unsafe (Knoll, Magis-Weinberg, Speekenbrink & Blakemore, 2015). There is a positive relationship between age and risk identification (Halpern-Felsher & Cauffman, 2001), with individuals under the age of 25 years demonstrating poor risk perceptions. Whilst adolescent risk-taking largely reflects experimentation rather than long-term problem behaviours (Cohn, Macfarlane, Yanez & Imai, 1995), the CF population does not have the freedom to experiment with such behaviours due to the severe adverse health effects these behaviours have upon CF (McEwan et al., 2012). Upon those foundations the researcher suggested that effective and deliverable behavioural interventions should be developed to support HCPs and patients further.

Forum and Twitter discussions between individuals with Cystic Fibrosis

Further evidence to support the conclusion that all individuals with CF need to be provided with information regarding the consequences of risky behaviours specific to CF, arises from discussions that some individuals with CF have on various forums and on Twitter. Many young people turn to social media for support and advice, with literature explaining how individuals with medical conditions often share information with others with

the same condition about their experiences via social media, developing their understanding of living with the condition (Shepherd, Sanders, Doyle & Shaw, 2015). The number of individuals seeking health information online within the UK has increased dramatically from 18% in 2008, to 43% in 2013, with an increase of 58% amongst individuals aged 25 to 29 years (Cole, Watkins & Kleine, 2016). It is reported that today, 70% of adults in the UK are using the internet for health advice (Massey-Chase, 2016). Social media and online forums provide individuals with the opportunity to disclose their engagement in risky behaviours, or thoughts of engagement to others and receive advice regarding these behaviours. These online platforms offer individuals with anonymity which is known to increase self-disclosure, with it being found that individuals self-disclose more in online environments than in person (Ma, Hancock & Naaman, 2016). In addition to anonymity, social media and online forums supply individuals with an audience that shares certain traits or experiences (Ma et al., 2016), e.g. an individual with CF may seek to use a forum specifically designed for the CF community. Consequently, online communication can yield peer support and peer understanding surrounding issues that young people may feel is absent from adult HCPs.

The use of social media and health forums by individuals seeking medical advice presents an opportunity to relieve pressures on HCPs, however this does depend on the quality of the information found online (Cole et al., 2016). When the researcher examined the conversations individuals with CF were having on various forums and on Twitter, it was indicated that some individuals with CF are unaware of the results of both risky behaviours and non-adherence, for instance some individuals discuss the possibility of missing creon tablets to lose weight. The idea of manipulating the use of creon tablets to lose weight is prevalent within the CF population, with a parent of a CF adolescent stating that she has seen many CF patients use creon to lose weight in order to fit into sociocultural expectations (Richards, 2015).

Many of the discussions on the forums and on Twitter surround the issue of smoking; with CF adolescents inquiring about the adverse health effects of smoking, and asking whether or not any other individuals with CF smoke. These discussions indicate that many individuals are unaware about what they can and cannot do with their CF, potentially as they have not been informed about the adverse health effects of these behaviours by HCPs. Some individuals explain that they do not necessarily want to engage in that behaviour (e.g. smoking marijuana), however they would like to know what health effects it could specifically have upon their CF.

Consequently, more information needs to be offered to individuals with CF about the adverse health effects of risky behaviours. This information needs to be administered to

individuals from their HCPs, instead of individuals using the internet to seek such advice from peers. Whilst the internet, particularly social media, is good for patients to use for emotional support, in terms of medical advice parents and HCPs have no control over what information is displayed upon these webpage's, with this information often not being accurate (Massey-Chase, 2016; Richards, 2015). Consequently, CF HCPs need to supply individuals with standardised information regarding the adverse health effects of risky behaviours, allowing individuals with CF to make a more informed choice about whether or not they want to engage in these behaviours in light of the consequences. However, with it being suggested that young people favour online communications as opposed to face-to-face communication, partially due to the anonymity online communication provides an individual with, health care could use the benefits of online communication when implementing health advice to young people. It is possible that apps and interactive anonymous online forums with HCPs could be created which offer individuals with CF health advice. This would therefore fulfil the need that is clearly there, to provide individuals with CF with more awareness regarding the adverse health effects of risky behaviours, in more innovative ways that address what young people want.

This doctoral research therefore explores the reasons why some individuals with CF engage in risky behaviours, highlighting interventions which could be used within the CF population to reduce the occurrence of such behaviours. This research also investigates HCPs views towards risky behaviours within the CF population, gaining insight into what interventions they believe would work. The researcher aims to collaborate with HCPs and patients to create a new intervention to address the issue of risky behaviours, which would be welcomed by both patients and HCPs alike. The transition evaluation, and the online communications that some individuals with CF have regarding risky behaviours, provides a strong rationale for this research, highlighting the need for new proactive interventions to be implemented within CF care, which potentially incorporate the use of technology. In order to conduct this research, the researcher conducted an in-depth literature review focusing on what influences the engagement of risky behaviours, specifically within a CF population, to identify any gaps within the literature where this research could be positioned.

CHAPTER THREE: WHAT INFLUENCES THE ENGAGEMENT IN RISKY HEALTH BEHAVIOURS?

Despite risky behaviours being prevalent within the CF population and having adverse health effects on individuals with CF, there is a lack of research exploring what influences engagement in such behaviours within the CF population, with previous research (Huq et al., 2011; McEwan et al., 2012; Verma et al., 2001) focusing upon the incidence, prevalence and effects of these behaviours (Tyc & Belzer, 2006). In addition there are a lack of effective interventions to reduce occurring risky behaviours within the CF population, as highlighted within the transition evaluation.

Adolescence in CF is a period where individuals are most vulnerable to health deteriorations, with some individuals starting to engage in non-adherence, as parents power of responsibility over the patient starts to diminish (Bregnballe et al., 2011; Bryon, 2015). Despite adolescence being identified as the healthiest and most resilient period of the lifespan, Bryon (2015) shows that overall morbidity and mortality rates increase from 200 - 300% from childhood to late adolescence within the general population, due to features of adolescent behaviour which are linked to poor health outcomes, such as an increase in risk-taking, sensation-seeking and erratic behaviour. The primary cause of death and disability during adolescence is due to problems with control of behaviour and emotions, resulting in alcohol and substance abuse, eating disorders, reckless behaviour etc; not ill health (Bryon, 2015; Lawrence, Appleton Gootman & Sim, 2009).

The experimentation of risky behaviours is “normal” during adolescence; however there is a line which causes these normal experimental behaviours to escalate to become extremely risky behaviours (Richmond, 2014); and this is also the case for the CF population. Bryon (2015) explains that adolescents with CF will behave like their peers without CF, and engage in these normal experimental behaviours. Therefore, if the contributory causes of adolescent and early adulthood morbidity in CF are related to problems with control of behaviour and emotion resulting in risky behaviours, then the focus of support, assessments and treatments during adolescence should not just be medical, but it also needs to acknowledge that during adolescence an individual's behaviour may be changing rapidly.

As normal experimental behaviours can escalate to become extremely risky behaviours, it is accepted that increasing adherence, and decreasing the initiation of risky behaviours is a positive outcome (Abbott, Dodd & Webb, 1996), whilst acknowledging that avoidance of regimens and the initiation in risky behaviours may represent an active choice (Mitchell & Selmes, 2007) which should be respected. However, individuals cannot make an

informed choice if they have not been presented with enough information about the consequences of such behaviours. Consequently, it is believed that proactive awareness should be presented to individuals with CF regarding the adverse health effects risky behaviour can have upon people with CF, to reduce the occurrence of such behaviours.

Whilst increasing an individual's awareness regarding risky behaviours is essential, it does have to be acknowledged that awareness regarding the adverse health effects of risky behaviours cannot always prevent initiation, with The Theory of Reasoned Action and The Theory of Planned Behaviour highlighting how a persons behavioural intention, and therefore their behaviour are influenced by multiple factors, such as their attitude towards the behaviour; their subjective norms which include their belief about important others' attitude towards the behaviour and their motivations to comply with others; as well as their behavioural control (Ajzen, 1988; Ajzen & Madden, 1986; Fishbein, 1967; Fishbein & Ajzen, 1975). Not surprisingly The Stages of Change Model suggests that interventions to encourage the cessation of a risky behaviour are most successful when an individual is already considering that behavioural change (Prochaska & DiClemente, 1982). Therefore, to create an intervention within the CF population to reduce the occurrence of risky behaviours, it is essential that awareness is not considered in isolation to the other factors that influence an individual's engagement. Such interventions should allow individuals with CF to make more informed choices on their engagement with risky behaviours, whilst being mindful of the factors that can influence an individual's engagement in such behaviours, with research needing to investigate what influences engagement within the CF population.

The influential roles of identity and acceptance in risky health behaviour engagement

There are a number of possible explanations as to why chronically ill individuals engage in risky behaviours. Chronically ill adolescents often experience a delay in growth and pubertal maturation (Rosen, 1991; Singhal, Thomas, Cook, Wierenga & Serjeant, 1994; Turkel & Pao, 2007), often have fewer close friends (Bernhard, 2014; Boyle, di Saint, Sacks, Millican & Kylczycki, 1976), fewer friends of the opposite sex (Bernhard, 2014) and date less often (Bernhard, 2014; Orr, Weller, Satterwhite & Pless, 1984) in comparison to the general population. Britto et al (1998) hypothesises that these maturational challenges contribute to the incidence of engagement in normalised risky behaviours in order to obtain peer acceptance.

Most risky behaviours are normalised within the general population, or within an individual's social group. Within the UK it is reported that 36% of smokers live in a social context where they are surrounded by more smokers than non-smokers, influencing an

individual's attitude towards this normalised behaviour (Buller et al., 2003). Similarly excessive alcohol consumption as a form of socialisation is often seen to be a normal experience during young adulthood (Seaman & Ikegwuonu, 2010), with binge drinking being identified as the characteristic drinking style in the UK for young adults (Martinic & Measham, 2008). Within some populations (particularly the student population) drug use is also normalised, with Price (2011) reporting that over 90% of University students have friends who actively take drugs. Parker, Williams and Aldridge (2002) also report that illicit drug use is becoming increasingly normalised within adolescents.

After alcohol and tobacco, marijuana is the most commonly used drug in the UK (Drugwise, 2016; FRANK, 2009), with 15.8% of individuals aged 16 to 24 years in England having used marijuana within a twelve month period, and 2.1 million people in total (aged 16 to 59 years) in England using marijuana, again within a twelve month period (Drugwise, 2016). Marijuana is easily accessible, and many people access it through social groups, therefore perceiving this being a criminal activity is low (Hathaway, 2004). Secondary school students report that marijuana is easy to access, and the majority of students view the behaviour to be recreational even if they themselves do not use it; highlighting that there is a high degree of social tolerance towards marijuana use (Hathaway, Comeau & Erickson, 2011). Adolescents often believe that marijuana cannot be harmful due to it being a natural substance (FRANK, 2009; NIDA, 2016); this broader cultural acceptance has been catalysed by the media (predominantly social media) where individuals openly advocate "pro-marijuana" perspectives (Hathaway et al., 2011; Hathaway & Erickson, 2003). Recent public discussions surrounding medical marijuana have also most likely had an influence upon adolescents' attitudes towards marijuana, with many young people believing that marijuana is a "safe drug" (NIDA, 2016).

The normalisation of risky behaviours may increase the likelihood of people with CF engaging, to be seen as "normal" and to support a non-illness identity. All patients have illness cognitions to provide themselves with a framework for coping and understanding their illness (Leventhal, Benyamini & Shafer, 2007a; Leventhal, Meyer & Nerenz, 1980; Leventhal & Nerenz, 1985; Leventhal, Weinman, Leventhal & Phillips, 2007b), with one cognitive dimension of these beliefs being identity. A retaliation against the illness identity has been seen in previous research; Bregnballe et al (2011) indicated that one of the main adherence barriers in CF is an unwillingness to take medication in public, due to fear of embarrassment.

Many adolescents with CF now attend College or University, and are therefore provided with the identity of being a "student". Students are more likely than the general population to smoke, drink alcohol or take drugs (NHS, 2016c), often due to the occurrence

of cheap student bars, the freedom of living away from parents, and peer pressure (Snipes & Benotsch, 2013). This peer pressure may have a greater influence in CF adolescents who have moved away from home to attend University, due to their thriving for peer acceptance and to be seen as normal, potentially increasing their likelihood of engaging in behaviours that are not highlighting their illness identity (Withers, 2012).

In looking at psychological factors that predict risky behaviours during adolescence, Withers (2012) states that adolescence is a time where teenagers are preoccupied with their appearance, and comparing themselves to their peers. Adolescents can suffer from psychological distress if they perceive themselves to be different to their peers, with this being most prevalent amongst chronically ill adolescents (Duff & Latchford, 2010; Withers, 2012). Having CF may present an increased risk factor for bullying, with people keeping distance from individuals with CF in case they "catch" CF (Richards, 2015), causing patients to hide their CF from others. The notion of hiding CF is evident within the CF population, with individuals often having a need to not be defined by their CF, allowing them a sense of normalcy, with the notion of hiding one's illness identity allowing the individual to avoid the embarrassment they feel when their CF is on display (King, 2015). As a consequence of people with chronic illnesses often having a desire for normalcy and hiding their illness from others, Withers (2012) speculates that CF adolescents would be more likely to experiment with risky behaviours if their peers also engage in these behaviours. This conformity would be a way for CF adolescents to reduce the differences between themselves and their peers, and to try and forget about the burden of CF, by having fun and enjoying themselves, providing themselves a normal identity.

Research shows the cognitions which predict risky behaviours within the general population include associating these behaviours with fun and pleasure, and the belief that these behaviours will reduce their stress, build up their confidence and enable them to be sociable (Charlton, 1984; Charlton & Blair, 1989; Ogden, 2012). Literature demonstrates how affective beliefs can influence an individual's motivations for engagement in risky behaviours, with Lawton, Conner and McEachan (2009) highlighting how negative affective beliefs can work to prevent initiation in a risky behaviour, whereas positive affective beliefs (associating the behaviour with fun and enjoyment) can influence engagement in such behaviours. The cognitions and affective beliefs an individual has regarding a risky behaviour are built through interactions with parents, siblings and peers, with these interactions having the ability to normalise risky behaviours (Mercken, Candel, van Osch & de Vries, 2011).

Lader and Matheson (1991) suggested that the main factor which predicts smoking is parental smoking, with children being twice as likely to smoke if their parents smoke, due to normalisation. In addition, Gutman, Eccles, Peck and Malanchuck (2011) demonstrated that negative family interactions are related to increased alcohol consumption and smoking in adolescents. Furthermore Lamb and Crano (2014) pointed out that parental beliefs about their child's involvement in risky behaviours may not be accurate, however they are influential due to the self fulfilling prophecy, with marijuana-abstinent adolescents being significantly more likely to initiate use if their parents believe them to be users, conversely, adolescent marijuana users are significantly less likely to continue engagement if their parents believe they are abstinent.

As a consequence of the increasing life expectancy within the CF population, it is not just an individual's family who can influence risky behaviour engagement. Today seven out of ten individuals with CF are in employment or education (Saldana & Pomeranz, 2012; Owen, 2016); which is accompanied with psychological benefits, with there being a lower incidence of depression in employed individuals with CF despite variability in symptoms (Burker et al., 2012). These psychological benefits are due to an array of factors, such as providing the individual with an additional identity (a working person identity) (Winefield et al., 2000). However if a risky behaviour is normalised within the workplace, it may motivate individuals with CF to initiate in that behaviour, to provide themselves with a normal identity. Therefore, despite it being positive that individuals with CF are living to an age where they can work, it is presenting HCPs with a welcomed challenge to try and reduce the occurrence of risky behaviour engagement, despite an individual's exposure potentially increasing as a consequence of interactions with their peers at work, or within their educational experiences, particularly if that individual has come from a family unit where risky behaviours are not normalised.

The issue with identity is closely linked with the labelling theory (Quicke & Winter, 1994) which suggests that when individuals are provided with a "label" it is often accompanied with negative consequences (Telford, Kralik & Koch, 2005), which individuals internalise, with the labels becoming self-fulfilling prophecies (Erikson, 1964). Chronically ill individuals are often aware of negative stereotypes society holds about them; with individuals potentially believing they do not fit in with social norms, contributing to a fragile sense of identity (Kelly, 1992). Stigmatisation around chronic illness can be a result of missing schooling and being unable to participate in extra-curricular activities, therefore their peers may see them as "the kid who's always sick" resulting in them being treated differently (Bernhard, 2014, p.1). This is difficult to cope with and may lead to an increase in engaging in risky behaviours to reduce others perceptions of their illness identity.

Laws et al (2012) states that people only become adherent to medical regimes, and do not retaliate against their illness when they have incorporated their illness into their identity and accepted their illness. The identity theory states that “the self” is constructed of many different identities based on an individual’s roles and relationships, with “the self” having to abandon some identities and incorporate others over time (Laws et al., 2012). Identity reformulation (Aujoulat, Marcolongo, Bonadiman & Deccache, 2008) is expected to occur during diagnosis of a chronic illness, requiring new behaviours within the individual, such as adherence; with Laws et al (2012) suggesting that it is only when this change in identity has occurred, and being accepted, that individuals will not engage in risky behaviours.

In terms of CF and identity, individuals are born with CF, so they predominantly will have always been aware of their condition; therefore it may be believed that individuals with CF would not have to incorporate their illness into their identity. However it is reported that this change in self for individuals born with a chronic condition can occur during adolescence; this change is gradual with adolescence being a time where new questions regarding their chronic condition emerge (Michaud, Suris & Viner, 2007). Such questions often surround the cause of their condition, the nature of their condition and their prognosis, with this being recognised as the individual incorporating their chronic condition into their body image and their sense of self (Michaud et al., 2007). Consequently, the change in self experienced by people who have been born with a chronic condition may occur during transition to adult care, with Withers (2012) reporting that transition can be an upsetting process, due to a loss of familiarity which creates anxieties within the individual (Taylor, Tsang & Drabble, 2006). Transition may occur co-incidentally as non-adherence becomes problematic (Viner, 1999), and the adolescent may interpret this as rejection from their childhood clinicians as a form of punishment (Withers, 2012); causing anxiety (Pacaud & Yale, 2005), which could lead to a retaliation against the illness identity.

Transition to adult care occurs during a crucial time for identity development; with adolescents entering the first of three psychological stages according to Erikson’s theory (Santrock, 1995): identity formation, with this typically occurring during adolescence where an individual discovers who they are; intimacy, with this typically occurring during young adulthood where an individual establishes stable intimate relationships; and generativity, with this typically occurring during middle age where an individual has a productive lifestyle (Pacaud & Yale, 2005). However, for chronically ill adolescents this transition is made more complex due to their illness (Yates et al., 2010). Pacaud and Yale (2005) suggested that diabetes created issues in the process of achieving identity, intimacy and generativity; with Jacobson, Hauser, Powers and Noam (1982) suggesting this could be due to the delay in

ego development that diabetic adolescents experience, due to the threat diabetes presents an individual with, in terms of future complications, which may impair their ability to imagine their future. The issues with psychosocial maturation within diabetes may also be present in CF adolescents, causing them to not incorporate their illness into their identity (Laws et al., 2012).

Further evidence for chronically ill adolescents not incorporating their illness into their identity comes from Yates et al (2010), who found that chronically ill adolescents state that their illness does not define their identity, with these adolescents expressing a desire to be perceived as normal adolescents engaging in normal activities. This desire for normalcy was further emphasised by Higham et al (2013) who found that individuals with CF hope to live a normal life, where they have long-term relationships, have children, and pursue a career. Many of these individuals emphasised that they are normal people doing normal things, with one participant disclosing that 80% of him is a bloke living his normal life, and 20% of him is CF (Higham et al., 2013). This desire for normalcy is healthy and understandable and is not necessarily problematic; it would however be seen to be problematic if it involved the engagement in normalised risky behaviours.

A crucial concept within identity is image; this was demonstrated by Yates et al (2010) who pointed out that many chronically ill adolescents favour a degree of invisibility towards their illness, allowing them greater normalcy, regardless of whether this costs them consideration off others. With CF, individuals often appear to be physically normal, with CF often being referred to as an invisible impairment (Tierney, 2012). However individuals may believe that their illness is on display when they have to engage in medical regimens, therefore some individuals with CF may consciously choose to be non-adherent and / or engage in risky behaviours, to provide themselves again with this sense of invisibility (Withers, 2012). Higham et al (2013) reported how some individuals with CF avoid treatments that they believe makes them look different to others.

A desire for invisibility about CF can often prevent individuals disclosing their CF status to others (Borschuk et al., 2014; Higham et al., 2013). Due to CF's increasing life expectancy, individuals with CF today are expected to disclose their illness identity to others (e.g. employers), with non-disclosure often having a negative impact upon an individual's psychological functioning (Borschuk et al., 2014; Higham et al., 2013), and providing individuals with a gateway to engage in risky behaviours which are normalised within their social group, to further provide themselves with this sense of invisibility. For instance, in Higham et al's (2013) research statements like "I've always hidden my CF"; "I don't like being different" emerged, this potentially suggests that if an individual has peers who engage

in risky behaviours, they may be motivated to also initiate in these behaviours, to provide themselves with a normal identity, and to reduce the differences between themselves and their peers. Furthermore, Higham et al (2013) demonstrated that to be perceived as normal, many individuals with CF (particularly female's) hide their illness identity from their new partners, with the majority of females with CF only disclosing their illness when they believe their relationship is going to be long-term. This could involve females with CF initiating risky behaviours that their partners engage in, providing themselves with a sense of invisibility towards their CF.

Literature also suggests that adherence is influenced by how an individual perceives their illness (Audulv, Asplund & Norbergh, 2010); for instance some individuals who hold a life-orientated illness perspective (those who focus upon their chronic disease as only part of their daily lives) often focus upon their wellbeing, and therefore they may engage in non-adherence or behaviours that are harmful towards themselves, to live a normal life (Audulv et al., 2010). Whereas people who possess a dominant disease-orientated illness perspective (where they define wellness as feeling physically well and focus on the medical and physiological aspects of their illness) view self-management as mandatory, regardless of the implications this can impose upon their social life (Audulv et al., 2010), and therefore they would not engage in risky behaviours that could compromise their health. Consequently, a desire to be perceived as normal (Higham et al., 2013; Yates et al., 2010), due to an individual's life-orientated illness perspective, could suggest that the patient has not incorporated their illness into their identity, meaning they have not accepted their prognosis, and therefore they cannot be expected to not engage in risky behaviours (Laws et al., 2012). These issues with identity and acceptance would only become a noticeable issue during transition to adult care; as it is only during this stage that individuals are expected to independently manage their treatments (Bregnballe et al., 2011).

The influential role of unrealistic optimism in risky health behaviour engagement

If someone has not accepted their illness then the engagement in risky behaviours could be a result of denial towards their CF (Telford et al., 2005). Higham et al (2013) suggested that people with CF can show signs of denial in an attempt to be perceived as normal, with denial being most predominant during adolescence, as it is during the transition to adult care where there may be an increased understanding of the progressive nature of CF and its future implications (The CF Trust, 2015; Withers, 2012). The CF Trust (2015) highlighted how some adolescents with CF avoid their CF, not acknowledging the severity or the deteriorating nature of their condition, often stating things such as: "CF doesn't impact my life"; "I never let it [CF] hold me back". In addition, when some CF adolescents were

asked about what is most stressful within their lives, their answers did not always include CF, instead they stated things such as "balancing social life, education and homework" (The CF Trust, 2015).

Denial within CF adolescents could result in the initiation of risky behaviours. Kubler-Ross (1969) states that individuals with chronic illnesses go through the following stages of emotional adjustment: denial, anger, bargaining, depression and acceptance. According to Laws et al (2012) acceptance is the period of time where the individual experiences identity reformulation, and can be expected to adhere to their medical regimens and not engage in risky behaviours, with denial being the first stage of the journey to acceptance.

Closely linked with denial is optimism, which is often used as a coping mechanism, in order to deal with both the physical and emotional demands of CF (Abbott et al., 2008). In terms of coping strategies, chronically ill individuals usually use strategies which encompass the method of coping (cognitive and behavioural) and the focus of coping (approach or avoidance) (Abbott et al., 2008; Holohan & Moos, 1987; Moos & Shaefer, 1993); with "approach" focusing an individual's attention on their illness, and "avoidance" diverting their attention away from their illness (Abbott et al., 2008). Avoidance as a coping strategy may result in a lack of interest in CF or medical regimens, which may involve the individual distracting themselves away from their illness (Abbott et al., 2008). In contrast, individuals who focus their attention onto their CF may closely monitor their condition, and have the fight to "beat" CF, and this constitutes an adaptive coping mechanism (Abbott, 2003; Abbott et al., 2008; Lazarus, 1966; Miller & Mangan, 1983; Roth & Cohen, 1986; Scheier & Carver, 1985).

The impact of coping strategies on psychological functioning has been widely researched, and good psychological health is associated with more adaptive coping strategies (Roesch & Weiner, 2001). In addition, Abbott et al (2008) explained a role for coping strategies in influencing an individual's quality of life, with individuals with CF who use optimism as a coping strategy having a higher quality of life and greater psychological resilience in comparison to other patients (Abbott, 2003). However, many scholars argue that this may be unrealistic optimism, which is the tendency for an individual to underestimate their likelihood of experiencing adverse events (Weinstein, 1980). This could result in biased health perceptions, which may be a manifestation of denial of CF's fatal nature (De Ridder, Fournier & Bensing, 2004; Taylor, 1989). Unrealistic optimism could mean that individuals deny the presence of physical symptoms which make them appear vulnerable (Taylor, 1989). Research on coping within CF is limited, and there is a lack of research examining the effects these coping strategies have upon the engagement of risky behaviours within the CF population.

In the general population, Weinstein (1988) suggests that individuals continue to engage in risky behaviours due to their inaccurate perception of risk and susceptibility. Unrealistic optimism has been viewed as an influential factor in the initiation of a variety of risky behaviours. Research points out that students who are unrealistically optimistic towards alcohol, consume more alcohol and experience more adverse effects (e.g. hangovers, missed lectures), with these students often possessing a hedonistic perspective (Bissett, Wood, Cox, Scott & Cassell, 2011; Dillard, Midboe & Klein, 2009; Henson, Carey, Carey & Maisto, 2006). Unrealistic optimism is also seen in smokers from the general population, with smokers often believing myths such as exercise will undo most of the adverse smoking effects (Weinstein, Marcus & Moser, 2005). Weinstein (1988) states that individuals are unrealistically optimistic due to them having selective focus, meaning they ignore behaviours they engage in which increases a risk (e.g. "I smoke despite my CF, but that's not important"), and focus on behaviours they engage in which reduces a risk (e.g. "but at least I take all my medication"); with this selectivity being compounded by egocentrism, with the individual ignoring others risk-decreasing behaviours (e.g. "everyone I know with CF takes all their medication, but that's irrelevant"); focusing upon times when they engage in health-promoting behaviours (e.g. "I always take my medication during the weekends") and ignoring times they do not (e.g. "I do not take my medication during the week whilst at College") (Weinstein, 1988).

The notion of selective focus within unrealistic optimism is closely linked to the notion of risk compensation, where an individual believes that a risky behaviour (e.g. smoking) can be compensated for by another set of behaviours (e.g. adhering to all medical regimens). Radtke, Scholz and Keller (2011) signalled that the more compensatory health beliefs an adolescent has about their risky behaviour, the less likely they are to stop engaging in this behaviour. Risk compensation is used as a mechanism to resolve the cognitive dissonance than many individuals who engage in risky behaviours have (Rabiau, Knauper & Miquelon, 2006), therefore allowing their engagement to continue by restoring a sense of cognitive consistency (Festinger, 1957). Consequently, in order to increase the chance of behavioural change, an individual's cognitive dissonance needs to be increased, creating an unpleasant state of tension within the individual (Festinger, 1957).

The notion of selective focus can be seen within the general population. Many smokers do have smoking-related illnesses but they do not acknowledge the health risks of smoking, due to unrealistic optimism (Borrelli, Hayes, Dunsiger & Fava, 2010). Bock et al (2001) indicated that 47.6% of smokers admitted to A&E for acute respiratory care do not believe that their condition is made worse (or caused) by their smoking behaviour. The precaution adoption process model (Weinstein, 1988, 1999) focuses on the association

between risk perception and health protective behaviours (e.g. smoking cessation) by investigating risk communication (Borrelli et al., 2010). Risk perception is a multi dimensional construct which includes an individual's felt vulnerability, optimism and their perceptions on how effective the precautions are (Borrelli et al., 2010).

Much literature has focused on the concept of risk perception within risky behaviours, and how this concept involves individuals processing risk information in a way which enables them to continue their behaviours (Jacks & Cameron, 2003). For example, some individuals with CF do engage in risky behaviours despite their adverse health effects, and despite warnings that appear within the general population, such as pictures of damaged lungs on cigarette packets (Moodie, Mackintosh & Hastings, 2013). In terms of pictorial images, they are often not effective in preventing smoking within the general population (Moodie et al., 2013) due to individuals managing to ignore the data or find reasons for rejecting it (Sherman, Nelson & Steele, 2000). Thus new interventions are required, both within the general population and within the CF population, in order to reduce the occurrence of risky behaviours despite unrealistic optimism within individuals.

In terms of risk perception, Halpern-Felsher, Biehl, Kropp and Rubinstein (2004) suggested that the higher vulnerability an individual perceives, the greater their intention will be to attempt cessation. These results are consistent amongst chronically ill individuals (Hay et al., 2007) with Borrelli et al (2010) indicating that when medically-ill individuals experience a change in their perceived vulnerability to diseases related to their risky behaviour, it predicts their likelihood for cessation; whereas individuals who display unrealistic optimism towards their illness are likely to continue their engagement. Based on Borrelli et al's (2010) findings it is plausible that individuals with CF who are unrealistically optimistic will continue their risky behaviour engagement until they experience a change in their perceived vulnerability (e.g. decrease in lung function), however this must be coupled with the individual perceiving that the precautions (cessation) will be effective and beneficial towards their health. Being unrealistically optimistic may be seen as an adaptive coping mechanism as it improves psychological quality of life, but it also may be seen as a maladaptive coping mechanism if there is an underestimation of the severity of disease, with an associated increase in engagement with normalised risky behaviours with detrimental physical consequences to health.

The role of motivation in risky health behaviour engagement

To understand why people engage in risky behaviours, we need to investigate what motivates individuals to initiate in risky behaviours, and what motivates cessation. Rapid brain changes occur between the ages of ten and twenty five years, with this transitional phase between the "child brain" and the "adult brain" being host to specific brain changes that underpin behavioural and emotional tendencies, which in turn can create problems that emerge during adolescence (Kuhn, 2006). These rapid brain changes include the prefrontal cortex being restructured resulting in the potential for poor decision making; the thinning of unused neural connections and pruning of synapses resulting in the potential for poor behavioural control; and an increase in myelination resulting in the potential for poor behavioural modulation (Bryon, 2015; Del Piero, Saxbe & Margolin, 2016). These brain changes have a number of implications for adolescents, including a reduced ability to consider long term consequences, and a poor understanding of what prevention means. Bryon (2015) states that adolescents do not intend to pursue health risk behaviours, however they are open to these behaviours due to their executive cognitive functioning and the notion of avoiding harmful outcomes not being fully developed. Instead adolescents possess an immature cognitive functioning where they have a high sensitivity to rewards and a low sensitivity to risks; motivations during adolescence are reward-seeking, and involve the avoidance of barriers to rewards (Bava & Tapert, 2010).

Bryon (2015) states that CF adolescents are seeking the same rewards as their peers, and have a need for strong peer identification which leads to engagement in risky behaviours. There is little reward in living with CF, with the pressures of managing CF often impinging upon the pressures of life (living with a partner, starting a family, starting an occupation, finding a social group) during adolescence and early adulthood. Consequently CF adolescents may be more motivated to conform to the pressures of life, and to not conform to the pressures of CF (e.g. adherence) in order to receive the rewards that adolescents typically strive for (e.g. peer identification).

Whilst adolescence is just a phase, the possibility that CF adolescents may not understand the need for CF treatments, or avoiding risky behaviours due their brain not being capable of absorbing and operationalising such information (Bava & Tapert, 2010), could have long-term health implications. Bryon (2015) stresses the importance of working to overcome the influence of peers and advocates that adolescents are to be included in discussions and decisions with their HCPs, with there needing to be an emphasis on reducing the occurrence of risky behaviours within these discussions.

In terms of motivations for engagement in risky behaviours, the Self-Determination Theory states that there are two different types of motivations (Deci & Ryan, 1985). Firstly an individual can have intrinsic motivation (autonomous motivations), which would fulfil personally relevant goals and satisfy that individual (Deci & Ryan, 2000), with this commonly being associated with the individual engaging in health-related behaviours, and fulfilling the basic need of autonomy (e.g. independently adhering to their medical regimens) (Deci & Ryan, 1985, 2000). The second type of motivation is extrinsic motivation (controlled motivations), where an individual is driven by external factors that often make the individual feel less personally satisfied, an example is peer pressure, which is commonly associated with individuals avoiding health-related behaviours (Deci & Ryan, 1985, 2000). With adherence, self-determination theory proposes that research needs to investigate how motivation can be transformed from extrinsic to intrinsic in order to increase adherence. This process of shifting motivation may prove difficult given that a person with CF will have had to adhere to a long list of complex and time-consuming medical regimens since childhood. Additionally, during adolescence engaging in risky behaviours may provide alternative intrinsic rewards which compete with adherence as a reward, such as autonomy, self-management and control over one's own life.

Stress as a form of motivation

Engagement in risky behaviours may also provide an alleviation to stress, with risky behaviours potentially being central to an individual's attempt at "reconciling health keeping when their reserves of emotional and physical energy are seriously depleted" (Graham, 1987, p. 55). For some, engagement in risky behaviours promotes a sense of wellbeing, therefore whether an individual views a behaviour to be risky or not, is a product of both beliefs and an individual's social world (Ogden, 2012).

With the increasing life expectancy many people with CF are now attending University and being in employment. Work is a positive experience for individuals with CF, with it being associated with increasing self-esteem, and physical and mental wellbeing (Targett et al., 2014). However, with many individuals with CF now being in employment, it increases the risk of exposure to occupational stress. It is reported that 488,000 people in the UK suffer from occupational stress (Health and Safety Executive, 2016), with this chronic stress commonly being the result of psychosocial hazards found within the workplace, such as workload (Cohen, David, Tyrell & Smith, 1991).

Occupational stress may be heightened for people with CF due to an increased need for time off work due to ill-health. Within the general population, there is anxiety around taking time off work for sickness, with many workers stating that there is already not enough

time to complete their work, often resulting in presenteeism (Cooper, 2013; Newcombe, 2013). People with CF may have to regularly take time off work to prevent their health deteriorating, with this having the potential to cause stress and anxiety within the person due to them becoming behind at work, and potentially needing to work overtime when they return due to their ever-growing workload (Newcombe, 2013). This may be made worse by some individuals with CF having poor energy levels, meaning they become easily tired.

However, not all workers with CF suffer from occupational stress, due to a variety of reasons such as their personality. Pessimistic individuals are more likely than optimistic individuals to see stimuli as hazards (Tuten & Neidermeyer, 2004). Nonetheless, if an individual with CF did suffer from occupational stress it could motivate them to engage in risky behaviours, particularly if these behaviours were normalised within their workplace, with such engagement being influenced by extrinsic motivations. The engagement in behaviours normalised by one's colleagues would allow the individual to minimise the differences there are between themselves and their colleagues, supporting their effort to not be defined by their CF.

The relationship between psychological distress and risky health behaviours

Whilst individuals may engage in risky behaviours with an aim to lessen their stress (Kassel et al., 2003), literature also indicates a relationship between the engagement in risky behaviours and psychological distress. Perkins, Karelitz, Giedgowd, Conklin and Sayette (2010) report that risky behaviours (predominantly smoking) are reinforced within individuals with a history of depression, and those with lower distress tolerance, due to the alleviation of stress they experience by engaging in these behaviours. Research also illustrates the effect that mood can have upon smoking interventions, with it being reported that a negative affect is related to smoking intervention failure (Breslau, Kilbey & Andreski, 1992; Hall, Munoz & Reus, 1994; Hall, Munoz, Reus & Sees, 1993). Similar results have been found when looking at excessive alcohol consumption, with people who experience psychological distress being twice as likely to be heavy or problem drinkers (Boden & Fergusson, 2011; Kavanagh et al., 2011). However, research cannot specify whether or not psychological distress results in the initiation of a risky behaviour, or whether psychological distress occurs as a consequence of engagement (Boden & Fergusson, 2011).

Research indicates that individuals with a chronic illness are at a greater risk of suffering from depression in comparison to the general population (Haire-Joshu et al., 2004). The prevalence of depression within the CF population does vary, with Latchford et al (2010) reporting that 21% of adults with CF have mild depression, and 12.9% of adults with CF

have moderate - severe depression. Consequently, due to the relationship between psychological distress and risky behaviour engagement, effort needs to be employed to identify such individuals who may be vulnerable to initiation. The focus of this intervention could be about highlighting individuals who are emotionally immature, and encouraging those individuals to develop emotional sobriety, due to research indicating a link between addiction and emotional immaturity, with individuals who turn to substance abuse often feeling unable to deal with their feelings (Sweet & Miller, 2016). In contrast individuals who have developed emotional sobriety often suffer less from stressful situations due to developing meaningful interpersonal relationships, being optimistic, and feeling able to deal with tough situations without abusing substances (Sweet & Miller, 2016). Consequently, developing emotional sobriety could form part of an intervention to reduce the occurrence of risky behaviours within the CF population, whilst acknowledging the other issues discussed earlier.

Research Aims

Given the adverse health effects of smoking, excessive alcohol consumption and illicit drug use within the CF population, more effective health promotion measures are needed to reduce the occurrence of these behaviours (McEwan et al., 2012), with the transition evaluation highlighting the need for new proactive interventions to be integrated into CF care to reduce the occurrence of such behaviours. There is a lack of research exploring what influences engagement with risky behaviours within the CF population, with existing literature (Ernst, Johnso & Stark, 2011; Higham et al., 2013) not incorporating risky behaviours into discussions surrounding the psychological implications of CF.

Previous research focusing on risky behaviours within the CF population has for the most part, taken a positivist approach, utilising questionnaires to investigate the incidence, prevalence and effects of risky behaviours (McEwan et al., 2012; Verma et al., 2001). Therefore, research is needed to progress previous work by investigating individuals' reasons as to why they do or do not engage in risky behaviours, with the current research utilising qualitative interviews to take an interpretive perspective. Personal identity, levels of acceptance and managing CF as an adult were some of the themes explored, with participants able to discuss issues that the researcher had not anticipated, empowering individuals through allowing their voice to shape this research due to it being person-centred, in line with the guidelines provided by Owen (2016).

CHAPTER FOUR: METHODOLOGY - AN EXPLORATION OF RISKY HEALTH BEHAVIOURS WITHIN THE CYSTIC FIBROSIS POPULATION

Risky behaviour engagement within the CF population is an under-researched area, with a poor understanding of why some individuals with CF engage in risky behaviours. Previous research within this area has taken a positivist approach, outlining statistics on the incidence, prevalence and effects of risky behaviours, with the current research aiming to provide a narrative behind these statistics, offering greater insight as to why some individuals with CF engage in such behaviours. Accordingly, this research emphasised the perspective of the individuality of each participant in exploring reasons for risky behaviour engagement. To conduct this exploration it was essential to collect data that was rich in its descriptive attributes, which could be obtained through in-depth interviews (Denzin & Lincoln, 2000; Howitt, 2013). All phases of data collection within this research did not just acknowledge "the individual", they also acknowledge the characteristics of the everyday social world which impact an individual's experiences. The research reports great detail regarding the lives of individual participants, and how their experiences have influenced their behaviours, attitudes and beliefs. All of which would not have been possible to obtain without the utilisation of qualitative methods, with qualitative interviews being one of the most widespread method of inquiry across social sciences today (Brinkmann, 2016).

Series of Events

Figure 1. An outline of the structure of the whole study which provided a qualitative exploration of experiences and beliefs around risky health behaviours in a paediatric and an adult Cystic Fibrosis population

Pre-Data Collection Activity

The researcher conducted an evaluation on the information received by individuals with CF in the UK during their transition, to investigate whether any information is provided to patients regarding risky behaviours.

- Nineteen Adult CF Units were contacted
 - Sixteen Adult CF Units replied
- Twenty Paediatric CF Units were contacted
 - Twelve Paediatric CF Units replied

Findings:

All the adult and paediatric units contacted do have procedures in place when an individual engaged in a risky behaviour, but more emphasis should be placed on preventing initiation, and this should start when most of those risky behaviours start, that is, before and during transition. Therefore qualitative research is required to inform such interventions, by investigating individuals' beliefs and attitudes towards risky behaviours.



Phase One Data Collection

- Twenty-four adult participants (male: 16, range 19-66 years, mean: 34 years) were recruited, with a median FEV₁ 60.77% predicted.
- Seventeen participants disclosed during the interview that they did engage in risky behaviours
 - Four of these participants were initially identified by their multi-disciplinary team to be "non-risky"

This phase of data collection focused upon an individual's feelings and motives during initiation, or explored why they had never engaged in risky behaviours, consequently retrospective qualitative interviews were used.

Findings:

This phase of data collection successfully provided insight into the variety of reasons why some individuals with CF engage in risky behaviours. It became evident that the initiation in such behaviours, or at least the contemplation of engagement, commonly occurs during adolescence. The second phase of data collection was therefore driven by these findings.



Phase Two Data Collection

- Ten paediatric participants (male: 5, range 12-18 years; mean: 14 years) were recruited, with a median FEV₁ 69.14% predicted.

Based upon the findings from phase one data collection the researcher considered it to be essential to talk with paediatric CF patients. This phase of data collection aimed to investigate paediatric participants' knowledge, beliefs and attitudes towards risky behaviours, at an age commonly associated with initiation. The semi-structured interviews conducted were prospective interviews.

Findings:

Overall, both phases of data collection highlight a variety of reasons why individuals may be motivated to initiate in risky behaviours. Within both phases of data collection some participants explained how they had not received awareness regarding the adverse health effects of risky behaviours from their HCPs. The researcher therefore deemed it essential to discuss the issue of risky behaviours with HCPs, to explore what awareness they provide their patients with concerning risky behaviours, and whether or not there are procedures in place to determine which patients receive this information.



Phase Three Data Collection

- Nine CF Specialist Nurses were recruited (three paediatric Nurses, five adult Nurses, one adult and paediatric Nurse; range of experience: 11 months - 23 years, mean = 14 years).

The researcher only recruited CF Specialist Nurses as both adult and paediatric participants disclosed that they are closest to Nurses than to other members of the multi-disciplinary team, therefore it was believed that Nurses would be well placed to offer valuable insights into the issue of risky behaviours and effective interventions. Telephone interviews were conducted due to their asynchronous communication of place.

Findings:

The findings from this phase of data collection coincide with the findings from the transition evaluation and the previous phases of data collection, with the need for new interventions being demonstrated, in order to reduce the occurrence of risky behaviours. As this phase of data collection only investigated how Nurses perceive the issue of risky behaviours, and what interventions they would like implemented, the researcher identified the importance of speaking to, and collaborating with other HCPs.



Phase Four Data Collection

- Four Dissemination Meetings were conducted

The researcher viewed the act of dissemination to be crucial for this research, as in order for the findings to be used to create an intervention that has practical applications, the researcher needed to gain the views of HCPs. The researcher believed that dissemination was the first stage of collaboration with HCPs to create an intervention, allowing HCPs the opportunity to critique and evaluate the findings generated during this research, helping to ensure the validity of the findings.

Findings:

HCPs acknowledged that risky behaviours are a new and growing concern within CF care, with HCPs agreeing that the provision of awareness regarding the adverse health effects of risky behaviours is not embedded within CF care. Therefore HCPs emphasised the need for new interventions to be integrated into CF care in an attempt to reduce the occurrence of such behaviours. The dissemination meetings produced strong conclusions and recommendations regarding what interventions could work in practice to reduce the occurrence of risky behaviours within the CF population.

The methodology used within each phase of data collection emerged following collaborations between the researcher and her supervisory team, as well as with HCPs who work within the field of CF. This has helped to ensure the validation of the methodology, with this research being an open and collaborative process, with the researcher welcoming feedback from others to help shape this research. A pre-data collection activity was conducted to offer insight into what information is received by individuals with CF in the UK surrounding the issue of risky behaviours during their transition. As discussed, this evaluation highlighted that despite all adult and paediatric CF units who were contacted having procedures in place when a patient engages in a risky behaviour, more emphasis should be placed on preventing initiation. It was therefore considered essential for qualitative research to be conducted to inform interventions aimed to reduce the occurrence of risky behaviours, by investigating individuals' beliefs and attitudes towards such behaviours (Figure 1). The researcher presented the findings from the pre-data collection activity at the CF Nursing Association Study Day allowing HCPs to evaluate the findings, helping to ensure theory triangulation. HCPs agreed with the researcher that qualitative research was needed within this area, pointing out that risky behaviours are often a missed area within CF care. Four phases of data collection were conducted to explore how best to address the issue of risky behaviours within the CF population.

Phase one data collection provided an exploration into experiences and beliefs regarding risky behaviours in an adult CF population. Before commencing data collection the researcher presented the research proposal to HCPs at each research site, allowing HCPs to inform this proposal ensuring the research would work in practice and would have the potential to generate useful findings which would have practical applications in informing healthcare. Adult participants were recruited for this phase of data collection as there was the expectation that some participants would have had experience with risky behaviour engagement, and therefore would be able to report what influential factors affected their engagement. With this phase of data collection focusing upon an individual's feelings and motives during initiation, or exploring why they have never engaged in risky behaviours, retrospective interviews were used. These interviews aimed to understand changes within participants over time, and to create a time dimension to the data, identifying influential factors which contribute to the initiation of risky behaviours within CF (De Vaus, 2006). Smedley et al (2015) report that retrospective interviews offer an accurate description of human behaviour within health research, with these interviews enabling individuals to assess the influence a situation had upon their identity and experiences, when they were more distanced from it (Taylor, 2008; Yates et al., 2010). Retrospective interviews aid participants in reconstructing their past, encouraging them to recall the process, choices and decision

making regarding risky behaviours as accurately as possible, with it being easier to disclose sensitive or embarrassing information when an individual is more distanced from the event (Gidlof, Holmberg & Sandberg, 2012).

Phase one data collection successfully provided insight into the variety of reasons why some individuals with CF engage in risky behaviours. During participant's retrospective accounts, many explained how their experimentation with risky behaviours, or at least their contemplation of engagement commonly commenced during adolescence. This highlights how interventions to reduce the occurrence of risky behaviours within the CF population need to be introduced during adolescence, when individuals are initially making decisions regarding such engagement. The second phase of data collection was therefore driven by these findings, with the researcher considering it to be essential to talk with paediatric CF patients before developing an intervention. Before commencing the second phase of data collection, the researcher presented the findings from phase one data collection, along with the proposal for phase two data collection to HCPs at the research sites for phase two data collection. This allowed HCPs to comment on the findings generated and the new research proposal, with this helping to ensure theory triangulation, and again ensuring that this research would work in practice and would have the potential to generate useful findings which have practical applications. This second phase of data collection aimed to investigate paediatric participants' knowledge, beliefs and attitudes towards risky behaviours, at an age commonly associated with initiation, ensuring that any interventions created are relevant to all individuals with CF, particularly adolescents. The semi-structured interviews conducted within this phase of data collection were predominantly prospective; with the exception of one interview where a participant discussed previously drinking excessive amounts of alcohol. The use of prospective interviews gave the researcher the opportunity to determine what type of, and at what point in time, interventions are needed to address the issue of risky behaviours, within a paediatric CF population. Prospective interviews present a deep understanding of participants' lives (Engstrom & Forsberg, 2011), allowing this research to examine participants' attitudes and beliefs towards risky behaviours in real time (Lally, 2007).

Overall, both phases of data collection highlight a variety of reasons why individuals may be motivated to initiate in risky behaviours, presenting evidence for the need to progress current interventions aimed to reduce the occurrence of risky behaviours within the CF population. Within both phases of data collection there was a reported lack of knowledge concerning consequences of risky behaviours, with some adult and paediatric participants explaining how they have not received awareness regarding the adverse health effects of risky behaviours from their HCPs. The researcher therefore deemed it essential to discuss

the issue of risky behaviours with HCPs, to explore what awareness they provide their patients with concerning risky behaviours, and whether or not there are procedures in place to determine which patients receive this information. During the course of this research, the researcher presented the emerging findings at a variety of national and international conferences, ensuring the validity of findings through the use of theory triangulation, with HCPs and academics agreeing that this research would benefit from direct collaborations with HCPs to provide practical insight into effective interventions to reduce the occurrence of risky behaviours.

Phase three data collection involved discussions with HCPs. CF Specialist Nurses were interviewed to gain insight into how Nurses perceive the issue of risky behaviours within the CF population. The researcher only recruited CF Specialist Nurses as it was believed that they would be responsible for delivering a new intervention regarding risky behaviours, in line with previous literature conducted within the general population (Cooley, Lundin & Murray, 2009; Fore, Karvonen-Gutierrez, Talsma & Duffy, 2014; Sarna et al., 2016). In addition, the first two phases of data collection signalled that individuals with CF are closer to Nurses than to other members of the multi-disciplinary team (MDT), often disclosing more information to Nurses. Therefore, it was believed that Nurses would be well placed to offer valuable insights into the issue of risky behaviours and effective interventions. The researcher conducted telephone interviews due to the asynchronous communication of place, enabling the researcher to interview Nurses from a range of geographical locations within the UK (Mann & Stewart, 2000). These interviews provided insight into CF care and strategy used to address the issue of risky behaviours, from a wider population than face-to-face interviews would have generated. In addition, the asynchronous communication of place can make individuals more willing to discuss sensitive accounts, which they may have been reluctant to discuss face-to-face (Mann & Stewart, 2000). For Nurses, sensitive accounts may have been perceived to be the identification of flaws within their service. The telephone interviews were synchronous communications of time, so like with the face-to-face interviews conducted in the previous phases of data collection, the researcher could ensure question wording and order were contextual and in response to the participants developing account (Braun & Clarke, 2013; Rubin & Rubin, 1995).

The findings from phase three data collection coincide with the findings from the transition evaluation and the previous phases of data collection, with the need for new interventions being demonstrated, in order to reduce the occurrence of risky behaviours. This research therefore provides an opportunity for the implementation of research informed practice within the CF population. As this third phase of data collection only investigated how Nurses perceive the issue of risky behaviours, and what interventions they would like

implemented, the researcher identified the importance of speaking to, and collaborating with, other HCPs in order for this research to have a "real world" impact in the practice of health care (Henriksen, Battles, Marks & Lewin, 2005). The final phase of data collection allowed the researcher to disseminate the research findings, allowing HCPs to critique the findings and offer suggestions regarding what interventions could work in clinical practice.

The researcher viewed the act of dissemination to be crucial for this research, as in order for the findings to be used to create an intervention that has practical applications, the researcher needed to gain the views of HCPs. Therefore, the researcher acknowledged the need to make HCPs aware of the research findings, in order for those HCPs to make use of such findings (Freemantle & Watt, 1994), with the researcher believing that dissemination was the first stage of collaboration with HCPs to create an intervention (Bradley, McSherry & McSherry, 2010). In disseminating the research findings, the researcher was complying with the guidelines by the NHS Institute for Innovation and Improvement (2010), and The Foundation of Nursing Studies (2010), ensuring the new knowledge this research generated was added to the field of CF (Pellecchia, 1999).

This final phase of data collection was a crucial process in ensuring the issue of risky behaviours within the CF population will be addressed using evidence based practice, where HCPs will make decisions on whether to implement future interventions based upon quality information which derived from research (Bradley et al., 2010; Scott & McSherry, 2009). Through disseminating the research findings with CF HCPs it has ensured that all team members are research aware (Scott & McSherry, 2009; McSherry & McSherry, 2001).

Analysis applied to each phase of data collection

For all phases of data collection, the audio recordings were transcribed by the researcher utilising the Jefferson transcription coding to focus upon phonetic and paralinguistic features as well as spoken words, recording what was said and how it was said (Heath & Hindmarsh, 2002). To reduce the occurrence of omissions and mistaken words within the transcripts, the researcher transcribed each recording within five days of conducting the interview or dissemination meeting, improving the quality of the transcripts as the memory of what happened during data collection (e.g. body language) rapidly fades (Braun & Clarke, 2013). The data was analysed using thematic analysis following Braun and Clarke's (2006) model as this is a flexible method. Thematic analysis was used as a contextualist method, positioned between the two poles of essentialism and constructionism, characterised by critical realism (Willig, 1999). A contextualist method was used due to the reasons for engaging in risky behaviours being context-dependent (Brendel & Jager, 2005),

therefore thematic analysis acknowledged how participants made meaning of their experiences, alongside the impact the broader social context has upon those meanings; indicating that meanings and experiences are socially produced and reproduced rather than being inherent (Burr, 1995). This research represented an ontological realistic approach, acknowledging that phenomena exist independently without individuals' perceptions, theories and constructions, whilst accepting a form of epistemological constructivism and relativism, where phenomena are inevitably a construction from an individuals own perspectives (Maxwell, 2012). With this research being characterised by critical realism it acknowledges there is no possibility of attaining a single, "correct" understanding of the world (Maxwell, 2012; Sims-Schouten, Riley & Willig, 2007); with this research acknowledging that mental states and attributes (e.g. intentions to engage in risky behaviours) are part of the real world despite them not being observable (Houston, 2001; Maxwell, 2012). Secondly, this research rejects the theory of causality and instead focuses on processes which influence risky behaviour engagement, in viewing these processes to be central to the explanation as to why some individuals with CF engage in risky behaviours despite their compromised health status (Maxwell, 2012; Parker, 1998).

Within each phase of data collection thematic analysis provided a rich thematic description of the entire data set, as risky behaviours within CF is an under-researched area (Braun & Clarke, 2006), where CF patients' views surrounding risky behaviours had not previously been known. In addition, the themes were identified in an inductive way, consequently the themes are data-driven and not the researcher's analytic preconceptions (Braun & Clarke, 2006; Patton, 2015). Furthermore, the themes identified were done so at the latent / interpretive level, meaning that this research went beyond the semantic content of the data, examining the underlying ideas and assumptions which shaped the semantic content (Burr, 1995). Therefore, the themes were not just descriptive; they were already theorised (Braun & Clarke, 2006).

To conduct thematic analysis within each phase of data collection, the researcher firstly became familiar with the data, paying attention to any patterns that occurred. Data familiarisation occurred firstly during data collection and transcription of the data, where the researcher actively processed the data. In addition, data familiarisation occurred as a consequence of the researcher reading through the transcripts several times. The early thoughts from the researcher about what was happening in the data suggested ways in which the data could be coded, offering ideas about the themes apparent within the data (Howitt, 2013).

Once the researcher was familiar with the data, the researcher coded each transcript line by line, ensuring the researcher was working with the detail of the data (Howitt, 2013). Each code provided a label to describe the content of the quote selected, with each code representing something interesting or important about that section of data. The codes generated were all data-led, guided by careful analysis of what was in the data (Braun & Clarke, 2006). On completion of initial coding, the researcher collaborated with her director of studies, allowing the initial codes to be evaluated and revised to ensure they were representing the content of the data. At this point the director of studies and the researcher became two raters who were coding the qualitative data to form the themes of the data. The researcher then created separate documents which contained the data for each code. In doing this it became clear whether the code's label was accurately representing the data within that code; whether data which received the same code were similar, or whether a new code was required to represent different data that had been placed within a code; and whether there were similarities between the data in different codes suggesting they should be combined (Howitt, 2013). The researcher then presented these revised codes to her director of studies, allowing for the codes to again be revised based upon evaluations which arose from these collaborations. The validity of the codes were ensured when the researcher and her director of studies were in agreement regarding each code.

Once the researcher and her director of studies were satisfied with the generated codes, reflecting upon and revising the initial codes, the researcher generated the themes of the data. To create the themes, the researcher categorised the codes into meaningful groups of codes, with the themes identifying major patterns which emerged from the codes (Braun & Clarke, 2013; Howitt, 2013). During this process the researcher collaborated with her director of studies, allowing the two raters to reflect and revise upon the early categorisation of codes, ensuring the validity of this process. When generating the themes the researcher created a word document for each theme, which contained each code represented within that theme, along with the accompanying data for each code. This allowed the researcher and her director of studies to review each theme, assessing whether each theme accurately represents the data, ensuring there is enough data to support each theme, and that each theme does not actually represent two different themes or sub-themes (Braun & Clarke, 2013; Howitt, 2013). The validity of the themes were confirmed when the researcher and her director of studies both agreed on the themes of the data and which codes should be represented within each theme. Through assessing how the themes support the data and the overarching theoretical perspective, the researcher defined what each theme was, which aspects of the data were being captured, and what was interesting about the themes. The process of thematic analysis was completed by hand for all phases of

data collection, with the collaborations between the researcher and her director of studies helping to ensure the inter-rater reliability of the data generated.

Considerations by the Researcher

The Researcher's Identity. During this research, the researcher spent time reflecting on how her identity could influence the data. Whilst it is acknowledged that participants feel more comfortable disclosing sensitive information to an individual who is broadly similar to themselves, it was not practical nor possible to match the researcher with participants based upon major social characteristics, therefore the researcher employed caution and sensitivity remaining mindful that participants may have been socially marginalised in ways she was not (Braun & Clarke, 2013). Despite the number of differences that would have been present between the participants and the researcher within phase one data collection with adult CF patients, their age was one social characteristic that was similar (mid – late twenties / early thirties), potentially making participants more comfortable when disclosing sensitive information; this may have been a result of participants not perceiving the researcher to be in a position of control of the interview (Braun & Clarke, 2013).

Nonetheless, the researcher's role as a "researcher" may have influenced such power relationship, with participants potentially perceiving the researcher to be an "expert", overriding other aspects of the researcher's identity even if this was shared with participants (e.g. age) (Clarke, Kitzinger & Potter, 2004). Furthermore, due to the potential disclosure of sensitive information, the researcher was prepared to deal with participant's distress, in such instances the researcher would have acknowledged participants distress, asking if they needed a break, and if they wanted to continue (or stop); the researcher would have allowed participants to express such distress whilst containing it within the context of the interview. The researcher would have diverted from the topic that was causing distress, and sensitively returned to the topic later in the interview if deemed necessary, and suggested by participants that it was acceptable to do so (Braun & Clarke, 2013). This technique was not needed to be employed within any of the four phases of data collection.

Within phase two data collection with paediatric CF patients, a major social characteristic that was different between the researcher and participants was age, with it being expected that participants viewed the researcher to be a lot older than themselves, potentially impacting upon the participants disclosure of information, due to the impact age can have upon the power relationship within interviews. The researcher's identity as a "researcher" will again have influenced participants disclosure, due to participants potentially perceiving the researcher to be an "expert" (Clarke et al., 2004). The researcher employed

effort during the interview to develop a sense of rapport to reduce the power imbalance present. Many participants offered detailed accounts into their lives, explaining their attitudes and beliefs towards their CF and associated health behaviours, therefore suggesting that participants felt comfortable to contribute to the interview, despite the power imbalance.

Validity

To ensure validity during this research an interview was conducted on the researcher to investigate any biases the researcher had which could influence the research outcomes. In addition, the researcher used a reflexive diary and demonstrated triangulation.

Interview Conducted on the Researcher. Dr Marian Crowley conducted an interview with the researcher to investigate the researcher's knowledge regarding CF, and what the researcher was interested in within this chronic illness, to identify any biases the researcher may have had that could have influenced the research outcomes. The interview suggested that the researcher has a personal insight into CF with the researcher's partner having CF. The researcher believed this insight would enable her to empathise with participants as she is aware of what the day to day living is like for an individual with CF. This interview indicated that in particular the researcher was interested in individual's views regarding their life with CF and the psychological implications this involves. The researcher has no personal experience of risky behaviours within CF (in terms of her partner). The researcher acknowledged the importance of individual differences in reasons for engaging in risky behaviours, with the researcher aiming to investigate the psychological implications within CF that can result in risky behaviour engagement, despite the adverse health effects.

Reflexive Diary. I kept a reflexive diary during this research enabling me to think in a critical and analytical way about the research during its progress, and enabling me to see how different areas of the research are related (Day, 2012). For instance, on 3rd May 2016, I wrote:

"This interview was the first paediatric interview where a participant disclosed risky behaviour engagement. I find it interesting how individuals aged 12-15 years often report being very anti such behaviours, where individuals aged 18+ years often report engagement / experimentation in such behaviours (from phase one data collection)."

During the research I documented within the reflexive diary how I was constantly aware of my identity as a researcher, of the research process and of how each played a role in shaping the data (Humphrey, 2014). For instance, on 22nd March 2016 I wrote:

"I conducted my first paediatric interview today. The interview was a lot more challenging than the adult interviews in terms of encouraging the participant to 'open up' instead of providing closed answers. This was to be expected due to the differences in age between myself and the participant. However, I did provide a range of prompts to encourage elaboration and believe that I managed to generate some useful data."

Within the reflexive diary I reported where the research inspiration arose from, how I generated new research ideas, and my awareness of the research context (O'Reilly, 2012). For instance, in November 2014 I wrote:

"I have decided to broaden my research so it incorporates all risky behaviours, as opposed to just smoking. Quantitative research has been conducted within the CF population focusing upon the incidence and prevalence of smoking, excessive alcohol consumption and illicit drug use. Qualitative research focusing upon all these behaviours will enable me to produce more informative findings for CF Clinicians, which will be applicable to a range of risky health behaviours."

The reflexive diary also made reference to my field notes documenting what was observed during the research including other's actions, conversations and my impressions, feelings and tentative models (Pritchard & Whiting, 2012). The reflexive diary indicated how naturalism was increased during the research as I was present in the CF clinics and wards on a regular basis, becoming "part of the furniture", therefore the research disturbed the natural clinic setting as little as possible (O'Reilly, 2012). For instance, I attended the adult CF clinic at the Royal Stoke University Hospital every Monday even if the Consultant had not identified a suitable patient to interview, providing an opportunity for individuals to be recruited on that day:

"I attended clinic today at the Royal Stoke University Hospital however I did not manage to recruit or interview any participants. I understand that at times I will have "wasted" journeys, however it does mean that my face stays familiar amongst the team".

Triangulation. Triangulation was generated to ensure that results accurately reflect the reasons that people gave for engaging in risky behaviours, and to be certain that the findings are supported by evidence, ensuring the validity of this qualitative work (Guion, Diehl & McDonald, 2011). This research involved data triangulation as multiple institutes were used to recruit participants for each phase of data collection, providing the research with different sources of information (Heale & Forbes, 2014). In an aim to generate theory triangulation, the researcher presented this research (aims and methodology to begin with, and then any findings as they emerged) at various national and international conferences,

and research meetings to use multiple perspectives to interpret the data (Guion et al., 2011). This enabled professionals outside of the field to comment on the theory and data generated, and to offer different perspectives on this data. The validity of findings was confirmed when professionals from different disciplines interpreted the information in the same way (Guion et al., 2011). These methods of triangulation demonstrate that the theories have been challenged and integrated to produce a clear understanding on why some individuals with CF engage in risky behaviours (Thurmond, 2001). Whilst presenting this research, the researcher reflected and acted upon points made by fellow academics and HCPs (Appendix A).

Conclusions

The methodology used within this research generated an in-depth understanding regarding the factors that influence the engagement in risky behaviours within both the adult and paediatric CF population, with HCPs highlighting what interventions they believe should be integrated into CF care to reduce the occurrence of risky behaviours. The following chapters describe each phase of data collection in detail, highlighting how each phase of data collection was conducted, and how the findings from each phase of data collection informed the next phase of data collection. The findings generated by this research do have clinical and practical applications when addressing the issue of risky behaviours within the CF population. This doctoral research has created strong conclusions and recommendations on how to progress current interventions, aimed to reduce the occurrence of risky behaviours within the CF population.

CHAPTER FIVE: METHODOLOGY - AN EXPLORATION OF RISKY HEALTH BEHAVIOURS WITHIN THE ADULT CYSTIC FIBROSIS POPULATION

The Research Sites

Participants were recruited from Birmingham Heartlands Hospital and the Royal Stoke University Hospital. These two research sites were chosen due to existing research collaborations and their geographical location.

Birmingham Heartlands Hospital is host to the West Midlands Adult CF Centre, who's MDT of HCPs includes Consultants, Registrars, Physiotherapists, Dieticians, a Social Worker, Psychologists and Specialist Nurses. This unit provides inpatient and outpatient care for adults with CF who are over the age of 16 years. A peer report concluded that this unit is a "large well-established centre, staffed by an enthusiastic and skilled MDT which is housed in a dedicated facility" (The CF Trust, 2013b, p, 1). The researcher had previously conducted research here investigating adherence, therefore the researcher had good working relationships with the MDT. In order to gain approval from the MDT for this research, the researcher presented the proposal and rationale during a MDT meeting. The team were supportive of the research aims and objectives.

The Royal Stoke University Hospital is host to the North West Midlands Adult CF Centre, who's MDT of HCPs includes Consultants, Specialist Nurses, Physiotherapists, Dieticians and an Arts Psychotherapist. This unit again provides inpatient and outpatient care for adults with CF. A peer report concluded that this unit is "a crucial resource for a large region that includes areas of social deprivation" (The CF Trust, 2013c, p, 3). The researcher had no prior research experience within this unit, however the Consultant when contacted was keen to be involved, believing the research is valuable. The research was discussed with the Consultant via email, and then following ethical approval the researcher was introduced to the MDT.

Participants

Twenty-four adult participants (male: 16, range: 19-66 years, mean: 34 years) were recruited, with a median FEV₁ 60.77% predicted (Table 1).

Participant Number	Sex	Date of Birth	Age	Latest Lung Function Result (FEV ₁)	Late Diagnosis
1	Male	20/12/1995	19 years	127%	
2	Male	21/07/1996	19 years	68%	
3	Female	14/03/1983	32 years	56%	
4	Male	11/07/1968	47 years	60%	Yes - aged 40 years
5	Female	04/10/1995	19 years	50%	Yes - aged 10 years
6	Female	15/05/1983	32 years	39%	
7	Male	14/02/1949	66 years	95%	Yes - aged 50 years
8	Female	18/12/1981	33 years	/	
9	Male	15/11/1989	25 years	87%	
10	Male	25/01/1983	32 years	30%	
11	Female	03/07/1986	29 years	75%	
12	Female	23/01/1958	57 years	51%	
13	Male	15/07/1981	34 years	32%	
14	Male	11/03/1982	33 years	75%	
15	Male	18/09/1981	34 years	46%	
16	Male	12/03/1972	43 years	/	
17	Female	22/03/1987	28 years	81%	
18	Female	22/07/1987	28 years	65%	
19	Male	22/06/1992	23 years	/	

20	Male	28/12/1979	35 years	27%	
21	Male	26/07/1982	33 years	26%	
22	Male	27/01/1969	46 years	26%	
23	Male	16/06/1994	21 years	48%	
24	Male	13/07/1984	31 years	110%	

Table 1. Medical and Demographic Data collected for all adult participants.

Seventeen participants disclosed during the interview that they did engage in risky behaviours, with four of these participants initially being identified by their MDT to be "non-risky" patients during inception. Furthermore, two participants who HCPs had identified to be "non-risky" during inception had a history of risky behaviour engagement prior to their late diagnosis of CF, which was disclosed during the interview. The researcher received no guidance from HCPs regarding a patient's history with risky behaviours until consent had been provided.

Inclusion Criteria: All adult patients were eligible to take part in the research, however adults who were known to have engaged in risky behaviours were specifically targeted for inclusion. These patients were identified through discussions with CF Consultants. The researcher included "non-risky" participants for two reasons:

1. CF Consultants may not be aware that individuals have engaged in risky behaviours, due to non-disclosure (this was the case for four participants; for some participants HCPs were not aware of the extent of participants engagement; the researcher did not disclose such information to HCPs). It is often easy for HCPs to identify individuals with CF who smoke, because of its respiratory implications. However, it is less easy to detect whether an individual with CF has engaged in drug use etc. Many participants who disclosed a history of drug use indicated that they had not informed HCPs of this behaviour (HCPs were often only aware of their smoking behaviour). Therefore, by including all adults with CF within the inclusion criteria, individuals were not excluded as a consequence of HCPs knowledge.
2. By including adults with CF who have never engaged in risky behaviours it allowed the researcher to draw comparisons between their beliefs, and the beliefs of individuals who have engaged in risky behaviours, to inform

interventions aimed to reduce occurring risky behaviours within the CF population.

Exclusion Criteria. Individuals were excluded if they had a lack of capacity (identified by their Consultant) and if they were non-English speakers. These individuals were identified through discussions with the CF Consultants and by consulting CF outpatient and inpatient lists.

Where possible all adults with CF who were eligible to participate were invited to do so until data saturation occurred. On occasions, eligible patients may have been missed as a consequence of the researcher interviewing another participant, or if the Consultants had failed to refer an eligible patient.

Measures

Semi-Structured Retrospective Interview. The researcher conducted semi-structured retrospective interviews with adults to investigate their views towards risky behaviours. For the purpose of the information sheet and verbal discussions with individuals regarding the research, the phrase "lifestyle choices" was used rather than "risky behaviours", as it is a less value-laden phrase and incorporates various behaviours that may or may not be perceived as risky by participants.

To achieve saturation the researcher undertook all transcriptions of interviews within five days after each interview was completed in order to identify when "nothing new" was being heard. A semi-structured interview schedule (Appendix B) was developed through consulting the existing literature, and draft schedules were discussed with both patient representatives and the researcher's supervisory team for their input. The researcher employed effort to ensure that the interview questions followed a logical order, in line with showed good practice, opening questions were less direct or probing and developed as the interview proceeded to explore in more detail personal lifestyle choices (Kvale & Brinkmann, 2009). In addition, the researcher ensured the interview questions were worded to encourage rapport, and were not leading, providing enough information to participants so they understood what the area of interest was, but participants were free to respond in whatever way they wished (Braun & Clarke, 2013). Probes or prompts were used within the interview to encourage elaboration; probes consisted of either an "mm" or a specifying question, signalling further information was required (Fielding & Thomas, 2008; Kvale & Brinkmann, 2009). The researcher also was careful not to interrupt or add comment until the

participant had finished answering a question, leaving a short period of silence where appropriate in order to give participants the opportunity to elaborate further.

The semi-structured interviews investigated participants' beliefs about their CF and the impact CF has upon their life, exploring reasons for engaging and not engaging in risky behaviours. This research focused upon the roles of identity, acceptance and unrealistic optimism in influencing risky behaviour engagement within the CF population; however this research was qualitative, allowing for exploration of the defined areas, and also elaboration by participants on other topics (Gill, Stewart, Treasure & Chadwick, 2008). The researcher did not rigidly adhere to the interview schedule, as question wording and order are contextual, and should be responsive to participants developing accounts (Braun & Clarke, 2013; Rubin & Rubin, 1995). The qualitative interviews enabled the research to take an interpretive perspective on risky behaviours within CF, creating humanistic research, which meant that individuals with CF, their pain, hopes and fears were not reduced to "technical guidelines about how to deal with things", instead the research viewed participants as people (holism) and acknowledged the importance of individual differences (Yates et al., 2010, p. 19).

The interview schedule commenced with a section of icebreaker questions which are important when discussing sensitive topics (e.g. life with CF), with the aim of creating a sense of rapport with participants, and encouraging greater depth in their subsequent answers (Cooley, Holland, Cumming, Novakovic & Burns, 2014), making them feel comfortable about contributing honestly during the interview (e.g. disclosing risky behaviour engagement) (Ashton, 2014). The icebreaker questions began by encouraging participants to discuss their views towards the research (e.g. *"What were your first thoughts when you were asked to take part in the research?"*), with the questions then becoming more personal by asking participants about what a typical day is like for them, however it was up to participants whether they discussed CF within their typical day.

The interview questions then invited participants to discuss the impact CF has on their life. The aim of these questions were to provide insight into what an individual's life is like with CF, with Cox (2015) demonstrating the need for research to investigate this using qualitative methods due to CF being a growing and a changing population. These questions predominantly focused upon the challenges of CF to highlight which aspects of their lives individuals require support with. This conversation was steered by any disclosed information during the ice-breaker questions, with the researcher planning to firstly focus upon treatment adherence, with the research framing non-adherence as a risky behaviour. The researcher had previously conducted research within the CF population focusing upon adherence, with

individuals often providing a large insight into their adherence efforts. Adherence is a topic that patients with CF are used to discussing on regular occasions with HCPs, therefore it was deemed that this would not be a sensitive topic for participants. As the interviews were semi-structured, participants could discuss any other ways they feel that CF impacts upon their life, with this section remaining broad and open-ended allowing participants to highlight issues that are pertinent to their life and individual circumstances (Cooley et al., 2014).

The interview schedule then focused upon the issue of risky behaviours specifically. It was expected that by this stage participants would have already disclosed whether or not they engage in risky behaviours, however if this was not the case the researcher asked participants a question to encourage disclosure:

"Are there any behaviours that you do engage in, or have engaged in, that others may say is not good for your health?"

The researcher then discussed any disclosed behaviours with participants in a non-judgemental way, gaining insight into participants' personal beliefs surrounding these behaviours. The handout that participants received alongside their consent to contact form illustrated that the researcher was not judgemental about the behaviours participants may have engaged in, and was not there to say what behaviours are "right or wrong". The handout stated that the research was interested in participants' personal views and experiences about their lifestyle choices, and how they impact upon their health and wellbeing (both in a positive or negative way). The researcher was interested in investigating whether participants had good awareness on the health effects of risky behaviours, as the transition evaluation suggested that individuals with CF may have poor awareness regarding the possible health consequences of some behaviours. In addition, the researcher was interested in investigating what motivated participants initiation, or why they decided to not engage in such behaviours, with a focus upon identity (Withers, 2012), acceptance (Laws et al., 2012), and unrealistic optimism (Weinstein, 1980). The next section of the interview then encouraged participants to discuss support they receive from others, including family, friends, HCPs and others with CF, in order to investigate whether or not this support has an influence upon individuals' decisions regarding risky behaviours. The researcher decided to ask participants specifically about any relationships they have with others with CF due to this being identified by patient representatives as a potential issue within the CF population, with the first two interviews conducted also highlighting this issue; therefore due to the risk of cross-infection, CF patients meeting face-to-face could also be seen as a risky behaviour.

Whilst the interview schedule aimed to generate rapport between the researcher and participants, and it was essential for the researcher to empathise with participant's potential

distress, the researcher had to remain professional as a researcher (Ashton, 2014; Hennink, Hutter & Bailey, 2011). The interview schedule aimed to make participants feel supported and comfortable to disclose potentially sensitive information, with the researcher communicating interest and concern for participants by being empathetic (Ashton, 2014; Patton, 2002), however the researcher acknowledged that to ensure the findings are credible the researcher's approach needed to be a balance between empathy and neutrality (Ashton, 2014). The researcher therefore communicated an understanding of the "positions, feelings, experiences and world views" of participants (Ashton, 2014, p.28), expressing a non-judgemental approach (Patton, 2015), whilst keeping some empathetic distance (Valentine, 2007) by listening, recording and observing the interviews, enabling the researcher to engage with participants without becoming too involved (Ashton, 2014). The researcher also ensured that she did not interrupt participants or break silences, enabling participants to reflect upon the discussions (Ashton, 2014). To confirm the researcher was correctly hearing and receiving participants' experiences, the researcher carefully listened to participants and responded to their discourse (Valentine, 2007).

The researcher also acknowledged that whilst the interview schedule allowed the researcher and participant to connect, enabling disclosure of information (Hennink et al., 2011), the researcher needed to reduce the rapport and create distance during the end of the interview (Ashton, 2014). Therefore, in line with Rubin and Rubin's (1995) suggestion, the interview schedule concluded with three questions which involved the participant hypothetically providing advice to a young person with CF and their family. The final questions allowed participants to summarise the main issues they had discussed, which Rubin and Rubin (1995) state allows participants to feel in control of the interview through providing their own narrative. The final question gave participants the opportunity to provide any information which they considered relevant ("*Do you have anything else to add?*"), ensuring participants felt that their contribution was valued, by portraying that their experiences will help others with CF (Ashton, 2014).

With this phase of data collection being retrospective, it is acknowledged that the ability to adequately detect change and identify influential factors is dependent on the researcher's ability to reconstruct the past using information participants provide (De Vaus, 2006). Therefore, the researcher conducted a series of simulated pilot interviews on psychology academics using role play scenarios before the study beginning, confirming the researcher's ability and the effectiveness of the interview schedule, with it being amended as necessary. In addition, after conducting two interviews, the recordings were listened to by the researcher and her supervisors, again to confirm the effectiveness of the interview schedule. Furthermore, during the process of interviewing and transcribing, the researcher

constantly reflected on the interview schedule allowing it to evolve in response to participants' experiences (Charmaz, 2002). An amendment was made which was the inclusion of a discussion as to whether or not participants meet face-to-face with others with CF, as it appeared that this was the case for some participants, this had not been anticipated by the researcher previously. Being in physical contact with others with CF is clinically inadvisable (Lamas, 2013) because of the risk of cross-contamination. Such contact could therefore be construed as a risky health behaviour.

Carrying out the Study

Once non-eligible patients had been identified, the MDT were able to approach all eligible patients at each clinic or on the ward and provide them with a handout explaining the research (Appendix C) alongside a consent to contact form (Appendix D). All patients were eligible, however when clinical staff were aware that an inpatient or outpatient had engaged in risky behaviours they were targeted. Once individuals had provided consent to be contacted by the researcher, the researcher contacted them within the next 24-48 hours, via telephone at a time convenient for themselves (mornings, afternoons or evenings - as indicated by patients). Data collection methods were led by clinical staff; at the Royal Stoke University Hospital the researcher attended clinic every week (which was held on Monday's), with staff believing it to be useful for the researcher to be on site to briefly talk to patients after consent to contact had been provided, enabling the researcher to provide further information to participants about the research. At Birmingham Heartlands Hospital, the researcher only attended clinics, or visited the ward when an interview had been arranged.

Once consent to contact was received the researcher explained the research verbally to individuals over the telephone (and face-to-face at the Royal Stoke University Hospital) and allowed them to ask any questions. If they were still interested in participating, the researcher arranged to meet patients at their CF centre at a time / date convenient for themselves (usually to coincide with outpatient appointments or scheduled inpatient stays). The MDT advised the researcher of the patient's arrival at clinic. The researcher approached desired adults with CF individually and asked if they were still willing to take part in the research.

The study was fully explained to patients, both verbally by the researcher and in the form of a written information sheet (Appendix E), to ensure patients truly understood the nature and purpose of the research, and patients again had the opportunity to ask any questions. Patients had a maximum of two weeks to decide on participation, to help facilitate informed consent. If patients wanted to participate they had to complete a consent form

(Appendix E) to ensure informed consent had been collected. Adequate records were kept of how, when and from whom informed consent was obtained. A coding method was used; participants were given a number which they wrote on their consent form with their name. The researcher stated this number at the beginning of the interview recording and wrote this number on their interview transcript (all data was anonymised and confidential; pseudonyms were used when writing this research up). Participants contact details (email address or telephone) were also collected so the researcher could contact participants at the end of the research to share the overall research findings. All confidential information and personal data was stored securely in a locked filing cabinet at the CF unit to avoid inadvertent disclosure.

Once informed consent had been obtained, participants then completed a semi-structured interview to investigate whether or not they had engaged in risky behaviours, and to investigate what motivated such decisions. The interview could be conducted on the same day as informed consent had been collected, alternatively participants could be interviewed on a separate day to suit their availability (twenty-two participants were interviewed on the same day, two participants were interviewed on a different day). The interview was conducted in a private room at the CF centre and lasted a maximum of 60 minutes; however it could be stopped earlier at participants discretion; within this research no participants requested for the interview to be stopped early. Participants did not have to answer any questions they did not want to. All participation was voluntary, and participants could withdraw from the research at any time without being penalised; within this research no participants withdrew. If participants had got distressed during the interview and expressed an interest to not continue, the interview would have been stopped immediately and a referral would have been made to their MDT; within this research no participants became distressed. Due to this research examining whether participants were unrealistically optimistic about their health the results could have upset participants. If participants had have requested their results, they would have only been able to view their own interview transcript along with any themes that emerged (it would not have been explained what the interpretation of the interview was); within this research no participants requested this information. If participants had disclosed during the interview that they wanted to quit their risky behaviours they would have been advised to seek help from HCPs, within this research no participants disclosed a desire to quit their behaviour.

Once the interview was complete participants were provided with a debriefing sheet (Appendix F), and again had the opportunity to ask any questions. The researcher then contacted all participants once the research had been analysed to share with them the overall research results and to provide the opportunity for results feedback (Appendix G).

Ethics Committee

Ethical approval was obtained via the Integrated Research Application System by NRES Committee East Midlands – Leicester, and the R&D departments at Birmingham Heartlands Hospital and the Royal Stoke University Hospital.

Analysis

As described in the analysis section within Chapter Four, the interviews were transcribed utilising the Jefferson transcription coding (Heath & Hindmarsh, 2002), with the data being analysed using thematic analysis following Braun and Clarke's (2006) model. Thematic analysis generated 138 initial codes, with these initial codes being revised to form 143 codes. An example of an initial code which was separated to form two distinct codes is highlighted below (see Appendix H for more examples):

- The data within the code "Occupational Identity" was separated to form two distinct codes:
 - **The impact Employment / Education has upon an individual's Identity with CF**, which explores both positive and negative impacts employment and education can have upon a CF patient's identity
 - **The relationship between an Occupational Identity and Risky Behaviours**, which represents how the workplace / educational institute can encourage a CF patient to engage in normalised risky behaviours

The researcher made inferences about what the codes meant enabling the codes to be combined into five overarching themes that accurately depict the data (Appendix I). The five themes generated are described in detail within the next chapter, utilising direct quotes and discussion around the reasons why some adults with CF may engage in risky behaviours.

CHAPTER SIX: ANALYSIS - AN EXPLORATION OF RISKY HEALTH BEHAVIOURS WITHIN THE ADULT CYSTIC FIBROSIS POPULATION

Thematic analysis was applied to the interview transcripts following the Braun and Clark (2006) model, which elicited key concepts that were evident when participants were discussing their experiences of living with CF, and their engagement with risky behaviours. Five themes were identified which were deemed essential when determining the understanding of all participants. The first theme, labelled as "All I've ever wanted is to be happy", highlights how a positive outlook is highly valued by individuals, providing insight into the role risky behaviours can play in influencing an individual's outlook. Theme two, "Are they sure I haven't just got asthma?", covers an area related to avoidance of CF, highlighting how avoidance can provide a gateway to risky behaviour engagement and non-adherence. The third theme, labelled as "If you haven't got support it can be detrimental to you because you need that support", outlines how a lack of support within an individual's private life can be associated with risky behaviour engagement, highlighting the role HCPs can play to reduce the occurrence of risky behaviours. Theme four, "Why should I let Cystic Fibrosis completely dominate my life", signals how a desire to not be defined by CF is influential upon one's adherence behaviours and engagement in risky behaviours. The final theme, labelled as "The biggest challenge is coming to terms with having Cystic Fibrosis", highlights how many individuals find acceptance towards their CF to be difficult, with individuals who demonstrated acceptance portraying how it can be associated with positive health behaviours. It is acknowledged that there are aspects of participants' experiences and understandings that overlap across these themes; however this was to be expected, as a good interpretation of understandings and attitudes specify these are never made up of isolated concepts (Fielden, Sillence & Little, 2011). All five themes will be further examined in the next segment, by utilising direct quotes and discussion around this topic area.

"All I've ever wanted is to be happy"

This initial theme explores how different individuals with CF view their life, and their future, providing insight into what influences an individual's outlook. A number of participants had a positive outlook towards their life and expressed optimism towards their future. James suggested that his positive outlook is due to his ability to lead a normal life when he is not experiencing exacerbations of his CF, explaining that it is only when he is ill with an infection that he notices his CF, James does not view himself to be ill until his symptoms become problematic.

*[James, 19 years]: "You don't notice you have it (.) unless: you're ill"

It would therefore not be advantageous to encourage participants like James to incorporate their CF into their identity, as it was adaptive for these "healthy" participants to not view themselves as being ill. Whilst these participants accept that they have CF, their outlook on their lives and their illness is strongly influenced by symptom presentation, with James not possessing an illness identity when he does not notice his CF, highlighting the fluidity of an individual's identity which can change over time and across circumstances.

For some participants their positive outlook towards their life was partly as a result of comparing themselves favourably to others, or by comparing CF to other conditions. Sarah believed that there are worst things that could happen to her than CF, allowing her to be positive regarding her life and future, due to her understanding of common humanity, that is, that everyone suffers.

*[Sarah, 32 years]: "There's worst people off than me [...] I've got two amazing children (.) a roof over my head (.) food you know (.) in my stomach # we've got an NHS that (.) you know (.) makes this capable (.) there's a lot of people worst off"

It was often the case that participants did not define themselves as being ill and appeared to possess a normal identity, when they were not experiencing exacerbations of their CF.

*[Ashley, 35 years]: "It's [CF] not as bad as a lot of people make it out to be [...] it's not the end of the world [...] when you've got CF it's not really as bad as people think"

Whilst many participants positive outlook was influenced by symptom presentation, for some participants their positive outlook was a product of engaging in behaviours which could be harmful towards their health, with some participants acknowledging these associated hazards. Matthew explained how using a steam room has a positive impact upon his life psychologically, improving his mood and making him feel "invigorated", despite acknowledging the CF-specific risks associated with this behaviour.

*[Matthew, 47 years]: "I shouldn't be going in there [steam room] [...] ↑ I feel good after [...] I know that there is a risk # but e:every now an then I just # if it's going to make me feel a bit better than what I'm feeling now then # I'll just go in"

Matthew appears to weigh up the potential costs and benefits of using the steam room to inform his behaviour, with him concluding that occasional use will have more beneficial effects than any potential detrimental consequences. At times then, participants appear to value their psychological functioning above their physical health, particularly when they consider themselves to be "well" at present.

Participants' reasons for engaging in risky behaviours varied greatly, with some participants explaining that their engagement was due to psychological distress. James explained how he coped with his depression through smoking marijuana, with this behaviour helping him to forget about his problems.

*[James, 19 years]: "It [smoking] helped me sort of just # forget about them [problems] (.) you know ## not bother with them (.) helped to (.) see the brighter side".

James was aware of the adverse health effects of smoking (both nicotine and marijuana) upon CF, however when suffering from depression James perceived that the psychological benefits of marijuana use were worth the potential risks. In addition, Nick also discussed the psychological benefits of engaging in risky behaviours, explaining how for years he had struggled with depression, regularly taking anti-depressants, however after using magic mushrooms his mood improved, resulting in him no longer needing anti-depressants.

*[Nick, 33 years]: "I love em [magic mushrooms] # I'm definitely (.) definitely going to do them again (.) cause they're brilliant [...] shortly after that I stopped taking my:y # antidepressants (.) and it was like pressing a (.) fa:actory reset"

Participants greatly value the psychological benefits they experience following their risky behaviour engagement, and therefore the risks of such behaviours is not the predominant aspect, rather they focused upon the benefits such behaviours have upon their lives.

For some participants their psychological distress was directly due to their CF. Sarah explained how challenging CF is to cope with, with her deteriorating health at times meaning that she has no life, instead she is just existing and constantly living in fear of CF's fatal nature.

*[Sarah, 32 years]: "I'm on antidepressants [...] I do get really really down [...] I just felt like I had no life [...] I wasn't living (.) I just felt like I was existing [...] it's [CF] not nice (.) and it's (.) not easy to cope with"

Many participants described how CF's fatal nature can result in anxiety, and this is exacerbated when individuals experience health deteriorations. Simon explained how he finds health deteriorations difficult to cope with both due to his diminished ability to engage in activities, and having to depend on others.

*[Simon, 33 years]: "You feel a bit (.) useless # a:and sad re:ally # you know ## cause I know I used to be able to do it [e.g. make his own bed] a fe:ew years back

it's a fu:unny position to be in at thi:irty three # when you se:ee other people an
tha:at"

For participants like Simon their deteriorating health means they cannot complete simple everyday tasks without relying on others, with their identity as grown adults being painfully compromised by their diminished ability. Health deteriorations can also prevent individuals engaging in their usual work or study related commitments. Andrew discussed the negative impact this has upon his life, resulting in disappointment and making it harder for Andrew to remain positive as his health deteriorations prevent him completing his PhD work, which had provided him with great enjoyment.

*[Andrew, 46 years]: "Fo:or the last # two yea:ars # my chest has gone do:ownhill [...] PhD works got less [...] disappointed # re:eally (.) re:eally disappointed"

Due to CF's deteriorating nature, many participants spoke about the challenge of dealing with frequent hospital admissions, resulting in participants not being able to see family or friends as frequently as they wish. Hospitalisation has a negative impact upon an individual's quality of life and psychological wellbeing, due to the interruptions imposed upon their everyday lives, with hospitalisation being a stressful time for patients and families.

*[Katie, 33 years]: "It's hard [hospital stays] [...] I honestly thought # as he [son] got older (.) it'd get easier # but na:ah (.) seeing his face when he has to go (.) and cause me and his Dad don't get on (.) I don't get to see him as much"

With CF's deteriorating and fatal nature, a number of participants articulated that CF's biggest challenge is adjusting to, and dealing with, loss.

*[Andrew, 46 years]: "Dealing with loss ## that's the biggest challenge (.) cause you lo:ose (.) some of your independence # you lo:ose (.) some of your control (.) you obviously lo:ose quality # in terms of what you can actually do # going out (.) being able to eat # e::erm:m # being able to do things when you want"

This "loss" referred to both individual loss of independence, control over their lives, quality of their lives and choices within their lives; as well as loss of others. For many participants, their fear of CF was exacerbated due to their exposure to CF's fatal nature.

*[Katie, 33 years]: "One of my friends died ### he was only ten at the time [...] that hit me quite ha:ard # and that's when my depression started re:eally bad [...] it does mentally scar you what you're going through"

Katie highlighted the challenges of getting close to others and losing them through CF, with this indicating what her future may entail. Many individuals did struggle to cope with CF's fatal nature, with a number of participants demonstrating pessimism towards their future, and possessing a negative outlook towards their life. Matthew who received a late diagnosis of CF aged 40 years, was preoccupied with death, in fearing that any infection could be fatal, regardless of his pulmonary function.

*[Matthew, 47 years]: "My fear is that (.) that the next cold I catch will be the flu # could be my last one (.) you know # I could end up with bronchitis (.) o:or ## pneumonia"

This fear can lead to extreme anxiety, living life fearing that it may be over at any point; with the desire expressed by participants to rebel against negative emotions towards CF by engaging in risky behaviours being easily understandable. Sam explained that as his CF progressively deteriorated he firstly used alcohol, followed by heroin to escape and to avoid CF, alleviating the stresses and anxieties that accompany his diagnosis.

*[Sam, 43 years]: "Things with the CF got mo:ore difficult # it [alcohol / heroin binge] became an easy wa:ay just to:o # sort of esca:ape (.) some of the:e (.) e:er:r # responsibilities and pressures:s [...] it's one wa:ay to ## tu:urn off (.) a:all the # stresses # and anxieties of ## a:and the awa:areness of having # e:erm:m # a condition to dea:al with"

Therefore, for a number of participants their engagement in risky behaviours was clearly linked to their understanding of CF's fatal nature, and their experience of CF's deteriorating nature. Another form of this rebelling that was apparent in the data was reduced adherence to medical regimens. This was particularly evident when participants were experiencing depression, despite them often acknowledging that their non-adherence will deteriorate their health further, exacerbating their depressive symptoms.

*[Will, 21 years]: "Being a bit (.) depressed I guess (.) you know you don't # you don't re:eally feel like doing your treatments to be honest # it's like a vicious circle [...] when you're feeling a bit do:own (.) you're feeling ill (.) you don't want to do your treatments # but then you feel wo:orse (.) an that makes you feel mo:ore down"

For Will the only way to break the "vicious circle" was to be admitted into hospital to improve his health, which in turn improved his mood, providing a "boost" to continue with his adherence post-discharge.

There was also evidence of participants using risky behaviours as a form of self-harm due to depression. When James spoke about his past engagement with marijuana he explained that although he knew this behaviour could adversely affect his CF, he continued his engagement as he valued the positive impact marijuana had upon his life psychologically, with his engagement alleviating his depressive symptoms. However, James also stated that his engagement was to "shunt his life span", with marijuana being used as a form of self-harm.

*[James, 19 yeas]: "I think it [smoking marijuana] was more of a::a (.) way of self-harming [...] I'd start it just to # take away the depression (.) and to sort of # shunt my life span a bit [...] I thought # forget about my CF [...] I'd rather live a short happy life # then a lo:ong # de:epressing [...] it crossed my mind that it would really damage me (.) now I can't remember if I wanted it to damage me # or I just didn't care about it damaging me"

Retrospectively James is unsure whether this was deliberate self-harm or not, however he strongly valued the feelings he received following his engagement. At that point in his life, James was not bothered about the consequences of marijuana, not viewing early death to be a bad thing, with the use of marijuana as a form of self-harm being advantageous as it is less noticeable than other forms of self-harm, therefore it was difficult for others to detect.

*[James, 19 years]: "I've always (.) always hated the idea of self-harming (.) cutting people (.) cutting themselves [...] I chose a different (.) method # that's less sort of (.) noticeable"

There was also evidence of participants using risky behaviours to escape their family circumstances, with some participants experiencing a lack of family support in helping them deal with their CF. Katie explained how she previously used cocaine due to her becoming the victim of domestic violence, where her partner physically abused her when she coughed. Therefore Katie explained how cocaine would stop her coughing, allowing her to escape the abuse.

*[Katie, 33 years]: "I got into a domestic violence relationship [...] if I coughed he used to punch me [...] cocaine's like an anaesthetic [...] it used to like (.) stop me coughing (.) so I used to take it more (.) and more (.) and more # to not get beat up"

The long term negative health impacts of cocaine were understandably of less concern to Katie as she faced an immediate serious and direct threat to her health. Consequently, Katie focused upon the benefits cocaine was having upon her life, describing cocaine as her

"crutch" which she used to help her deal with any issues she encountered within her life, with some participants appearing to engage in risky behaviours to escape both their CF and family circumstances.

A number of participants also explained how their feelings of stress and / or psychological distress were as a consequence of their employment or education. Will explained how his University work, coupled with his complex and time-consuming medical regimens, resulted in him feeling stressed, with his use of ecstasy relaxing him and alleviating this stress.

*[Will, 21 years]: "When I was at uni:i (.) I was quite stressed # so # you know (.) with a:all the work (.) and a:all the treatment (.) this [ecstasy] was a wa:ay (.) .hhh (.) to release (.) a:all the tension"

Will's initiation in ecstasy was due to experimenting with drugs whilst at University, a behaviour which Will found normal whilst at University, however his continuation was as a consequence of the benefits he received following his engagement, in providing him with a positive outlook for that period of time.

The presence of a positive outlook was valued by participants, with some explaining that when they were not experiencing enjoyment through engagement with risky behaviours it resulted in cessation. Sarah explained that she stopped smoking cigarettes due to boredom, stating that "they don't do anything", in particular smoking did not make her high and therefore she did not see the point in continuing her engagement, as they were costing her money but not doing anything.

*[Sarah, 32 years]: "They [cigarettes] don't make me high (.) like what's the point"

Nonetheless, some participants suggested that if these behaviours were providing them with enjoyment then their engagement would have continued. Therefore despite some participants cessation with one risky behaviour, it may be that those participants would replace that behaviour with another, that would provide enjoyment. Sarah explained that despite stopping smoking cigarettes, she did continue smoking marijuana which she believed was different to cigarette smoking as it provided her with enjoyment, allowing her to escape from her anxieties surrounding CF's fatal and deteriorating nature.

*[Sarah, 32 years]: "Weed was different [to cigarettes] # weed was fun [...] that [weed] was a escapism for me ### even though your problems are still there the next day # you know (.) on the night time I would just be chilled out"

Sarah explained that if her CF was not as severe as it is today she would still smoke marijuana due to these psychological benefits, however she is now aware that her health would not be able to handle such engagement, and therefore she believes that the potential physical risks of marijuana use outweigh these psychological benefits.

Whilst a number of participants indicated that their initiation in a risky behaviour was to alleviate their feelings of stress, anxiety or depression, and to avoid their life, predominantly due to CF, some participants explained that it was not until cessation that they experienced a positive outlook. Katie explained that since she has stopped using drugs she is a lot happier within her life, and that retrospectively she can see how drug use was having a negative impact upon her life, causing her to be moody and at times suicidal.

*[Katie, 33 years]: "I'm happy now [...] instead of being cra:anky all the time [when using drugs] (.) and moo:ody (.) and ti:ired # one minute I'd be alright (.) I'd be alright # the next I'd be .hhh (.) drop completely # and I'd burst out crying (.) be suicidal"

Despite Katie believing that her drug use was having a positive impact upon her life by allowing her to escape her problems, Katie can now appreciate that during that period of time she was not happy. In order to deal with her problems Katie now uses adaptive coping mechanisms, predominantly involving her talking with her sister and close friend. Katie, like other participants, indicated how her cessation has increased her self-esteem, with her associating her drug use with negative behaviours, whereas she now feels that she is a good person who is able to develop meaningful relationships, be optimistic and cope with challenges without using maladaptive coping mechanisms.

*[Katie, 33 years]: "I actually like being sober [...] I didn't like the person I was before because I was ly:ying # I was letting everybody do:own (.) I was feeling gui:ilty all the time [...] I actually think I am a good person [...] my sister says to me (.) you know (.) I like this Katie # even my friends say it [...] I'm happy now"

Whilst an individual's outlook towards their life with CF was important in influencing engagement with risky behaviours and non-adherence, it became evident that it is potentially how an individual perceives their illness which acts as a mediating factor. Some participants considered self-management (such as adherence) as mandatory within their lives, regardless of the impact it may have upon their social life. Being physically "well" was the primary focus underpinned by a clear understanding of the serious and even fatal consequences of not engaging in self-management.

*[Matthew, 47 years]: "It's either # do it [medical regimens] (.) or feel lousy all day (.) for not having done it [...] if I wasn't to take (.) the # the medication [...] the chances are (.) I could possibly be dead"

Viewing adherence as mandatory is then advantageous for physical health, but it can be disadvantageous psychologically. Andrew described how this view can cause him to be self-critical, and to lack self-compassion during incidences of occasional non-adherence. Andrew appeared to be making a connection between his actions and their physical response, particularly when he is unwell.

*[Andrew, 46 years]: "I bash myself over the head for it [non-adherence] [...] whip myself [laughs] [...] wh:hy did I do that # particularly when you feel bad"

How an individual perceives their illness can change over time and across circumstances. Laura explained that during the weekdays she views adherence to be mandatory in order to improve or maintain her current and future health, whereas during the weekends she is focused upon enjoying herself, valuing her psychological health above her physical health; believing that she can engage in risky behaviours (alcohol consumption) as her weekday adherence is maintaining her health.

*[Laura, 28 years]: "I just felt li:ike ## in the week was fo:or me to do me medications (.) so Monday to Friday (.) and then Saturday and Sunday was my:y time # for me:e # to go:o (.) and let me self loose # and thing # just ha:ave fun"

Laura does not view her medical regimens to be part of "her time", instead she indicated that in order for her to be herself she needs to be away from CF, which she allows herself to do during her weekends. For other participants this change in perspective was not bound to certain days, instead it appeared to be determined based upon their current health status. Sam explained that he engages in alcohol or heroin binges until he encounters "health problems", which results in him becoming focused upon his medical regimens in order to improve his health; consequently Sam's behaviour appears to be reliant upon symptom presentation.

*[Sam, 43 years]: "Sometimes I'm focused on just doing my medication (.) my (.) you know # a:all my sort of CF treatment (.) that ki:ind of thing [...] if I'm # in a:a # sta:age where I'm u:using:g [alcohol or heroin] then I can # I'll be try:ying to fit that round:d # doing other stuff as well"

Overall, this theme highlights participants quest in developing a positive outlook towards their life, with some participants appearing to be fighting a battle in order to

incorporate CF into their lives in a way which is manageable, meaningful and possible, with this resulting in individuals engaging in self-negotiations around adherence and risky behaviour engagement.

"Are they sure I haven't just got asthma"

This second theme explores the role of avoidance in CF and how this provides individuals with a gateway to engage in both non-adherence and risky behaviours. A number of participants were able to ignore or to forget about the severity of their CF, particularly when they were feeling well, and therefore not focusing on having an illness identity. James clearly describes how insignificant CF is in his life when he has no symptoms, with his behaviour appearing to be in response to the lack of symptoms he experiences, allowing him to lead a "normal" life.

*[James, 19 years]: "I can't stress enough CF has virtually been (.) nothing to me [...] I feel like a normal (.) healthy person"

Many participants do not focus on their CF until they develop an infection, with Richard believing that his lack of symptoms exacerbated his denial towards his CF and made accepting CF a challenge, he explains that he was previously really healthy and was the same as his peers, in terms of his behaviours and identity.

*[Richard, 34 years]: "When I was younger I was in denial with my CF # cause I (.) I was really healthy [...] I # was the same as everyone else (.) I could do everything that everyone else could [...] I was no different # so I was in denial"

Whilst some participants appeared to forget about their CF due to a lack of symptoms, other participants explained how they hate CF and the restrictions it imposes upon their life, resulting in these participants intentionally avoiding their CF.

*[Daniel, 25 years]: "As a kid you don't want to [...] I can't run with my friends # do this (.) that (.) the other (.) you see the limitations # and then you realise why (.) and then you hate it [CF] [...] it just went on (.) like # a denial stage ## like teenage years"

Daniel explained how his CF prevented him engaging in normal activities with his peers, causing his illness identity to be on display, resulting in Daniel avoiding his CF. When individuals do avoid or ignore their CF it presents a challenge in understanding treatments' necessity. Richard explained that when he was younger and did not experience symptoms he did not understand why he needed to adhere to a long list of medical regimens, as he

was living a normal life. Instead Richard felt that his HCPs had overestimated his diagnosis, and that he did not have CF.

*[Richard, 34 years]: "What am I doing this [physiotherapy] for (.) my chest's fi:ine # o:or:r you know (.) I've ju:ust been to play football a:all afternoon # what am I doing this for [...] sometimes I thought (.) I don't think I've got CF [...] o:or:r # are they su::ure # are they su:ure I haven't (.) I haven't just got asthma"

Consequently, whilst it may be psychologically adaptive to not possess an illness identity, this can have negative impacts upon physical health due to the impact ignoring or avoiding one's CF has upon adherence efforts, with the data highlighting a relationship between denial, or avoidance of CF, and the engagement in non-adherence.

Denial regarding treatments' necessity can be reinforced when there is no experience of adverse health effects from non-adherence, or no experience of noticeable benefits from adherence. Some participants talked about the lack of short-term benefits they receive from treatment adherence whilst they are "healthy". Jessica explained how she did not experience symptoms of CF when she was younger, therefore she did not see why she needed to be adherent, with these beliefs being reinforced when she did not experience symptoms following non-adherence as an adult.

*[Jessica, 32 years]: "I didn't see the point in them # when I was younger because I was so well # I didn't understand # when I didn't take ## any of the tablets (.) I didn't really get poorly (.) so I was just like well >I don't need em then< [laughs]"

Even when participants did experience a health decline following non-adherence, they did not always believe that this was as a consequence of their adherence efforts. James explained how he recently suffered from pneumonia which he believed was due to "bad luck", explaining that he is frequently non-adherent however that rarely impacts upon his health.

*[James, 19 years]: "It's [pneumonia] just ## luck (.) I'd say # bad luck [...] I ha:ardly (.) ever take my treatment [...] I'm not ill that often"

For some participants their belief that treatments are not effective was due to their awareness of CF's fatal nature regardless of adherence. Ben explained how he had witnessed his brother's CF deteriorate, resulting in his passing away, despite his excellent adherence efforts.

*[Ben, 34 years]: "My brother did everything [adherence] (.) religiously (.) by the book (.) an he just went do:ownhill like that"

People with CF often receive little positive reinforcement following their adherence efforts, due to CF's deteriorating nature. To overcome this participants did discuss how HCPs try to aid individuals understanding that adherence will prolong their good lung function, and improve their life expectancy. However, a number of participants (adolescents and young adults) said that they did not always fully understand what prolonging good lung function actually means.

*[Jessica, 32 years]: "Even though there is someone saying it will ma:ake # this better (.) or # it will (.) prolo:ong (.) your (.) good lung function (.) you don't really understand what pro:olonging # good # lung functions is really"

HCPs efforts to encourage adherence are not always successful, with these participants still not understanding why they need to adhere to medical regimens, particularly when their symptoms are not present.

Even when participants did understand the discourse of HCPs it did not always encourage their adherence efforts. Stephen explained that because adherence only prolongs his health, as opposed to "curing" CF, he does not value his adherence.

*[Stephen, 19 years]: "To Consultants and to the Professors (.) like treatment is re:eally (.) really (.) it's like top priority but to me it isn't [...] why should your treatment be main priority # when it's not doing anything # it's prolonging it [CF]"

Stephen is therefore facing a dilemma where others are telling him that treatments should be a priority, but clearly for Stephen it is not. Stephen explained how his priority is to live his life, doing what "normal people do", valuing his psychological wellbeing, with lesser regard for physical health implications, with this appearing to be influenced by symptom presentation.

*[Stephen, 19 years]: "To me my treatment isn't the top priority (.) it should be (.) but it isn't # because obviously I want to live my life man (.) I want to do what normal people do [...] I'd rather have a laugh with my mates [...] maybe it might be my top priority in a few years time when I am (.) stuck in a hospital bed and I literally can't go anywhere"

In addition, some participants' beliefs regarding treatments lack of effectiveness were formed and reinforced by their childhood experiences. Emma explained how she had not adhered to her treatments during childhood due to her Father preventing her access to her antibiotics,

however she still had good health therefore Emma did not see the need for adherence during adulthood, as she had experienced no adverse health effects from non-adherence.

*[Emma, 57 years]: "I've had to grow up without it [treatments] [...] I did have a poorly chest (.) so I thought I'll start taking them [antibiotics] (.) and I took the bottle out (.) there was only one in the bottle (.) my °Dad had had them° [...] I was fri:ightened to go to the Doctors and say my Dad's had them (.) in case they °spoke to my Dad° [...] I just le:earnt to cope without them [...] I haven't grown up with a regimen of:f # treatments (.) like everybody else (.) so:o # I'm a:always going to be different"

The data demonstrates the complexity of factors that contribute to adherence, with time and context having a large impact on adherence behaviours. Some participants adhered to their treatments, despite explaining that they were in a state of denial regarding their CF. Richard explained that his adherence, despite denial, was due to him being in a structured routine where adherence is integrated.

*[Richard, 34 years]: "I wasn't ma:ade to do them by my pa:arents but it just became:e pa:art of my routine (.) from such a young age [...] for me:e doing that was (.) was a no:ormal thing [...] I did them at home anyway # so:o [...] I was only doing that in front of my family # so:o # that # didn't matter (.) in terms of my denial"

In addition to the impact avoidance of CF has on adherence efforts, the data also suggested a relationship between avoiding one's CF and the engagement in risky behaviours. A number of participants who engaged in risky behaviours did not acknowledge the adverse health effects associated with these behaviours. Will was raised to believe that drug use could have fatal consequences, he explained that following experimentation with illicit drugs as a form of escapism from CF he changed his attitude towards drug use. Will did not experience any adverse health effects of drug use, and the consequences that he had been taught would occur (death) did not happen, instead Will found that for him drugs provided him with benefits.

*[Will, 21 years]: "You're a:always brought up to think >you'll die< (.) >you'll die< stra:ight away [with drugs] [...] when you fi:rst try it you think (.) well ## it's not tha:at bad [...] no:othing's gone wrong (.) you know # an you have a re:eally good time"

In addition, some participants explained how they experienced beneficial health effects from their risky behaviour engagement. This was mainly amongst participants who smoked

marijuana, with Mark explaining how he believed that marijuana use results in a respiratory improvement.

*[Mark, 23 years]: "It [weed] can help in a lot of wa:ays as well [...] there a:are certain benefits to it [...] it (.) does actually # stra:angely enough ## once you've had a bit (.) re:eally # re:eally settle your chest (.) it feels re:eally (.) re:eally clear"

Many participants believed that marijuana cannot be harmful due to it being medicinal in some countries, with the health improvements that participants experienced reinforcing this belief.

*[Sarah, 32 years]: "I don't feel like it [marijuana] is as bad as all the media makes out (.) you know # it's a na:atural thing (.) that grows (.) it's (.) medicinal in some countries"

Some participants rationalised their engagement with risky behaviours by explaining that they engage in compensatory health-promoting behaviours. Sam explained how his engagement with illicit drugs did not have a negative impact upon his health due to his adherence maintaining his health.

*[Sam, 43 years]: "I don't think it [recreational drugs] had a particularly (.) ne:egati:ive impact [...] du:uring that period I was keeping myself ve:ery healthy [...] I was compliant # I was getting a lot of exercise"

Consequently, Sam appeared to underestimate the risks of drug use, and instead focused upon the health-promoting behaviours which he engaged in, demonstrating evidence of selective focus. Further evidence of selective focus was when participants experienced adverse health effects of a behaviour, so they adapted that behaviour to become less harmful. Rob explained that when he experienced adverse health effects from smoking marijuana, he adapted that behaviour by vaping marijuana, to reduce the adverse health effects experienced in order to maintain the beneficial effects, with Rob valuing the positive impact marijuana has upon his life psychologically, making him feel "calmer and more relaxed".

*[Rob, 32 years]: "That [vapour marijuana] was alright [...] it's a healthier way of smoking it"

Participants who described themselves to be in a state of denial towards their CF often desired a sense of normalcy, with this frequently involving the engagement in risky behaviours. Many participants did value the psychological benefits that avoiding one's CF

has upon their life, with Richard explaining that when he was in a state of denial regarding CF it enabled him to engage in "normal" activities and lead a "normal" life. Richard explains that due to accepting the true nature of his diagnosis he puts "limits" on himself, preventing him engaging in certain activities for the benefit of his physical health, despite the detrimental impact this has upon his psychological health. Such change in health beliefs could be due to the consequence age can have upon health within CF.

*[Richard, 34 years]: "Whilst being in denial (.) whilst that wa:as bad [...] I used to ### get on with stuff mo:ore (.) I would be like (.) well I'm ba:ad (.) but I'm going to keep going cause I haven't got CF [...] now I'm mo:ore aware of what I can (.) and I ca:an't do [...] with CF (.) you can fa:all into a spi:iral where ## it's not li:ike you feel sorry for yourself (.) but you put limits on yourself ## an:nd stop yourself from doing stuff"

However, as discussed, while not possessing an illness identity appears to be psychologically advantageous, when individuals were avoiding their CF they often dismissed awareness provided to them from HCPs regarding risky behaviours. Sarah explained how she did not believe smoking would have adverse health effects despite HCPs warnings, this was during a period of time where Sarah did not experience symptoms of her CF and did not experience adverse effects from her smoking behaviour, therefore providing her with the belief that she was healthy and could continue her engagement.

*[Sarah, 32 years]: "Like later on in the future they [HCP's] said it [smoking] will (.) it will affect your lungs when you're older [...] no it won't happen to me:e # I'm fi:ine"

In addition to risky behaviour engagement, many participants who ignored or avoided their CF explained how they do not disclose their illness identity to others. Nick explained how disclosure becomes harder with age, particularly when considering intimate relationships, with participants coming into contact with more people, and therefore being expected to disclose their CF to more people.

*[Nick, 33 years]: "It's got ha:arder to tell people as I've got older [...] da:ating and stuff like tha:at # I don't know # when (.) is the ri:ight time to tell em (.) cause I suppo:ose # you know (.) fo:or them (.) being with me is going to be (.) a new experience (.) some of them might not be up fo:or it"

Many participants explained how they did not believe others needed to be aware of their CF as their CF does not impact upon their life, with these participants leading a normal life and not possessing an illness identity.

*[Andrew, 46 years]: "I didn't think it [CF] was that ba:ad you see [...] I didn't think you should be aware of it because it doesn't affect me ## day to day [...] it wasn't affecting my life"

For other participants their non-disclosure was due to them not wanting to be judged based upon CF, therefore such participants kept CF as a separate part of their life, allowing them to have a normal identity in public, promoting their psychological wellbeing.

*[Claire, 29 years]: "Try and avoid the fact that I've got it re:eally a:and # it's the last thing # you'll find out about me [...] I don't want to be judged on that # I don't want to be like Claire who's poorly"

Participants discussed how their non-disclosure enabled them to be non-adherent and engage in risky behaviours, as their peers were not aware that they needed to engage in medical regimens, and were not aware of the specific adverse health effects risky behaviours could have; with CF's invisible nature aiding individuals' non-disclosure.

Overall this theme indicates that the avoidance of CF plays an important role in an individual's adherence efforts and risky behaviour engagement. However, the way in which this avoidance towards CF is translated into action (or non-action) in terms of adherence and risky behaviour engagement is influenced by a number of factors. Whilst a number of participants who described themselves to be in a state of denial regarding their CF engaged in risky behaviours, this was not always the case, with some participants who described themselves to be in a state of denial explaining that they have never engaged in risky behaviours, due to these behaviours not being normalised within their environment.

*[Richard, 34 years]: "I was in denial with my CF # cause I (.) I was re:eally healthy # I was the sa:ame as everyone else [...] none of me mates smoked # no one in me fa:amily ## smokes:s ## e:er:r ## so I've come from an environment where # smo:oking's not ## it's not done (.) I'm not exposed to it ## I've no desire to do it"

Consequently such participants would not have been provided with a normal identity if they engaged in these behaviours, with group identity and social norms being influential upon individuals decisions to engage in such behaviours.

"If you haven't got any support it can be detrimental to you because you need that support"

This theme focuses upon the beneficial effect support from others can have for people living with CF, as well as the adverse effect a lack of support can have. The support this theme mainly focuses upon is that from an individual's family, friends and HCPs, and suggests that in terms of providing awareness regarding risky behaviours there is an expectation that this is integrated into CF care. Family support was considered necessary and important, with a number of participants explaining how their family have prevented them engaging in risky behaviours by providing good awareness regarding the potential adverse health effects of engagement, and by protecting them from environments which would expose them to these behaviours. Nick explained that by being protected from environments where people were smoking, he understood the detrimental effect smoking could have upon CF.

*[Nick, 33 years]: "Mo:om had a:always protected me from people who smo:oked [...] be:eing protected from it I have kno:own that it's bad"

The data also indicated that some participants never engaged in risky behaviours as they feared the consequences from their family. Lucy acknowledged that her Mother would have punished her if she drank alcohol whilst underage, therefore despite this behaviour being normalised Lucy did not try alcohol until she was above the age of 18 years, when her Mother would then allow her to go to the pub with her friends.

*[Lucy, 28 years]: "Mum would have killed me [if drank alcohol underage] [...] when me Mum was a:allowing me to start going out with my friends:s (.) when I was over the pubs:s # that's when I sta:arted drinking"

Participants explained that positive family relationships did not only prevent initiation, they also encouraged cessation, with James stopping smoking due to his family not being happy with his smoking behaviour, therefore he was aware that cessation would improve his family relationships, due to his family feeling cessation was important for his health.

*[James, 19 years]: "I did it for family [stopped smoking] [...] a lot of my family wasn't happy with the fact I was smoking"

Many participants explained how their family relationships did improve as a consequence of cessation, reducing the likelihood of relapse, as participants became dependent upon their

family to help them cope with difficult times, instead of using risky behaviours as a coping mechanism.

*[Katie, 33 years]: "I'm quite close to my sister now # e:erm I tend to talk through things with her [instead of using cocaine] (.) and get things out in the open"

However, some participants did not disclose their engagement to their family, therefore their family could not encourage cessation. Will explained that his family would not understand why he uses drugs, therefore he has never disclosed his engagement to his family.

*[Will, 21 years]: "I don't re:eally tell my family anything [...] I don't think my Mom would understand [about drug use] # my Brother wouldn't # my Brother would think (.) o:oh I've got to tell Mom # so I don't re:eally have that"

Even when a participant's family provided awareness regarding risky behaviours it was not always successful. Will explained that his family is naive and are not aware of the substances he could access, with Will already smoking marijuana before his Mother provided awareness regarding the adverse health effects of marijuana use.

*[Will, 21 years]: "My Mom did wa:arn me when I went to uni # ↑don't do any we:eed # ↓I was like yeah a:alright (.) but I'd already done it # I think my Mom's a bit naive # she doesn't re:eally know there's a lot of stronger stuff (.) so rea:adily available"

In addition, some participants did not disclose their behaviours due to anticipated consequences, they employed effort to hide their risky behaviour engagement to avoid such discipline.

*[Stephen, 19 years]: "I was hiding it [weed] from my foster carers [...] if they'd have found out I was smoking that (.) I'd have been in hell"

A strong family motivator to aid cessation was when participants became parents, with Sarah describing how once she became pregnant she stopped smoking marijuana due to a need to not only care for herself as a Mother, but also to care for her unborn child.

*[Sarah, 32 years]: "As soon as I got pregnant (.) obviously it completely changes [stopped smoking marijuana] (.) you've got someone else to think about"

The influence of a child upon cessation was also evident within male participants, with Stephen and James discussing that if they were to become Fathers it would motivate their cessation, due to them then needing financial security and having a new focus in life.

*[Stephen, 19 years]: "If I had a kid [...] somat that would change your situation that you wouldn't be able to do it [smoke marijuana] anymore [...] if I had a kid on the way # I just wouldn't like cause you're saving your money init"

For one participant it was not pregnancy that motivated cessation, but rather the impact their behaviours had upon their child. Katie explained how frightening her accidental cocaine overdose was for her son, motivating her cessation, with this having beneficial impacts upon her relationship with her son.

*[Katie, 33 years]: "The look on his [sons] face # worry [after accidental cocaine overdose] ## I thought I'm not doing this again # that's it # just the look on his face ## every time I think about coke now (.) I think about his face [...] gives me the # boost"

In addition to the influential role families can play in influencing risky behaviour engagement, the data also illustrated the beneficial impact participants families have upon their adherence efforts. Transition to adulthood appeared to be a challenge in terms of adherence efforts, with participants being expected to take on more, and have a more active involvement in treatment decisions. Ben explained how during his teenage years where independence was first encouraged his adherence "slipped", with him not looking after himself as well as he should have done without his Mother integrating his medical regimens into his life.

*[Ben, 34 years]: "My Mom did everything fo:or me (.) she'd la:ay my tablets out of a mo:orning (.) put my nebuliser there # did my physio:o # a:an I think # when I was a teenager anyway (.) everything slipped an I didn't look after myself to:oo good"

It is not just essential for families to facilitate adherence, Nick indicated that families should make an individual aware of treatments' necessity, ensuring the individual will independently maintain their future adherence.

*[Nick, 33 years]: "Make them understand wh:hy they need to be doing [treatments] ## why they need to be making the right decisions"

Whilst participants discussed the challenge of independent adherence, some participants did still experience support with their adherence during adulthood, discussing the importance of personal relationships upon health. Relationships appear to have beneficial health impacts

both psychologically and physically, with partners being there for both practical support (e.g. reminding the individual to adhere to their treatments), and emotional support (e.g. providing encouragement to adhere to the complex and time-consuming treatment regimen).

*[Nick, 33 years]: "If you're in a relationship (.) you're in mo:ore of a routine [...] you've got someone the:ere (.) to give you a ha:and [...] I was in a relationship for a good two:o (.) or three years:s # and I suppose that was a good ti:ime for health"

Andrew discussed how the emotional support from his wife and family motivates him to adhere to his treatments to prolong his life with his family.

*[Andrew, 46 years]: "I've got a wife # an I've got two daughters # and e:erm:m # I want to be around as long as possible for them [therefore motivates adherence]"

However, despite this motivation other factors also influence an individual's ability to fully adhere to their treatments, with Sarah explaining how parenthood means that she has to integrate her treatments into a new and disruptive life with her children, where she has less time for herself.

*[Sarah, 32 years]: "All my time and effort (.) and energy (.) and mental strength (.) goes on my children (.) and trying to give them a no:ormal life"

Whilst being in a relationship was positive for one's health, relationship breakdowns were detrimental, with Simon discussing how he has engaged in risky behaviours as a way of coping with his multiple relationship "break ups".

* [Simon, 33 years]: "When I used to split up with her [girlfriend] I used to get fed up # stressed and upset ### I don't know wh:hy (.) but I did # you know (.) a:and then I saw this guy (.) I said I'll tr:ry this (.) I'll tr:ry that (.) and then smo:oked heroin"

The value of support was further demonstrated when some participants did not have strong family support, resulting in detrimental impacts upon their life. Stephen explained how his volatile relationship with his Mother resulted in him smoking marijuana as a form of escapism.

*[Stephen, 19 years]: "I argue with my Mom everyday [...] full blown arguments # she's in my face (.) I'm in her face (.) screaming (.) an (.) you know what I mean (.) she's slamming (.) banging things # that's why I smoke weed everyday [laughs]"

As well as initiation, some participants explained how their families were aware of their risky behaviour engagement however they did not encourage cessation. This was often due to the

family normalising that risky behaviour, which in itself was often a contributing factor which resulted in the participants initiation. Jessica explained how she believes that her Mother did not try to stop her smoking due to her Mother also smoking, and therefore believing it would be hypocritical to encourage cessation, despite the adverse health effects this could have upon Jessica's CF.

*[Jessica, 32 years]: "Mum ju:ust said # we:ell (.) you're sixteen # an:n (.) if you want to smoke (.) then you know # what the consequences will be (.) and I think because she smoked (.) she felt like she couldn't say"

For some participants their negative family relationships were directly due to their CF, with their family not supporting their life with CF. These participants therefore explained how they had to deal with the physical and emotional aspects of CF on their own, with Katie discussing how her family did not facilitate her adherence, resulting in poor adherence as well as drug use as a form of escapism.

*[Katie, 33 years]: "I've dealt with my illness by myself for a long (.) lo:ong time [...] I didn't feel like anybody ca:ared sometimes [...] that's what the drugs were about I think # not having to deal with it sort of thing"

This lack of family support was often due to participants family having negative attitudes towards CF, with a number of participants indicating that their family was in denial regarding CF, and often in regards to CF's genetic component. This denial resulted in Katie feeling unwanted and impacted upon her attitude towards CF, resulting in Katie not disclosing her illness to others ensuring her normal identity was on display to others. Consequently this non-disclosure enabled Katie's non-adherence and risky behaviour engagement, with CF's invisible nature aiding this non-disclosure.

*[Katie, 33 years]: "I never told anybody I had CF when I was younger [...] I was ash:hamed [...] my Dad's family ## always denied that it was anything to do with them [...] I think I was always being made to (.) feel unwanted"

A number of participants also discussed the importance of friendships and the impact they have upon health behaviours. Many participants spoke about the sense of belonging they feel from their friends, and how friendships make them feel normal by being accepted into a social group, providing them with a normal identity. Even when participants illness identity was on display in front of their friends, Andrew indicated that by maintaining these friendships the individual still receives a sense of normalcy and a break from CF.

*[Andrew, 46 years]: "He [friend] just rang me out the blue # we was on the phone for an hour an a half [...] that was re:eally good [...] it makes you feel no:ormal again # even though you're hearing about their lives an thinking >I wish I could do that I wish I could do that< # it's still nice to hea:ar (.) what they're doing [...] it takes you back"

A number of participants also described how their friends would not allow them to engage in risky behaviours, as they are aware of the CF-specific adverse health effects, with many participants valuing their friendships.

*[Stephen, 19 years]: "They won't let me smoke fags [...] they said to me like (.) if we ever see you spark up a fag (.) we'll slap it out your hand"

Due to individuals valuing their friendships, it was not surprising that many participants initiated in risky behaviours due to their friends normalising such behaviours. Jessica explained that for her, smoking marijuana felt normal when she was with her friends, with such engagement providing her with enjoyment and social acceptance.

*[Jessica, 32 years]: "I'd go out with my friend # and we'd go to ## our friends house (.) and they'd all be smoking [marijuana] [...] it was just a # like a # social thing [...] it was just the norm (.) like I just got passed it [spliff] (.) so I did it"

When behaviours were normalised by a participants social group, many participants highlighted their belief that engagement in such behaviours formed part of their group identity, with Sam explaining that he only engaged in heroin use when he was in social situations with his peers.

*[Sam, 43 years]: "It was the:e (.) e:er:r # crowd that I was in (.) sort of # the type ## the type of behaviour that wa:as going on [heroin use] (.) so it just seemed na:atural to:o ## yeah # to (.) to (.) join in"

The behaviours of an individuals' peers strongly influence their own behaviour, with it being evident that a change in friendship group often resulted in cessation, as that behaviour was no longer normalised.

*[Jessica, 32 years]: "I stopped hanging around with that friend # it was just purely # I used to smoke it [marijuana] when I was with her (.) and the (.) bunch of (.) people (.) we used to hang with [caused cessation]"

Whilst the majority of friendships discussed were referring to individuals within the general population, some participants discussed their friendships with others with CF. Many of these participants viewed these friendships to be positive, despite the risk of cross-

contamination, with Sarah explaining how she ignores in-hospital segregation because of the psychological benefits such friendships have upon her life, with no one else being able to understand the reality of CF.

*[Sarah, 32 years]: "I've always disregarded those # rules [...] because for me (.) those people have got me through some majorly tough times [...] seeing that other people know exactly what you're going through cause (.) no other person (.) on (.) this (.) planet (.) knows what a CF person goes through (.) other than a CF person"

Many participants who did mix with others with CF believed that it will not be harmful towards their health, with Richard explaining that he has grown up in a generation of CF care where he was able to mix with other individuals with CF, therefore creating his belief that such communication will not have adverse health effects. Such participants appear to focus on their psychological health rather than their physical health, particularly if they have not experienced any detrimental consequences to physical health.

*[Richard, 34 years]: "I've come through a generation where you used to be sat in a waiting room next to (.) kids with CF [...] I think that as long as you meet up # and you're responsible ##### then it's alright"

Many participants talked about how in-hospital segregation is associated with increasing isolation, however for some participants when they were informed about the potential adverse health effects of cross-contamination they appeared to value their physical health above their psychological health, and decided to not mix with others with CF, regardless of their generational upbringing.

*[Sam, 43 years]: "I used to [mix with CF patients] # before ## infection control became an issue [...] it did take a certain ## social element out [...] there was that ## therapeutic effect of just being able to share things about # the condition # with people that # understand it ## intuitively"

Not all participants however found mixing with others with CF beneficial, with Sarah discussing how upsetting these friendships can be due to them highlighting CF's fatal nature.

*[Sarah, 32 years]: "I didn't want to make any more [CF] friends cause I was sick of losing people [...] I couldn't cope with it"

In addition, some participants, did not want to make friends with individuals with CF as they wanted to have their own friends who did not have CF, potentially in response to their illness identity, enabling them to possess a normal identity in public.

*[Ashley, 35 years]: "I kind of # wanted to make my o:own friends [...] just because they've got CF as well doesn't mean I want to be friends with them"

With the support an individual receives in their private life (predominantly from their families and peers) varying between participants, an important source of support identified is that from HCPs. Whilst HCPs are very supportive, a number of participants believed that HCPs only understand textbook CF, rather than the reality of the condition, with Claire believing that it is impossible for anyone to understand what it is like to live with CF.

*[Claire, 29 years]: "Very like idealistic # and very textbo:ook # and very ## not able # to # relate it to someone's real life [...] they're [HCPs] like ↑o:oh do you just want to do your physio in the car when you're driving along in the morning ## ↓are you having a laugh [laughs] [...] do you just want to get up ten minutes earlier and do that neb ###↓ok if I turn that round would you"

Negative views towards HCPs were often in response to HCPs focusing upon aspects of an individual's health which are deteriorating, instead of highlighting areas which they are managing well. Emma talked about the need for HCPs to focus on hope and inspiration during clinic appointments, to maintain an individual's psychological wellbeing and provide them with positive reinforcement for their self-management.

*[Emma, 57 years]: "It's very very ra:are you would come to a clinic (.) and people will say you're doing well [...] they can tend to focus on # let's fix this [...] I remember one ti:ime I was in clinic # a:all my results were up # apart from my FEV₁ # was do:own a little bit # and he (.) totally (.) focused on that"

As well as clinic being described as a negative environment, Emma explained how it can be confusing due to a lack of consistency provided by different HCPs, often resulting in the individual not understanding what treatments they need to adhere to, and how they adhere to them.

*[Emma, 57 years]: "No two people from the clinic have ever sung from the sa:ame hymn sheet [...] then you'll get a new person and they'll sing from a different hymn sheet [...] two Consultants # one would say one thing (.) one would say the other # so:o # whichever one I picked I was arguing with the other one"

In terms of risky behaviours, a number of participants discussed how HCPs had not provided CF-specific awareness. Some participants stated that they had been asked if they engaged in "risky" behaviours, however it was only ever a question, with awareness being provided on an individualised basis in response to this question.

*[Stephen, 19 years]: "When I go to clinic appointments they say are you a smoker (.) an I say no [...] the Nurses for the kids ward when I was a kid obviously used to say well ↑ Stephen make sure you don't start smoking [...] I didn't listen [...] it's just one of them # >don't smoke< [...] they didn't tell me any things that would happen (.) or what effects it would have on me"

Many participants believed that awareness regarding the CF-specific adverse health effects of risky behaviours could have prevented their initiation, by making them fear the potential health effects at a young age.

*[Stephen, 19 years]: "They tell you not to smoke but ## they don't go deep enough into it [...] if they'd have shown me [...] like things # CF lungs [...] if I'd have seen pictures an stuff (.) I probably would (.) have been scared to do it (.) I probably would have been at that age (.) because I was only about eight when I remember starting talking about it "

Participants suspected that HCPs do not provide this awareness regarding the adverse health effects of risky behaviours, as they do not have sufficient knowledge surrounding risky behaviour engagement. Will explained that he believes HCPs are not aware of what substances are readily available within the general population, therefore he believes that HCPs are not aware that they need to provide patients with such awareness.

*[Will, 21 years]: "I think they're naive to what you can get your hands on [...] I could get my hands on anything [...] a: any kind of drug [...] nobody in he:ere would be saying (.) o:oh Will don't do that (.) don't do that # they don't (.) re:really expect that you could do that"

In addition, some HCPs were unaware that their patients had engaged in risky behaviours, as some participants did not disclose their engagement to their HCPs. Will explained that he did not disclose his drug use to HCPs as he did not want to be judged, or to have his provision of care compromised, indicating that an intervention is required to encourage disclosure, so HCPs can treat patients being fully aware of their personal condition.

*[Will, 21 years]: ">No no no< [does not disclose drug use to HCP's] # it's only because I don't want to be judged [...] if I told them (.) everything [...] I wouldn't feel like I'd get the better ca:are # the best ca:are [...] they might look at me a bit different"

Despite some participants not disclosing their engagement in risky behaviours to their HCPs, many participants did talk favourably about their close relationships with HCPs,

acknowledging that HCPs are empathetic towards adherence, shaping treatment plans according to an individual's lifestyle, therefore placing emphasis upon psychological factors as well as pharmacological, all of which is aligned to a person-centred care.

*[Nick, 33 years]: "With Doctors # they're willing to meet you ha:alf wa:ay (.) to a certain extent (.) just because of the nature of the beast [...] we do (.) take a:all our own tablets ## it's a:all self-medicated "

The majority of participants spoke favourably about their Nurses, believing that they are the most approachable member of the MDT. Participants often valued their relationships with Nurses, viewing Nurses as friends or even family members, with Nurses often easing an individual's time during hospitalisation.

*[Katie, 33 years]: "I class these Nurses as my family [...] they're the only people I had at one point (.) in my life [...] that's why I used to struggle to go ho:ome [...] sometimes I would make myself ill to come in (.) cause I knew (.) that I had people to talk to"

With many participants discussing their close friendships with their Nurses, some participants indicated how at times these relationships were potentially not professional. Nicola explained how Nurses have contributed to the normalisation of excessive alcohol consumption, openly discussing their experiences with alcohol. In addition, Katie discussed how Nurses turn a "blind eye" to CF patients mixing, despite the risks of cross-contamination.

*[Nicola, 19 years]: "Most of the Nurses do [drink alcohol] (.) they can't turn around and tell me o:oh you can't do this # they turn round and say o:oh (.) e:erm (.) I was bladdered on my Birthday"

*[Katie, 33 years]: "We don't listen to that crap [cross infection] [...] it's all bollocks [...] the Nurses don't give jack shit"

Despite the impact such communications could have upon an individual's health, the fact that Nurses approach patients on a "human level" appears to foster a close patient-clinician relationship, with participants feeling supported by their Nurses.

Another source of support identified within the data is that from a participant's employment or educational experiences. Some participants did demonstrate that their employers are understanding towards CF, however this was not the case for all participants,

with Matthew explaining that his managers do not care about his CF, with this having the potential to result in occupational stress.

*[Matthew, 47 years]: "Managers at work # they're just focused on one thing (.) an that's getting the work out the door (.) like they aren't bothered # well I feel they aren't bothered how you're feeling (.) as long as that job's getting done [...] I don't feel as if I've got the confidence to go up to one of the managers an say listen >I can't go as quick as everyone else< cause I'm feeling a bit tired"

With many participants identifying that risky behaviour engagement helps to alleviate stress, the presence of occupational stress could result in risky behaviour initiation. The initiation in a risky behaviour could also be influenced by an individual's workplace normalising that behaviour. Nicola explained how she is given alcohol as an incentive after work, normalising excessive alcohol consumption, encouraging individuals to initiate in that behaviour to provide themselves with a normal identity whilst at work.

*[Nicola, 19 years]: "After # work [barmaid in a nightclub] you always get a drink # you get a free drink (.) and then you have that and then they go out after (.) so I just go with them [...] when you work with alcohol you're surrounded by it"

Educational experiences can also normalise risky behaviours, with Nick explaining how he viewed excessive alcohol consumption to be part of his University experience.

*[Nick, 33 years]: "You go to u:uni # you do a:all the drinking games [...] I was like I've never re:eally done drinking ga:ames # this is quite fun [...] when I'm with my uni fri:ends (.) I suppose drink is ## a pa:art of it"

The data does clearly illustrate the influential role of normalisation, as when risky behaviours were not normalised participants often did not initiate in such behaviours.

*[Richard, 34 years]: "None of me mates smoked # no one in me fa:amily smokes:s ## I've come from an environment where it's not # smo:oking's not ## it's not done (.) I'm not exposed to it ## I've no desire to do it"

Even when participants were in an environment where typically risky behaviours are normalised, participants explained that if the behaviours were not normalised within their social group they would not conform to such behaviours, as a normal identity within that social group would not involve engagement.

*[Richard, 34 years]: "I had mates who I knocked about with [...] none of us: we:ere:e ## that bothered about that sort of thing [...] they were a:all at uni:i to be at uni (.) not to muck about and pa:arty"

This theme therefore highlights how the role of others can be influential in promoting health behaviours, and preventing risky behaviour engagement; however the role of others can also encourage risky behaviour engagement predominantly due to normalisation. The need for HCPs to provide all patients with information regarding risky behaviours, regardless of an individual's personal condition is therefore highlighted.

"Why should I let Cystic Fibrosis completely dominate my life?"

Whilst the role of others can have beneficial health effects in working to prevent engagement in risky behaviours, as identified this is not always the case, with some individuals explaining how their engagement with risky behaviours was due to such behaviours being normalised within their environment. When participants engaged in normalised risky behaviours it was often due to their effort to not be defined by their CF. Many participants discussed how they are more than their CF, with Emma explaining how she is the same as everyone else, and it is only when she attends clinic appointments that she feels different due to them reminding her of her CF.

*[Emma, 57 years]: "I didn't see myself as anything other than # everyone else (.) and to a certain extent that's still how I view myself [...] it's only when I come to clinic that I feel different"

Many participants engaged in behaviours which were separate to their CF in order to just be themselves, rather than being them with CF. Ben explains how he behaves in a way which does not identify him as having CF, with others not being able to single Ben out due to him engaging in "normal behaviours", promoting his psychological wellbeing.

*[Ben, 34 years]: "You feel like you're no:ormal [when drinking alcohol] # you're not isolated # you're just (.) a no:ormal person that day # a:and the thousands of people around you (.) they don't know any different"

Some participants explained how they value this sense of normalcy above their physical health, with Stephen discussing how he smoked marijuana without considering the impact this could have upon his CF, because he cared more about social acceptance than his CF, in order to protect his psychological wellbeing.

*[Stephen, 19 years]: "I didn't think about my health (.) I just wanted to (.) I just cared about fitting in"

Due to many participants valuing a sense of normalcy, they often valued CF's invisible nature, ensuring their normal identity in public. Daniel explained how no one ever questions him about his CF as it is not visible to the outside world, something which Daniel is appreciative of in order to allow him to lead a normal life.

*[Daniel, 25 years]: "No one ever questions (.) o:oh you've got an illness # they wouldn't know from looking at me (.) that's the best thing really"

The invisibility of CF was not always considered a positive thing though, with some reporting that this invisibility causes ignorance from others. Lucy explained how society often does not understand CF or the challenges faced, due to people with CF looking "normal" to the outside world.

*[Lucy, 28 years]: "Because I look well # people (.) presu:ume I'm well # a:an when I'm # struggling # people don't tend to understand that I'm struggling [...] you look (.) the sa:ame as everyone else # then it's kind of (.) you're expected to do the sa:ame as # everyone else"

Visibility and invisibility of CF is situational and temporal, with it being plausible that Lucy may at other times be glad that her CF is not visible. The data indicates that an individual's perception of their identity can change as their disease progresses, with participants who perceived themselves to be healthy welcoming CF's invisible nature, however as health deteriorates individuals require more support from others, with CF's invisibility often preventing such support from happening. Richard explained that when he was younger he was healthy, therefore it was not adaptive for him to possess an illness identity (particularly in public), it was only when his health started to deteriorate that he accepted CF's true nature and incorporated his illness into his identity.

*[Richard, 34 years]: "I was really healthy (.) I:l # was the sa:ame as everyone else (.) I could do everything that everyone else could # spo:orts (.) and all that sort of stuff # I # I was no different"

Whilst health deteriorations resulted in some participants accepting their illness identity and engaging in health promoting behaviours, others focused upon the fact that these health deteriorations impact upon their ability to engage in normal activities. Health deteriorations therefore had a negative impact upon some participants psychologically, due to their desire to keep up with their peers, in order to have a sense of normalcy.

*[Lucy, 28 years]: "As I get older I find it's # harder to keep up with them [friends] [...] it makes you feel a bit # crap [...] I want to do it (.) but it's # you can't physically # do it # like everyone else can"

Consequently, it was evident that the visibility of an illness identity due to health deteriorations can have a negative impact upon an individual's wellbeing, with Sarah stating that she feels like a non-entity when using her wheelchair, due to people staring, and sometimes disregarding her. Therefore an individual's illness identity often prevents individuals living the normal life they desire.

*[Sarah, 32 years]: "People will stare [when in a wheelchair] ## and just completely (.) disregard you (.) as a human being # it's cr:razy [...] you just feel like you're (.) a non (.) entity # you just feel like you're not a person anymore"

In terms of treatments, Nick spoken about the emotional aspect of adherence, with treatments being a continuous reminder of CF's fatal nature.

*[Nick, 33 years]: "It [treatments] reminds you of how fu:ucked you could be [...] it takes you on that journey every day # when you don't do it you kind of feel a bit normal"

It is difficult for individuals to step away from CF even for a short time, due to the action of engaging in treatments every day, several times a day; therefore it is easy to see how non-adherence can offer a temporary respite from the constancy of identifying oneself as being ill, providing some psychological relief and comfort in feeling "normal". Some participants did demonstrate how non-adherence is a way of reducing the differences between themselves and their peers, in order to support their efforts of acquiring a normal identity when they are with their peers.

*[Emma, 57 years]: "It's [treatment] one more thing that make me different (.) from the family [...] being different # and perhaps not wanting to be different comes into it a lot ## like not wanting to be seen taking your creon [...] you may just find a way of taking your creon when nobody's looking (.) so you're not different"

A desire for normalcy was evident amongst many participants, however participants actions to acquire a normal identity varied. Some participants discussed how adherence allows them to possess a normal identity, with Lucy explaining how adherence improves her health, helping to prevent health deteriorations, allowing her to lead a normal life and to be perceived by others as being normal.

*[Lucy, 28 years]: "I don't li:ike it [CF] stopping me from doing anything [...] I look after myself [adherence] (.) to stop it [CF] from stopping me from doing stuff"

This desire for a normal identity appeared to be heavily valued by participants until they experienced significant health deteriorations, with participants who had previously engaged in non-adherence, then often acknowledging treatments' necessity and valuing their physical health as a consequence of symptom presentation.

*[Richard, 34 years]: "My health was very good (.) I would be able to: o ## e:erm (.) miss (.) the (.) odd (.) one [treatment] [...] it wouldn't re:ally # matter"

In addition to adherence, many participants explained how they were provided with a normal identity when in public through risky behaviour engagement, with Sarah appearing to retaliate against her CF by engaging in risky behaviours in order receive a sense of normalcy.

*[Sarah, 32 years]: "Definitely # just to (.) fit in ## to feel normal [...] that is a big part of it [risky behaviour engagement] [...] it's bad enough that people question you over your tablets at that age [...] let alone (.) not being able to go and let your hair down a little bit when everybody else does"

Such participants were often conforming to their peers' behaviours, allowing themselves to adopt the same identity as their peers and to be accepted by that social group. Many participants explained how such engagement provided themselves with enjoyment, with Stephen explaining that it is important for him to live his life and do what he wants to do, instead of letting CF rule his life, with Stephen valuing his psychological health over his physical health.

*[Stephen, 19 years]: "My main priority [...] with a life threatening illness that's going to kill you (.) that should be ## living your life # doing what you want # ticking off your bucket list [...] I don't let CF rule my life (.) it never has done # not a day of my life has CF took over me [...] if you let your illness rule you # then you're not going to live are you [...] you need to go out an live your life"

Even when participants acknowledged the potential CF-specific adverse health effects, some continued their engagement as it allowed them to have a life away from CF, which was important to many. Ben highlighted how he needs a life away from CF to ensure his psychological wellbeing, despite acknowledging the adverse health effects associated with the behaviours that he engages in to ensure he leads a life away from CF.

*[Ben, 34 years]: "If I go out and I have eight pints # next morning my chest is rubbish (.) but then I think # what do you do ## you've got to have some form of life [...] surely you should be entitled to do (.) some normal things [...] why should I let it [CF] completely dominate me life [...] if I feel I want to go out (.) I'm gonna go out"

With many participants not wanting CF to define their identity, it was not surprising that many participants did not want others to be aware of their illness identity, preventing them disclosing their CF status to others, such as their colleagues.

*[Jessica, 32 years] "My work colleagues don't know I've got CF [...] I don't want sympathy [...] I don't want people to look # at me (.) any (.) different (.) cause some people do change (.) and they're like (.) ↑oh it's alright (.) you don't have to do this [...] I try and carry on # as (.) normal as possible"

There were many identified reasons as to why participants did not want to disclose their illness identity to others, with many participants indicating that their non-disclosure is to provide themselves with a normal identity in front of others. Mark explained that he does not disclose his CF status to others as he does not want to be treated differently, with many individuals viewing CF to be a disability, which Mark disagrees with.

*[Mark, 23 years]: "I think # as soon as you start to talk about something serious like that [CF] (.) it's a bit of a downer on the situation # people might ## view it as a disability (.) and I definitely do not view it as a disability (.) and I don't want people to be ## thinking me ## giving me any kind of # special needs (.) cause they know that # and (.) I don't want to be treated any # any differently [...] there's nothing which I limit myself to # so I don't think anyone else should"

In particular participants spoken about how difficult it is to disclose their CF to people they are dating, fearing the relationship will end following disclosure. Therefore a number of participants often did not disclose their illness identity unless they perceived their relationship was going to be long-term.

*[Claire, 29 years]: "Dating people and meeting people < # > that's the last thing you want to tell people < (.) and when you do (.) that's a very serious conversation [...] with my ex ### I told him like (.) after a few weeks (.) we'd been dating quite a lot [...] I knew I was getting a bit invested in him (.) and I thought (.) if I tell him this now # he can # go # before # I get hurt"

It appears that the majority of participants only allowed their illness identity to be on display to others when they had accepted CF's severity and deteriorating nature, with such

participants reporting that they no longer felt embarrassed when adhering to their treatments in public, with Laura then acknowledging treatments' necessity.

*[Laura, 28 years]: "You do:o get some funny looks [when taking tablets] sometimes # but (.) the way I see it # well if I do:on't ta:ake these I'll be dead"

Overall, a desire to not be defined by CF appears influential upon one's adherence behaviours and engagement in risky behaviours. However, a large mediating factor affecting engagement in such behaviours appears to be the process of accepting CF's true nature.

"The biggest challenge is coming to terms with having Cystic Fibrosis"

This final theme identifies how a number of participants found accepting CF's true nature to be challenging, with this being particularly challenging when participants considered themselves to be healthy. It was often only when a participant's health deteriorated that they started to accept the severity and deteriorating nature of their condition.

*[Richard, 34 years]: "The biggest cha:allenge for me (.) was ## when (.) my health dipped (.) was coming to te:erms:s (.) with it # with having it [CF]"

When participants stated that they had accepted their CF, it appeared that they were not just acknowledging their diagnosis, but they had accepted CF's true nature, with Katie highlighting that CF is a disability, and is associated with a reduced life expectancy. In addition, participants who appeared to have accepted their CF were keen to emphasise that despite CF being an invisible impairment, they are ill.

*[Katie, 33 years]: "You have got to realise that you have got a disability [...] you have got a shorter life expectancy"

Some participants appeared to have not just accepted their illness, but also appeared to have accepted treatments' necessity. However, this acceptance towards adherence did not always encompass all treatment modalities, with participants often categorising treatments based upon the benefit participants felt from treatments. James explained how adverse health effects following non-adherence to creon tablets ensure that he will always adhere to that treatment.

*[James, 19 years]: "My creon are the most important things (.) I'll have them [...] If I don't take my creon (.) then I'll notice (.) I'll get stomach ache (.) so I've got to take them # I always take them"

Consequently, adherence for many participants was influenced by short-term treatment benefits, with participants adherence decisions being based upon their immediate symptoms. A number of participants indicated that they self-medicate, with James only accepting the necessity of all his treatments when he is not well.

*[James, 19 years]: "When you're not ill # you don't notice that you have CF (.) so you tend to just forget about the medication and ### not take it (.) but ## when I do get ill # I'll do anything I can (.) to get rid of the illness"

James explained that when his symptoms are not present he does not consider himself to be ill, promoting his psychological wellbeing by providing relief from CF's enduring nature, however this appears to be associated with poor adherence.

A number of participants explained how they only came to accept treatments' necessity due to health deteriorations as a consequence of their non-adherence, with this acceptance resulting in Ashley employing effort to adhere to his medical regimens in order to improve his health.

*[Ashley, 35 years]: "I was going out (.) a:all the time at uni # I kind of slipped a lot of my medication [...] that's when # the lowest of my health # and that's kind of (.) wh:hy:y # after I finished University I went back to living with my parents ## so they could help me (.) bri:ing my health back up"

Other participants discussed how they came to accept treatments' necessity with age, explaining that it is only at this stage in their health that they can see the benefits of their adherence efforts.

*[Ben, 34 years]: "The effort you put in no:ow (.) you won't get results until later on [...] I mean I'm thirty fo:our # there's no wa:ay I thought I'd live that long (.) the wa:ay I was when I was younger # a:an I'm thinking no:ow in my teenage yea:ars if I had put that extra effort in ## I might have been even we:ell # even better off no:ow"

Acceptance with age could be due to health deteriorations resulting in individuals feeling more of a beneficial effect from their adherence efforts. However it could also be due to adults having the cognitive ability to understand treatments' necessity, understanding the long-term benefits adherence will provide them with. When participants explained that they had accepted treatments' necessity it was associated with positive attitudes towards adherence, with participants not being embarrassed about performing medical regimens in front of others, and often not desiring invisibility towards their condition, as they were

comfortable with having their illness on display. Andrew acknowledged that without his adherence efforts his health would rapidly deteriorate.

*[Andrew, 46 years]: "They've a:all said here # that # if I hadn't adhered # to my treatments [...] they don't quite put it this way # but they say you'd be six foot under # and I think that's pretty true (.) having seen some of my friends who haven't # adhered to it # you see people go downhill re:eally quickly"

Some participants also appeared to have accepted the adverse health effects associated with risky behaviours. This was often due to participants experiencing health deteriorations as a consequence of engagement, often resulting in cessation. Such participants often no longer desired a normal identity by engaging in these normalised behaviours, instead they were focused upon their physical health.

*[James, 19 years]: "I stopped smoking (.) my lung function got better [...] the main reason I stopped is because # getting that pneumonia (.) my lungs were getting ## awkward # struggling to breathe # painful # so last thing I wanted was:s (.) a fag"

Acceptance regarding these adverse health effects was not just isolated to individuals who had engaged in risky behaviours, with some participants who had not engaged in such behaviours also accepting these adverse health effects, with this preventing their initiation. Claire explained that she would never smoke despite it being normalised within her environment, due to her experiencing the adverse health effects of passive smoke. Therefore Claire appeared to value her physical health above a desire for normalcy.

*[Claire, 29 years]: "I would just walk past someone [who was smoking] and I'd be coughing [...] walking past a cloud of smoke makes you feel horrible"

In order for participants to accept the adverse health effects of risky behaviours, participants needed good awareness regarding these adverse effects, resulting in such participants viewing these behaviours in a negative light.

*[Matthew, 47 years]: "Things are bad enough with the CF (.) why are you wanting to make things worse through smoking ## an what are you gaining from smoking (.) like it's not enhancing your life ### it isn't making the CF any better # it's going to make it worse"

Even when risky behaviours were normalised by participants peers, their awareness regarding the adverse health effects often prevented their initiation. Lucy discussed how she

was able to make an informed choice regarding smoking due to being aware of the consequences of this normalised behaviour.

*[Lucy, 28 years]: "At high school (.) quite a few of my friends: stated smoking [...] I think because I know how important it is to breathe # an breathing is difficult anyway (.) I just don't know why people want to do that # to themselves"

Awareness can be provided in a number of ways, with some participants stating that HCPs have discussed risky behaviours with them.

*[Ben, 34 years]: "They don't say don't smoke (.) they put it in a way where you know it's bad for you (.) and it's going to affect your lungs even more"

However, a number of participants reported a lack of awareness provided from HCPs, despite some participants believing that this awareness could have prevented their initiation. An example of participants who were not provided sufficient awareness regarding risky behaviours comes from Will and Sarah. Will explains how he is unsure whether he is allowed to drink alcohol whilst on antibiotics, with Sarah discussing how she was never informed that co-codamol can be addictive, with Sarah developing an addiction that was never detected until she experienced near fatal side effects.

*[Will, 21 years]: "I don't know if that [drinking whilst on antibiotics] affects me: health # but # they haven't told me any different (.) when they prescribe it (.) they don't say (.) right you can't drink [...] I don't know if the assume you know # but I've never (.) ever been told [laughs] # so I just carry on as I am [drinking whilst on antibiotics]"

*[Sarah, 32 years]: "I got put on it [co-codamol] without been told that they're addictive: [...] I was (.) I was getting it from here (.) and my GP # so I was getting double the amount [...] I got called up on it once by a Doctor (.) but I was in complete denial [...] they were like look you're having too many (.) and I'd make up excuses saying I've lost some [...] I've kept some at my Mom's:"

Whilst Will and Sarah will have been informed through leaflets enclosed within the medication about the adverse health effects of co-codamol, and the implications of drinking alcohol whilst taking antibiotics, their experiences highlight the need for more specific and clear guidelines.

When participants had been provided with sufficient awareness regarding the true nature of their CF, and appeared to have accepted their CF, this was often associated with a

change in an individual's perceptions towards their illness, with acceptance commonly being associated with participants believing that health-orientated behaviours are mandatory.

*[Will, 21 years]: "You have to do it [...] if I'm out with my friends lets sa:ay (.) I sort of have to sa:ay # o:oh I've got to get back tonight # I ca:an't stay over at my mates house cause I've got to get back an do my stuff (.) an take my tablets"

Following acceptance it appeared that participants main priority was not about living their life how they wanted to; instead they appeared to define wellness as feeling physically well, and focused upon the medical and physiological aspects of their illness. Such participants appeared to value engagement in health-related behaviours, regardless of any restrictions this imposed upon their social life, with such participants being comfortable in disclosing their illness to others. However, for other participants awareness and acceptance regarding CF was associated with negative outcomes.

*[Stephen, 19 years]: "I came to terms with it [CF] when I was like # eight years old # I remember been in primary school # crying on the toilet # cause like I actually found out ## what it meant [...] I got dead upset [...] I'm going to die when I'm thirty odd"

Awareness regarding CF resulted in anxiety amongst some participants, particularly in regards to CF's fatal nature, with Daniel explaining that this awareness frightened him, resulting in him wanting to escape and avoid his CF.

*[Daniel, 25 years]: "With CF it's common that you have a short life span (.) and that # sca:ared me [...] I didn't wana have it [CF] # didn't wana know it"

Some participants coped with CF's fatal nature by rebelling against HCPs guidelines, engaging in risky behaviours despite their awareness regarding the adverse health effects of such engagement. Katie explained how she focused upon living her life in the "here and now" as she thought she would not survive into adulthood, resulting in her engaging in risky behaviours.

*[Katie, 33 years]: "I was told I wouldn't live to see sixteen [...] so I went through life:e (.) partying [...] I always thought o:oh god I'm not going to be old enough to do (.) you know # so that was my theory (.) just pa:arty (.) and be happy"

With psychological health, some participants believed that acceptance and awareness about CF's true nature was not adaptive, with avoidance of one's CF providing participants with a better quality of life, as acceptance prevented them engaging in several activities. Participants portrayed how following acceptance they became mindful about

engaging in health-promoting behaviours, and avoiding behaviours that could negatively impact upon their health, with this putting restraints upon their lives, impacting upon their psychological wellbeing. However, acceptance and awareness did not always result in adherence or prevent risky behaviour engagement, highlighting that the factors which influence such behaviours are complex. In terms of adherence some participants spoke about the challenges of dealing with health deteriorations, with Claire stating that although she is aware of treatments' necessity, she physically cannot adhere to her treatments when she is ill due to her diminished energy.

*[Claire, 29 years]: "If (.) you're # re:ea:ally poorly # do you know when you're on the absolute wo:orst day of having the flu # flued up [...] you should (.) definitely # do them [treatments] mo:ore than ever (.) but you've not got the # energy to # turn over # let alo:one ## get out of bed and do it all"

In addition some participants discussed how work can prevent adherence. Mark explained that due to his work commitments he sometimes does not have time to adhere to his treatments, with shift work making adherence even more complicated.

*[Mark, 23 years]: "I do:o need to take it [treatments] (.) but # it takes so:o lo:ong # it's bo:oring # I just want to go to bed [...] especially # like # with some of my old jobs:s # I used to come in re:eally late (.) and then I'd have to make up the vial (.) wait for the vial to be ready # so I'd be fa:alling to sleep # waiting for this thing to be diluted # then take it"

Another adherence barrier identified was the role of psychological distress, with participants discussing how when they experience symptoms of depression they cannot adhere to their treatments, although non-adherence worsens their health and negatively impacts upon their mood. Furthermore, some participants reported non-adherence due to a dislike for treatments and a desire to live their life.

*[Stephen, 19 years]: "I'm not a big fan of treatment as it is [...] it's always going to be coming faster towards me than it is to (.) these other sufferers (.) that (.) take (.) take their medication [...] the more medication you can take the longer your life sort of goes on (.) but you know ## for me ## I'm not a fan of it # I'm really not"

In terms of risky behaviours, some participants still engaged in these behaviours despite accepting their CF, and being aware of the potential adverse health effects. A number of participants discussed how psychological distress, particularly depression, had motivated their engagement, with James discussing how he started to smoke due to his

depression despite previously resenting smoking, with such engagement alleviating James' psychological distress and promoting his psychological wellbeing.

*[James, 19 years]: "Feeling a bit depressed (.) which is when I started [smoking] (.) like before then (.) I was proper (.) no (.) like # anti-smoke"

In addition, some participants acknowledged that they were aware of the adverse health effects associated with their risky behaviour engagement, however they had not experienced any adverse health effects, allowing their engagement to continue, with their experiences providing them with an optimistic outlook towards risky behaviour engagement. Some participants demonstrated unrealistically optimistic views towards their risky behaviour engagement, by comparing their behaviour with other uncontrollable factors. Nick compared his use of marijuana to car emissions present when walking down the street.

*[James, 19 years]: "CF affects your lungs (.) smoking affects your lungs (.) so obviously it's not a good combination [...] but when I'd tried it # I realised it (.) it didn't # re:eally affect me"

*[Nick, 33 years]: "I suppose smoking a bit of weed's not good for you (.) is it (.) e:erm:m # ha:aving a lung condition (.) but you know # stuff (.) emissions come out of ca:ars when you walk down the street (.) you're breathing them in (.) so it's tit for tat isn't it"

Furthermore, some participants reported engaging in risky behaviours due to their desire for a normal identity when in public. Nick explained that it is normal to want to smoke marijuana, use illicit drugs and drink alcohol even when he knows he should be adhering to his medical regimens, again demonstrating that such participants focus upon their psychological wellbeing as opposed to their physical health.

*[Nick, 33 years]: "If I'm feeling shit # like I'd still go out and drink lo:oads of pints (.) even though I'm feeling shit [...] I should be doing (.) my inha:alers # eating some good food (.) a:and maybe going for a run # get some rest [laughs] # but I'll be like na:ah (.) fuck it (.) lets go to the pub [...] it is quite natural to want to go for a drink # want to smoke a bit of weed # maybe take an ecstasy pill in your twenties"

In addition, whilst it was indicated that acceptance can aid the cessation of a risky behaviour; it did not always prevent the engagement in a second risky behaviour. James explained how he stopped drinking excessive amounts of alcohol, as he acknowledged that this behaviour was harmful due to symptom presentation. However, James replaced his

excessive alcohol consumption with smoking marijuana, which James stated is less dangerous, allowing his engagement to continue.

*[James, 19 years]: "I used to like # proper want to get drunk all the time (.) an then when I moved to weed (.) that stopped [...] there's no negative effects:s of weed [...] alcohol's worse at the end of the day"

Participants often explained how their new risky behaviour allowed them to remain in line with their group identity, ensuring their normal identity within that group, and on occasions alleviating their stress, both of which promotes an individual's psychological wellbeing.

*[Jessica, 32 years]: "I couldn't drink as much (.) because ## like blue wickeds (.) I think the blue in it (.) the dye (.) or whatever it is (.) used to play havoc with my sto:omach [so used drugs instead] [...] that [drugs] would keep me on the same path as everybody else (.) like (.) up there (.) instead of me being the sober one"

*[Sam, 43 years]: "It was # stre:ess:s [...] I didn't re:eally like the (.) e:er:r (.) effects of # dri:inking (.) e:er:r ## there's a kind of headachy::y (.) aspect of (.) alcohol that I:l (.) don't particularly enjo:oy [...] I just chose a sort of (.) single hit of (.) smo:oke (.) of heroin ### yeah (.) instead of (.) e:er:r (.) drinking half a bottle of wi:ine [...] It was a substitution"

Overall this theme identified the potential relationship between acceptance and the engagement in health promoting behaviours. However the factors that influence risky behaviour engagement are manifold; therefore an intervention to reduce the occurrence of risky behaviours within the CF population, and to encourage adherence, cannot just focus upon increasing an individual's awareness. This theme therefore aligns with the previous four themes in identifying another factor that can influence engagement in such behaviours. Acceptance and awareness should not be understood in isolation, as the data illustrates that engagement is potentially the result of a complex interaction between an individual's identity, acceptance, the support they receive from others, the challenges they experience in response to living with CF, and their attitude towards their life with CF. Therefore interventions need to be mindful of all these factors in order to attempt to reduce the occurrence of risky behaviours within the CF population.

Discussion

The data provides an exploration into experiences and beliefs around risky behaviours within an adult CF population. Participants had a range of experiences with risky behaviours giving a number of different reasons for engagement. The data produced is retrospective, which enabled older participants to talk about how things were when they were younger, particularly in terms of their adherence efforts, and experiences with risky behaviours; with participants being able to discuss how things are different now. The change in behaviours and beliefs that some participants discussed were dependent upon a number of factors, such as an individual's health status, their peer group and a change within their responsibilities.

With today's improvement in CF treatments quality of life is improving, with many participants describing how they lead a "normal life" engaging in "normal activities", particularly during adolescence and young adulthood when they are often relatively well (Götz & Götz, 2000). Being able to live a normal life was most likely to be experienced when participants were feeling well, allowing them to focus on other things rather than having CF, and experience a more positive outlook towards their life and future. Participants positive outlooks were often supported by comparisons to others, concluding that things could be a lot worse than CF. Evidence of comparing one condition with another resulting in optimism is demonstrated within parental attitudes towards CF, with CF parents alleviating their stress by comparing their child to other children they perceive "more ill" (Moola, 2012).

For some participants it appeared that when they were able to forget about their CF, due to their symptoms not being present, they did not possess an illness identity. Other participants explained how they retaliated against their illness identity, to embrace the same identity as their peers. The emphasis that many participants placed upon being normal and living a normal life is evident within many individuals with CF (King, 2015; Yates et al., 2010), with individuals often stating that they hope to live a normal life where they have long-term relationships, have children and pursue a career (Higham et al., 2013). For many this desire for normalcy was accompanied with a desire to fit in with their peers, with some explaining how their engagement in risky behaviours forms part of their socialisation within their social group, in line with previous findings within the general population (Seaman & Ikegwuonu, 2010). Being informed about the adverse health effects did not always result in non-engagement with risky behaviours, some participants still engaged in these behaviours in response to their illness identity, in order to reduce the differences between themselves and their peers (Higham et al., 2013; Withers, 2012). Such participants often demonstrated their life-orientated illness perspective explaining that they engage in such behaviours for fun and

enjoyment (Audulv et al., 2010), focusing upon their psychological health and wellbeing, with the enjoyment and pleasure individuals receive from their risky behaviour engagement promoting their continuation. The influential role of peers was signalled when some participants experienced a change in friendship group resulting in the cessation of their risky behaviour, demonstrating that their engagement was based upon extrinsic motivations, where their behaviours were heavily influenced by external factors (Deci & Ryan, 1985, 2000).

Bryon (2015) explains that adolescents with CF will behave like their peers without CF, and will engage in normalised risky behaviours, with adolescence being a period of time associated with heightened risk-taking behaviours, with this being supported by the present research. Adolescents are less likely than adults to perceive situations as unsafe (Knoll et al., 2015), with the experimentation of risky behaviours being normal during adolescence (Cohn et al., 1995; Richmond, 2014), however the CF population does not have the same freedom to experiment with such behaviours (McEwan et al., 2012). This highlights the need for patients to be made aware of the CF-specific adverse health effects of risky behaviours by HCPs. Nonetheless, some participants explained how they had not been provided awareness by HCPs, believing that HCPs are not aware of what substances are readily available within the general population, with literature indicating that most Doctors know less about illegal drugs than their patients do (Viner & Macfarlane, 2005).

Some participants believed that awareness would have prevented their initiation, however this is questionable, with it being well established within literature that awareness and knowledge regarding adverse health effects generally is not enough to motivate cessation, or prevent initiation (Derman & Akan, 1995). In terms of cessation it is indicated that despite an individual's awareness regarding the adverse health effects of a behaviour, an individual needs to be self-motivated to cease their engagement, with health promotion measures being unsuccessful within individuals who do not have any intention to change their health behaviours (Chatwin et al., 2014). Participants indicated how their behavioural intention can be influenced by a number of factors.

As suggested by The Stages of Change Model, interventions to encourage the cessation of a risky behaviour are most successful when an individual is already considering that behavioural change (Prochaska & DiClemente, 1982). Consequently prior to an individual contemplating a behavioural change, effort needs to be employed to change their attitude towards that behaviour (Ajzen, 1988; Ajzen & Madden, 1986; Fishbein, 1967; Fishbein & Ajzen, 1975). To promote behavioural change it is important that the individual can comprehend the awareness provided, with some participants highlighting how they did

not have the cognitive ability to understand and operationalise health information that HCPs had provided them with, due to the information being too complex. This awareness did not result in participants experiencing a change within their behavioural intention, as they could not process such information. It is therefore important that health advice is age appropriate (Bryon, 2015), providing the opportunity for such information to have an impact upon an individual's attitude towards the behaviour, and therefore their behavioural intention (Ajzen, 1988; Ajzen & Madden, 1986; Fishbein, 1967; Fishbein & Ajzen, 1975).

Whilst awareness and knowledge cannot always be relied upon to produce behavioural change, the data does show that it can have an impact on behaviours within some individuals. Some participants explained how they did not engage in risky behaviours which were normalised within their social group, due to their good awareness regarding the adverse health effects. Awareness can be provided in many ways, with it being apparent that when awareness is provided through medication leaflets, e.g. do not drink alcohol whilst taking antibiotics, it is not always successful, with Raynor and Knapp (2000) stating that only 21% of individuals within the general population read all of their medicine leaflets, highlighting the need for awareness to be individually provided and explained to all patients, particularly those with distinct medical needs (Raynor, Silcock, Knapp & Edmondson, 2007).

Given the complex relationship between awareness and abstinence, the influence of external factors on engagement in risky behaviours was explored. In line with The Theory of Reasoned Action and The Theory of Planned Behaviour (Ajzen, 1988; Ajzen & Madden, 1986; Fishbein, 1967; Fishbein & Ajzen, 1975), participants indicated how they greatly value the opinions of their peers, with participants subjective norms often encouraging their engagement in risky behaviours, despite their awareness regarding the adverse health effects. Therefore despite an adult participant retrospectively suggesting that awareness would have prevented initiation, when they were an adolescent this may not have been the case, due to their desire to comply to the behaviours of individuals within their social group. Consequently, with most adolescents having a desire for strong peer identification (Bryon, 2015), their peers' behaviour is very important in determining their engagement in order to receive a sense of normalcy, regardless of one's awareness.

Many participants spoke about the importance of not being defined by CF, with participants explaining how they are provided with a sense of normalcy as CF is often an invisible impairment (Tierney, 2012). In the present study many people spoke about how CF's invisible nature is a positive thing, allowing them to fit in with their peers, as their peers cannot physically identify any differences between the individual and themselves (Withers, 2012). Visibility of an illness identity is often difficult to cope with, with some participants

explaining how the stares and questions from others regarding their illness is discomforting, with literature explaining that this is associated with negative emotions (Withers, 2012), and has the potential to result in social anxiety (Burker et al., 2012; Orenstein, 2004). In order to maintain CF's invisibility, many participants often fail to disclose their CF status to others, with CF's invisible nature aiding this non-disclosure (Borschuk et al., 2014; Higham et al., 2013; Tierney, 2010). Some participants explained how they do not disclose their illness to others as they keep CF as a separate part of their life, with participants explaining how they are capable of hiding their illness from a vast number of people including their partners, with some participants not disclosing their illness identity to their partner unless they perceive the relationship is going to be long-term, in line with Higham et al's (2013) findings.

This desire to not be defined by CF also resulted in a number of participants not adhering to certain treatment modalities, due to the identity adherence provides the individual with. One of the main adherence barriers within CF is an unwillingness to take medication in public (Bregnballe et al., 2011), with many participants not wanting their peers to see their illness identity, ensuring their normal identity in public (Yates et al., 2010), and allowing them to be accepted within their social group (Duff & Latchford, 2010; Withers, 2012). An individual's desire for normalcy can be translated into different behaviours, with some participants explaining how they do not want to look like the traditional image of CF, therefore they adhere to their treatments so that they remain well and their CF is less obvious to others. This is in line with the social comparison theory (Festinger, 1954), with such participants making downward comparisons, involving them comparing themselves favourably to others with CF, raising their self-esteem, encouraging their adherence to continue so that they do not fit this traditional image of CF (O'Brien et al., 2009; Tierney, 2012).

Whilst many participants did highly value a sense of normalcy within their lives, the data demonstrated that as an individual's disease progresses, it becomes more difficult for the individual to appear "normal". This shift in appearance is seen to be a very difficult time emotionally and psychologically, where participants explained that they were forced into a position of accepting an illness identity and often had to reconsider their health behaviours. Participants who had previously had poor adherence discussed that as their disease progressed they began to accept treatments' necessity, incorporating their illness into their identity, with Laws et al (2012) stating that individuals only become adherent when they have accepted their illness. Acceptance regarding CF was often accompanied with participants disclosing their illness to others, aiding their adherence efforts in public. Acceptance requires individuals to go through the stages of identity reformulation (Aujoulat et al., 2008), which typically occurs during diagnosis, however with individuals with CF being born with the

condition some participants explained that they have never known any difference in terms of their CF. Nonetheless, many participants did demonstrate how they do not always possess an illness identity, with this being dependent upon health status, presenting symptoms, age and situational factors. Consequently, despite individuals being born with CF, CF is not a static experience as an individual's condition fluctuates, with the way an individual identifies themselves changing overtime and across circumstances. Many participants demonstrated how they only started to incorporate their illness into their identity when their health deteriorated, as prior to that point the participant discussed living a normal life, illustrating a good quality of life (Götz & Götz, 2000).

Quality of life was important to many, with the data suggesting that participants who are optimistic towards their life and future possess a life-orientated illness perspective (Audulv et al., 2010). Participants optimistic outlook appeared to increase their quality of life, with such participants focusing upon the enjoyment they receive within their lives, with literature stating that this results in psychological resilience (Abbott, 2003; Abbott et al., 2008). A life-orientated illness perspective did appear to result in psychological benefits, with some participants describing how they will engage in a behaviour despite acknowledging the associated risks, as they believe the psychological benefits are worth the possible risks, representing their intrinsic motivation (Deci & Ryan, 1985, 2000). Other participants however viewed self-management as mandatory, with such participants appearing to possess a disease-orientated illness perspective (Audulv et al., 2010) and consequently avoiding risky behaviours. The way an individual perceives their illness can change overtime and across circumstances, with participants indicating that at certain times (e.g. during weekdays) they can possess a disease-orientated illness perspective, where they engage in health-promoting behaviours; however at other times (e.g. during weekends) they can focus upon their psychological wellbeing, engaging in behaviours which provide them with enjoyment, demonstrating their life-orientated illness perspective. Individuals who had good adherence and engaged in a risky behaviour often believed that the risky behaviour would not cause adverse health effects, due to their adherence protecting and promoting their current health status. This is evidence of risk compensation (Rabiau et al., 2006), with it being acknowledged that the more compensatory health beliefs an individual has regarding their risky behaviour, the lower their readiness is to attempt cessation, with compensatory health beliefs often being a mechanism to resolve cognitive dissonance (Radtko et al., 2011).

A further influential factor associated with risky behaviour engagement within the data was the occurrence of psychological distress, with research demonstrating that many individuals engage in risky behaviours to alleviate their stress (Boden & Fergusson, 2011; Kassel et al., 2003; Kavanagh et al., 2011). Depression does often worsen medical

prognoses, due to psychological distress playing a role in the development of substance use disorder (Jeppe, Szabo & Smith, 2015). Participants within the current research suggested that their psychological distress was a factor in their engagement, in an attempt to alleviate their negative emotions, with research explaining that the cognitions which predict risky behaviour engagement include the belief that these behaviours will reduce their stress (Charlton, 1984; Charlton & Blair, 1989).

For some participants their stress was a direct consequence of their employment or educational experiences. CF's increasing life expectancy means that many individuals with CF do work (Saldana & Pomeranz, 2012), with employment being associated with psychological benefits (Burker et al., 2012). However, with literature demonstrating that 488,000 people in the UK suffer from occupational stress (Health and Safety Executive, 2016) it is not surprising that individuals with CF may be exposed to this stress. The issue of occupational stress may be heightened for individuals with CF who have to frequently take time off work for hospitalisation, resulting in presenteeism (Cooper, 2013; Newcombe, 2013). Consequently, CF individuals may engage in risky behaviours to alleviate their occupational stress, in order to help them relax, feel happier and calmer (Kassel et al., 2003), with many participants explaining how the engagement in risky behaviours was associated with psychological benefits.

Psychological distress was also experienced as a direct consequence of life with CF. The emotional burden of living with a condition that is life limiting was discussed by a number of participants. Many individuals with CF do feel anxious in response to their CF and experience depressive feelings (Withers, 2012), which in turn can increase the possibility of them engaging in risky behaviours as a way to alleviate the anxiety. It was clear from the data that anxiety is understandably worsened when health deteriorates, as this puts a strain on existing coping mechanisms, and can lead people to seek or increase the use of additional coping mechanisms that may not be adaptive (Orenstein, 2004). Frequent deteriorations in health results in more frequent hospital admissions which place additional psychological burdens on patients and their families (Antos, Quintero, Walsh-Kelly, Noe & Schechter, 2014).

Hospitalisation impacts upon an individual's social and private life, with in-hospital segregation resulting in isolation and loneliness (Lamas, 2013; Visse, Abma, Oever, Prins & Gulmans, 2013). A number of participants discussed this and explained how they do not follow the in-hospital segregation rules, as they believe that the psychological benefits accompanied with communicating with other individuals with CF outweigh any potential risks. Many participants did not believe that there are any risks from communicating with

others with CF, with these participants potentially demonstrating unrealistic optimism (Weinstein, 1980), with their beliefs being influenced by their generational upbringing.

In addition to hospitalisation, transition to independence also presents several challenges for many people, and can have a particular impact on adherence. Participants spoke about how the decrease in family support during transition to adult care often results in poorer adherence, and this is a major concern during adolescence (Bregnballe et al., 2011). Transition to adult care can be an upsetting process, due to the amount of changes that occur (Withers, 2012), with it being expected that individuals will become more aware about CF's potential future consequences as they are provided with more information from the adult CF team. This increase in awareness may result in identity reformulation (Aujoulat et al., 2008), demanding new behaviours such as independent adherence. However the process of identity reformulation may upset individuals as they realise CF's true implications. This anxiety (Pacaud & Yale, 2005) could be in response to their illness identity, with some participants engaging in risky behaviours and non-adherence to deal with their negative emotions towards CF, and to retaliate against the illness identity that they feel CF imposes upon their life.

The retaliation against an illness identity due to negative emotions was also at times due to denial. Literature reports that individuals with CF can demonstrate denial in an attempt to be perceived as normal (Higham et al., 2013). The data highlighted how an individual can be in denial about a number of different aspects of their CF. Some participants were in denial regarding their diagnosis, questioning both the diagnosis and severity of their CF. This led them to also question treatments' necessity resulting in poor/non-adherence. Denial is the first stage of the journey to adherence according to Kubler-Ross's model (1969); with an individual being expected to go through the following stages before they accept their condition, and therefore accept treatments' necessity: anger, bargaining, depression. The questioning of one's diagnosis and the severity of their illness is a common experience within chronic conditions, with it having both adaptive and maladaptive properties. Denial can protect an individual from overwhelming feelings of anxiety, however despite this psychological benefit, denial can result in misunderstandings within individuals regarding the severity of their illness, their prognosis and their need for treatments (Vos, Barker, Stanley & Lopez, 2007).

In terms of treatments' necessity, the data signalled that an individual's denial can be influenced by a number of factors. Childhood experiences had a big influence upon an individual's understanding regarding the need for treatment, with individuals who had not been raised in an environment which encouraged health-related behaviours, not

understanding why they needed to adhere to these treatments during adulthood. Participants' good health despite non-adherence strengthened the denial stage of emotional adjustment (Kubler-Ross, 1969), resulting in poor/non-adherence. In addition, other participants explained how their denial was reinforced when they experienced no noticeable benefits from their adherence efforts, or no adverse health effects from non-adherence. Many participants focused upon the short-term treatment benefits, without consideration for long-term benefits, with adherence decisions being based on immediate symptoms (Abbott et al., 1994). Even when some participants did experience adverse health effects from their non-adherence they still did not always associate their behaviour with the health deterioration, indicating their failure to integrate their illness into their identity (Laws et al., 2012).

Whilst this resistance to accepting treatments' necessity may be due to denial, there are several other barriers to adherence. Bryon (2015) suggests that adolescents with CF may be less able to consider long-term consequences from non-adherence, with a number of participants supporting this assertion explaining that they do not understand HCPs' discourse. This highlights the need to ensure all interventions used are age-appropriate allowing individuals to process the information. Age in itself is a barrier to adherence, as adolescents and young adults under the age of twenty-five years possess an immature cognitive functioning, with these individuals often not understanding the true nature of risks (Bryon, 2015; Del Piero et al., 2016). Individuals under the age of twenty-five years often have a high sensitivity to rewards and a low sensitivity to risks (Bava & Tapert, 2010; Bryon, 2015), with participants demonstrating that motivations during adolescence and young adulthood are reward seeking, involving the avoidance of barriers to rewards, such as non-adherence. A further barrier to adherence present within the data was a lack of positive reinforcement (Kettler et al., 2002), with many participants demonstrating their awareness that their health will progressively deteriorate regardless of their adherence efforts.

In terms of influencing risky behaviour engagement, participants who engaged in such behaviours often focused on the perceived benefits to their health, rather than the possible adverse health effects. This was particularly evident amongst participants who smoke marijuana, where they describe experiencing respiratory improvements following their engagement, with these participants focusing upon short-term effects rather than the long-term effects of usage, demonstrating their inaccurate perception of risk and susceptibility (Borrelli et al., 2010; Weinstein, 1980). It is acknowledged that when individuals believe their "risky" behaviour offers some benefits towards their life it reduces their cognitive dissonance, and therefore allows them to continue their engagement, restoring a sense of cognitive consistency (Festinger, 1957). Consequently, in order to increase the chance of behavioural

change an individual's cognitive dissonance needs to be increased, creating an unpleasant state of tension within the individual (Festinger, 1957).

The perceived benefit from marijuana use that participants discussed is also found within the general population, with many individuals perceiving marijuana to be a harmless substance, viewing it to be a recreational drug and not a "hard, illicit drug" (Hathaway et al., 2011). In line with the data, many adolescents believe that marijuana cannot be harmful due to it being a natural substance (FRANK, 2009; NIDA, 2016), with "pro-marijuana" perspectives being easily available via social media (Hathaway et al., 2011; Hathaway & Erikson, 2004). Recent public discussions surrounding medicinal marijuana will have also influenced adolescents attitude towards marijuana, with many believing that marijuana is a "safe drug" (NIDA, 2016), which again was outlined within the data. In addition to resolving cognitive dissonance (Festinger, 1957), the belief that a risky behaviour is beneficial, demonstrates unrealistic optimism (Weinstein, 1980), which has the potential to lead to biased health perceptions.

Individuals are unrealistically optimistic due to selective focus, where individuals ignore behaviours which increase a risk, and focus upon behaviours which reduce a risk (Weinstein, 1988), again demonstrating evidence of compensatory health beliefs (Radtke et al., 2011). Further evidence of selective focus was when a participant acknowledged the adverse health effects of smoking marijuana due to symptom presentation, so he adapted that behaviour by vaping marijuana, without acknowledging the adverse effects still present. Vaping is a relatively new behaviour which has also undergone a rapid normalisation process, with electronic cigarettes not just being used by individuals who wish to quit their smoking behaviour (Tan, 2015), they have provided marijuana users with a new method of inhaling cannabinoids, which individuals believe is less harmful (Giroud et al., 2015).

However avoidance of CF, or even denial, did not always result in risky behaviours, or non-adherence, with such behaviours being influenced by a number of factors, such as the support an individual receives from others. A large source of support for many participants was family support. Participants explained that when their family members provide them with awareness regarding the adverse health effects of risky behaviours, and protect them from environments where these behaviours are present it often prevents initiation, with participants not wanting to upset their family members or deviate from their social norms. Such support also appeared to be effective from a participant's peers, with individuals being more likely to listen to their peers than parents or HCPs (Bryon, 2015).

In addition to awareness regarding the adverse health effects of risky behaviours, some participants explained how they never initiated in such behaviours as they feared the

consequences they would receive from their family (e.g. discipline), with adolescent substance use initiation being mediated by changes in parental monitoring within the general population (Dishion, Nelson & Kavanagh, 2003). Risky behaviour engagement does put strain upon families (Galvani, 2015), with participants often describing how their family relationships improved following cessation, reducing their motivation to relapse, as they became dependent upon their family to help them cope with difficult times, instead of using risky behaviours as a coping mechanism (Mathieu, 2011).

Another family motivator which encouraged cessation and adherence was becoming pregnant, with many female participants stopping their engagement with risky behaviours as soon as they became pregnant. Male participants also explained how becoming a parent would motivate their cessation. However, literature does indicate that risky behaviours are prevalent during pregnancy, with 35% of young pregnant women in the UK smoking throughout pregnancy, with only 17% who smoke using "stop smoking services" (Marteau, Thorne, Aveyard, Hirst & Sokal, 2013). Nonetheless, pregnancy within CF is a different experience, with individuals feeling privileged stating things such as: "I never thought being a Dad would happen" (The CF Trust, 2016b). Even for females with CF who are usually fertile, their pregnancies are often planned, and they receive a large input from their CF teams during pregnancy to maintain their health, therefore experiences are different to females within the general population (The CF Trust, 2016b).

Whilst family support has favourable health outcomes, a lack of support can be detrimental. Some participants explained that due to their negative family relationships they use risky behaviours to improve their mood, and escape such negativity, with literature demonstrating that negative family interactions are related with increased alcohol consumption and smoking within adolescents in the general population (Gutman et al., 2011). In addition to negative family relationships, relationship breakdowns were also considered detrimental to health, with some participants engaging in risky behaviours to alleviate their negative emotions, with it being reported that relationship breakdowns have an effect upon depression, anxiety, substance use and dependency (Coleman & Glenn, 2009), particularly when the individual has experienced multiple relationship breakdowns (Barrett, 2000).

In terms of support, as well as families and peers, many participants spoke favourably of their HCPs, in particular their Nurses. It is commonly reported that individuals favour Nurses over other HCPs (Read & Mayberry, 2000), due to building patient relationships being central to a Nurses role (Collins, 2015; Van den Heever, Poggenpoel & Myburgh, 2015). Some participants did explain how despite their families and HCPs efforts,

they will never know what it is really like to live with CF, with HCPs themselves acknowledging that they cannot understand, nor imagine what it is like to live with a chronic condition (Lamberts, 2010). This is a barrier to effective prevention advice, with participants explaining how their priorities in life are different to what others believe their priorities should be, with many participants focusing upon their psychological wellbeing due to their reduced life expectancy. Consequently, Schwartz (2016) stated that CF treatment needs to move away from the medical model to personalised medicine, where HCPs should acknowledge the whole person and be mindful of their blind spots, in the sense that they do not have the illness. Participants explained how emotionally difficult it can be when HCPs focus upon aspects of their health which are deteriorating, instead of acknowledging aspects which they are managing well, with parents at the UK CF Conference (2016) explaining that HCPs discourse needs to refer to hope and inspiration. Therefore, it is essential that CF care continues in its aim to provide personalised patient centred care, where HCPs focus upon the individual and their psychological needs, as well as their physical needs. In addition, with CF's improvement in life expectancy it is essential for CF HCPs to become more aware of the "new" challenges CF patients face (Horky, 2014), in an attempt to reduce the occurrence of risky behaviours within the CF population.

Conclusions

Overall, this phase of data collection successfully provided insight into the variety of reasons why some individuals with CF engage in risky behaviours and do not engage in health-promoting behaviours. A desire for normalcy was seen to be important to many, with this desire being associated with the engagement in normalised risky behaviours, often as a retaliation against the illness identity. Evidence of a life-orientated illness perspective was also prevalent, with participants reporting that they engaged in risky behaviours for fun. There was also a reported lack of knowledge concerning consequences of risky behaviours, in line with the transition evaluation, with many participants stating they had not been informed of these by HCPs, despite the current research highlighting the importance of awareness, with patients who had good awareness of the consequences of risky behaviours often accepting that they cannot engage in such behaviours.

This research highlights the need for more effective health promotion measures to reduce the occurrence of risky behaviours within the CF population. The participants' narratives were retrospective, which provided a time dimension to the data, enabling the research to capture changes within participants, identifying influential factors which contribute to the initiation of risky behaviours within CF (De Vaus, 2006). In creating an intervention within the CF population, it is suggested that this intervention needs to firstly

raise an individual's awareness of what risky behaviours are, and what adverse health effects such behaviours can specifically have upon their CF. In terms of adherence, again an intervention needs to firstly focus upon increasing an individual's awareness regarding treatments' necessity, and the adverse health effects of non-adherence. It is apparent that this awareness needs to be provided to all individuals with CF, regardless of their personal condition from their HCPs, which at present appears to not be standard practice. This awareness would provide individuals with the opportunity of making a more informed choice as to whether or not they want to engage in risky behaviours and / or non-adherence in light of the consequences, as it has to be acknowledged that engagement in such behaviours is an active choice, and should be respected. In order for HCPs to provide awareness on risky behaviours, HCPs themselves need to be made more aware of what risky behaviours are current within the general population, as there was the belief amongst participants that HCPs are not aware of what substances their patients may have access to.

In addition to individuals' awareness regarding risky behaviours and adherence, HCPs need to be mindful of the influence psychological distress, avoidance of one's CF and negative family interactions can have upon an individual's engagement; with it commonly being reported that all three factors are associated with engagement. Therefore whenever psychological distress, avoidance of CF or negative family relationships are detected or suspected, HCPs should be mindful of what behaviours these constructs could potentially result in, and again raise an individual's awareness of the adverse health effects of risky behaviours and non-adherence, as well as helping individuals cope with these aspects of their lives to reduce the occurrence of risky behaviours within the CF population.

Importantly, this phase of data collection highlighted that risky behaviour initiation, and the engagement of non-adherence commonly occurs during adolescence. The researcher therefore deemed it necessary for a second phase of data collection to be conducted within the paediatric CF population, before work on an intervention commenced. This second phase of data collection aimed to investigate paediatric participants' knowledge, beliefs and attitudes towards risky behaviours, at an age commonly associated with initiation, ensuring that any interventions created are relevant to all individuals with CF, particularly adolescents where it is assumed interventions will be targeted.

CHAPTER SEVEN: METHODOLOGY - PAEDIATRIC CYSTIC FIBROSIS PATIENTS' **ATTITUDES AND BELIEFS REGARDING RISKY HEALTH BEHAVIOURS**

The Research Sites

All participants were recruited from the paediatric CF population at Birmingham Heartlands Hospital and the Royal Stoke University Hospital. These two research sites again were chosen due to their geographical location, with both hospitals being used within the first phase of data collection, and therefore being fully informed regarding the study's aims, process and intended outcomes.

Birmingham Heartlands Hospital is host to a paediatric CF MDT of HCPs including Consultants, Specialist Nurses, Physiotherapists and Dieticians. This unit provides inpatient and outpatient care for paediatric CF patients until 17 years of age, with a report published by the CF Trust (2014) indicating that this unit is part of a large specialist clinical network comprising of hard-working, dedicated and well-established teams, which are greatly appreciated by patients and parents. In order to gain approval for the research off the paediatric MDT, the researcher presented the preliminary findings from phase one data collection, the research proposal and rationale to the CF MDT (Appendix J).

The Royal Stoke University Hospital is the location of the North West Midlands Paediatric CF Centre, which hosts a MDT of HCPs including Consultants, Specialist Nurses, Physiotherapists, Dieticians and Psychologists, providing inpatient and outpatient care for paediatric CF patients. A peer report concluded that despite the paediatric unit being "relatively small with approximately 100 full and shared care patients", it does serve a "large geographical area with significant socioeconomic deprivation" (The CF Trust, 2013c). To gain approval for the research off the paediatric MDT, the researcher presented the preliminary findings from phase one data collection, the research proposal and rationale at the North West Midlands CF Centre Regional Meeting (Appendix J).

Participants

Ten paediatric participants (male: 5, range: 12-18 years; mean: 14 years) were recruited, with a median FEV₁ 69.14% predicted (Table 2).

Participant Number	Sex	Date of Birth	Age	Latest Lung Function Result
1	Male	23/11/2001	14 years	/
2	Male	15/08/2001	14 years	80%
3	Female	03/10/2003	12 years	50%
4	Male	01/10/2002	13 years	82%
5	Female	24/04/2004	12 years	94%
6	Male	10/08/1997	18 years	/
7	Female	05/04/2003	12 years	28%
8	Female	27/12/2001	13 years	85%
9	Male	14/09/2000	16 years	65%
10	Female	06/06/2004	12 years	/

Table 2. Medical and Demographic Data collected for all paediatric participants.

Adolescents with CF were eligible to participate regardless of whether or not they had experience of engaging in risky behaviours.

Exclusion Criteria: Individuals were excluded if they had a lack of capacity (identified by their Consultant) and if they were non-English speakers. These individuals were identified through discussions with the CF Consultants and by consulting CF outpatient and inpatient lists.

Where possible all adolescents with CF who were eligible to participate were invited to do so until data saturation occurred. On occasions, eligible patients may have been missed as a consequence of the researcher interviewing another participant, or if the Consultants had failed to refer an eligible patient.

Measures

Semi-Structured Interview. The researcher conducted semi-structured interviews with paediatric CF patients to investigate their awareness and views towards risky

behaviours; with the researcher transcribing all interviews. The interview schedule (Appendix K) was adapted from the interview schedule used within phase one data collection through collaborations with the researchers supervisory team, with the interviews investigating what paediatric patients believe would influence their future engagement in risky behaviours (if anything), and why they believe some adults with CF engage in such behaviours. These interviews focused upon the key themes which emerged during phase one data collection.

The interview schedule again commenced with a section of ice breaker questions. Due to adolescents being less likely than adults to report engagement in risky behaviours (Ross-Durow, Veliz, McCabe & Boyd, 2015), these ice breaker questions were essential to instigate a good researcher-participant relationship, developing rapport and ensuring participants felt safe to disclose information and elaborate on sensitive topics (Ashton, 2014). The ice-breaker questions were the same questions used for phase one data collection. It was found within phase one data collection that the final ice-breaker question was a good starting place for participants to provide insight into their life with CF, predominantly highlighting any challenges they encounter.

The interview then encouraged participants to discuss the impact CF has upon their personal life, with this discussion being responsive to participants developing accounts (Cooley et al., 2014; Rubin & Rubin, 1995). As with phase one data collection, this conversation was in line with Cox's (2015) guidelines in providing insight into what it is like to live with CF in the growing and changing population that CF is today. Based upon the findings from phase one data collection, there was a focus upon the participants' experiences around telling others that they have CF, as many adult participants highlighted that they often do not tell others about their CF. Therefore, the researcher was interested in young people's experiences and decision making around telling others that they have CF, with literature recognising that many chronically ill adolescents favour invisibility towards their illness, allowing them greater normalcy (Yates et al., 2010).

Within this section focusing upon life with CF, the interview predominantly focused upon how young people view adherence. Within phase one data collection participants openly discussed issues surrounding adherence, highlighting factors which influence both adherence behaviours and the engagement in risky behaviours, with the relationship between adherence and risky behaviours being highlighted within other chronic conditions (Mays et al., 2012), however this was the first piece of research which had investigated adherence and risky behaviours together within the CF population. Adolescence is a crucial time for adherence, with individuals becoming more responsible for their own medical regimens; therefore the researcher was interested in investigating how adolescents with CF cope with

this transition, with previous literature (Bregnballe et al., 2011), and the findings from phase one data collection indicating that this can be problematic.

The interview schedule then specifically focused on the issue of risky behaviours. Within the paediatric population the research was not necessarily focusing upon the participant's own engagement, instead this research was investigating participants' awareness and knowledge on risky behaviours, and their beliefs towards such behaviours, as it was acknowledged that prospective interviews can be influenced by social desirability bias (Schwarz, 2004), despite the researcher's effort to generate rapport. This section of the interview schedule also focused upon the normalisation of risky behaviours, which was identified to be important in influencing initiation within phase one data collection. The researcher was therefore interested in whether adolescents with CF are exposed to this normalisation, and how that impacts upon their beliefs towards risky behaviours. The researcher discussed these behaviours with participants in a non-judgemental way in the hope of gaining a true reflection of participants' personal beliefs surrounding these behaviours. The researcher also gave participants the option to discuss their attitudes and beliefs towards risky behaviours in third person, asking participants why they think others (and others with CF) engage in such behaviours, potentially highlighting their intentions to initiate in such behaviour without personalising the discussion.

The next section of the interview encouraged participants to discuss any support they have from others. The role of others was found to be crucial in influencing adherence, and preventing initiation of risky behaviours within phase one data collection. Therefore, the researcher was interested to see how this is experienced by younger people. Within this section there was the opportunity to discuss the issue of cross-contamination, which for the adult population was often ignored. However, many adult participants highlighted that the disregard of such rules was due to a generational occurrence; therefore the researcher was interested to see how the paediatric CF population view cross-contamination, after being raised in a generation where HCPs employ effort to discourage patients mixing.

As with phase one data collection, the researcher employed effort to encourage elaboration within participants during the interview (Ashton, 2014; Fielding & Thomas, 2008; Kvale & Brinkmann, 2009; Valentine, 2007, 2014), with it again being essential for the researcher to reduce the rapport, and create distance during the end of the interview (Ashton, 2014). Therefore, the interview ended with the same three questions used for the adult population, allowing participants to feel their contribution to the research was valued (Ashton, 2014).

Carrying out the Study

Discussions were held with CF Consultants at Birmingham Heartlands Hospital and the Royal Stoke University Hospital, to devise a list of all paediatric CF patients that did not meet the eligibility criteria. This list of patients was used by the MDT to identify eligible patients and to provide them and their legal guardians with a handout (Appendix L) explaining the research along with a consent to contact form (Appendix M). Once legal guardians had provided consent to contact, the researcher contacted them within the next 24-48 hours via telephone at a time convenient for themselves (mornings, afternoons or evenings - as suggested by the guardian). The researcher explained the research verbally to the guardian and allowed them to ask any questions. If they were still interested in the research, the researcher arranged to meet the paediatric patient with their legal guardian at their CF centre at a time / date most convenient for themselves (usually to coincide with outpatient appointments or scheduled inpatient stays). The researcher was not present at clinic appointments or during inpatient stays until consent to contact had been received.

The researcher was present in the waiting room of clinic or on the ward on the pre-arranged days. A member of the MDT advised the researcher when the eligible patient along with their legal guardian arrived at clinic and what doctor's cubicle they were in, or advised the researcher what room the patient with their legal guardian was in on the ward. The researcher approached the patient in the presence of their legal guardians and invited them to take part.

The study was fully explained to patients and guardians, both verbally by the researcher and in the form of a written information sheet (See Appendix N & O), with both patients and guardians having the opportunity to ask any questions. The patient and guardian received different information sheets to aid their understanding of the research process and purpose. Patients and guardians had a maximum of two weeks to decide on participation, to help facilitate informed consent. If the legal guardian wanted their child to participate they had to complete a consent form (Appendix N). If the patient wanted to participate they either had to complete an assent form (used for patients aged 12 - 15 years) (Appendix P) or a consent form (used for patients aged 16 - 17 years) (Appendix Q); the patient could only participate if consent had been obtained from both the patient (or assent) and their legal guardian.

A coding method was used so that participants' names did not appear on interview data ensuring all data was anonymised and confidential (pseudonyms were used for the write up). The researcher also collected contact details (telephone number, email address)

from the guardian to forward the overall results of the study. All of this personal data was kept strictly confidential.

Participants then independently engaged in a semi-structured interview to investigate their awareness and views towards risky behaviours. Interviews were conducted in the absence of participants' legal guardians, unless participants explicitly expressed a desire for them to be present. Five interviews were conducted where guardians were present for the duration of the interview, one interview was conducted where the guardian was present for the start of the interview but left before a discussion on risky behaviours commenced. The interview could be conducted on the same day as informed consent, alternatively the researcher could interview participants on a separate day to suit their availability (nine participants were interviewed on the same day as consent was provided, one participant was interviewed on a separate day). The interview was conducted in a private room at the CF centre and lasted a maximum of 60 minutes, however it could be stopped earlier at the participants discretion; within this research no participants stopped the interview early. Participants did not have to answer any questions they did not want to. All participation was voluntary, and participants could withdraw from the research at any time without being penalised; within this research no participants withdrew. If participants had got distressed during the interview the interview would have been stopped immediately and a referral would have been made to their MDT; within this research no participants became distressed. Once the interview was complete participants were provided with a debriefing sheet (Appendix R), and again had the opportunity to ask any questions along with their legal guardians. The researcher then contacted all participants (via their legal guardians) once the research had been analysed to inform them of the overall research results and to ask for results feedback (Appendix S).

Ethics Committee

Ethical approval was obtained via the Integrated Research Application System by NRES Committee East Midlands - Leicester, and the R&D departments at Birmingham Heartlands Hospital and the Royal Stoke University Hospital.

Ethical Considerations

Young people should be treated with the same degree of protection regarding confidentiality and anonymity as adults when engaging in research. Additionally, researchers have a duty to ensure the safety of young people, over their responsibility of guaranteeing confidentiality in cases of child protection (Shaw, Brady & Davey, 2011). Confidentiality can only be broken in exceptional circumstances where it is deemed that the risks to participants

(or others) health, safety or welfare, outweigh participants right to confidentiality (Royal College of General Practitioners [RCGP], 2011). Therefore the researcher had a protocol in place informed by previous safeguarding policies (Gloucestershire Confidentiality Policy, 2005; NSPCC, 2013; RCGP, 2011; Shaw et al., 2011) to address any safeguarding issues that arose (Appendix T). No safeguarding issues did arise within this research, therefore confidentiality did not have to be broken, however this section outlines when confidentiality would have been broken.

Literature outlines that researchers have a moral obligation to break confidentiality if participants disclose being the victim of an unreported crime, or if the researcher feels participants are at risk of harm (physical or psychological) (Wiles, Crow, Heath & Charles, 2006); such harm usually surrounds that from crime, suicidal attempts / thoughts, or self-harm; or can refer to the harm of others. In terms of the researcher's legal obligation, the researcher would have had to disclose information which suggested participants (or others) were in, or could be in a life-threatening situation (e.g. self-harm, suicidal attempts), or participants were being threatened by an abuser (Gloucestershire Confidentiality Policy, 2005). However, the researcher did not have a duty to break confidentiality due to drug use, illegal or sexual activity, unless it met with the previously mentioned exceptional circumstances.

In terms of participants reporting engagement in risky behaviours the researcher, along with the researcher's supervisory team devised a checklist (Appendix T), outlining when confidentiality would be broken. In terms of sexual activity, a researcher does not have to disclose sexual activity in under 13's, as this is at the discretion of the researcher, e.g. if a 12 year old was engaging in consensual sexual activities with another 12 year old, confidentiality does not have to be broken (RCGP, 2011). However, if participants disclosed such information and the researcher had not reported it to a suitable authority, the researcher would have scrutinised this decision making further with the supervisory team. In terms of sexual activity, the researcher would only have disclosed such behaviour if it appeared that participants were being coerced, or if participants were under the age of sixteen years and engaging in sexual activity with an individual significantly above the age of sixteen years, with the RCGP (2011) stating that a power imbalance is indicated by an age gap of more than five years. In terms of consent the RCGP (2011) states that a young person may not have been able to provide consent to sexual activity if they were under the influence of drink or drugs, therefore confidentiality would have been broken. With substance use (smoking, drug use, or alcohol consumption) the researcher acknowledged her moral duty to break confidentiality if participants had not provided consent to participate in any of these behaviours (e.g. peer pressure); if participants were engaging in excessive amounts of

any of these behaviours which could cause harm to their health, and if they were unaware of such harm.

The researcher explained clearly to potential participants the limits of confidentiality through both the information sheet, and verbally during the consent process. If the researcher had felt that confidentiality needed to be broken the researcher would have discussed with participants the benefits of disclosing such information to HCPs, in the hope of gaining participants consent to break confidentiality. The researcher would have asked participants if there was a member of staff at their CF centre they would prefer the researcher to talk to first; if participants had no preference the researcher would have discussed the issue with the Consultant at the CF centre. However, if participants refused to allow disclosure of such information the researcher would have consulted the supervisory team in order to decide whether disclosure without consent was justified. The participant would have been informed before disclosure was made, if this was the decision (RCGP, 2011).

The researcher acknowledged that the consent process continues for the duration of participation, and participants have the right to withdraw at any time. There are a variety of ways in which participants can withdraw their consent as outlined by Skånfors (2009); for instance paediatric participants may say "no" to answering some questions, may show no response during the interview, or ignore the researcher. The researcher was aware of these indicators to ensure the research was sensitive to participants' wishes (NSPCC, 2013); within this research no participants demonstrated these behaviours.

As the interviews were independent, in order to protect the researcher all interviews were conducted in a private room at participants CF centres, which HCPs were aware of. In addition, participants' legal guardians were present in the CF centre nearby (in calling distance), but were not able to overhear the conversations (at the participants discretion) (Shaw et al., 2011).

As this research was qualitative it had the potential to go into more depth than a quantitative approach, providing a platform to discuss issues which the researcher had not anticipated (NSPCC, 2013). Therefore to minimise the risk of personal or social harm to participants, the interview schedule was structured to ensure that difficult topics were given enough time for discussion (NSPCC, 2013).

Analysis

As described within the initial analysis section within Chapter Four, the interviews were transcribed utilising the Jefferson transcription coding (Heath & Hindmarsh, 2002), with the data being analysed using thematic analysis following Braun and Clarke's (2006) model. Thematic analysis generated 128 initial codes, with these initial codes being revised to form 113 codes. An example of a code that was deleted is highlighted below (see Appendix U for more examples):

- **Adherence is more difficult during weekends**

The reason for deleting this code is because it only contained one quote which could be represented by another code: "Adherence stops the participant engaging in normal activities". The quote was explaining how during weekends the participant wants to be lazy and engage in normal activities, as opposed to waking up early to adhere to his medical regimens.

The researcher made inferences about what the codes meant enabling the codes to be combined into four overarching themes that accurately depict the data (Appendix V). The four themes generated are described in detail within the next chapter, utilising direct quotes and discussion around CF adolescents' attitudes and beliefs regarding risky behaviours.

CHAPTER EIGHT: ANALYSIS - PAEDIATRIC CYSTIC FIBROSIS PATIENTS' **ATTITUDES AND BELIEFS ON RISKY HEALTH BEHAVIOURS**

Thematic analysis was applied to the interview transcripts following the Braun and Clark (2006) model, which identified four themes within the data. The first theme, labelled as "The most challenging aspect of Cystic Fibrosis is getting up every morning to do your treatments", highlights the impact adherence has on the lives of adolescents, with many participants viewing non-adherence as a risky behaviour. Theme two, "Don't keep Cystic Fibrosis to yourself" focuses on the beneficial effect support from others can have on an individual living with CF, as well as the adverse effects a lack of support can have. The third theme, labelled as "I wish I did not have Cystic Fibrosis, that would be wicked", provides insight into the impact CF can have upon an adolescent's identity. The final theme, "A lot of people with Cystic Fibrosis do take it for granted and smoke and do stupid things", highlights the role knowledge has in encouraging adherence efforts and influencing engagement with risky behaviours. It is recognised that there are aspects of participants' experiences and understandings that overlap across these themes; however this was to be expected (Fielden et al., 2011). All four themes will be further examined in the next segment, by utilising direct quotes and discussion around this topic area.

"The most challenging aspect of Cystic Fibrosis is getting up every morning to do your treatments"

This initial theme acknowledges that for a paediatric population a risky behaviour that may be most prevalent is poor adherence or non-adherence, with this theme providing insight into the impact adherence has on the lives of adolescents with CF, signalling CF adolescents' views towards their treatment adherence, and the challenges associated with adherence, in particular on developing independence. Many participants explained how adherence is hard, discussing a variety of reasons as to why they find it difficult. Some participants believe they are prescribed too many medications, with adherence therefore demanding a lot of time from participants. With participants describing a large treatment burden, many explained how it is difficult to integrate their treatments into their everyday lives; with participants finding it increasingly challenging to integrate treatments within their lives when they have difficulty in interpreting and understanding their complex regimens. A number of barriers to adherence were identified by participants, with the data highlighting how the experience of treatment burden is due to a number of different issues, and fluctuates over time.

At the age of 13 (approximately five years before transition), Charlotte pointed out how difficult she would find independent adherence, with Charlotte finding her treatment regimen to be confusing because of the severity of her condition resulting in her having a large treatment burden.

*[Charlotte, 13 years]: "It's [CF] too much headache [...] like I'm to:oo ill # a:and it's to:oo confu:using # I have to have my medicines (.) >which one to have<"

Due to the amount of treatments individuals with CF are expected to adhere to, many participants explained how adherence impacts upon every aspect of their day.

*[Abi, 12 years]: "I (.) get up (.) do my physio:o (.) an then (.) do my colomycin # have brea:akfast (.) an then # do something # get ready and go to school # do a:all my wo:ork # have lunch (.) have break # and then (.) come back home # do my dna:ase (.) and then # ha:ave dinner (.) and then (.) I wa:ait (.) like (.) I think it's an hour (.) an do my physio:o an I do my (.) colomy:ycin on the night"

Such narratives clearly illustrate the time-consuming nature of treatment adherence within CF. Whilst many participants viewed all treatments in a negative light, it was clear that in particular their negative views surrounded time-consuming treatments, with many participants explaining how they favour less time-consuming treatments.

*[Tim, 18 years]: "There a:are certain treatments that a:are # a bit mo:ore difficult # just because they're mo:ore time-consu:uming"

Participants suggested that these time-consuming treatments prevent them engaging in normal activities. Emily demonstrated the impact adherence has on her identity, explaining how her nebulised therapies prevent her engaging in normal activities with her friends after school, which would provide herself with a sense of normalcy.

*[Emily, 14 years]: "You're tr:rying to lead a (.) no:ormal life # tr:rying to (.) go out # after scho:ool [...] go out (.) ska:ating (.) ska:ateboa:arding # an stuff like that [...] it's ki:inda like ## ho:ow to # dea:al with it # if you know what I mea:an ## with the nebuli:sers (.) an stuff ## I just want to be a no:ormal person # like I just want to go outsi:ide"

As well as their time-consuming nature, some CF treatments are also unpleasant, which participants explained reduces their motivation for adherence. Charlotte discussed how difficult she finds being fed through her percutaneous endoscopic gastrostomy (PEG) feeding tube due to it commonly resulting in nausea.

*[Charlotte, 13 years]: "I don't like that [being fed through PEG tube] # it takes a lo:ong time [...] I feel full # to:oo full # I feel si:ick and bla:ah (.) bla:ah # I feel sick toda:ay"

Thus because of these unpleasant symptoms, Charlotte struggles with her "feed" regularly, wishing that she did not have to adhere to this treatment modality. Whilst Charlotte described a daily struggle, other participants highlighted the impact of becoming unwell on the experience of treatment and adherence, with participants discussing how certain treatment modalities become more difficult to adhere to when they are ill with an infection. Tony explained that when he is feeling unwell he finds physiotherapy particularly difficult due to him not having the required energy to perform airway clearance.

*[Tony, 13 years]: "The physio # do you know (.) if you feel like ill # it just feels ha:arder to do a:all the breathes"

Due to the various challenges associated with one's adherence, many participants outlined how adherence does require motivation and commitment. Tony explained how he often "can't be bothered" to start his physiotherapy regimen due to its time-consuming, and at times unpleasant nature, despite recognising its effectiveness.

*[Tony, 13 years]: "Physio:o # that's just the lo:ongest one [...] when I'm ha:alf way the:ere (.) I'm a:alright # but it's like at the beginning # like o:oh (.) I ca:an't be bothered"

Many participants openly discussed how they believe non-adherence would have a positive impact upon their life psychologically, with Sophie explaining how she would be more relaxed within her life without having to adhere to her medical regimen. Sophie discussed how her CF treatments cause her to worry, and that with non-adherence she would be able to engage in normal activities, which her time-consuming medical regimen can interfere with.

*[Sophie, 12 years]: "I think I would be a bit mo:ore # re:ela:axed (.) about thi:ings (.) and not ha:aving to worry as much [with non-adherence] [...] I'd probably just pla:ay out"

Such narratives suggest that these participants have a life-orientated illness perspective where they desire a sense of normalcy. This desire for non-adherence could result in future poor or non-adherence when they become independent over their treatments, with this non-adherence potentially providing the individual with a sense of normalcy within their lives and a normal identity in front of others. Even when participants had good awareness about

treatments' necessity, it did not always prevent their desire for non-adherence, with it being completely understandable why many participants expressed this desire given the high demands of such treatments. Adam explained how he wishes he did not have to adhere to his physiotherapy regimen which would allow him to engage in normal activities, despite acknowledging that this non-adherence would exacerbate his symptoms causing a decline in his health.

*[Adam, 16 years]: "Researcher: Are there any treatments you wish you could miss out

Adam: [Shakes acapella device] this

Researcher: What is it about that then

Adam: It can just take a while

Researcher: And what is it you'd prefer to be doing

Adam: Probably just watching tv # on me xbox

Researcher: And if you didn't do that treatment how do you think it would make you feel

Adam: I'd # probably feel # worse about myself # cause # I probably wouldn't be able to do as much really (.) at all"

Not surprisingly, with many paediatric participants explaining that adherence is challenging, many emphasised that they require help with their adherence. At the age of 18 years, where independence is encouraged, Tim explains how hard he would find independent adherence, valuing the support his parents provide him with to assist with his adherence, to keep him healthy.

*[Tim, 18 years]: "Parents # they're quite regimental [laughs] [...] they kind of push me to do everything in a certain time ## which to be honest is quite nice # it keeps ya healthy don't it [...] I think it would be more difficult [without parental support] # cause I know people that # parents (.) don't (.) really # an they do struggle more # cause they haven't got the constant reminder"

Many participants recognised the need for adherence support. Charlotte explained that if her Mother was not there to support and to remind her to perform her medical regimens, it would result in unintentional non-adherence, predominantly due to forgetfulness.

*[Charlotte, 13 years]: "My Mom needs to remi:ind me someti:imes to do the medica:ation [...] I wouldn't take em"

Due to many participants emphasising their need for family support, highlighting the positive impact it can have upon their physical health, it is not surprising that some participants signalled how they come to rely upon this support, and therefore believe that when they enter adolescence and adulthood, independence in adherence will be challenging. Charlotte explained how she is fine adhering to her treatments regardless of the situation (e.g. day trips) as her parents are always there for support, however she acknowledges that this would be different without their support, highlighting how this could lead to future poor or non-adherence particularly when engaging in activities outside of her normal routine.

*[Charlotte, 13 years]: "Researcher: If you're out for the da:ay # is it mo:ore difficult to do your treatments then

Charlotte: >Not if my Mom an Dad are going to be with me then it's okay< [...] it mi:ight be ha:ard # it mi:ight be different [without parental support]"

Even when some participants stated that they would manage their treatments independently, their discourse suggested otherwise. For instance, although Chris stated that he would be fine with independent adherence, his hesitations, and stating phrases like "I guess I would be alright", suggests his uncertainty.

*[Chris, 14 years]: "Researcher: In terms of your treatments (.) say in the futu:ure (.) when (.) ma:aybe # maybe you mo:ove out (.) o:or anything like that # ho:ow do you think you'll fi:ind doing a:all your treatments by yourself # ma:aybe one da:ay

Chris: # O:oh ### I guess I'll be a:alright # I guess"

In addition, the presence of participants' legal guardians within some interviews will have had an impact upon the information disclosed by participants, there was evidence of this during discussions with Mandy. During the beginning of the interview Mandy's Mother and Nurse were present, with Mandy explaining that adherence to physiotherapy is "quite easy" as she is used to her physiotherapy regimen. However, when her Nurse had left the room Mandy explained that in reality she is not always adherent to her physiotherapy, explaining that she does not have time to adhere to this treatment before school.

*[Mandy, 12 years]: "Researcher: You said you do physio (.) befo:ore school # and after school

Mandy: Well # not rea:ally # not in the mo:ornings # because I'm not really liking physio [...] I literally wake up like # ten minutes before I have to leave the house in the morning [laughs]"

This highlights how individuals may present their adherence to HCPs in a way that is different to reality. For Mandy it appeared that she told HCPs that she was adherent to physiotherapy as she knew she should be adherent to this treatment modality, and potentially did not want to receive negative feedback from HCPs regarding her adherence efforts.

Whilst many participants did discuss how challenging independent adherence would be, and therefore explaining how they welcome support with their treatments, some participants explained how they do not welcome such support. Emily stated how she feels ready to become independent, but her Mother is holding her back and not recognising that Emily at times is being independent, and does not need reminding to adhere to her treatments. Emily explained how such reminders annoy her and cause her to retaliate against her treatments.

*[Emily, 14 years]: "I:l # want to [be independent] # but ## I fe:eel like I'm getting he:eld back to do that # because # no o:ones letting me do it [...] say if I ne:eed to take my tablets (.) I'll a:already be in the middle of doing it an Mum will be like ↓o:oh take your tablets # ↑well I ha:ate being told (.) what to do:o [laughs]"

Mandy also suggested that when her Mother and Grandmother "nag" her to adhere to her treatments it reduces her motivation for adherence, indicating how such nagging causes her to retaliate against her Mother and Grandmother, although she can appreciate that they only "nag" because they care.

*[Mandy, 12 years]: "If I'm sitting with my Mom (.) she nags me that much [to do treatments] [...] then she tells my Nan (.) and the next day my Nan's like >wh:hy didn't you do this< [...] I know they ca:are (.) but ## I don't like being shouted at"

The challenges of independence were not just discussed as future anxieties, some participants explained how they are independent with their treatments and recognise the challenges associated. One challenge that many participants discussed was forgetting to adhere to a certain treatment modality, demonstrating unintentional non-adherence. Despite Emily discussing how her Mother holds her back and is not enabling her to be independent

with her adherence, she also discussed how recently she has had poor adherence to her nebulised treatments. Emily stated that this poor adherence is due to forgetfulness, due her desire for a sense of normalcy, and to engage in normal activities. Emily appeared to actively avoid her nebulised therapy as she wants to forget about it, in line with her desire for normalcy. This highlights the difficulty in balancing the needs and desires of young adults to be independent, alongside the need for supporting and ensuring treatment adherence.

*[Emily, 14 years]: "My (.) nebuli:iser [laughs] # I've probably done about m::m ##
about:ut # thre:ee (.) in the pa:ast (.) like # fo:our weeks:s [laughs] [...] I kinda (.)
fo:orget about it # because you're tr:rying to lead a (.) no:ormal life"

Many participants, such as Sophie pointed out that to overcome forgetfulness and to aid their adherence efforts they use a structured routine, with participants clearly indicating how routine and structure support adherence. A structured treatment routine was used by participants who were independent (or becoming independent), and also by participants who still received parental support with their adherence efforts. Participants explained how this routine helps them (and their parents) to not forget their treatments, as such routine becomes integrated into their everyday lives.

*[Sophie, 12 years]: "<It's [adherence] ea:asy> [...] we (.) just (.) ha:ave (.) a ti:ime to
do it (.) sort of thi:ing # of a mo:orning we have a routi:ine"

Besides unintentional non-adherence, Mandy highlighted how psychological distress can also impact on adherence, with Mandy explaining that when she experiences health-related stress and anxiety, often after a bad day at the hospital, it reduces her motivation for adherence. Mandy recognises that not doing her treatments can make her health worse and consequently make her more anxious, with Mandy talking about how frustrating this is for her.

*[Mandy, 12 years]: "I'm mo:ore likely to not do them [treatments] and I don't
understand that [...] if I'm worried I get angry with myse:elf # and then I say things I
don't me:ean [...] it a:all goes back to (.) because I've had a bad day at the hospital"

Not all participants who were independent with their adherence found it to be a challenge, with Sophie explaining how she felt ready to take on such independence, and likes to independently integrate her treatments into her life.

*[Sophie, 12 years]: "I have started to (.) putting together my o:own
medica:tions [...] Mum a:aked if:f # I was a:alright # an I said I'd quite like to do it"

However, with these participants being adolescents it has to be questioned whether or not these responses were influenced by social desirability bias. When talking with Chris in the presence of his Father it was acknowledged how parental and adolescent views towards independence vary. Chris believed that he is quite independent with his treatments, however his Father disagreed.

*[Chris, 14 years]: "I # I'm u:usually quite (.) indepe:endent (.) when it comes to meds:s

Father: [What] you mean (.) so we:e put them out for ya (.) an you take em [...] that's not independent

Chris: °It is:s independent°

Father: It's not # just cause I'm not putting it in ya mouth (.) doesn't mean I don't put em out for ya an say (.) here's ya medicine (.) here's your creon # here's ya (.) fe:eeding tu:ube # we do it a:all for ya"

Despite the potential for social desirability bias within participants responses, those who did report treatment independence appeared to have accepted their CF, with this assertion being supported by such participants not being afraid to have their illness identity on display. Emily explained how she does not mind publically adhering to her medical regimens, explaining that despite her CF she is the same as everyone else, and therefore possess a normal identity.

*[Emily, 14 years]: "I don't re:eally hide it [CF] # it's like when I've got to take my tablets (.) >I take them< [...] I just see myself like (.) ano:other person # I a:am # like (.) somebody else # just different # I'm not li:iike ## a sma:all person in the corner (.) who:o's ## not recognisable"

Emily clearly highlights how possessing an illness identity or a normal identity is not categoric or simple. Emily is able to show that she has CF in front of others, but she does not see herself as having an illness identity. Such participants view themselves to be normal and do not have a desire to hide their illness from their peers. Adam explained how CF does not stop him enjoying his life, with Adam being comfortable adhering to treatments in front of others and talking to others about his CF to raise their awareness.

*[Adam, 16 years]: "Researcher: Do you tell others about your CF

Adam: Well # yeah ## we had it in Science the other day and Miss wanted me to tell everyone about it [...] I was fine with that [...] I'd tell anybody [about his CF]"

Some participants did demonstrate acceptance towards their CF, with many of these participants also demonstrating acceptance towards treatments' necessity. Individuals can only accept their CF and accept treatments' necessity through awareness. Tim explained that despite it being a challenge to adhere to his treatments every morning, he is adherent because he is aware that such adherence will help to prolong his lung function.

*[Tim, 18 years]: "[The most challenging aspect of CF is] probably getting up every mo:orning to do your treatments:s # wo:orking it out so you've got time to do them [...] but because I know it's go:ing to help me in the lo:ong run (.) it doesn't re:eally bother me"

Overall, it is evident that the impact adherence has on an individual living with CF varies between individuals, although understandably most people did view CF to be a challenge. Several participants talked about the need for support from others to aid with their adherence efforts, and this support was not just isolated to one's adherence, but also for other aspects of their lives, such as providing them with awareness on the adverse health effects of risky behaviours.

"Don't keep Cystic Fibrosis to yourself"

This second theme focuses on the beneficial effect support from others can have on an individual living with CF, as well as the adverse effects a lack of support can have. The support this theme mainly focuses on is that from an individual's family, friends and HCPs. Many participants underlined how support from others is a necessity to aid their life with CF, with Liam pointing to how individuals with CF must seek out such support and take advantage of it, rather than hiding their concerns which could have a negative impact on their psychological health.

*[Liam, 14 years]: "Tell someone about it [CF] if you're worried # don't keep it to yourself (.) get attention [...] you must share it with someone"

The support paediatric participants predominantly referred to originated from their family, with many participants understanding that CF is not just experienced by the patient, it also causes concern and worry for family members. Mandy explained that when she is at hospital she does not just worry for her health, she also worries about how her family would react to negative news, highlighting the emotional burden CF has upon her life, and her family's life.

*[Mandy, 12 years]: "I don't just worry when I go to the hospital # about # how my hea:alth is # I worry about how my family will react to it"

Mandy highlights how her concern for her family and how her family are feeling about her being unwell is an additional worry for individuals with CF, which could make such individuals feel as if they are a burden to others, with this being an additional burden to having CF.

Participants looked favourably on family support, recognising its need. In addition to aiding with adherence, participants suggested that family support can be imperative in preventing individuals engaging in risky behaviours. Tim explained how his family have prevented him from smoking through providing good awareness regarding the adverse health effects, and through protecting him from environments which would expose him to second-hand smoking.

*[Tim, 18 years]: "Since I've been bo:orn (.) my:y Mum an Dad drilled into my head if you smoke you di:ie # that's pre:etty much ho:ow they put it to me # so:o # I've kind of just (.) tr:ried to keep awa:ay [...] I think that was a bi:ig thing for them to te:ell me # to make sure I didn't do it"

During the interviews where parents were present, many of them emphasised how they believe it is their duty to ensure their child is fully aware of the CF-specific adverse health effects of risky behaviours.

*[Chris, 14 years]: "Father: I think it's the conversations you have at ho:ome # as a pa:arent you talk about stuff [regarding illicit drug use]"

The data suggests that when an individual has good awareness regarding these adverse health effects it works to prevent initiation, with many participants not desiring to engage in these behaviours due to their awareness, and due to them appearing to have accepted their illness identity, and therefore accepting they cannot engage in such behaviours.

*[Adam, 16 years]: "I was fi:ine with it # I don't re:eally mind not smoking # >I probably wouldn't smoke anyway< [...] I just think they [smokers] look like idiots really # smo:oking # it's going to affect them when they get o:lder and everything"

Besides family members providing participants with awareness, some participants explained how they would never engage in such behaviours as they fear the consequences from their family. Tim explained how he is aware that his Mother and Father would not want to see him if he did smoke, particularly because of the emphasis they have placed on encouraging Tim not to smoke, and therefore would not want to watch Tim weaken his health unnecessarily. As well as punishments, some participants, such as Mandy, explained

how they would not engage in risky behaviours as they are aware that such engagement would disappoint their families.

*[Tim, 18 years]: "I think I would go as fa:ar as saying (.) my Mom an Dad would not want to see me:e [if the participant smoked] [...] obviously they drilled it into me:e # and because they've said (.) it ca:an kill me # they'd ki:ind of sa:ay # well (.) you're ki:illing yourself # so:o (.) what's the point # I don't want to watch you ki:ill yourself # an I do:o (.) true:ely believe (.) they would # just cut me o:out"

*[Mandy 12 years]: "I ca:an't [smoke] # not only because of my CF # but # just the disappointment that my Mom would have # and my family"

Participants who did have good awareness regarding the adverse health effects of risky behaviours from their families, and were aware that their family would discipline them for such engagement, often explained how such behaviours were not normalised within their family, therefore their engagement would not provide them with a normal identity.

However, not all participants received support from their families, with some participants having negative family relationships. Emily discussed how she does not seek support from her Mother, instead she turns to HCPs with any worries she has, due to her Mother making her feel unwanted. This has resulted in Emily being quite independent within her general life, and also in terms of managing her CF, despite only being 14 years.

*[Emily, 14 years]: "I'm quite indepe:endent # if I did have a:any worries I'd see my Docto:or [...] I don't re:eally speak to my Mom about it [...] I've a:always being to:old like # mista:ake child [...] there are some things you would say to your friends:s (.) but you wouldn't say to your Mom [laughs] # some people would actua:ally say like (.) a:all the things they say to their mates (.) to their Mum # because they have that (.) bo:ond (.) but I don't"

A lack of family support can have damaging effects upon an individual's life, with it being plausible that negative family relationships could influence an individual to engage in risky behaviours, as a coping mechanism to deal with such negativity. Therefore despite Chris's Father believing it is the role of parents to educate their child regarding the CF-specific adverse health effects of risky behaviours, the data illustrated how a participants family does not always provide such awareness, with some families normalising risky behaviours. Tony explained how both his parents smoke, with this exposure causing Tony to view parental smoking as normal.

*[Tony, 13 years]: "I know that my Mom an Dad smoke [...] I do:on't (.) re:eally feel anything # cause I'm (.) so:ort of used to it ## it just seems no:ormal"

Consequently, such normalisation could have an influential role in future initiation, to hold a normal identity. Furthermore, when a participant's family engaged in a risky behaviour it often provided access to that behaviour, with Tony explaining how he drinks alcohol at family parties due to both of his parents, and nearly everyone he knows drinking alcohol.

*[Tony, 13 years]: "My Mo:om (.) my Da:ad # nearly everyo:one that I kno:ow [drinks alcohol] [...] I've tr:ried it # it was when # we was like at this (.) pa:arty (.) like wedding # >family pa:arty wedding<"

However, the data indicates that normalisation by a participant's family does not always result in a desire for initiation, it appeared that an influential factor affecting initiation was awareness of the CF-specific adverse health effects. Mandy indicated her anger regarding her Father's smoking behaviour, acknowledging the adverse health effects it will have upon her Father, and therefore the emotional impact it will have upon herself, and her family when he "suffers from his consequences".

*[Mandy, 12 years]: "I ha:ate it when my Dad smokes ## I feel it's unfa:air # on the who:ole family # like what the bloody hell does he think # if he's smo:oking fags (.) an he gets cancer (.) it's his fa:a:ult # and we:e'll have to suffer from his consequence ## it's stu:upid"

The family is only one source of support identified. A number of participants discussed the importance of friendships, and the impact they can have on their health behaviours. Many participants, such as Tim and Liam, spoke favourably upon the support they receive from their friends, with such support being provided as a consequence of the participant disclosing their CF.

*[Tim, 18 years]: "I a:always tell a:all my close friends [about CF] (.) people I go out with (.) just in case something happens # so they know (.) kind of thi:ing"

*[Liam, 14 years]: "Researcher: what cha:anges [after disclosure of illness identity]

Liam: ### They tr:ry an help me a little bit"

Disclosure of one's CF suggests that these participants are comfortable with having their illness identity on display in front of their friends. It does however have to be acknowledged that these participants may not be comfortable in having their illness identity on display in other situations, as an individual's identity is not static, and is often dependent upon social

factors. Whilst some participants explained that they will tell anyone about their CF, being comfortable with having their illness identity on display in public; others explained that they only disclose their CF to their close friends, as in front of others they want to appear normal and not have their CF visible. The data did mark that disclosure appears advantageous for a participant's health, with Tony talking about how disclosing his CF to his friends has enabled him to display his illness identity and adhere to his medical regimens in front of his friends.

*[Tony, 13 years]: "They [friends] don't mi:ind [the participants adherence efforts] (.) cause they re:eally ## they quite kno:ow about it"

In addition to adherence, a number of participants described how their friends would not allow them to engage in risky behaviours, as they are aware of the CF-specific adverse health effects. Tim explained that due to him educating his friends regarding the impact smoking could have on his CF, he knows that his friends would never allow him to smoke.

*[Tim, 18 years]: "I kno:ow # friends would have a go at me:e ## I can remember (.) I went to the shop for me ma:ate once:e # an e:erm:m (.) picked up cigarettes # another friend se:een me wa:alking do:own the street with em # an he to:ook em off me [...] I kno:ow my friends would flip [...] because !:'ve dri:illed it into their head (.) that I ca:an't do it"

However, not all participants had friends who worked to prevent initiation, with some participants signalling how peer pressure or normalisation of a risky behaviour by their friends can result in a desire for initiation. Mandy explained that when her friends offered her a cigarette she did contemplate smoking to receive a normal identity within that social group. However Mandy's awareness regarding the adverse health effects of smoking prevented her initiation on that occasion. Nonetheless, with Mandy explaining how bad it made her feel when she refused to smoke, it could impact her decision if she was offered to partake in a risky behaviour again, with adolescents often valuing social acceptance.

*[Mandy, 12 years]: "I've been offered a fag [...] I was out with my ma:ates # a:and they were a:all smoking # and someone (.) gave me a fag # I held it in my hand # I was about to # but I just thought ### no # I ca:an't [...] if I didn't have CF (.) I think I would have (.) to be honest [...] I was trying to be # co:ool [...] it ma:ade me feel so ## ba:ad ## not having this fag"

However, the data suggested that when a participant had accepted their CF, and were aware of the CF-specific adverse health effects of risky behaviours, it often prevented a

desire for initiation, with Liam explaining how he views the use of Shisha in a negative light and therefore would never experiment with this behaviour despite his friend's engagement.

*[Liam, 14 years]: "Researcher: Do you know anyone who does those behaviours:s [Shisha]

Liam: Yeah # my friend #

Researcher: And what do you think of your friend who does them

Liam: E:erm:m ## bad #

Researcher: Seeing your friend (.) does it ever make you want to try it

Liam: No # it's bad"

Whilst most of the friendships discussed were referring to individuals within the general population, some participants discussed their friendships with others with CF. Many of these participants viewed these friendships to be positive, despite being aware of the risk of cross-contamination. Some participants explained that they ignore the rules surrounding in-hospital segregation because of the beneficial effects such friendships have upon their life, with Charlotte describing the support she receives from others with CF, and the support she provides them with, with them being there for any CF-related questions that she may have.

*[Charlotte, 13 years]: ">I like it< [mixing with CF patients] # reason wh:hy # cause if they've got a:any questions they could a:ask me # o:or if I've got any questions I could a:ask them"

Participants who were compliant with non-contact with other CF people expressed regret that they could not have this contact, and recognised how valuable it could be for them, acknowledging that it is only others with CF who truly understand what they are going through. Mandy explained how she has tried to communicate with others with CF through emails, however that has been unsuccessful, with Mandy recognising the positive impact such communication could have upon her life.

*[Mandy, 12 years]: "I've tried emails (.) but they [others with CF] never reply [...] speaking to people # it'd be rea:ally nice [...] I'd like to know someone else who has the same as me [...] someti:imes I just want to let it a:all out [worries] # but # people [without CF] don't understa:and # from my perspective"

Whilst many participants demonstrated the benefits of communicating with others with CF, Tim indicated that sometimes others with CF can normalise risky behaviours, explaining how on one occasion individuals with CF stated that the use of marijuana is beneficial, stating they can smoke marijuana as their treatment adherence will maintain their health.

*[Tim, 18 years]: "I kno:ow # a lot of people [with CF] do it [marijuana] [...] they a:always sa:ay (.) well I:l do it (.) beca:ause (.) >I do:o my treatments:s< (.) an I do everythi:ing else (.) to keep myself hea:althy # so I think I can have my little bit on the si:ide"

These compensatory health actions could be detrimental upon the health of others with CF, with individuals valuing the opinions of their friends, potentially motivating individuals to also engage in such behaviours. Unrealistically optimistic views were also demonstrated, with some participants who ignored the rules surrounding in-hospital segregation, underestimating their likelihood of experiencing adverse events. Tim appeared to focus on the psychological benefits such communication has on his life, with Tim weighing up the risks such communication could have upon his physical health, and considering them to be worth the benefits. Tim appeared to value his psychological health, demonstrating his life-orientated illness perspective.

*[Tim, 18 years]: "I do:on't (.) pe:ersonally (.) think it's [cross-contamination] a bi:ig problem # even though it's been pro:oven to be # I think that ## it (.) >ma:akes your life ea:asier if you speak to someone with CF< # so # wh:hy # not (.) do it"

Tim explained that despite the risks of cross-contamination been proven, he does not perceive cross-contamination to be a big problem, highlighting how personal experience is weighed as more relevant than evidence.

As well as the role families and friends can play in influencing an individual's attitudes and beliefs towards risky behaviours, the data also highlighted the role schools can play, illustrating that schools often provide awareness on the adverse health effects of risky behaviours. Emily explained how she will never smoke due to her awareness of the adverse health effects this can have upon individuals, with this awareness being provided through her education at school.

*[Emily, 14 years]: "I would ne:ever do tha:at [smoke] # cause I just # couldn't # get my head round wh:hy:y people do that to their bo:ody # >even like hea:althy people<

[...] I've done so: many anti-smo:oking and anti-alcoho:ol campaigns with scho:ool
(.) an we learn about it in science:e (.) I'm like mega:a high on (.) not (.) to smo:oke"

Although this awareness is not CF-specific, it can still play a role in preventing initiation, due to the suggested relationship between awareness and abstinence. In addition to school providing awareness, the data pointed to how some individuals become aware of the adverse effects of risky behaviours through television programmes, with Tony discussing how he became aware of the adverse health effects of illicit drug use purely through watching programmes which document their effect.

*[Tony, 13 years]: "I watch twenty four hours in NHS [laughs] # and they say how ## some of them a:are like dru:uggie:es # so like # it can affect your brain an that ca:an't it # an like a:all your hea:art an lu:ungs # everywhe:ere in your body"

Not only do television programmes provide awareness on the adverse effects of risky behaviours, participants discussed how the television can also provide awareness to society regarding CF, with Abi explaining how she is fine disclosing her CF to her friends as they are aware of what CF is through learning about it from television programmes.

*[Abi, 12 years]: "Researcher: And you're fi:ine telling friends [regarding CF] ## do you think they understa:and what it is:s"

Abi: Yeah # because they've seen it on TV # so they know what it is:s"

Such awareness will hopefully help to reduce the ignorance that some participants believe society has regarding CF, with Chris explaining that not many individuals within the general population understand what CF is, with this therefore having the potential to result in a lack of support or compassion from individuals within the general population, particularly due to CF's invisible nature.

*[Chris, 14 years]: "It's difficult to expla:ain (.) but I don't think many people get what it [CF] is (.) exactly:y # I think the o:only thing they kno:ow (.) is that it is a lu:ung disease"

The varied levels of support received from family and friends highlights the importance of consistent clear support and advice from HCPs, in influencing whether or not an individual will adhere to their medical regimens, and not engage in risky behaviours. Many participants spoke favourably about their HCPs, stating how supportive they are, with many participants referring to the support which derives from their Nurses. Many participants preferred to speak to Nurses over other HCPs as well as their parents.

*[Charlotte, 13 years]: "Researcher: Who do you go to if you have any questions about CF ## any questions:s (.) o:or concerns about CF
Charlotte: Ask my Mom (.) o:or [Nurses name]"

However, whilst many participants spoke favourably about their HCPs, Mandy identified a gap within CF care, demonstrating the need for consistent psychological support. Mandy explained how beneficial it was when she received psychological support from a Psychiatrist, explaining that it is easier to talk to someone she does not know about her worries, with Mandy not wanting to burden her Mother with these. However presently Mandy does not receive any psychological support, which as discussed is having an adverse impact upon her self-management, with Mandy not adhering to her treatments when she feels anxious.

*[Mandy, 12 years]: "I've been asking my hospital for ages if I can see my Psychiatrist again (.) but they just don't get back to me # cause I seen my Psychiatrist (.) I got really close to one ## I was rea:ally (.) rea:ally close to him # and then he left # and then I got transferred to another one # we wasn't as close # I only sa:aw her for about two months (.) and then she left # and now # I have no one ## I don't like talking to my Mom about it [worries] (.) I'll be straightforward # it's easier to talk to someone who has heard it a:all before"

In addition to general support, many participants pointed out that their awareness regarding the adverse health effects of risky behaviours has derived from HCPs. Tony explained how his Nurse informed him about the detrimental effect smoking could have upon his CF, with Tony stating that prior to this he was not aware of these adverse health effects, demonstrating the need for such awareness.

*[Tony, 13 years]: "When [Nurses name] came to our house (.) we had a talk about (.) smo:oking an a:all that # she told me ho:ow it can be bad for your lu:ungs # and how sometimes you ma:ay have to get a lu:ung transplant (.) an a:all that # like fresh new lu:ungs [...] knowing me I would probably think it's a:alright [without awareness] # people that I kno:ow smoke"

However, despite this awareness appearing to have beneficial effects upon individuals, influencing their attitudes and beliefs towards risky behaviours, it became evident that this awareness is provided on an individualised basis. For instance, Tim believed that he had only been provided with awareness on the adverse health effects of smoking as he instigated the conversation.

*[Tim, 18 years]: "I think it [smoking] ha:as been brought up [by HCPs] befo:ore [...] but # it's mo:ore me # kind of # sa:aying (.) about it ## a:asking about it [...] in

ho:ospitals they don't ki:ind of # ta:alk about precautions of things # they're mo:ore ta:alking about your treatments an stu:uff"

There was also evidence of participants not being provided awareness of the adverse health effects of risky behaviours from HCPs, with this often causing participants to have poor awareness. Abi explained how her HCPs have never discussed alcohol consumption with her, with Abi not understanding what adverse health effects are associated with excessive alcohol consumption, and in particular how this behaviour can impact her CF.

*[Abi, 12 years]: "Researcher: Has anyone ever told you # anything (.) about drinking alcohol

Abi: No:o [...] I don't get like # wha:at's bad about it # I know it's like alcoho:ol (.) but # like wha:at's # there's something in it (.) o:or ## I dunno:o"

Thus if participants do not have this awareness, if such behaviours were to become normalised within their environment they may be motivated to initiate in such behaviours to receive a sense of normalcy. Such participants would be unable to make an informed choice regarding engagement in these behaviours as they are unaware of the consequences such engagement could have upon their health, and specifically their CF. Due to the suggested relationship between awareness and abstinence, the need for HCPs to inform all individuals about the adverse health effects of risky behaviours, despite their personal condition is highlighted. Some participants demonstrated a need for such awareness at an earlier age than currently provided.

*[Tony, 13 years]: "Researcher: If you was to meet a you:unger person than you with CF (.) is there anything you'd tell them

Tony: Yeah # like do:on't smoke an a:all that (.) cause it can make your health re:eally bad # an probs the do:ocs wouldn't have told them (.) cause they're still at a young a:age"

Overall this theme highlights the impact others can have upon a individual's life. The role of others can be influential in promoting health behaviours, and preventing the engagement in risky behaviours. However this theme identifies that on occasions the role of others can work to encourage initiation through normalising risky behaviours, therefore it is suggested that some adolescents with CF may engage in these behaviours in their future in order to possess a normal identity.

"I wish I did not have Cystic Fibrosis, that would be wicked"

This theme provides an understanding on how CF can have an impact upon an adolescent's identity. It illustrates how adolescents with CF react to this impact upon their identity, focusing upon how non-adherence and the engagement in risky behaviours can assist individuals with CF in possessing a normal identity, particularly when in front of others. Many participants demonstrated a strong belief that they are not defined by CF, believing they are more than an individual with CF.

*[Emily, 14 years]: "I just see myself like (.) ano:other person"

This emphasis on being normal demonstrated by Emily and a number of other participants highlights that these participants know there are differences between themselves and their peers, due to CF, but it is clear that CF is not what defines these individuals. Such participants explain that they are the same in many ways to their peers, and different in many other respects, which are not to do with CF. Emily explains that she views herself to be the same as everyone else, as she is recognisable with her own identity which does not include CF.

*[Emily, 14 years]: "I'm not li:ike ## a sma:all person in the corner (.) who:o's ## not recognisable # I'm quite # a lo:oud person [laughs] most of my friends would sa:ay that # an that I'm ru:ubbish with ti:ime [laughs]"

It is clear that Emily is not the person that she thinks others might expect her to be with CF, she is not small, quiet, unrecognisable or a good timekeeper, with Emily not allowing stereotypical views of CF to define her identity. The fact that participants, such as Emily, do not see themselves as fitting into the stereotype of what others might expect of someone with CF appears to be adaptive for their psychological wellbeing, with participants describing that they live a normal life with their peers. To perceive living a normal life did vary between participants, with some participants showing the retaliation against CF allows them to lead a normal life, whereas other participants viewed CF to be normal, with such participants explaining that they are used to their condition and the everyday routine it imposes upon their life, with it appearing that such participants have accepted that routine.

*[Sophie, 12 years]: "I don't re:eally mi:ind (.) because (.) I haven't like # not # had CF (.) sort of thi:ing (.) so ## but # I ju:ust # <thi:ink of it as (.) no:ormal>"

Participants such as Sophie are more likely to continue adhering to their medical regimens independently as they enter adolescence and adulthood, due to viewing their CF to be normal, and not demonstrating a desire to retaliate against their illness identity.

A desire for normalcy for some participants involved them discussing how they wished their life did not consist of CF, as they highlighted how hard it can be to live with the condition, which is preventing some participants living the normal life they desire. Charlotte explained how she is currently on the lung transplant list, consequently CF has a big impact upon her life, involving numerous treatments to adhere to, resulting in Charlotte not being able to attend school as she is too ill. Like many individuals with CF, Charlotte understandably explained how she does not like CF and the implications it imposes on her life.

*[Charlotte, 13 years]: "I wished I never had CF (.) actually ## it would be wicked"

Participants who had strong negative views towards their CF explained how they do not disclose their illness to others, in order to prevent their illness identity being on display in public, due to their desire for normalcy, with non-disclosure representing an individual's attempt to retaliate against their CF. Tim explained how he decided to not disclose his CF to others during his school life as he did not want to be treated differently. Tim talked about how he sees himself to be normal, and therefore wanted to be treated as a normal individual.

*[Tim, 18 years]: "Throughout school (.) a lot of people didn't know I had CF [...] when people do know you've got (.) things wrong with ya ## they tend to (.) change [...] I prefer to be treated just # as any other individual"

It is often easy for individuals with CF to not disclose their CF to others due to CF's invisible nature, with some participants valuing this invisible nature due to their negative past experiences when they allowed their illness to be on display. Emily explained how she was bullied following disclosure of her CF, which has therefore resulted in her now hiding her illness identity from others in order to be seen as a normal individual.

*[Emily, 14 years]: "Not (.) many (.) people in my school know # >that I've got CF < [...] only (.) a couple of close friends know (.) and friends that I used to be friends with (.) but (.) then I got bullied by them [...] the school that I'm at ## are quite (.) bitchy ## in that they say (.) stuff # an twist it [...] if I said I take tablets # they'd change it an say that I do (.) drugs"

Negative responses towards an individual's illness can have detrimental psychological implications upon the adolescent. Many adolescent participants indicated how they value their friendships, and often employ effort to ensure there are minimal differences between themselves and their peers, with many adolescent participants valuing acceptance from their social group.

Whilst the data clearly highlights how disclosure of one's CF is often not easy, with participants explaining how they are cautious about how and when they do disclose their illness identity to others; other participants discussed how they were comfortable when disclosing their CF to others. Mandy explained how she tells others that she has CF, with such disclosure often occurring due to individuals asking questions regarding health behaviours which Mandy engages in, such as using her inhaler or eating large portions of food, with Mandy discussing how she does not hide these behaviours from others, or hide her illness identity.

*[Mandy, 12 years]: "I tell them what it [CF] is:s [...] sometimes I eat a lot # and they're like >how come you eat so much and never put on like a pound< "

Whilst Mandy was comfortable with disclosing her illness identity to anyone who enquired about her health behaviours, some participants did highlight that their disclosure was predominantly to individuals who they believe needed to know, with Tim explaining that he only discloses his CF to individuals who he is going to be spending time with so that they are aware of what to do if something was to happen to him. Therefore such participants like Tim appear to analyse the necessity of such disclosure before disclosing their CF to others.

*[Tim, 18 years]: "I just don't mention it [CF] if it's not needed to be mentioned [...] I a:always tell a:all my close friends (.) people I go out with (.) just in case something happens # so they know (.) kind of thi:ing"

Paediatric participants who did disclose their illness identity, viewed disclosure in a positive way, appearing to value their illness identity being on display due to the positive outcomes they experienced. Mandy explained how she likes the attention she receives from others when she discloses her CF, with Tony discussing how disclosure of his CF provides him with support from others, allowing him to adhere to his medical regimens in front of others, preventing his peers asking questions about his treatments, as such disclosure informs them about these treatments.

*[Tony, 13 years]: "It's better [following disclosure] (.) because # I don't have to keep expla:aining # like # >wh:hy do you need to take tablets< # >wh:hy does he need to do that< # >wh:hy does he need to do this<"

Disclosure of one's CF makes public adherence easier for the individual, particularly when they have experienced positive responses from their peers. Chris explained how individuals in the general population do sometimes stare because of his nasogastric tube. This made Chris nervous about going to school with his feeding tube, however Chris discussed how not

many of his friends stared at his tube, with all his friends now being used to it, resulting in Chris refusing a PEG feeding tube which would not be visible to others, because, as his Father explained "he doesn't like the idea of having a hole in his stomach", with Chris stating that he became used to having his feeding tube visible.

*[Chris, 14 years]: "At fi:irst it was kinda like # I didn't re:eally want to go to school with it [feeding tube] ### bu:ut # after a while (.) I started getting used to it [...] not many people sta:ared when I first went in [...] some people asked # what happened # what's that"

Chris points out that at first he was very unsure and anxious about going to school with his nasogastric tube in, but clearly he had no choice. The response from others made it less difficult for Chris to display his illness identity, and in time he, and others got used to his tube being visible. It appeared that through disclosure of one's illness, and having their illness on display, paediatric participants were educating their peers about CF, resulting in such participants often being confronted with familiarity from others regarding their CF. When participants were comfortable with disclosing their CF to others, it was indicated how such participants have integrated their CF into their life and recognise their illness identity in all situations, with such participants, such as Sophie, not desiring invisibility towards their CF.

*[Sophie, 12 years]: "Someti:imes like # at scho:ool (.) so:ome people come up to me an a:ask (.) <wh:hy I'm ta:aking # mediaca:ation> # like ta:ablets [...] I don't mi:ind telling them # I don't mi:ind people kno:owing about it"

Many participants did desire normalcy within their lives, with participants engaging in different behaviours in order to receive a sense of normalcy. Some participants discussed their desire for non-adherence in order to be provided with a sense of invisibility towards their CF; whereas Tim reported that for him adherence allowed him to possess this normal identity.

*[Tim, 18 years]: "I like to be classed as no:ormal # and I won't be classed as no:ormal if I don't do my treatments"

Tim is highlighting how the beneficial health effects of adherence allow him to lead a normal life, and to be perceived by others as being normal, with this raising his self-esteem and therefore encouraging his adherence efforts to continue. A desire for normalcy was also at times associated with a desire to engage in risky behaviours. Tim explained how he will drink alcohol due to him valuing the enjoyment provided through such engagement, suggesting

that he possess a life-orientated illness perspective, where he acknowledges the importance of living his life and doing what he wants to do, instead of letting CF rule his life.

*[Tim, 18 years]: "A lot of people associate dri:inking (.) as a # bad behaviour # but I don't # I just see that as a:a # part of fun # li:ife # cause yes it ca:an affect you # but not in the sa:ame # with your lu:ungs if you smo:oke # do you know what I mean"

Tim makes a clear distinction between risky behaviours, viewing alcohol consumption to be less harmful than smoking, allowing his engagement with alcohol consumption to continue. This could be the result of unrealistic optimism, or could be as a consequence of Tim having a lack of awareness regarding the CF-specific adverse health effects of excessive alcohol consumption.

Many other participants within this phase of data collection had not had experience of engaging in risky behaviours, with participants talking about their beliefs and attitudes towards such behaviours rather than their experiences. Many participants did highlight the importance of having a normal identity and fitting in with their peers through talking in third person, potentially suggesting their beliefs without confirming such assertions. Tony explained that he believes that some people with CF do smoke due to such behaviours being normalised within their environment, with Tony expressing the belief that engagement in such behaviours would allow the individual to conform to their groups identity. Tony had previously discussed how smoking is normalised within his environment by his parents, therefore through talking in third person Tony has potentially signalled how easy it would be for him to smoke.

*[Tony, 13 years]: "I'd say probably quite a fe:ew people (.) like te:eenagers:s (.) an that # some adults:s might [smoke] with CF [...] cause probably the a:area they've been brought up in # o:or some of the friends they have"

Many participants, like Tony, believed that engagement in risky behaviours is largely influenced by the behaviours of individuals peers, with conformity to the groups identity being a way for CF adolescents to adopt the same identity as their peers, in an attempt to forget about the burden of CF, by enjoying themselves, ensuring their psychological wellbeing.

Many paediatric participants did speak about how various risky behaviours are normalised within their lives. The data provided evidence of a new risky behaviour which has undergone a rapid normalisation process in recent years, with the data referring to the use of vaping as an alternative to cigarette smoking. Adam pointed out how adolescents are not

always using e-cigarettes for smoking cessation, with Adam witnessing some of his friends smoking e-cigarettes and then progressing onto smoking "normal" cigarettes.

*[Adam, 16 years]: "Mo:ore of them do these e cigarettes [...] one of me mates (.) he smo:oked an e-cigarette (.) and now he's started smo:oking [...] it's just encouraging them to smoke"

Adam explained how the normalisation of vaping has resulted in adolescents viewing engagement to be "cool", therefore encouraging other adolescents within that social group to initiate in that behaviour, in order to receive a normal identity and to be accepted within that group.

*[Adam, 16 years]: "They still think it's [e-cigarettes] cool [laughs] [...] like me mate was making loads of little ci:ircles as he was blowing out [laughs] # they think it's cool"

The normalisation of a risky behaviour by an individual's social group does have the potential to be detrimental upon the health of an adolescent with CF. However, many participants within the current research stated that they would not engage in such behaviours despite normalisation. Chris explained how smoking is normalised within his year group at school, however he views this behaviour in a negative light, with Chris pointing out that he is aware that smoking is bad for his CF and would have dramatic adverse health effects.

*[Chris, 14 years]: "Most the people in my class do [smoke] # it's ridiculous [...] I think they're re:eally (.) stu:upid"

Overall, it appeared that an influential factor affecting one's desire for initiation in a normalised risky behaviour is awareness regarding the CF-specific adverse health effects of that behaviour, and potentially the acceptance of one's CF, demonstrating that engagement in such behaviours is multi-factorial.

"A lot of people with Cystic Fibrosis do take it for granted and smoke and do stupid things"

This final theme provides an understanding on the role knowledge has in encouraging adolescents with CF to adhere to their medical regimens and gain independence for their adherence as they enter adolescence. It also displays the role knowledge has in working to prevent the initiation of risky behaviours amongst adolescents with CF, through acknowledging the CF-specific adverse health effects. This theme highlights however that even when an individual has good awareness regarding the adverse health effects of non-adherence and / or risky behaviours, it does not always prevent such behaviours, or prevent a desire for such behaviours.

Many participants signalled that the first step to engaging in health promoting behaviours, and not engaging in risky behaviours was to have good awareness regarding CF, with participants explaining how this awareness results in positive behaviours for their health, as they understand the detrimental impacts non-adherence or risky behaviours can have on their CF. Tim explained that when individuals with CF have not accepted CF's true nature, and consequently take their health for granted, it can result in risky behaviours, with such individuals not acknowledging the adverse health effects such behaviours can have on their CF.

*[Tim, 18 years]: "I believe it is true that a lot of people with CF do take it for granted (.) and # smoke # and do stupid things:"

With individuals being born with CF, some participants explain that they have always been aware of their CF and the implications it has upon their life. Tim stated that he has never know any difference in terms of his life with CF, with his adherence becoming an everyday routine.

*[Tim, 18 years]: "Because I've lived with it [CF] a:all my life # I kind of # it's [adherence] just an everyday routi:ine for me"

The role of structure and routine in aiding with adherence efforts is clearly demonstrated within the data, with many participants highlighting how a structured routine helps to reduce forgetfulness within adherence, protecting and promoting their physical health. In addition to a structured routine, the data illustrates the importance of awareness surrounding treatments' necessity in encouraging adherence efforts. Charlotte demonstrated her awareness of CF's fatal nature without adherence, emphasising the need for adherence post-transplant.

*[Charlotte, 13 years]: "I will get po:oorly (.) an po:oorly # a:and I will (.) end up dy:ying # if I don't take em [treatments] # so I have to take em [...] so I'll have my lung transplant an I'll have o:other medica:ation an I'm not even allowed to miss that # not even one da:ay"

Such awareness, and acceptance towards treatments' necessity was seen to be essential in encouraging individuals to adhere to their medical regimens, or at least be motivated to adhere to such treatments, with this acceptance meaning that even when participants disliked their treatments they still had the motivation for adherence, as they acknowledged treatments' necessity to improve or uphold their health.

*[Sophie, 12 years]: "<I don't like ha:aving to do a:all the medica:ation> (.) but I know that I ha:ave to do it to sta:ay well"

Whilst adherence for the paediatric population is heavily influenced by an individual's legal guardians, regardless of their beliefs and attitudes towards adherence, a personal good awareness of treatments' necessity does suggest that such participants would be likely to independently adhere to their treatments in the future. Tim explains that the most challenging aspect of CF is waking up every morning to do his treatments, but because he is aware of the health benefits he will receive from his adherence efforts he is motivated to overcome the challenge of early morning awakenings to adhere to his treatments.

*[Tim, 18 years]: "Because I know it's go:oing to help me in the lo:ong run (.) it doesn't re:eally bother me"

During this transitional period it is expected that some guardians will still be playing a big role in their child's adherence and this was clear from participants, with Tim stating that his parents still have a big involvement in aiding his adherence efforts. How treatments are managed as an adult may be quite different, consequently it will not be until adulthood that the true influence of acceptance and awareness regarding treatments' necessity will be visible.

Many participants also discussed their awareness regarding the adverse health effects of risky behaviours, with such awareness often causing participants to view these behaviours in a negative light, suggesting that such participants have accepted that they cannot engage in these behaviours to protect their health. Chris compared smoking to self-harm, recognising that smoking within CF can have fatal consequences, with Chris explaining that he would never smoke with CF due to this awareness, despite it being normalised within his environment.

*[Chris, 14 years]: "Smo:oking (.) drinking # that kind of thing [...] they're stupid [...] it's basically like cutting yourself ain't it # it's killing yourself"

Some participants were aware that risky behaviours are "more risky" to their health due to their CF, in comparison to the general population. Tony believed that risky behaviours for the general population are more focused upon criminal behaviours, whereas he makes the distinction that for an individual with CF, risky behaviours are any behaviours that can deteriorate their health.

*[Tony, 13 years]: "If it's like for CF # like (.) like # smo:oking (.) drinkin an that (.) an dru:ugs [are risky behaviours] # but if it's like a no:ormal person (.) probably like brea:aking in (.) o:or somat [...] they're [smoking, drinking, drugs] risky for everyone (.) re:eally # but it's mo:ore risky for CF (.) cause that can make em mo:ore ill"

Tony was recognising that while the experimentation in normalised risky behaviours is risky for everyone, it is "more risky" for the CF population. It did appear that when individuals had good awareness regarding their CF they could appreciate that any behaviour is risky which adversely effects their health, again acknowledging that behaviours which are risky to the CF population may be different to those for the general population. Tim, along with many other paediatric participants viewed non-adherence to also be a risky behaviour.

*[Tim, 18 years]: "Any ki:ind of behaviour that can affect your lu:ungs # even if it's down to not doing treatments # I count that as a ri:isky behaviour"

A participant's awareness on the adverse health effects of risky behaviours originated from a number of places. A number of participants explained how their knowledge provision had originated from their HCPs. Participants such as Tony reported being informed about the adverse health effects of risky behaviours by HCPs, however there were gaps within their knowledge, demonstrating the need to revisit such information on a regular basis with CF adolescents.

*[Tony, 13 years]: "I've lea:arnt (.) like # [Nurses name] told me about that [drug use] as well # we spoke about a:all # like smo:oking (.) drinking # an the dru:ugs # but I ca:an't # remember # like ## I know people inject themse:elves with it # an that can make their bloodstrea:am # e:er:r # like # not hea:althy"

Tony explained how alongside the conversations he had with his Nurse regarding risky behaviours he was also provided with standardised written information, outlining the consequences of such behaviours, to compliment the verbal information provided. However, this again was not sufficient, with Tony remembering that he has been informed regarding

the adverse health effects of excessive alcohol consumption, but not remembering what these adverse health effects are.

*[Tony, 13 years]: "Researcher: Has anyone ever he:ere [hospital] talked about drinking lo:ots of alcohol

Tony: No:o ## o:oh wait (.) probably [Nurses name] when she came over to my house #

Researcher: Yeah # do you remember what she said

Tony: No # I've got this like (.) folder about CF an everything # there's leaflets about it

Researcher: O:oh so it's in there # do you rea:ad the leaflets

Tony: Yeah (.) >I've read em<"

Tony's discourse (talking very fast) potentially suggests that he has not read the leaflets that he was provided with regarding excessive alcohol consumption. This highlights that even when information is provided verbally, and in written form, people may not access such information.

In addition to HCPs, many participants reported receiving awareness regarding the adverse health effects of risky behaviours from their families, both from discussion and observation. Liam explains how he would never smoke after witnessing his Grandad experience adverse health effects from smoking, with Liam also at times experiencing symptoms of passive smoking.

*[Liam, 14 years]: "My (.) Grandad does it [smokes] [...] [makes Liam feel] bad because he is a:always coughing [...] I start to cough a little bit"

This highlights how seeing firsthand the health impact of a risky behaviour can be a positive learning experience. Liam has been able to witness the long-term impact of smoking from his Grandad, with this impact not being evident within peer group smoking, where fitting in, being cool and being normal are more immediate desires, and the negatives are not apparent.

Another common way adolescents gain awareness of the adverse health effects of risky behaviours is through their education, mainly through lessons (PSHE, Science) and activities they do at school which promotes health keeping behaviours. While such awareness is not CF-specific, it still appears to resonate with some individuals with CF, and

often results in them accepting that they cannot engage in such behaviours. Another way participants received awareness, which was not CF-specific, was through watching television programmes which had documented such adverse health effects. Mandy demonstrated how the exposure to such adverse health effects had an impact upon her affect, resulting in Mandy having no motivation to engage in drug use.

*[Mandy, 12 years]: "I had a panic attack at school # we watched a video about what drugs do to you # your face ## these people were rea:ally scaring me [...] I would never do it [smoke marijuana]"

Whilst certain television programmes do document the adverse health effects of risky behaviours, the data also highlights the role television can have in promoting risky behaviours through advertisements. Tony explained how he understands excessive alcohol consumption can have adverse health effects upon an individual, with this being documented on Eastenders, however he acknowledged how the adverts on television promote alcohol consumption, making it look like a pleasant behaviour to engage in, encouraging initiation.

*[Tony, 13 years]: "I watched Eastenders:s and I seen Phil Mitchell needs a:all these transpla:ants (.) so # I knew that [alcohol is bad] [...] but in the adverts:s (.) they make it seem like a good thing [...] the drinks:s (.) makes it look refreshing:g [laughs]"

Therefore the television alongside all forms of mass media can have a negative influence upon the engagement of risky behaviours.

The data did demonstrate the imperative nature of awareness, with Tony explaining that without the awareness his Nurse provided him with regarding the adverse health effects of smoking, he would have potentially engaged in that behaviour, as he was unaware of the harmful impacts it could have on his CF.

*[Tony, 13 years]: "Knowing me I would probably think it's [smoking] a:alright [without awareness from HCP] # people that I kno:ow that smoke (.) they probably wouldn't be in that much trouble # like (.) like with their hea:alth or anything"

For other participants it was an experience that prevented their risky behaviour engagement rather than any awareness which was provided. Tim explained how he stopped drinking alcohol due to his liver function deteriorating.

*[Tim, 18 years]: "When I fi:irst tu:urned eighteen I just seen it a:as I'm eighteen now (.) I can do it [drink alcohol] # but # obviously wi:ith ## my liver function went do:own

so I just said to myse:elf ## sa:ame again ## it's mo:ore my health [...] the sca:are of the liver function # kind of # pu:ushed me awa:ay from drinking a bit"

It appeared that through experiencing these adverse health effects of excessive alcohol consumption, Tim valued his physical health above his psychological health.

Consequently awareness is not always enough to prevent an individual initiating in a risky behaviour or encouraging their cessation. An intervention therefore cannot just focus upon increasing an individual's awareness regarding the adverse health effects of risky behaviours, with it being noted that in some cases the discourse of participants suggests that their awareness will not prevent their experimentation in a risky behaviour. For instance, the pauses made by Sophie when asked if she would find it easy to refuse a cigarette from her friends, suggests that her answer could be due to social desirability bias.

*[Sophie, 12 years]: "Researcher: What about your friends # what about if they started to smoke # just hypotetica:ally # and they offered you a cigarette # do you think you'd find it ea:asy to say no:o

Sophie: E:erm:m # I'd just ## not agree with them"

Some participants provided reasons as to why others with CF may engage in risky behaviours despite their awareness. Some participants discussed how psychological distress could motivate individuals to engage in risky behaviours, to promote their psychological wellbeing, explaining how CF may encourage some individuals to engage in such behaviours as if their health is already bad there is nothing to stop their engagement.

*[Sophie, 12 years]: "Ma:aybe:e (.) if (.) something's happened (.) in their life # that's (.) like (.) dri:iven em (.) to do it [alcohol/drug use] so:ort of thi:ing # like (.) they're depre:essed (.) o:or something like that [...] sa:ay if ## when they were little (.) they hadn't done the medication (.) so they'd be re:eally bad # they (.) mi:ight # just do it [smoking/alcohol/drug use] # sa:ay # well I'm not going to get any better (.) so I mi:ight as well"

The fact that Sophie, at the age of 12 years, identified that individuals with CF do not get any better, clearly highlights what young people with CF are facing in dealing with the emotional burden of CF and its deteriorating nature. Inviting young people to discuss the reasons why others engage in risky behaviours, allows them to talk about this without personalising it. Participants could therefore say things without directly implicating themselves, with this being a more comfortable way of disclosing difficult issues. Some participants made no reference to CF when talking in third person, potentially demonstrating how they feel towards

their CF and their potential future engagement in risky behaviours, without confirming such assertion.

*[Sophie, 12 years]: "Someti:imes ## like (.) sa:ay # they have a ## health issue # o:or something # an sa:ay # they (.) we:eren't in a (.) very (.) good # state (.) sort of thing # they ma:ay think (.) well # I'm bad a:already # I mi:ight as well [smoke]"

Overall this theme identified the potential relationship between acceptance, awareness and the engagement in health promoting behaviours amongst CF adolescents. However as outlined within this theme the factors that predict risky behaviours are manifold; therefore an intervention to reduce the occurrence of risky behaviours, and to encourage adherence cannot just focus upon increasing a CF adolescents awareness of such adverse health effects. This theme therefore aligns with the previous three themes in identifying another factor that can influence engagement in such behaviours. Acceptance and awareness should not be understood in isolation, as the data illustrates that engagement is potentially the result of a complex interaction between how an individual is coping with the emotional burden of CF, the support they receive from others, and how they define themselves. Therefore interventions need to be mindful of all these factors in order to attempt to reduce the occurrence of risky behaviours within the CF population.

Discussion:

The data provides an exploration into attitudes and beliefs around risky behaviours within a paediatric CF population. Participants had a range of different attitudes towards risky behaviours, suggesting a number of different reasons for why others engage in such behaviours. The data produced is prospective, which has presented a deep understanding into participants' lives, examining individuals' attitudes and beliefs towards risky behaviours in real time. When paediatric participants were asked about what they regard as a risky behaviour, many participants identified non-adherence as a risky behaviour, demonstrating their awareness regarding treatments' necessity. This suggests that a large amount of emphasis is placed upon encouraging adherence within the paediatric CF population, with many participants having good awareness regarding what they need to adhere to and why. This awareness on the adverse health effects of non-adherence appeared to have resulted in some paediatric participants accepting the need for adherence, which has involved them incorporating their illness into their identity and accepting their CF (Laws et al., 2012).

Whilst some participants did appear to have accepted their CF, within the paediatric population this may not be representative of acceptance. It is plausible that this apparent acceptance is due to paediatric participants having a lack of awareness towards CF's true

nature, and its future implications. Adult participants, within phase one data collection, indicated that many individuals with CF are able to live a normal life when they are younger and their health is relatively good, explaining that they only came to truly accept their CF when they experienced health deteriorations. Therefore many adolescents with CF may not be fully aware of CF's implications, due to them not experiencing significant health deteriorations, consequently it has to be questioned whether adolescents with CF are fully accepting their CF, particularly with many participants discussing their desire for normalcy. It has to be acknowledged that acceptance of CF may develop in stages, and may change over time, particularly in response to changes in health. Priorities are different at different ages, for younger people support with living a "normal" life may be more important as demonstrated within this research.

Many participants did identify the most challenging aspect of living with CF is their adherence to their complex and time-consuming medical regimens, with many paediatric participants stating that it would be difficult to independently integrate their treatments into their lives. There were several reasons why participants found adherence to be challenging; some explained how they believe they are prescribed too many medications, with Wilderman (2015) speculating that a decline in pulmonary function within CF can be a direct consequence of poor adherence, with this poor adherence being due to the individual having to adhere to too many medications. Due to the amount of medications individuals with CF are prescribed, it is not surprising that many paediatric participants indicated that they favour treatments which demand less time, in line with previous quantitative research (Bregnballe et al., 2010; Keyte et al., 2017b, 2017c). In addition, participant's negative views towards adherence, and the limitations adherence imposes upon their lives appeared at times to be influenced by psychological distress, mainly anxiety and depression. Whilst research has shown that levels of anxiety and depression are similar between individuals with CF and the general population (Quittner et al., 2014), the impact of even slightly increased levels of psychological distress may be detrimental for an individual with CF, with evidence linking depression with inferior lung function and quality of life being reported and replicated (Quittner, Modi, Lemanek, Ievers-Landis & Rapoff, 2008).

Many participants explained that despite their awareness regarding treatments' necessity, they could see how non-adherence could have a positive impact upon their life psychologically, allowing them to lead a "normal life" by engaging in normal activities with their peers. Non-adherence would be a way for paediatric participants to reduce the differences there are between themselves and their peers, and support a normal identity (Withers, 2012). This emphasis on being normal despite suffering from a chronic illness is evident within previous literature, highlighting that chronically ill individuals perceive there to

be more to their identity than their illness (Higham et al., 2013; Yates et al., 2010). This demonstrates participants life-orientated illness perspective (Audulv et al., 2010), with such participants appearing to value their psychological health above their physical health. This desire for non-adherence therefore has the potential to result in future poor or non-adherence when the individual becomes independent over their treatments, representing their efforts to avoid their CF, to be provided with a normal identity (Withers, 2012). However, not all participants believed that they would be provided with a normal identity through non-adherence, instead one participant acknowledged the engagement in adherence provides an individual with a sense of normalcy. This is evidence of the social comparison theory (Festinger, 1954), with the participant comparing himself favourably against others with CF, with this raising an individual's self-esteem, encouraging their adherence to continue so that they remain well and do not appear to fit with the traditional image of CF (Tierney, 2012).

Many participants explained how they would find independent adherence to be difficult, highlighting the challenges that they will have to face when they do independently maintain their treatment regimens. It is widely acknowledged that self-management with adherence amongst CF adolescents is a challenge, with individuals reporting that adherence is difficult predominantly due to time pressures, competing priorities and a lack of perceived consequences of non-adherence (Sawicki, Heller, Demars & Robinson, 2015). In order to improve adherence Sawicki et al (2015) highlight that adolescents with CF must accept treatments' necessity and become independent with their treatments, despite their anxieties about such independence, with successful adherence often being facilitated by a structured treatment routine (Horne et al., 2006). Evidence of this was found within the data, with participants who had been given adherence support, but were then given some independence reporting that they found independence to be easy, predominantly because they were aware of treatments' necessity, resulting in them potentially not only accepting their CF, but also accepting the need for adherence (Laws et al., 2012). It was apparent that such participants (with the help of their guardians) had created a structured daily routine to aid with treatment adherence (Sawicki et al., 2015), with some participants stating that without parental support they sometimes engage in unintentional non-adherence (Horne, 2000), predominantly due to forgetfulness.

Independence with adherence is not just difficult for individuals with CF, the data highlighted the transfer of treatment responsibility is also difficult for parents (Filigno et al., 2012), with some participants explaining how their parents are holding them back from independent adherence. The difficulty for parents is often heightened when they are witnessing their child's poor treatment adherence during their transition to independence

(Coon, 2015). However not all participants had difficulty with independent adherence, with some appearing to have integrated their illness into their identity, accepting treatments' necessity (Laws et al., 2012), with these participants often focusing upon the need for adherence demonstrating their disease-orientated illness perspective (Audulv et al., 2010). These participants often explained how they were comfortable in disclosing their CF to others, and publically adhering to their medical regimens, showing that they have no desire to hide their illness from their peers, as they do not wish to be provided with a sense of invisibility towards their CF.

With many participants having a desire for normalcy, it was not surprising that some found disclosure of their CF to be challenging. Literature does illustrate that many chronically ill individuals do desire a sense of normalcy (Keyte et al., 2017b, 2017c; Withers, 2012). Some participants indicated how the visibility of their illness identity is difficult which motivates their non-disclosure, with previous research highlighting how when adolescents perceive themselves to be different to their peers they often experience negative emotions (Withers, 2012). An example was when a participant got bullied following her disclosure of her CF, with this being in line with previous discussions by CF parents who stated that CF makes adolescents a prime candidate for bullying (Richards, 2015). Such negative responses to an illness identity could have detrimental psychological implications upon an adolescent, with adolescents often employing effort to ensure there are minimal differences between themselves and their peers, as adolescents often highly value the opinions of their social group, and desire acceptance within that group (Withers, 2012). As highlighted within the data it is often easy for individuals with CF to not disclose their CF to others due to CF's invisible nature (Tierney, 2010). Some participants explained how they will disclose their CF status but only to their close friends. It is widely acknowledged that disclosure during adolescence is a challenge within chronic illnesses, with adolescents who hide their illness identity often worrying about whether their friendships will continue post-disclosure (Wiener & Battles, 2006). Nonetheless participants did value the benefits they received post-disclosure, even if that disclosure was only with their close friends, with this disclosure allowing participants to display their illness identity and adhere to their medical regimens in public (Wiener & Battles, 2006).

In addition to adherence and disclosure, when participants had good awareness regarding their CF they often did not have a desire to initiate in risky behaviours, regardless of whether or not these behaviours were normalised within their environment. Participants who did have good awareness regarding the adverse health effects of risky behaviours often recognised that these behaviours are more risky for them because of their CF than they are for the general population. Some participants acknowledged that although the

experimentation in risky behaviours is normal during adolescence, the engagement in such behaviours would have extreme detrimental impacts upon their CF. One participant was able to differentiate between risky behaviours, highlighting how excessive alcohol consumption is "less" harmful than smoking, with smoking being an extremely risky behaviour for his CF. This participant demonstrates unrealistically optimistic views towards excessive alcohol consumption, with this participant processing risk information regarding excessive alcohol consumption in a way which allows him to continue this behaviour (Weinstein, 1983). It is plausible that this participant felt that his sense of self-integrity was threatened when presented with information regarding the adverse health effects of excessive alcohol consumption. This may explain why the participant appeared defensive regarding his alcohol consumption, rejecting the associated risks by comparing such risks to the risks from smoking, concluding that alcohol will not have an adverse effect on his health, as alcohol is not as dangerous as smoking is to CF, demonstrating evidence of the self-affirmation theory (Sherman et al., 2000; Jacks & Cameron, 2003).

The experimentation of risky behaviours is "normal" during adolescence (Richmond, 2014), with Bryon (2015) suggesting that adolescents with CF will behave like their peers without CF. However, within the current research there was little disclosure of engagement in risky behaviours, despite many participants expressing a desire for normalcy, therefore some narratives could have been influenced by social desirability bias. Nonetheless, within the data the importance of awareness regarding the adverse health effects of risky behaviours in preventing a desire for initiation was clearly demonstrated. Awareness regarding risky behaviours can originate from many individuals, predominantly parents, peers and HCPs. Evidence suggests that health information from peers has a greater impact than that from HCPs or parents (Bryon, 2015). However paediatric participants did greatly value their parents' opinions, with some explaining how they would not engage in risky behaviours in order to avoid discipline from their families, and due to them not wanting to disappoint their families, with Dishion et al (2003) demonstrating how adolescent substance use initiation is mediated by parental monitoring in the general population.

It is well acknowledged within literature that awareness regarding the adverse health effects of risky behaviours does not always prevent initiation or encourage cessation, with The Theory of Reasoned Action and The Theory of Planned Behaviour highlighting how many factors can influence an individual's behavioural intention, and therefore behavioural change. These factors encompass an individual's attitude towards the behaviour, their subjective norms as influenced by others, and their behavioural control (Ajzen, 1988; Ajzen & Madden, 1986; Fishbein, 1967; Fishbein & Ajzen, 1975). The Stages of Change Model highlights that interventions to prevent risky behaviour engagement are more successful

when an individual is already contemplating that behavioural change (Prochaska & DiClemente, 1982), with awareness not always being enough to encourage such change in behaviour.

Within the data it appeared that personal experience is weighed more heavily than knowledge, with participants continuing to mix with others with CF as they have not experienced any adverse health effects, despite being aware of such potential effects. Similarly one participant explained that he would never smoke due to witnessing the adverse health effects of smoking within his Grandad. This highlights how experiencing first-hand the health impact of a risky behaviour can be a positive learning experience, with these long-term impacts not being evident within peer group risky behaviour engagement. Witnessing such adverse health effects can result in participants not valuing normalcy, or desiring to conform to these normalised behaviours, accepting that they cannot engage in such behaviours due to their health (Laws et al., 2012). Exposure to the adverse health effects of risky behaviours can also be provided through television programmes, with participants signalling that this exposure prevents their desire to initiate in these normalised behaviours. This is supported by previous research in the general population, demonstrating that visualisation interventions are more effective than language based messages, with it being believed that these images have an impact upon one's affect, motivation and therefore behaviour, with these images being more memorable than words (Karamanidou, Weinman & Horne, 2008; Lee, Cameron, Wunsche & Stevens, 2011). Affective beliefs are often described within literature to be significant predictors of risky behaviours. When an individual has a negative affect regarding a behaviour they are less likely to engage in that behaviour, with individuals being more likely to engage in a behaviour when they have a positive affect about that behaviour (Lawton et al., 2009; Rhodes, Fiala & Conner, 2010).

Whilst the television can provide awareness regarding the adverse health effects of risky behaviours, some participants explained how it can promote risky behaviour engagement, mainly through advertisements and programmes documenting the positive impact such behaviours can have upon an individual's mood. "The Only Way Is Essex" is a reality series which often appeals to adolescent viewers, the show was previously sponsored by "WKD" and often contains scenes where the cast are on nights out, displaying the positive effects of alcohol use. Research within the general population indicates that such exposure is associated with the likelihood of adolescents starting to drink alcohol, and will increase the alcohol consumption of those who already drink (Anderson, de Bruijn, Angus, Gordon & Hastings, 2009).

Because of the awareness an individual receives within their private life varying between participants, it is acknowledged that CF-specific awareness needs to be provided to all individuals with CF from their HCPs. The data highlighted that awareness from HCPs regarding the adverse health effects of risky behaviours is often provided on an individualised basis, however due to the suggested relationship between awareness and abstinence within this research there is a need for this awareness to be provided to all patients regardless of their personal condition. Nonetheless, even when participants received awareness from their HCPs it was not always sufficient. Awareness was often provided on a verbal basis, thus different patients could receive different amounts of information. Participants were often able to remember that they have been informed regarding the adverse health effects of a behaviour, however they had gaps within their knowledge regarding why these behaviours are risky. It is acknowledged that due to CF's improvement in life expectancy, individuals with CF are now faced with "new" issues, such as a vulnerability to engage in risky behaviours, which CF HCPs may overlook (Horky, 2014). Consequently it appears that new interventions are needed to be integrated into CF care on a proactive basis. These findings are in line with phase one data collection and the transition evaluation, illustrating that more emphasis needs to be placed on reducing the occurrence of risky behaviours due to the CF population not having the freedom to experiment with such behaviours (McEwan et al., 2012).

Conclusions

Both phases of data collection provide insight into the variety of reasons why individuals with CF may be motivated to initiate in risky behaviours, and engage in poor/non-adherence. Overall it is concluded that a desire for normalcy was seen to be important to many adolescents and adults with CF, with literature acknowledging that this desire for normalcy can be accompanied with the engagement of normalised risky behaviours, and non-adherence in response to the illness identity. Evidence of a life-orientated illness perspective was also prevalent, with some adult participants reporting that they engage in risky behaviours for fun. The role of affective beliefs was clearly demonstrated within both phases of data collection, with adults explaining how enjoyment and pleasure increases the continuation of a behaviour, whereas adolescents explain how a negative affect reduces their motivation for a behaviour. In general amongst both adult and paediatric participants there was a reported lack of knowledge concerning consequences of risky behaviours. Through the researcher's reflections it was highlighted that different participants from the same CF centre did not have the same awareness regarding risky behaviours. Some participants reported not being informed by HCPs regarding risky behaviours, whereas other

participants had been informed, suggesting that HCPs approach the issue of risky behaviours on an individualised basis. Some paediatric participants reported that they received leaflets informing them about risky behaviours, whereas other paediatric participants from the same CF centre did not make reference to such leaflets. This demonstrates the need for more effective health promotion measures in order to reduce the occurrence of risky behaviours within the CF population, by approaching the issue on a proactive basis, where all individuals receive standardised information regarding the CF-specific adverse health effects of such behaviours regardless of their personal condition.

Another area of interest identified within the researcher's reflections is that only one paediatric participant reported engagement with a risky behaviour, the participant was 18 years old and reported previously drinking alcohol excessively. It was found that the majority of other paediatric participants (all under the age of 18 years) were very "anti" such behaviours, whereas many individuals aged 18 years and above (from phase one data collection) appeared to have experimented in risky behaviours, or at least considered such experimentation. It is therefore interesting to think what happens during these years which changes an individual's attitude towards such behaviours, often resulting in initiation or experimentation. Paediatric participants may have been reluctant to discuss any desires to initiate in risky behaviours with the researcher due to the differences in age between the participants and the researcher impacting upon the power relationship within the research (Braun & Clarke, 2013; Descombe, 2014). Due to the researcher being a lot older than participants, the researcher was interviewing across differences, which can be difficult when trying to establish rapport. Such differences in age, alongside the researcher's identity as a researcher would have caused participants to view the researcher as an "expert", affecting their disclosure of sensitive issues, potentially due to fearing the researcher would pass on such information to HCPs, despite the researcher explaining the bounds of confidentiality. With paediatric participants rarely discussing any desire to initiate in such behaviours to the researcher, who is outside of their health care team, it is expected that adolescents with CF are less likely to discuss any desires, intentions or engagement in risky behaviours with HCPs. Therefore work needs to be done in order to encourage such disclosure, or to provide individuals with an alternative route of disclosure.

Overall, this research highlights the juxtaposition between clinical recommendations, and personal life strategies undertaken by individuals with CF to support their identity, with this representing a challenge for individuals with CF, their families and HCPs alike. To reduce the occurrence of risky behaviours within the CF population, more information needs to be provided to patients by HCPs about the engagement in such behaviours. Individuals would then be free to make a more informed choice in light of the consequences regarding

engagement. Understanding the dilemma highlighted within this research will aid the development of interventions, with both phases of data collection providing an interpretative perspective on the reasons why some individuals with CF engage in risky behaviours and non-adherence. With many participants within both phases of data collection reporting a lack of awareness regarding the adverse health effects of risky behaviours provided by HCPs, the researcher deemed it essential to talk with HCPs regarding what awareness they provide patients with, and which patients they provide this awareness to. The researcher decided to recruit CF Specialist Nurses for the next phase of data collection, due to participants within both phases of data collation describing Nurses to be the most approachable member of the MDT, disclosing more information to Nurses. Therefore, it was believed that Nurses would be well placed to offer valuable insights into the issue of risky behaviours and effective interventions. In addition it was believed that Nurses would be responsible for delivering a new intervention regarding risky behaviours in line with previous literature conducted within the general population (Cooley et al., 2009; Fore et al., 2014; Sarna et al., 2016). The third phase of data collection therefore involved conducting semi-structured interviews with CF Specialist Nurses, to investigate how they perceive the issue of risky behaviours within the CF population, and to gain insight into what interventions they believe would work in practice to reduce the occurrence of such behaviours.

CHAPTER NINE: METHODOLOGY - CYSTIC FIBROSIS SPECIALIST NURSES' **PERCEPTIONS OF RISKY HEALTH BEHAVIOURS**

Participants

Nine CF Specialist Nurses were recruited, all of whom worked in different UK CF units (three paediatric Nurses, five adult Nurses, one adult and paediatric Nurse; range of experience: 11 months - 23 years, mean = 14 years).

Measures

Telephone Interviews. The researcher conducted semi-structured interviews via telephone with CF Specialist Nurses to gain insight into how they perceive the issue of risky behaviours within the CF population. One face-to-face interview was conducted with a participant who expressed a wish for this methodology, this was an option to all Nurses.

To achieve saturation the researcher transcribed all interviews. A semi-structured interview schedule (Appendix W) was developed through collaborations with the researcher's supervisory team and through consulting existing literature, and the previous two phases of data collection. These interviews aimed to progress the findings from the transition evaluation which indicated the issue of risky behaviours is often neglected within CF care. The researcher therefore investigated CF Specialist Nurses' awareness about risky behaviours within the CF population, and how Nurses currently address this issue. This research was qualitative, allowing the methodology to explore the defined areas, while allowing elaboration on other topics (Gill et al., 2008), providing an interpretive perspective on how CF Specialist Nurses perceive risky behaviours, creating humanistic research (Yates et al., 2010).

The interview schedule commenced with a section of ice breaker questions to generate rapport (Ashton, 2014; Cooley et al., 2014), with the interview then encouraging Nurses to discuss what it is like to work within the CF population, mainly focusing upon the challenges of CF, such as its deteriorating and fatal nature. Literature reports that the most challenging aspect of being a CF Specialist Nurse is when a patient becomes ill and passes away. Nurses often state that when they lose a patient they feel like they've lost a family member as a consequence of developing strong relationships with CF patients, due to their high patient contact (Rhys, 2011). It is reported that CF Nurses deal with this loss through accepting that they did their best for that patient (Rhys, 2011). Research shows that CF HCPs are competent in helping patients adjust to decreased health, however they are less

well prepared to assist patients whose health has improved (Horky, 2014), therefore the researcher also investigated this assertion.

The semi-structured interviews also focused upon the issue of disclosure, investigating whether Nurses believe patients tell them the truth. This is based upon the findings from phase one data collection, which showed that with risky behaviours many patients either fail to disclose engagement to HCPs, or they do not disclose the extent of their engagement; in line with previous research (Viner & Macfarlane, 2005). The interviews therefore focused upon how a Nurse would respond if they suspected a patient was not disclosing information to them. This information may not necessarily be about risky behaviours, as this section remained broad and open ended (Cooley et al., 2014). It was speculated that CF Specialist Nurses would highlight the issue of adherence, with literature marking that poor adherence is a major concern within the CF population (Barker et al., 2012; Daniels et al., 2011; Keyte et al., 2017b, 2017c), with this also being highlighted during the previous phases of data collection. Therefore, the next section of the interview specifically focused on poor adherence, to investigate CF Specialist Nurses' views on whether they perceive poor adherence to be a major concern as reported within literature, and what new interventions they believe would work to encourage adherence.

The interview schedule then focused upon CF Specialist Nurses' views on risky behaviours. This section firstly aimed to progress the transition evaluation by investigating how Nurses inform patients about risky behaviours, which patients they inform (e.g. are all patients informed, or only those who engage in such behaviours), and what behaviours they provide awareness on; with the findings from the previous phases of data collection suggesting that many CF patients are not informed regarding the adverse health effects of such behaviours specific to CF. This section then investigated Nurses' views regarding whether risky behaviours are an issue within the CF population, and whether they are aware of how prevalent such behaviours are, as the findings from phase one data collection suggested that many patients do not disclose engagement to HCPs. This section then ended by investigating Nurses' views on what new interventions would work to address this issue.

As with the previous phases of data collection, the researcher's approach was a balance between empathy and neutrality (Ashton, 2014). In order to make participants feel their contribution was valued the interview ended by asking participants to describe an intervention they would like to see implemented to address the issue of risky behaviours, discussing barriers and enablers to such intervention.

Carrying out the Study

The researcher contacted the CF Nursing Association (CFNA) via email, informing them about this study and providing them with an information sheet (Appendix X). The CFNA then emailed all CF Specialist Nurses informing them about the research via an information sheet (Appendix Y) (the email had been generated via the researcher), and if a CF Specialist Nurse was interested in participating they were asked to email the researcher. The researcher was available to meet with Nurses at their CF unit at a date / time convenient for themselves, or would communicate via email or telephone, further explaining the research (and again providing them with the written information sheet) and answering any questions. If Nurses still wished to participate they were required to complete a written consent form (Appendix Y), to ensure informed consent had been collected; Nurses were given a maximum of two weeks when deciding on participation.

The Nurses then completed a semi-structured interview, investigating how they perceive the issue of risky behaviours within the CF population. A coding method was used during this research; Nurses were given a number which was written on their consent form with their name. The researcher stated this number at the beginning of the interview recording and wrote this number on the transcript (pseudonyms were used for the write up). This enabled the Nurses to disclose accurate information representing the reality of practice within their CF unit to address risky behaviours, without their colleagues knowing what they had disclosed. The interview was arranged at a time / date convenient for the Nurses, with the interview lasting a maximum of 60 minutes; however the interview could be stopped earlier if Nurses wished this to be the case. No Nurses requested the interview to be stopped early. The Nurses did not have to answer any questions they did not wish to. All participation was voluntary, and the Nurses could withdraw from the research without being penalised; within this research no Nurses withdrew their participation. Once the interview was complete the Nurses received a debriefing sheet (Appendix Z), and again had the opportunity to ask questions. The researcher then contacted all Nurses via email once the research was complete to inform them of the overall research results and to ask for results feedback (Appendix AA).

Ethics Committee

Ethical approval was obtained by the Business, Law and Social Sciences Ethics Committee at Birmingham City University.

Analysis

As described in the initial analysis section within Chapter Four, the interviews were transcribed utilising the Jefferson transcription coding (Heath & Hindmarsh, 2002), with the data being analysed using thematic analysis following Braun and Clarke's (2006) model. Thematic analysis generated 72 codes. The researcher made inferences about what the codes meant enabling the codes to be combined into three overarching themes that accurately depict the data (Appendix BB). The three themes generated are described in detail within the next chapter, utilising direct quotes and discussion around CF Nurses' perceptions towards risky behaviours.

CHAPTER TEN: ANALYSIS - CYSTIC FIBROSIS SPECIALIST NURSES' PERCEPTIONS OF RISKY HEALTH BEHAVIOURS

Thematic analysis was applied to the interview transcripts following the Braun and Clark (2006) model, which identified three themes within the data. The first theme, labelled as "Cystic Fibrosis care as a changing environment", highlights CF Specialist Nurses' views towards CF care, and how CF care has changed over time. Theme two, "Cystic Fibrosis Specialist Nurses knowledge regarding a patient's life", focuses upon the awareness CF Specialist Nurses have regarding what influences their patients' decisions surrounding health behaviours. The final theme, labelled as "Effective health promotion advice: What works?", demonstrates what interventions CF Specialist Nurses believe need to be implemented to encourage health promoting behaviours, and reduce the occurrence of risky behaviours within the CF population. It is acknowledged that there are aspects of the Nurses' ideas and understandings that overlap across these themes; however as with the previous two phases of data collection this was to be expected (Fielden et al., 2011). All three themes will be further examined in the next segment, by utilising direct quotes and discussion around this topic area.

Cystic Fibrosis Care as a changing environment

This initial theme focuses upon CF Specialist Nurses' views towards CF care, and how that care has changed over time. CF Nurses demonstrated a passion for their role, with them pointing out that they are more than a Nurse, being there for more than the medical needs of individuals with CF. Many Nurses such as Sharon indicated that their role involves them being a "patient advocate", and attending to all needs of their patients, encompassing their psychological and medical needs.

*[Sharon, 8 years, Paediatric Nurse]: "My role is # ce:ertainly as a patient advoca:ate (.) as well [...] it's a unique position to be in"

With being a "patient advocate", many Nurses agreed the most enjoyable part of their role is forming relationships with their patients over a long period of time, with Natalie explaining how CF Nurses meet with their patients regularly throughout their lives, being able to support patients through the lifespan.

*[Natalie, 15 years, Adult Nurse]: "It's very nice to have relationships over a lo:ong time # some of the patients (.) are very # admira:able (.) in ho:ow they manage everything # a:and (.) it's quite rewa:arding being able to suppo:ort (.) e:erm:m # patients in their li:ife # e:erm:m # in that respect"

CF Nursing is a demanding role, which can be emotionally draining when supporting an individual with CF throughout their whole life. Nurses explained that the hardest part of their role is accepting CF's fatal nature, with many Nurses explaining how they found it difficult to deal with death when they first entered their position, after forming strong relationships with their patients who they got to know personally. This was most difficult when the Nurses were of a similar age to the individuals with CF who passed away, with Natalie explaining how she could identify with these patients and their lives. Nurses explained the way in which they individually deal with death does change over time, in order to cope with CF's fatal nature.

*[Natalie, 15 years, Adult Nurse]: "At first it [death] was very hard for me (.) because I was at a similar age (.) to a lot of the patients who I'd built relationships with (.) and you could associate with the same age group as yourself very easily [...] I suppose now (.) I still have relationships with the patients (.) but [...] I've changed with how I deal with it [...] I deal with it in a different way"

Natalie found it difficult to verbalise how she now deals with death stating "I can't really explain it very well to you". Her narrative suggests that now she is not of a similar age to patients it has become slightly easier to deal with death, potentially due to the relationships she forms with patients being different due to this age gap, nonetheless it is very clear and understandable that death is still an area of Natalie's job in which she struggles with.

In terms of CF care as a whole, Nurses pointed out that it is not standardised across all CF units, with this being most apparent to Nurses who have worked in multiple centres, such as Alice who has been a CF Specialist Nurse for 21 years and worked in three different centres. As a consequence of Alice's experience within different CF centres, she expressed the opinion for the need for certain things to become standardised, such as the use of medications, and how to deal with exacerbations.

*[Alice, 21 years, Adult Nurse]: "I've worked in three different centres (.) and it's interesting how differently (.) clinicians operate across country [...] we really should start standardising what we do # in terms of ## immuno-modulator drugs [...] prophylaxis # preventions # how we (.) manage (.) exacerbations [...] it's interesting how differently the Europeans work to us # in terms of how they approach CF"

In addition to standardised care, Nurses also value the use of individualised care, believing this is the most successful form of care. Nurses, such as Michelle expressed their belief that working with patients and listening to what patients want, results in positive health outcomes, such as adherence.

*[Michelle, 4 years, Paediatric Nurse]: "Everyone is so:0 # so:0 ## positive # in terms of the professionals [...] working for that individual patient # so I'm very much in a team that # it's a:all for the patient"

The importance of psychological factors was also portrayed within this phase of data collection. Many Nurses, such as Jayne, indicated how it is important to talk to individuals with CF on a human-to-human basis, whilst remaining professional. This develops a strong sense of rapport, and a positive relationship between the patient and HCP, with Nurses believing this encourages patients to be more honest regarding their CF and health behaviours, and is therefore associated with positive health outcomes.

*[Jayne, 11 months, Adult Nurse]: "I try and take off the Nurses cap a little (.) and speak one (.) on (.) one # as a human being [...] they tend to open up (.) and give me something back"

In addition, with CF care now having a focus upon psychological factors, Nurses explained how important it is to attend to their patients' emotions, due to CF providing individuals with challenges such as health deteriorations. Kirstie explained how CF care also focuses upon increasing an individual's quality of life, and helping them enjoy their life by making their CF easier to manage e.g. by administering home intravenous antibiotics.

*[Kirstie, 22 years, Paediatric Nurse]: "We know it's a life limiting condition [...] I think you can do a lot with that ## so you can put the quality there"

It is well acknowledged that optimism can increase a patient's quality of life, therefore it is not surprising that CF care tries to provide patients and families with future hope and optimism. CF Nurses do this in a variety of ways, with Kirstie explaining how in her centre they show adolescents with CF the "normal" life that some adults with CF live.

*[Kirstie, 22 years, paediatric nurse]: "We for example # have a (.) folder of which CF adults contribute to (.) obviously if they consent to it # where they take photographs of what they've been up to (.) and then we give that to the families in our clinic to have a look through to see what people are up to # to give them a sense of hope"

Nurses explained that to provide individuals with CF and their families with optimism, it is essential for Nurses to also be optimistic for CF's future, with Michelle discussing how she is optimistic due to the research, money and recognition which is presently being invested into CF.

*[Michelle, 4 years, Paediatric Nurse]: "If I wasn't positive fo:or them (.) ho:ow can I expect them to be positive fo:or themselves # and ho:ow can you live with CF and not tr:ry to be positive"

Remaining positive and optimistic for patients is a huge demand on Nurses, however Michelle recognises the need for this in order to maintain patients' optimism, due to the emotional burden CF does present individuals with.

In addition to this focus upon optimism and quality of life, CF care is also changing in its delivery method, with many Nurses identifying a role for technology (such as a Skype Triage) in caring for individuals with CF at home, instead of regularly bringing them into clinic. This would reduce the risk of cross infection, and potentially have an impact upon an individual's quality of life.

*[Jayne, 11 months, Adult Nurse]: "There's new things on the horizon # we're no:ow looking into (.) e:erm:m # sort of # test a (.) Skype like Tria:age # that's already in progress in (.) in clinics (.) in Wa:ales [...] some patients ne:eed to come to clinic mo:ore than others:s # so it's to se:ee whether o:or not (.) we can tria:al # mana:age (.) them (.) from ho:ome [...] we a:are looking for wa:ays to (.) to keep them hea:althier for lo:onger # we don't a:always have to bring them to clinic if they're not feeling very well # perha:aps we could have a look at them at ho:ome and see ho:ow they get on"

A reduction in the number of hospital visits would not just reduce the risk of cross-contamination, it would also result in less reminders for patients regarding their disease and how they may deteriorate. CF care is also changing through medical advances, with many Nurses excited by the new emerging medications, providing CF Nurses with optimism for the future of CF.

*[Sharon, 8 years, Paediatric Nurse]: "I think we:e (.) are a:almost (.) getting into an exciting e:era of (.) next genera:ation treatments [...] I don't know wh:ere it'll lead up (.) but (.) it'll ce:ertainly lead us to the next step up from CF modula:ators (.) a:and correctors # so it'll be the next genera:ation of CF ca:are"

Hope and optimism towards this new era of personalised medicine within CF is not just experienced by Nurses, it is experienced by everyone involved within an individual's care; patients, families and HCPs alike. Nurses however did point out that particularly within the short-term, when a new treatment is introduced it increases a patient's treatment burden,

demanding more time from individuals, which is identified as a major barrier to adherence within CF.

Whilst Nurses predominantly focused upon the large number of positive changes within CF care, they did also identify some issues. Firstly, a major issue surrounded funding, with many of the new medications not currently being funded by the NHS. In addition, with CF entering an era of personalised medicine, it is resulting in increased longevity, with Nurses explaining that they believe their job will become more complex, due to individuals with CF being vulnerable to more complications with their increasing life expectancy.

*[Debbie, 23 years, Adult Nurse]: "With our patients living longer (.) their lives aren't # particularly # easy # because they're getting more and more (.) CF related issues [...] I would say it's (.) it's made the job more complex"

In addition to complications, Dawn explained how the role of a CF Specialist Nurse does not just involve dealing with classic CF patients anymore, with Nurses often seeing patients who are in the "CF-spider" category, where they screened positive for CF but have an indeterminate diagnosis as a consequence of the nationwide newborn screening implemented in 2007. Dawn also explains how HCPs now have to deal with patients who have two identified CF genes but have a normal sweat test, with Dawn identifying that currently CF care does not know how best to care for such patients, as they do not know what their future will hold, acknowledging how CF care is a changing environment.

*[Dawn, 20 years, Adult and Paediatric Nurse]: "We don't (.) know (.) what the future holds for them # there's a whole host of different patients # we have some who sit in the grey area (.) where their sweat chloride sits between forty and sixty (.) so they're probably pancreatic sufficient # possibly (.) you know (.) generally well # but some can have quite problematic chest disease # so I think there are (.) variations now # I think probably (.) twenty years ago (.) I would have never thought there were patients who were pancreatic sufficient (.) I just thought they were all the same [laughs]"

Furthermore, many CF Nurses explained that with life expectancy increasing, and with many individuals with CF entering adolescence and adulthood being relatively well, CF care now needs to address the issue of risky behaviours. Michelle explained how risky behaviours have only recently become an issue within her CF centre, however she identifies that it is a "real concern" that needs to be actively addressed.

*[Michelle, 4 years, Paediatric Nurse]: "There are a few patients (.) who have just got # a lot (.) go:ing on # and pote:entially (.) da:abaling in thi:ings # a:and for us (.) that's obviously a re:eal conce:ern with trea:atments (.) a:and their health (.) a:and everything else # it's only ju:ust becoming an issue in more recent yea:ars # we're only no:ow starting to think # this # this could happen to a:any of our patients actually ## we're re:eally trying to focus in on it with our Psychologist"

Whilst many Nurses did acknowledge that risky behaviour education needs to be a focus of CF care, in order to reduce the occurrence of such behaviours, not all CF units are addressing this issue. Nurses suggested that psychology could play a role in reducing the occurrence of risky behaviours within the CF population, pointing out that psychology is being integrated more and more within CF care. Nurses are very aware of CF's psychological implications, and welcome psychological support within their CF MDT's.

*[Michelle, 4 years, Paediatric Nurse]: "We've got a Psychologist now full ti:ime # and that's bri:illiant (.) cause she would see them quite a bit # for e:everythi:ing # and that's crucial # that's getting bi:igger (.) and bi:igger (.) and bi:igge:er aspect of CF (.) that it ever used to be"

Overall this theme indicates that CF care is a changing environment, and now is an environment where pharmacological and psychological factors are equally considered. In addition, Nurses appreciate the need to actively address risky behaviours within the CF population, with the effectiveness of such interventions being dependent upon HCPs knowledge on what risky behaviours are current within the general population, as well as the reasons why individuals with CF may engage in such behaviours.

Cystic Fibrosis Specialist Nurses knowledge regarding a patient's life

This second theme provides insight into CF Specialist Nurses knowledge regarding their patients' lives, and how much awareness they have regarding what influences their patients' decisions regarding health behaviours. Some Nurses admitted that they do not know their patients very well, as predominately they focus upon their medical condition, rather than focusing upon their patients' lives, however Kirstie did explain that there is a need for this to happen.

*[Kirstie, 22 years, Paediatric Nurse]: "I probably don't know my patients as well as I ought to [...] natura:ally we're going to focus on that [medical side] mo:ore # but [...] it's good to look at the (.) bi:igger picture:e"

While some Nurse stated that they do not focus upon the "bigger picture" of their patients' lives, the majority of Nurses did have insight into what an individual's life is like with CF, and often demonstrated strong relationships with their patients. Dawn explained how she is able to detect patients' anxieties, despite patients often not vocalising these, with Debbie explaining how she can predict how different patients will cope with different aspects of their disease.

*[Dawn, 20 years, Adult and Paediatric Nurse]: "Some of the te:ena:agers (.) ca:an (.) displa:ay behaviour (.) that reflects their stress and anxiety [...] they ma:aybe:e (.) a:aren't able to voca:alise it # >I'm really worried about my future< # >I know I'm sick< (.) >am I going to die:e< [...] none of that comes out (.) different behaviours come out"

*[Debbie, 23 years, Adult Nurse]: "We do know patients so:o well that we can # actually # guess in a way (.) ho:ow they're going to cope with each situation # so we can actually ## ta:alk to them (.) and advi:ise them and gu:uide them # using the best way fo:or that patient"

An area where Nurses demonstrated a good insight into their patients' lives was regarding adherence, and what motivates adherence decisions. In particular, Nurses acknowledged the difficulties for individuals with CF during their transition to adult care, with Kirstie explaining that Nurses expect trouble during adolescence, as they appreciate how hard independence with adherence is, especially alongside the other challenges that adolescence presents.

*[Kirstie, 22 years, Paediatric Nurse]: "Young people are expected to kno:ow about their treatment (.) ri:ight at the very time they're getting their head arou:und (.) rela:ationshi:ips (.) sexua:ality # everything that comes in their teenage yea:ars"

Nurses also identified other barriers to adherence such as a desire for a normal identity and wanting to live a normal life, therefore suggesting how a life-orientated illness perspective can result in poor adherence. Due to Nurses being aware of adherence barriers, which are more prevalent within certain treatment modalities (e.g. pancreatic enzymes), some Nurses, such as Kirstie, explained how they address these issues with all patients on a proactive basis, in an attempt to encourage adherence.

*[Kirstie, 22 years, Paediatric Nurse]: "Some thi:ings which are a:always there [...] people say (.) not ta:aking creon at school because they're embarrassed [...] so we address that (.) when they first go to school [...] kno:ow it's going to be a hu:urdle for some people (.) a:and address it for everyo:one"

Nurses also pointed out that acceptance plays a role within adherence, suggesting that if an individual has not integrated their illness into their identity then they may be in a state of denial regarding their CF. Jayne demonstrated her belief regarding the negative impact denial can have upon one's adherence efforts.

*[Jayne, 11 months, Adult Nurse]: "I think a lot of it comes down to (.) denial a lot of the time # they think things aren't that bad (.) well actually they are"

In addition to the psychological implications, Nurses also explained that an individual's poor adherence can be due to a lack of time, therefore Nurses suspect that individuals prioritise their treatments based upon their short-term consequences. Michelle explained that if Nurses understand what treatments an individual struggles with, they can manipulate their treatment plan to fit within their lifestyle and encourage adherence.

*[Michelle, 4 years, Paediatric Nurse]: "It may be a time issue (.) it may be a socialising issue # it may be a body conscious issue # there's different ways you can (.) almost (.) manipulate medication"

Within this research Nurses clearly identified that they are fully aware of the difficulties that patients face, and how these difficulties differ between treatments and between different people's needs. Nurses employ a great deal of effort to support their patients, often on an individualised basis, and to understand what life is like for them. To encourage an individual's adherence efforts, Nurses illustrated how they provide awareness to patients. Some Nurses believe this works best using case study examples of how non-adherence can result in health deteriorations. To encourage adherence through awareness, Nurses acknowledged the need to identify patients who struggle with their adherence, in order to provide those patients with the most support. However, Natalie explained that the way in which Nurses question patients regarding adherence influences patients' honesty, with Nurses needing to communicate a non-judgemental approach.

*[Natalie, 15 years, Adult Nurse]: "I don't think they tell the truth # but I don't think we ask always the right questions ## so for example # I would maybe say # are you on >so and so drug< # they'll say yes:s (.) and I won't go on to say ## how many times have you managed to take it this week ## but if I was to [...] then (.) I think I'd get the honest answer"

Nurses have highlighted the importance of fitting care to each individual patient, therefore there may be a reason why Nurses do not push certain patients when asking about adherence efforts. However, the importance of Nurses being aware of the reality of an

individual's adherence efforts should be acknowledged. It is possible that when a patient experiences a health deterioration, a HCP who is not informed about the patient's adherence efforts would prescribe additional treatments to improve the patient's disease progression, which of course would not be successful if the patient is already struggling with their adherence efforts.

In addition to adherence, Nurses also discussed their knowledge regarding risky behaviours, highlighting their awareness that these behaviours are prevalent within the CF population, describing such behaviours as a growing concern. However, despite many Nurses recognising this issue, not all CF units fully address the issue of risky behaviours. Michelle, explained that Nurses require more education to be able to provide such awareness.

*[Michelle, 4 years, Paediatric Nurse]: "I want to be a bit mo:ore knowledgeable # because [...] it will affect them so:o much (.) if we don't get to the bottom of it"

While it is well acknowledged that some HCPs know less about illegal substances than their patients do, it should be expected that when HCPs know a patient engages in risky behaviours, awareness is provided, nonetheless Jayne explains that this is not always the case.

*[Jayne, 11 months, Adult Nurse]: "We do:o # have a fe:ew pa:atients (.) who we kno:ow # dabble (.) in a few things (.) they shouldn't # but there's no:othing # we don't give a:any information # we don't have (.) e:er:r # leaflets here (.) from an infectious control point of view # we don't keep a sta:and or anything"

This demonstrates the need to implement standardised interventions within the CF population to address the issue of risky behaviours, both on a reactive and proactive basis. Nurses did demonstrate the need for interventions after witnessing the detrimental, and on occasions, fatal nature of risky behaviours within CF patients. Dawn explained that risky behaviour engagement is a new thing that CF Nurses are witnessing, and therefore they have only recently realised the need for such interventions, both to raise their awareness, and patients' awareness regarding the adverse health effects of risky behaviours specifically within CF.

*[Dawn, 20 years, Adult and Paediatric Nurse]: "There was a death (.) in adults # in CF services (.) from a young man (.) who:o ## extre:eme risk ta:aking behaviour # he died # not as a result of his Cystic Fibrosis # but of the substance he took [...] that

ha:ad an impact on a:all of us # to think that wa:as (.) ha:appening # and if it is:s happening # ho:ow can we identify it"

It is acknowledged that Nurses already do an incredibly complex and difficult job within CF, therefore adding preventative education to Nurses current role presents an additional task for Nurses. Many Nurses were able to offer their insight into potential predictors of risky behaviour engagement within the CF population. Nurses were aware of the pressures on young people to behave like their peers, and how this might result in engaging in risky behaviours.

*[Michelle, 4 years, Paediatric Nurse]: "They think wh:hy (.) why not (.) when everyone else is [engaging in risky behaviours] [...] if they're hanging around with that sa:ame group that do:oes (.) you don't want to feel different (.) when you probably (.) already do:o feel different"

In addition to identity, Nurses also identified the issue of stress, believing that CF imposes more stress upon individual's lives, and therefore alongside family, employment, study issues, patients may be motivated to initiate in such behaviours in order to alleviate their stress. Some Nurses did discuss the importance of providing awareness to CF patients regarding the adverse health effects of risky behaviours, with Dawn identifying that this would allow patients to make a more informed choice about their engagement.

*[Dawn, 20 years, Adult and Paediatric Nurse]: "I do:o think it's impo:ortant [to raise awareness on risky behaviours] [...] I do:o feel it is:s a valu:ue to do it ## but you know [laughs] what they do with the informa:ation is up to them # as long as I'm confident that I've gave them the best informa:ation that I ca:an"

Nurses did acknowledge that awareness they provide a patient with will not necessarily prevent their engagement with a risky behaviour, with Dawn explaining that HCPs cannot take responsibility for patients' actions outside of their care. However, Dawn believed it was important that HCPs provide patients with all the awareness they can do regarding the adverse health effects of risky behaviours, allowing patients to make a more informed choice as to whether or not they want to engage in such behaviours in light of the consequences. Some Nurses gave examples where they had provided awareness, but patients appeared to retaliate against such advice and engage in normalised risky behaviours, which on occasions had health implications. Nurses were often aware as to why patients retaliated against their advice, with Kirstie identifying young adults inability to consider long-term consequences.

*[Kirstie, 22 years, Paediatric Nurse]: "Sometimes understanding the effects on your liver (.) on your medication is difficult (.) difficult to get their heads round [...] what's happening in ten years time (.) doesn't seem to ## hit them"

While many Nurses identified the need for interventions to be integrated into CF care to address the issue of risky behaviours, they highlighted that a barrier to such intervention is the fact that risky behaviours are a changing environment. Alice acknowledged that smoking is becoming less prevalent within the general population, and other behaviours (such as drug use and the use of e-cigarettes) are gaining popularity. Nurses were therefore highlighting how they require education on what behaviours their patients may be exposed to, and how they may impact their CF, in order for Nurses to be able to educate patients.

*[Alice, 21 years, Adult Nurse]: "One of the Respiratory Consultants was commenting on the fact (.) that you know # in another (.) sixty years (.) they won't have anything to do # because (.) the amount of cigarette smoking is dropping [...] I think teenagers now are more likely to take a pill (.) than to smoke [...] we have to now change our mindset # about what that [risky behaviours] means to CF"

While many Nurses identified that risky behaviours are a concern within the CF population, some Nurses explained how difficult it is to imagine their patients engaging in such behaviours.

*[Michelle, 4 years, Paediatric Nurse]: "I guess you can't even imagine that they're going to think about it [risky behaviours] [...] I don't think it's very common [...] they're all (.) so aware of how much it can (.) impact upon your breathing (.) and shortness of breath # and that's (.) >scary and horrible and frightening<"

This did result in some Nurses, such as Jayne, not perceiving there to be a need for interventions to be implemented to address the issue of risky behaviours within the CF population.

*[Jayne, 11 months, Adult Nurse]: "A lot of them # do:on't really do (.) all the bad things [...] there's not really room for us to then introduce more ways to keep them on the right track (.) because a lot of them are already on it"

Whilst Nurses indicated that risky behaviours are not as prevalent within the CF population as they are within the general population, this research does demonstrate that risky behaviours are still a major concern for those who do engage in such behaviours, and therefore interventions do need to be implemented to reduce the occurrence of such behaviours, with this intervention firstly needing to involve staff training.

*[Michelle, 4 years, Paediatric Nurse]: "Support fo:or us [...] what to look out fo:or # and ho:ow to address it [...] there is so:o much that ca:an happen # probably ha:alf of it we're unawa:are of (.) what ki:inds of risky behaviours they could enga:age in # I wouldn't even have a clu:ue about [laughs]"

Overall, this theme highlights the need to raise Nurses' awareness regarding what risky behaviours are prevalent within the general population, as well as to increase their awareness as to what impact such behaviours can have upon CF. In addition, this theme highlights the need for interventions to be implemented within CF care to provide awareness to patients on a proactive and reactive basis.

Effective health promotion advice: What works?

This final theme provides insight into what interventions Nurses believe need to be implemented to encourage health promoting behaviours, and reduce the occurrence of risky behaviours within the CF population. All three phases of data collection suggest a role for the avoidance of one's CF in engaging in risky behaviours, and non-adherence. Therefore a potential avenue CF care could focus on is to encourage acceptance regarding CF, whilst instilling a sense of hope and optimism within patients. This is currently not addressed within all CF units, with Dawn explaining that they do not have an active process within their centre to address CF's true nature, including its fatal nature.

*[Dawn, 20 years, Adult and Paediatric Nurse]: "We don't have a a:active process (.) to sit young people do:own and sa:ay (.) >do you realise you've got a life limiting disea:ase< [...] we wouldn't # avo:oid it (.) if pa:atients (.) so:ort of # a:asked us about it # but it isn't something we make a po:oint out of discussing with them"

It does have to be considered whether it is a Nurses role to advise patients regarding CF's fatal nature, especially if parents do not want these discussions to be had with their children. Nurses did discuss how they often go to great lengths to provide a positive outlook for patients, with Kirstie explaining how at her CF unit they provide patients with photographs of adult CF patients enjoying an active life. Therefore, the process of accepting one's CF is complex, and it is recognised that acceptance is not always in a patient's best interests, with acceptance regarding CF's fatal nature potentially having negative implications upon an individual's psychological wellbeing. Nonetheless, with HCPs not providing awareness to patients regarding the true nature of their CF, it is possible that patients do not have this knowledge, potentially fostering a sense of denial within patients, which as recognised can result in non-adherence, and the engagement in normalised risky behaviours. Consequently through informing patients about CF's true nature, it would highlight to patients the

importance of adherence and the avoidance of risky behaviours to prolong their good lung function; however it is essential that such awareness is provided whilst instilling a sense of hope and optimism within patients. It is possible that this awareness could focus upon the practicalities of life with CF, highlighting what an individual can and cannot (or should not) do with their CF in order to protect their health.

Nurses also acknowledged the need for interventions to specifically encourage adherence. As outlined previously, interventions targeting adherence are now changing, with room for technology, such as Skype Triages. In addition, some Nurses, such as Kirstie, identified a potential role for mentoring to encourage adherence, in order to take the emphasis off Nurses providing an intervention due to the lack of time HCPs have to spend with each individual patient.

*[Kirstie, 22 years, Paediatric Nurse]: "We could do a lot mo:ore [to encourage adherence] # if we had ti:ime fo:or # for individual patients a bit mo:ore [...] mento:or # somebody who ca:an help them on a da:ay to da:ay basis [...] you need to pick out tho:ose individua:als (.) where they ne:eed that bit of mentorship # be able to wo:ork with them a bit mo:ore in-depth"

Mentoring would involve CF patients communicating with one another via technology to encourage positive health behaviours, with this having the potential to reduce isolation amongst patients, allowing patients to ask questions which they may not be comfortable asking HCPs.

In addition to adherence, Nurses identified the need for interventions on risky behaviours to be implemented within CF care. Nurses explain that it is only recently that interventions have started to be implemented to address risky behaviours, with not all units currently addressing such issue. Consequently, Nurses acknowledge that they are missing patients who are engaging in such behaviours, and therefore such patients are not receiving the awareness required to encourage cessation. It was explained by Michelle that some CF units rely on patients instigating a conversation regarding risky behaviours, or disclosing engagement before awareness is provided, indicating that many interventions used at present are reactive.

*[Michelle, 4 years, Paediatric Nurse]: "With transition that [risky behaviours] becomes one of the:e areas we discuss (.) but # e:erm:m # no:ormally it's them a:asking us (.) you know # o:or we hear they've been out dri:inking (.) so we have that conversa:ation"

This outlines a gap for proactive interventions, to provide awareness before initiation, engagement or experimentation has occurred. Proactive interventions do currently exist, with one intervention being identified within both the transition evaluation, and by Nurses within this phase of data collection. The intervention identified was the “ready, steady go” questionnaires (University Hospital Southampton, 2014) which are administered three times prior to transition, and contain two questions relating to risky behaviours, to identify whether or not individuals understand the risks associated with such behaviours. Within this phase of data collection Kirstie and Dawn, who are both from different CF units, reported using this intervention, believing it allows them to have a platform to instigate such discussions with patients.

*[Kirstie, 22 years, Paediatric Nurse]: "We use it [ready, steady, go] as a forum to discussing the issues:s (.) which is brilliant (.) cause actua:ally having something (.) piece of paper in front of you:u # you don't have to have that embarrassing (.) eye balling conversa:ation [laughs] # which young people ha:ate [...] it's a standa:ard thing # so you know what to discuss [...] we <go through # sexual hea:alth> # >recreational drugs< # smo:oking"

The ready, steady, go intervention is not without its flaws, with Kirstie and Dawn both fearing that this intervention could become a “tick box exercise”, believing that some Nurses do not have the "conversation" regarding the adverse health effects of risky behaviours with their patients. Furthermore, the ready, steady, go paperwork has an accompanying set of paperwork to be used at the adult unit after transition (hello paperwork), however Kirstie indicated that the adult unit at her hospital have not taken this intervention on board.

Kirstie and Dawn also discussed the verbal information they provide their patients with, as well as using the ready, steady, go intervention, in an attempt to prevent initiation of risky behaviours, therefore being proactive.

*[Dawn, 20 years, Adult and Paediatric Nurse]: "When they get to thirte:een (.) pa:art of that consulta:ation [annual review] (.) will inclu:ude # not a va:ast amount (.) but we will refer to >drugs and alcohol< (.) and the wa:ay tho:ose # can affect (.) Cystic Fibrosis"

It is positive to see that some CF units do approach the issue of risky behaviours on a proactive basis with all patients regardless of their personal condition, providing patients with the opportunity to make a more informed choice about their engagement in such behaviours in light of the consequences. However, Nurses did highlight that verbal information is associated with limitations, with information not being standardised and being dependent

upon the HCP who provides the information, and the clinic environment. HCPs have less time to spend with individual patients during busy clinics, therefore it may be considered less important to discuss risky behaviours with patients who HCPs believe are not engaging in such behaviours. Consequently, Nurses recognised the need to accompany verbal information with written information. Kirstie and Dawn, who did use the ready, steady, go intervention, explained how beneficial it would be to have resources to support the verbal discussions, whether that is on paper or via technology.

There was evidence within two different CF units of patients being provided with supplementary written information on risky behaviours. Dawn explained how when she discusses fertility and safe sex with adolescent CF patients, she also uses written and visual information (in the form of a fact sheet) to aid patients understanding, with patients being able to take this information home. The use of written information to accompany verbal information ensures standardisation, with all patients receiving and having access to the same information. In addition to the use of a fact sheet, Alice explained how patients have access to leaflets which they can pick up within their clinic rooms regarding risky behaviours. Alice also explained how her CF unit uses newsletters again to raise awareness of specific risky behaviours, especially if HCPs suspect a number of patients are engaging in that behaviour.

*[Alice, 21 years, Adult Nurse]: "If a patient hadn't disclosed their engagement # but you (.) hi:ighly suspected they were experimenting (.) or engaging in such behaviours we put it in the newsletter # as things come up (.) we tend to say (.) right # this ma:ay become an issue across the board [...] sometimes we just try to get patients to talk about what they did and why it was a bad idea"

In addition to the written information that all patients have access to, Alice explained that there is a conversation with patients regarding these behaviours as well, to try and increase their awareness, in an attempt to prevent initiation. Alice explained how these discussions are often on a reactive basis, in response to HCPs suspicions that those patients are contemplating engagement, or have experimented with that behaviour.

Many Nurses did identify the need to use technology to provide this written information, as it was well recognised that adolescents and young adults commonly communicate online and through various mobile apps, therefore many Nurses stressed the importance of fostering such communication style in order to reach their patients.

*[Alice, 21 years, Adult Nurse]: "Online is so ke:ey # every teenage I meet is su:urgically attached to their phone # it's such an ea:asy way to # provide information

(.) cause that's what they want to look at # they don't want to be talked at # they want to find this information # so whether you could put it on things like Facebook # Twitter # CF apps [...] I think the only way you're going to grab their attention is in the media form they're used to"

The use of social media was identified as a potential avenue to explore, with this being a familiar platform for patients to communicate over. Many individuals with chronic illnesses do seek advice through communicating with individuals with the same condition as them via social media. The use of social media therefore could be applied to addressing the issue of risky behaviours, as well as adherence within the CF population. However, social media does have barriers, such as safeguarding issues, and whether online patient communication will encourage face-to-face communication. Online communication would need to be closely monitored by HCPs. In addition to the use of social media, other Nurses expressed a need to improve their websites, to again provide a platform to raise CF patients' awareness regarding risky behaviours. This again would fit in with adolescents and young adults' communication style, and would eliminate some safeguarding issues associated with the use of social media. Not only would the use of technology potentially be favoured by patients, it would also be less time demanding for HCPs, with many Nurses explaining that they do not have time for in-depth conversations regarding risky behaviours with "non-risky" patients, due to how busy the clinic environment is.

Nonetheless, despite there being a need for technology based interventions, the data indicated that this should not replace the verbal discussions that HCPs have with patients, particularly those who they suspect are engaging in such behaviours, or those who have disclosed such engagement. This suggests that technology could be used on a proactive basis, whereas predominantly verbal discussions could be used on a reactive basis. Nurses explained that when they suspect a patient is experimenting in risky behaviours, the verbal discussions need to be individualised, with Nurses needing to demonstrate a non-judgemental approach. Besides providing an individualised approach, Nurses also stressed the importance of revisiting information on risky behaviours to ensure patients have not forgotten the information. Nurses believe revisiting information should be a combination of verbal and written information, even though in reality Dawn explains that within her CF unit this information is only revisited on a verbal basis.

*[Dawn, 20 years, Adult and Paediatric Nurse]: "It's not just a one off at thirteen (.) because (.) you know (.) two years down the line (.) you ask them # ↑>can you remember that conversation we had about such and such< # ↓ they will invariably say no:o"

Furthermore, Nurses also emphasised the need to integrate psychology within such interventions, due to them acknowledging the connection between a patient's psychology and their behaviours, with Nurses explaining that any psychological issues firstly need to be addressed in order to encourage cessation. Dawn acknowledges that CF Specialist Nurses are not competent in helping patients deal with their psychological issues, and therefore acknowledges the need for Psychologists to be integrated into the CF MDT.

*[Dawn, 20 years, Adult and Paediatric Nurse]: "I'm not always good at the psycho-social stuff # but when we have the people [Psychologist and Social Worker] in place (.) I think (.) that re:really helps # we can start to deal with the psyche:e"

Nurses emphasised the need for psychological interventions to be employed on a reactive and proactive basis, potentially by using screening. Due to Nurses being aware of possible predictors of non-adherence and risky behaviours, they recognised the role of a psycho-social team screening patients for such "predictors", and providing "at risk" patients with awareness on a proactive basis. However, Dawn explained how not all CF units have a Psychologist at present.

*[Dawn, 20 years, Adult and Paediatric Nurse]: "We've not got a Psychologist # we've not had one for an awful long time # and I think (.) if we had a Psychologist # within our service # who was (.) screening patients and picking things up # I think ## it would be much better [...] we should be looking for that [mental health issues] on an annual basis # and we should be screening that out [...] we're doing absolutely no:othing"

When discussing Nurses' ideas surrounding future interventions they emphasised the need to target these interventions at the right population, with emphasis firstly needing to be placed on "the right age group". The data coincided with the previous phases of data collection, in indicating that discussions, and awareness regarding risky behaviours need to be provided to patients from a younger age than present practice. However, while Nurses acknowledged the lowering age of initiation, they commonly suggested that awareness should be provided from age fourteen years and above, whereas the results from phase one data collection suggest that experimentation, or at least contemplation starts in some individuals from the age of twelve years; therefore for some individuals fourteen may be "too late" to provide a proactive intervention. In addition, Nurses explained that more effort needs to be placed on providing interventions to the "hard to reach patient group", who HCPs know are engaging in such behaviours and not adhering to their medical regimens, however they rarely attend clinic appointments.

*[Jayne, 11 months, Adult Nurse]: "We don't re:really have patients who would come every six we:eks (.) who we know have a drug problem (.) o:or a drink problem (.) o:or smo:oke"

Potentially interventions delivered using technology could be a way of providing such awareness to this "hard to reach group", without them physically being present within the hospital setting; it would then be up to the individual as to whether they engaged with such resources. In addition, Nurses also believed that future interventions need to be developed through patient input, with many Nurses identifying a role for the results of the previous two phases of data collection to shape such interventions.

*[Dawn, 20 years, Adult and Paediatric Nurse]: "It'd be re:really interesting to hear (.) what the young people a:are saying [about risky behaviours] (.) beca:ause I think # that would then # info:orm # ho:ow you (.) tr:ry (.) to identify it (.) I suppo:ose"

In terms of ideas for future interventions, Nurses identified two possible interventions. Firstly, as with adherence, some Nurses believed mentorship could be used to address the issue of risky behaviours, with Kirstie explaining how it would provide young CF patients with a platform to discuss issues with individuals who are away from their family and HCPs.

*[Kirstie, 22 years, Paediatric Nurse]: "Something like the mento:oring (.) would be the best approach # I think [...] so you've got somebody (.) e:erm:m (.) that you can tu:urn to (.) to ask sort of (.) life questions:s to"

In addition, four Nurses emphasised the need to have some form of staff training to raise HCPs awareness as to what risky behaviours are "current" within the general population, how they could identify those within their patients, and what impact such substances have upon CF.

*[Alice, 21 years, Adult Nurse]: "I think # it would be useful # for people # mo:ore knowledgeable than me (.) about what the current tre:endy things a:are # it's tough enough to keep up to date on a:all the things that are changing # without having to read up on # the latest ecstasy # designer drug is [laughs]"

By providing such awareness it would allow HCPs to share that awareness with patients through whatever platform the CF unit desired, both on a proactive and reactive basis. Lee also acknowledged that staff training would increase HCP's confidence in raising the topic of risky behaviours with patients, believing that currently not all HCPs are comfortable with confronting the issue due to their limited knowledge regarding the adverse health effects of risky behaviours.

*[Lee, 14 years, Adult Nurse]: "I'm not sure if a:all team members are confide:ent (.) when assessing patients # risky behaviour # to dea:aling with any issues that ma:ay come up [...] I think it'd be:e (.) useful # for there to be mo:ore (.) tra:aining (.) more educa:ation for the staff # more CF team members should be comforta:able (.) a:asking the questions:s # identify:ying the issues (.) and dea:aling with them as well"

However, whilst these Nurses stressed the need for such education, they did identify some barriers, such as the limited amount of time HCPs have to attend staff training. Therefore Lee explained how such training could potentially be integrated into regional meetings etc, instead of making a separate occasion for HCPs to attend.

*[Lee, 14 years, Adult Nurse]: "To identify:y risky beha:aviours (.) and to talk to patients about that ## they're soft ski:ills (.) but they can take ti:ime (.) for (.) professionals to beco:ome proficient to tho:ose ski:ills # so I think those would be the ba:arriers re:eally"

Overall, this theme identifies that many Nurses do acknowledge the need for new interventions to be implemented into CF care regarding risky behaviours, with it appearing necessary to provide awareness to all patients on a proactive basis, through both verbal information and supplementary written information. Nurses believe that technology based interventions would be most successful for patients, due to it fostering the communication style of adolescents and young adults. In addition, Nurses also expressed a need for staff training, due to them having gaps within their knowledge regarding risky behaviours, in terms of which behaviours are current within the general population, and what impact such behaviours could have upon CF patients.

Discussion

The data provides an exploration into how CF Specialist Nurses perceive the issue of risky behaviours within the CF population, providing insight into what interventions they believe would work. Nurses had a range of different experiences with risky behaviours within their patient group, influencing their attitudes and beliefs regarding the need for an intervention. The data was produced using telephone interviews, with the asynchronous communication of place encouraging Nurses to discuss sensitive issues, which they may have been reluctant to discuss face-to-face (Mann & Stewart, 2000). Nurses were positive about their role, enjoying their job and their high patient contact. Adult and paediatric participants within the previous phases of data collection highlighted the strong relationships they have with their Nurses, viewing Nurses to be the most approachable member of the MDT; this is in line with previous literature within the general population (Collins, 2015; Read

& Mayberry, 2000; Van den Heever et al., 2015). These close patient-Nurse relationships mean that many Nurses have a good insight into what an individual's life is like with CF, being able to detect anxiety within patients, and predict how different patients will cope with different aspects of their disease.

Working within the CF population is challenging when faced with CF's fatal nature, with many Nurses explaining how dealing with death is the most challenging part of their role, especially when Nurses were of a similar age to patients. This is in line with previous literature where CF Specialist Nurses discuss the challenge of dealing with death, with many Nurses stating that the only way they can deal with this continuous loss is the acceptance that they did their best for each patient who passes away (Rhys, 2011). CF's fatal nature is an emotional burden for patients, therefore Nurses explained that in order to help patients cope with their CF they encourage patients to be optimistic towards their life and future. Optimism can increase a patient's quality of life (Abbott et al., 2008), with optimism being evident within both the first and second phase of data collection, with participants who did demonstrate optimism towards their life and future often leading a "normal" and enjoyable life despite their CF, and the challenges that imposes upon their life (Abbott et al., 2008; Götz & Götz, 2000). In order for patients to be optimistic, Nurses explained how they also needed to be optimistic towards the future of CF care. Nurses optimism can help encourage positive changes in a patients attitude and beliefs towards their condition (Goodwin, Curry, Naylor, Ross & Duldig, 2010), however remaining positive can be difficult for Nurses, and can be an additional pressure of their job, especially when faced with upsetting and distressing events, but having to remain positive for other patients.

Not surprisingly a major focus of CF care is adherence, with many Nurses explaining how the use of individualised care helps to promote an individual's adherence efforts. The use of individualised care was favoured by adult participants within phase one data collection, with participants explaining how HCPs meet patients "half way" with their adherence, recognising that it is patients who have to administer the medication themselves. Adult participants explained how HCPs allow patients to shape their treatment plan to a certain extent, sympathising with occasional non-adherence, highlighting the importance of shaping treatment plans according to an individual's lifestyle, placing emphasis on psychological as well as pharmacological factors (Horne, 2000). In order to encourage patients to be open about their adherence efforts, Nurses explained how they need to talk to patients on a human-to-human basis, developing rapport with patients. Nurses believe that a strong patient-clinician relationship is associated with positive health outcomes, in terms of encouraging patients to be open regarding their adherence efforts, enabling HCPs to structure the patient's treatment plan around their lifestyle. This is in line with previous

literature which demonstrates the positive impact the patient-clinician relationship has upon health outcomes within the general population (Kelley, Kraft-Todd, Schapira, Kossowsky & Riess, 2014).

Nurses demonstrated their clear understanding on the barriers patients face towards their adherence, in particular acknowledging the difficulties individuals with CF face during their transition to adult care. Previous literature (Barker et al., 2012; Bregnballe et al., 2011), along with the previous two phases of data collection, highlight how difficult independence with self-management is, with this having the potential to result in poor adherence. When discussing what reduces an individual's adherence efforts, many Nurses identified how individuals with CF desire a sense of normalcy, with this being in line with the previous phases of data collection, in highlighting how a life-orientated illness perspective can result in poor adherence (Audluy et al., 2010). In addition to identity, Nurses also explained how an individual's poor adherence can be due to denial either regarding their CF, or regarding treatments' necessity, with this being highlighted by adult participants within phase one data collection, and being in line with previous research (Laws et al., 2012). Nurses also explained that an individual's poor adherence can be due to a lack of time, which Bregnballe et al (2011) and a number of adult and paediatric participants highlighted to be a major barrier to adherence. Therefore Nurses suspect that individuals focus upon the short-term consequences of treatment as suggested by previous literature (Abbott et al., 1994; Keyte et al., 2017b, 2017c), with adult participants within this research explaining how they are more likely to adhere to a treatment if they experience an immediate benefit. In order to encourage an individual's adherence efforts, Nurses explained how they provide awareness to patients regarding treatments' necessity, with the previous phases of data collection suggesting that awareness and acceptance towards CF and treatments' necessity is influential within adherence efforts.

CF care is a changing environment, with many Nurses explaining how their CF units are exploring how they could use technology (e.g. Skype Triage) to reduce the number of hospital visits patients have. This would not just save time for HCPs, it would also be advantageous for patients to not keep having reminders of their CF, and how their health may deteriorate. Adult participants within phase one data collection explained how emotionally difficult it is to see others with CF who have deteriorated more than themselves, as it serves as a reminder of what their future may entail. Individuals with CF have reported health benefits following the use of technology to monitor their health, due to them being able to actively view changes in their e.g. weight, and act accordingly (The UK CF Conference, 2016). CF care is also changing in terms of what needs to be addressed with patients, with Nurses identifying how risky behaviours are a growing concern within the CF

population. While previous research indicates that risky behaviours are not as prevalent within the CF population as they are within the general population (McEwan et al., 2012; Verma et al., 2001), this research signals that risky behaviours are a major concern for those who do engage in such behaviours, highlighting the need for more effective health promotion measures to reduce the occurrence of such behaviours. Nurses did indicate that they do lack awareness regarding risky behaviours, in terms of what behaviours are prevalent within the general population and what impact they could have upon CF patients, with this being suspected by adult participants within phase one data collection. It is well acknowledged that some HCPs know less about illegal substances, than their patients do (Viner & Macfarlane, 2005), with Nurses identifying the need to have some form of staff training to raise their awareness regarding risky behaviours, allowing them to then pass on this knowledge to their patients.

Nurses did have good awareness regarding what influences the engagement in risky behaviours within the CF population, highlighting how a desire for normalcy could lead to the engagement in risky behaviours, in order to adopt the same identity as one's peers, with this being identified within previous literature (Bryon, 2015; Duff & Latchford, 2010; Withers, 2012), and within the previous phases of data collection. Nurses also identified the issue of stress, believing that the stress of living with a chronic condition, coupled with the stress an individual experiences within their private life could motivate an individual to engage in risky behaviours, with previous literature (Boden & Fergusson, 2011; Kassel et al., 2003; Kavanagh et al., 2011) and adult participants explaining how risky behaviour engagement can alleviate feelings of stress and anxiety.

With risky behaviours not being as prevalent within the CF population as the general population, some Nurses did not perceive there to be a need for interventions to be implemented, explaining how most patients are already "on the right path" and are not engaging in risky behaviours, as found within the paediatric population. However, the adult population clearly explained the need for awareness, stating that this could have prevented their initiation with risky behaviours. Many Nurses did recognise the need for awareness due to the severe adverse health effects risky behaviours can have upon an individual with CF, however they correctly identified that awareness does not always prevent initiation, as demonstrated within the previous phases of data collection. Nurses believed that adolescent patients sometimes engage in risky behaviours despite health advice from HCPs, due to their inability to consider long term consequences (Bryon, 2015), with such Nurses demonstrating the need to progress current interventions.

Within this research some Nurses highlighted how they do not make patients aware of the true nature of their CF. The process of accepting one's CF is complex, and it is recognised that it is not always in a patient's best interests. Nonetheless, with HCPs not providing this awareness to patients regarding the true nature of their CF, it is possible that patients do not have this knowledge, potentially fostering a sense of denial within patients, which is recognised by Laws et al (2012) can result in non-adherence and risky behaviour engagement (Withers, 2012). Whilst phase one data collection identified that for some patients it is advantageous for them to not possess an illness identity, Goodwin et al (2012) highlights the importance of patients being informed about the true nature of their chronic condition, in order to be empowered to carry out self-management of their condition. Goodwin et al (2012) explains the importance of providing information that gives a realistic, but positive outlook on an individual's condition, explaining what their condition is, what might happen in their future, and who they can contact for help and support. The importance of raising one's awareness regarding CF was identified by Toth (2016), who explained how in the USA some CF units have an additional annual assessment to help young adults take ownership of their CF, and understand CF's true nature. It is believed that such intervention would be most successful if it focused upon the practicalities of CF, explaining what CF is, and what it means for an individual's life. This could focus upon what behaviours that individual can or cannot engage in, with emphasis being placed on the importance of adherence and the avoidance of risky behaviours. Such acceptance could focus on the challenges that adolescents with CF face in terms of lifestyle choices, helping them decide what choices are adaptive for their health, rather than focusing upon CF's fatal and deteriorating nature, which as highlighted can be associated with psychological implications.

A further suggestion regarding a new intervention was the use of mentoring to promote adherence, and reduce the occurrence of risky behaviours. Online Patient Advisory Groups and adult mentoring have been successfully set up within the USA, to allow CF patients to communicate and encourage positive health behaviours amongst one another. Moog (2016) highlights how these groups reduce isolation amongst patients, and allow patients to ask each other questions which they would not ask HCPs. In order for all CF patients within the unit to benefit from the discussions the Patient Advisory Group has, Moog (2016) explains how a newsletter is distributed to all patients based on these discussions. In considering the transcripts from the previous two phases of data collection, it is believed that this suggestion would be welcomed by patients, due to them often desiring to communicate with other CF patients, and feeling isolated due to patient segregation (Lamas, 2013).

Within all phases of data collection the need for proactive interventions to address the issue of risky behaviours was recognised. Some Nurses did explain that their units do

currently use proactive interventions; two Nurses referred to the use of the ready, steady, go questionnaires (University Hospital Southampton, 2014). While it is positive that these units are addressing the issue of risky behaviours, Nurses acknowledged that this intervention is not without its flaws. As highlighted within the transition evaluation, just because a patient has indicated they understand the risks of a behaviour does not mean they do not engage, or do not desire to engage in that behaviour. It also has to be questioned whether patients disclose their true attitudes and beliefs towards such behaviours, with it being plausible that patients respond in a positive way to be viewed favourably by their clinicians' due to social desirability bias (Krumpal, 2013; Lippitt et al., 2014; Sanzone et al., 2013). Some Nurses also discussed the use of verbal information to provide proactive awareness regarding risky behaviours. However, again while this is positive, the use of verbal information alone can be criticised. Literature indicates that patients within the general population forget up to half of the verbal information/advice that has been given within five minutes, and recall only 20% of the information (Entwistle & Watt, 1998; Little et al., 1998). Nurses also acknowledge the limitations of these proactive interventions, and therefore identify the need to accompany verbal information with written information, with literature illustrating that patient retention of information can be improved with supplemental written information (MacFarlane et al., 2002).

Many Nurses did identify the need to use technology to provide this written information, as it was well recognised that adolescents and young adults commonly communicate online and through various mobile apps (Peacock & Sanghani, 2014). The use of social media has started to be explored within CF care, for instance Smith and Gouick (2015) used a closed Facebook group to encourage CF patients to exercise and support one another, with half the participants reporting that the use of social media maintained their motivation to exercise. The use of social media therefore could be applied to addressing the issue of risky behaviours, as well as adherence within the CF population. Many Nurses identified that the awareness provided to patients regarding risky behaviours needs to be revisited on several occasions, with the need for this being emphasised by paediatric participants within the second phase of data collection. Paediatric participants often discussed that HCPs have provided awareness regarding risky behaviours, however participants could not describe what the adverse health effects of risky behaviours are. Best practice does need to be employed when revisiting such information, as some adult participants within phase one data collection explained that they were frequently asked about their awareness on e.g. smoking, however information was not disclosed to raise their awareness.

Conclusions

Overall this phase of data collection points out that whilst the majority of CF Specialist Nurses acknowledge that risky behaviours are becoming a major concern within the CF population, the way CF units address the issue of risky behaviours varies greatly. Some Nurses explained that it is only recently that their unit has started to address this issue, however Nurses often identified flaws within their unit's interventions. For instance, it appeared that some units rely upon patients disclosing their engagement with risky behaviours, or instigating a conversation before any awareness is provided. In addition, the majority of CF units who do provide awareness only provide verbal information, with many Nurses stating that this now needs to be progressed to provide patients with accompanying written information, whether that is on paper or via technology.

This phase of data collection does coincide with the findings from the transition evaluation and the previous phases of data collection, in indicating that risky behaviours within the CF population are predominantly approached on an individualised basis. Consequently, within all phases of data collection the need for new interventions is demonstrated, in order to reduce the occurrence of risky behaviours within the CF population. This research therefore provides an opportunity for the implementation of research informed practice within the CF population, in terms of addressing the issue of risky behaviours in a standardised way through listening to patients' and Nurses' beliefs regarding current practice, and how they believe such practice should be progressed.

However, this third phase of data collection only investigated how Nurses perceive the issue of risky behaviours within the CF population, and what interventions they would like implemented. The researcher therefore identified the importance of speaking to, and collaborating with other HCPs, in order for this research to have a "real world" impact in the practice of health care (Henriksen et al., 2005). This final phase of data collection allowed the researcher to disseminate the research findings, allowing HCPs to critique the findings and offer suggestions regarding what interventions would work.

CHAPTER ELEVEN: METHODOLOGY - DISSEMINATION MEETINGS

Participants

HCPs who work within the CF MDTs (adult and paediatric teams) at Birmingham Heartlands Hospital and the Royal Stoke University Hospital were recruited. Both hospitals were research sites for the first two phases of data collection, illustrating their invested interest within this research. Three dissemination meetings were conducted:

- 07/11/2016 - Birmingham Heartlands Hospital adult CF team
- 09/11/2016 - Royal Stoke University Hospital adult and paediatric CF teams
- 06/12/2016 - Birmingham Heartlands Hospital paediatric CF team

Measures

Dissemination Meeting. The researcher followed the guidelines outlined by Henriksen et al (2005) and Lakhanpaul et al (2014) in order to create a dissemination plan. The researcher disseminated the overall research findings from the previous three phases of data collection, believing that these findings would be of interest to CF HCPs as they were outlining an issue related to safety in patient care.

The researcher delivered the dissemination meetings to various MDT members at each research site, as the researcher believed that different MDT members would have different ideas for future interventions, and bring different sources of knowledge to the meetings. For instance, phase one data collection suggested that patients disclose different information to Nurses than they do to Doctors, which could therefore influence Nurses and Doctors views towards suitable interventions. In addition, when designing each phase of data collection the researcher had discussed ideas with all members of the MDT at each research site, therefore it made sense to disseminate findings to all MDT members.

The researcher disseminated these findings face-to-face with HCPs by asking for time during MDT meetings at the CF units. The researcher disseminated the findings through utilising a PowerPoint presentation, thoroughly explaining each finding to HCPs. Once the researcher had presented the findings, the researcher encouraged HCPs to discuss the research using a plan (Appendix CC) in line with Henriksen et al's (2005) guidelines. It was hoped this plan would encourage HCPs to critique the findings and offer their suggestions for interventions that could work.

Although the findings from this doctoral research remained static, the way in which these findings will be presented for publication have been influenced by the outcome of the dissemination meetings. These meetings have illustrated what findings are relevant to CF HCPs, allowing the researcher to present the findings for publication which meet the needs of these professionals, supporting the application of findings in practice (Bradley et al., 2010).

Carrying out the Study

The researcher contacted the lead Consultant from each CF unit (Birmingham Heartlands Hospital adult and paediatric units; The Royal Stoke University Hospital adult and paediatric units) who had been liaising with the researcher during the first two phases of data collection via email or telephone, informing them about this phase of data collection. The researcher forwarded the CF units an information sheet (Appendix DD), and if the unit required further information the researcher was available to discuss the research further either via telephone, email or in person. If verbal consent was provided by the CF unit, the researcher then proceeded to arrange a suitable date / time for the dissemination meeting (this was often during MDT meetings).

HCPs then attended the dissemination meeting, where they were informed of the overall findings from the doctoral research utilising a PowerPoint presentation (Appendix EE). The researcher invited HCPs to critique the findings and offer their views on which findings were of interest to them. The researcher asked HCPs to provide their views on whether they believe an intervention is required to reduce the occurrence of risky behaviours within the CF population, and offer suggestions on what interventions they believe would work in practice.

The dissemination meetings were conducted in a private room at the CF units and lasted a maximum of 60 minutes, however they could be stopped earlier if the MDT wished this to be the case; within this research no meetings were stopped early. HCPs did not have to answer any questions they did not wish to. All participation was voluntary, and HCPs could withdraw from the research at any time without being penalised; within this research no HCPs withdrew. Once the dissemination meeting was complete, HCPs again had the opportunity to ask questions.

Ethics Committee

Ethical approval was obtained by the Business, Law and Social Sciences Ethics Committee at Birmingham City University.

Analysis

As described within the initial analysis section within Chapter Four, the dissemination meetings were transcribed utilising the Jefferson transcription coding (Heath & Hindmarsh, 2002), with the data being analysed using thematic analysis following Braun and Clarke's (2006) model. Thematic analysis generated 15 codes. The researcher made inferences about what the codes meant enabling the codes to be combined into two overarching themes that accurately depict the data (Appendix FF). The two themes generated are described in detail within the next chapter, utilising direct quotes and discussion around CF HCPs ideas regarding future interventions to address the issue of risky behaviours.

CHAPTER TWELVE: ANALYSIS - DISSEMINATION MEETINGS

Thematic analysis was applied to the interview transcripts following the Braun and Clark (2006) model, which identified two themes within the data. The first theme, labelled as "Awareness is already provided to adolescent Cystic Fibrosis patients regarding risky health behaviours", demonstrates the awareness CF patients already have access to on risky behaviours, mainly from the NHS and their educational experiences. Theme two, "HCPs ideas regarding future interventions to address the issue of risky health behaviours", points out the practical applications of this research, highlighting what interventions CF HCPs would like to see integrated into CF care. Both themes will be further examined below, by utilising direct quotes and discussion around this topic area.

Overall all HCPs within the dissemination meetings recognised that risky behaviours are becoming a major concern within the CF population, with many HCPs acknowledging that they could do more on the issue of risky behaviours, both in adult and paediatric units, illustrating that the provision of awareness regarding the adverse health effects of risky behaviours is not embedded within their practice. HCPs agreed that best practice regarding risky behaviours does not always happen, explaining that not all patients are being approached regarding this issue.

*[Paediatric Nurse (1)]: "There's a form they put in the notes # that the outpatient staff are meant to ask [includes risky behaviours] # I haven't seen that for a long time

[Paediatric Consultant (1)]: No: it is still around actually"

Even when best practice is employed with written information being provided, HCPs often acknowledged that they are aware that the majority of patients do not read this information.

*[Paediatric Nurse (2)]: "I used to give them booklets ## about # sex and drugs ## but (.) I know they probably wouldn't read it ## we haven't stopped giving them out"

This demonstrates the need to progress current interventions in order to place more emphasis on the issue of risky behaviours, in an attempt to reduce the occurrence of such behaviours within the CF population, with some HCPs identifying that their CF units do not use any interventions to address risky behaviours.

*[Paediatric Nurse (2)]: "I know when I used to do Asthma clinic ## I always used to ask about smoking (.) and I don't do it within CF clinic"

Nonetheless, not all HCPs initially identified the need to have an intervention implemented within CF care, with some HCPs suggesting that patients receive awareness regarding the adverse health effects of risky behaviours from elsewhere, and therefore it is not necessary for HCPs to provide such information. A common belief was that adolescent CF patients receive awareness regarding smoking, excessive alcohol consumption, illicit drug use and risky sexual behaviour from their school.

*[Paediatric Consultant (1)]: "They get educa:ated at scho:ool ## they get quite a lot of information about these things at scho:ool # which # the drug information for instance at scho:ool is mo:ore up to date than what I kno:ow"

While it is often the case that education about risky behaviours is provided within schools, this education is not always successful, with Chowdry, Kelly and Rasul (2013) reporting that there is little consensus between schools regarding which approach is most effective to reduce occurring risky behaviours, and what age group should be targeted, with the current generation of prevention programmes typically using a range of different techniques. It was concluded that when schools just focus upon the consequences of such behaviours the intervention is not successful, with interventions needing to be interactive as opposed to passive in order to have more success (Chowdry et al., 2013). HCPs may have overestimated the quality of the awareness individuals receive from their school, and therefore may not have realised the need to have this awareness implemented into CF care, with some HCPs believing that their role should potentially be to reinforce the message from school, therefore not focusing too much time upon risky behaviours.

*[Paediatric Consultant (1)]: "I'd have thought o:our role was mo:ore to ## briefly reinfo:orce what school is # and also ma:aybe emphasise if there a:are significant increased risks because of the:eir health ## ra:ather than doing a:all of their sex ed"

With HCPs reinforcing the message provided by schools it would reduce the amount of time HCPs need to dedicate to providing awareness on risky behaviours, allowing them to continue with the many other aspects there are to their role. However, if schools cannot provide awareness on risky behaviours effectively, it does have to be questioned how HCPs can be expected to do this as well, alongside all their other pressures. According to Chowdry et al (2013) the information provided by schools, and reinforced by HCPs would need to move away from focusing on just the outcomes of risky behaviours through passive information.

Some HCPs did notice that they should not rely on schools providing awareness, as the awareness a school provides, and the technique used by that school is all dependent upon the school's curriculum and values.

*[Paediatric Consultant (2)]: "If they [the school] don't sign up to # some of those lessons [PSHE] # then # they won't get access to sex education # which other kids may have

[Paediatric Nurse (1)]: It depends if they go to a Catholic school"

In addition, some HCPs acknowledged that regardless of the effectiveness of school-based interventions for the general population, this awareness is not CF-specific, therefore it may not resonate with CF patients as it does not inform them about the health effects they could personally experience. Predominantly it is expected that risky behaviour education in schools will focus upon the elevated risk of cancer associated with such behaviours, with some HCPs pointing out that again this may not resonate with CF patients, due to cancer predominantly occurring in individuals at an age which is above the life expectancy for CF.

*[Dietician]: "At school they're not going to be focused on that [CF risks] are they # they're going to be focusing on the cancer risk [...] there's a difference # CF patients thinking life expectancy wise # cancer risk # it doesn't matter"

In addition to school-based interventions, some HCPs believed that sufficient awareness regarding the adverse health effects of risky behaviours would be provided through the NHS, targeted at adolescents, predominantly provided online.

*[Adult Consultant (1)]: "You would hope so that somewhere ## in the NHS there must be some teeniebob information on (.) sex drugs and rock and roll I would have thought"

Whilst NHS choices (2017) does provide sufficient information online regarding smoking, excessive alcohol consumption, illicit drug use and risky sexual behaviours, as with the education provided through schools, this information is not CF-specific, therefore this information would potentially not resonate with CF patients. In addition, no one provides this information to adolescents with CF, it is up to the individual to search for this information online, with HCPs acknowledging that patients are competent in doing this. Nonetheless, without this information being CF-specific an individual cannot make an informed choice about whether or not they want to engage in such behaviours in light of the consequences. In terms of CF-specific awareness, there is limited awareness provided online, with the CF Trust not providing advice regarding smoking or illicit drug use, and only providing minimal

information about excessive alcohol consumption (The CF Trust, 2010), with this information appearing to be targeted to adults with CF, despite it being acknowledged that initiation commonly occurs during adolescence.

During the dissemination meetings, many HCPs began to recognise the need for an intervention to be implemented within the CF population, to address the issue of risky behaviours. Many HCPs felt that initially an intervention needs to target HCPs, in order to raise their awareness on risky behaviours. Many HCPs responded that they do not know the impact risky behaviours can have upon CF (excluding smoking), resulting in them not being confident in addressing the issue of risky behaviours with their patients.

*[Paediatric Consultant (1)]: "I suppose the question is is the risk greater than if you've got CF [...] what about # alcohol # it's ## you know (.) drinking to excess is a bad idea: a ## is it worse because you've got CF"

Consequently, many HCPs recognised that they often only discuss smoking within their CF unit, as they feel confident regarding the CF-specific adverse health effects, nonetheless they do appreciate that patients are potentially subject to other risky behaviours.

*[Paediatric Consultant (1)]: "I think other than # how it affects your treatment # I think we know # very little # about whether there is health impacts (.) for # non smoked marijuana"

Many HCPs did emphasise the need for staff training to raise their awareness regarding the CF-specific effects of risky behaviours (particularly excessive alcohol consumption and illicit drug use), which they could then inform patients about. In addition, many HCPs acknowledged the need to have general training regarding risky behaviours, in order to be aware of what risky behaviours are prevalent within the general population, and how they may identify such behaviours within their patients, with many HCPs accepting that their patients are likely to know more about risky behaviours than they do, as identified within the previous phases of data collection.

*[Adult Nurse]: "They know more about what drugs are out there than we do [...] it's often an education to us when they do admit what drugs they're taking ## haven't got a clue really about what effect they're going to carry ## really"

HCPs identified that they are unsure on how they should address the issue of risky behaviours with patients, with some HCPs emphasising that they simply do not have the training to effectively reduce the occurrence of such behaviours within the CF population.

*[Adult Consultant (2)]: "Is it that we are badly trained to promote this health behaviour [...] I know I am # I've never been trained on this"

In addition to reducing the occurrence of these behaviours, HCPs explained that without sufficient training they do not feel confident in dealing with information that patients disclose, often not being aware of when confidentiality should be broken.

*[Physiotherapist]: "Sometimes it's not knowing what to do with that information as well when you get it # cause then you've got the awkward do I tell the parents # or not ## it depends what it is # is it safeguarding # isn't it safeguarding [laughs]"

Thus, HCPs were agreeing that staff training is required within the CF population, to not just provide HCPs with CF-specific awareness, but also to inform their practice as to how to approach the issue with all patients regardless of their personal condition, as well as issues such as confidentiality and safeguarding.

HCPs believed that with this training they would then be able to provide sufficient awareness to patients, with HCPs being in agreement that such awareness should be provided in absence of parents or guardians. This would establish a trusting relationship between the patient and HCP, providing a safe environment for disclosure, ensuring confidentiality, with HCPs stating this awareness should start before adult care, in line with the findings from the previous phases of data collection.

*[Adult Consultant (1)]: "I think by the time they come to us # if they haven't had some kind of intervention # we've missed ## how many of them haven't we # cause we get them at what # nearer seventeen now # sixteen [...] it's probably a little bit after the horse has bolted"

In addition, HCPs stated that such awareness needs to be revisited on several occasions to ensure its effectiveness. Consequently, many HCPs agreed that an opportunity to provide regular awareness could be during annual reviews, with this providing HCPs the opportunity to provide standardised proactive awareness.

*[Paediatric Consultant (1)]: "I think actually we should be more proactive shouldn't we # we can't ask every single time we see them ## but annual reviews"

The use of annual reviews was emphasised during all three dissemination meetings, with the researcher receiving an email following the second dissemination meeting by an Adult Consultant stating that the research has practical applications, and therefore that CF unit

was adding a section onto their Annual Review form for risky behaviours, ensuring the adult team at least enquires about this on regular intervals.

HCPs were keen to emphasise the need to provide more than verbal awareness, in line with previous literature, with Chowdry et al (2013) stating that awareness should be interactive as opposed to passive. Consequently, many HCPs agreed that effort should be employed to use technology to provide such awareness, with this being the platform that adolescents commonly use to communicate through. HCPs believed that technology would provide adolescents the opportunity to access CF-specific information regarding risky behaviours, without asking HCPs for advice and guidance, ensuring confidentiality. HCPs believed that patients are less likely to instigate a conversation regarding risk behaviours with HCPs, due to patients being aware that such behaviours are possibly not good for their health, however they do not know the CF-specific adverse health effects of such behaviours. In addition, HCPs explained how difficult it is to instigate a conversation regarding risky behaviours with adolescent patients who they have known for a long period of time, and formed strong relationships with.

*[Paediatric Consultant (2)]: "Whenever we do our initial assessments (.) there's questions on the:ere ## risks to self and others:s # through self-h:arm # but also drinking (.) alcohol ## drugs etc # which feels ea:asy to ask when you're meeting someone for the fi:irst time (.) getting a lot of info:ormation from them

[Paediatric Nurse (1)]: Yes # rather than kno:owing them for yea:ars and yea:ars

[Paediatric Consultant (1)]: That's pa:art of the problem I think ## it makes it ha:arder"

This highlights the nature of nursing and caring for a population of people long-term, with HCPs highlighting how the close, personal relationships they form with patients can impinge upon their ability to ask personal or sensitive questions to patients, potentially due to embarrassment and not wanting to damage the strong patient-clinician relationship. Therefore HCPs believe the use of technology could overcome these awkward conversations.

Conclusions

The dissemination meetings provide the researcher with clinical and practical insight into how these doctoral findings can inform current advice and practice in addressing the issue of risky behaviours within the CF population. Overall, HCPs acknowledge that they have limited awareness regarding the impact risky behaviours (predominantly excessive

alcohol consumption and illicit drug use) have upon CF patients, therefore they do not feel confident in instigating conversations regarding such behaviours. Consequently proactive awareness regarding risky behaviours appears to be rarely incorporated within CF care, with all CF units who the researcher contacted identifying procedures they have in place when a patient engages in a risky behaviour, but rarely discussing attempts to prevent initiation. HCPs were keen to identify that awareness regarding risky behaviours should not just be provided on a reactive basis, therefore they identified the need to have some form of staff training to raise HCPs awareness regarding these behaviours, allowing them to then correctly and confidently provide awareness to all patients on a proactive basis.

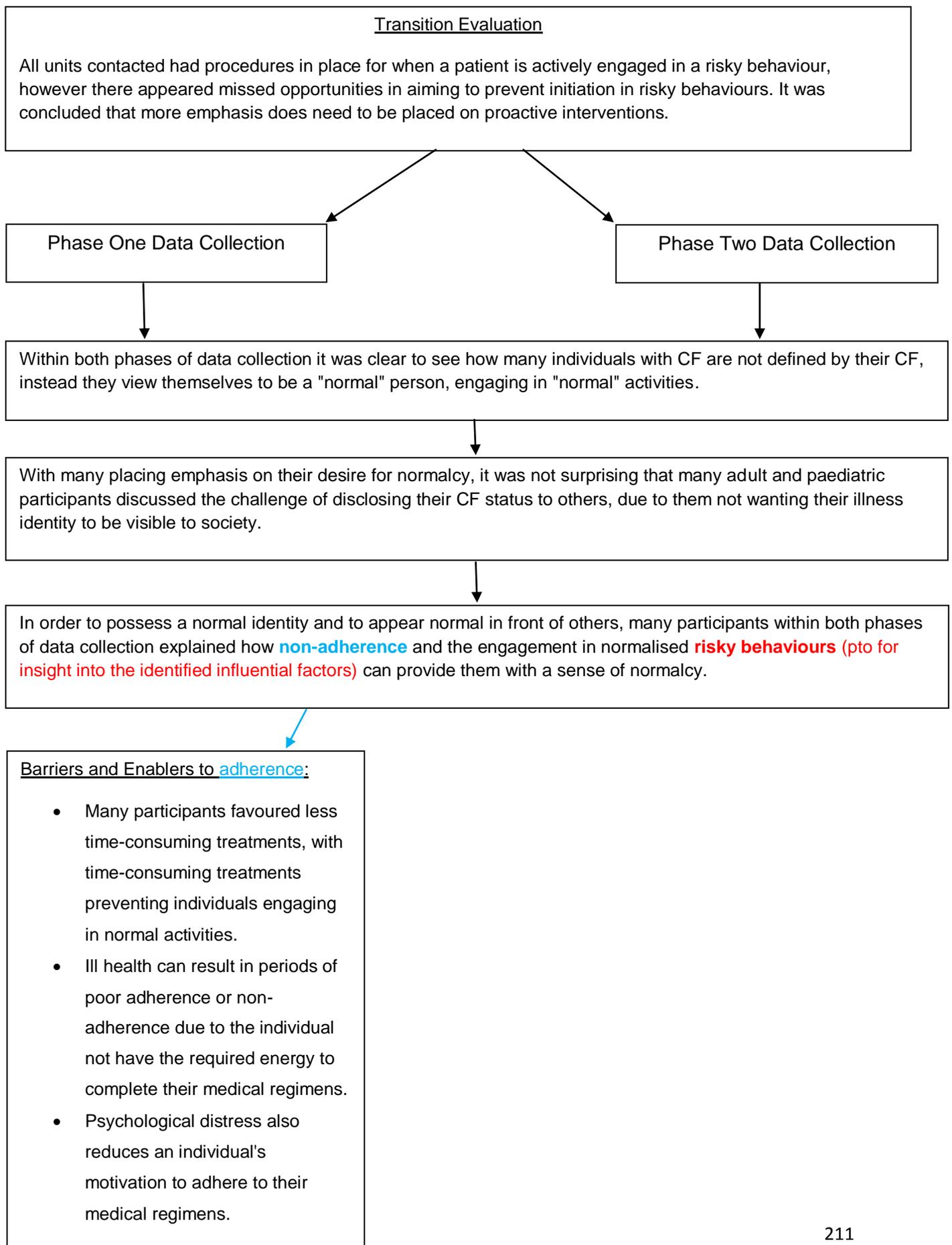
In providing awareness to patients, many HCPs identified that this should not just be done through verbal discussions, with it commonly being emphasised that technology should be used to provide such awareness. HCPs identified how technology could be used by presenting links on the CF unit's website which would provide standardised information across all CF units. In addition HCPs also identified the role that smart-phone apps could play to raise patients' awareness regarding risky behaviours. The use of smart-phone apps has been implemented into CF care in order to encourage adherence amongst patients (Smith, 2013).

It is documented that CF patients do see the benefit of smart-phone apps (such as Cystix) to assist with self-management, allowing them to set reminders to take their medication, providing dietary advice and also promoting psychological wellbeing by allowing them to communicate with other CF patients (Hilliard et al., 2014). Consequently if apps do exist which are aimed at the CF population, potentially work could be done to integrate education regarding risky behaviours into these apps, through working with experts who can provide CF-specific awareness about the adverse health effects of risky behaviours. It is believed that this information would need to be continually reviewed due to new risky behaviours which emerge on a regular basis, such as new legal highs, or vaping which has undergone a rapid normalisation process in recent years. In addition these apps could also contain tools to help patients avoid engagement in risky behaviours, with an obvious example being the use of an alcohol tracker. This would enable individuals to track how many units of alcohol they are consuming, to try and motivate them to only drink moderate amounts of alcohol, and to avoid excessive alcohol consumption and binge drinking (Change4Life, 2017). Overall the dissemination meetings, along with all previous phases of data collection do highlight a missed area within CF care, with this research demonstrating how best to inform current advice and practice to reduce the occurrence of risky behaviours within the CF population.

CHAPTER THIRTEEN: OVERALL SUMMARY

Before commencing this doctoral research, the researcher conducted a transition evaluation to investigate what information is provided to patients on risky behaviours, with this evaluation demonstrating that different CF services address risky behaviours in different ways, with many units not incorporating risky behaviours as a formal part of their transition process. All units contacted had procedures in place for when a patient is actively engaged in a risky behaviour, however there appeared to be missed opportunities in aiming to prevent initiation in risky behaviours. It was concluded from this transition evaluation that more emphasis does need to be placed on proactive interventions, with the researcher identifying the need for qualitative research to inform interventions, by exploring individuals' beliefs and attitudes towards risky behaviours (See Figure 2 for a visualisation of the overall findings of the four studies).

Figure 2. A mind map representation outlining the overall findings of the studies.



What influences the engagement in risky behaviours?

Awareness:

Participants highlighted the importance of awareness to help individuals understand why they cannot engage in such behaviours. This awareness originated from a number of sources:

- **Family** (providing awareness, protecting their child from environments where risky behaviours are normalised, discipline)
 - Not all families provide this support, with some families normalising risky behaviour engagement
- **Friends** (this is often successful as adolescents and young adults value social acceptance)
 - When friends normalise risky behaviours it can result in initiation due to a desire for social acceptance, with participants then seeing that risky behaviour as part of their group identity
- **HCPs**
 - This awareness is provided on an individualised basis, with some participants explaining they have not received any awareness (pto for insight into how this informed phase three and phase four).

Awareness is not enough to prevent an individual initiating in a risky behaviour

Individuals can engage in risky behaviours to improve their quality of life and psychological wellbeing. **Psychological distress** can result in an individual engaging in a risky behaviour, to alleviate their feelings of stress and anxiety despite their awareness regarding the associated risks.

Denial regarding CF can provide an individual with a gateway to engaging in risky behaviours. Even when participants reported awareness regarding the adverse health effects of risky behaviours, some participants still engaged in risky behaviours due to compensatory health promoting beliefs and selective focus.

Negative relationships (e.g. domestic violence, arguments) can result in risky behaviour engagement to escape these negative relationships and improve an individual's psychological wellbeing.

Not wanting to be defined by CF can motivate individuals to engage in behaviours which are away from their CF, these are often **normalised behaviours**, which could include risky behaviours normalised within an individual's environment.

Whilst acceptance often results in health promoting behaviours, it was indicated that individuals may still engage in risky behaviours despite accepting their CF due to:

- Psychological Distress
- A desire for normalcy
- Not experiencing any of the adverse health effects
- Unrealistic Optimism

Pto for insight into how this has informed the recommendations for future interventions.

Phase Three Data Collection

Phase Four Data Collection

With adult and paediatric participants demonstrating that the issue of risky behaviours is approached on an individualised basis, the researcher identified the importance of speaking with HCPs to investigate how the issue of risky behaviours is approached in reality.

HCPs identified that risky behaviours are a new issue within the CF population which are a major concern, having fatal consequences upon some patients. HCPs acknowledged that they do need to do more to address the issue of risky behaviours as the provision of awareness regarding the adverse health effects of such behaviours is not embedded within their practice.

Despite HCPs identifying the need for interventions to be embedded within practice, it was identified that HCPs themselves have poor awareness regarding what risky behaviours are present within the general population, what impact they can have upon CF patients and how to address this issue with patients.

It was identified that awareness regarding the adverse health effects risky behaviours can specifically have upon CF needs to be provided to patients on regular occasions by HCPs. It was believed that this awareness should be delivered using the communication style preferred by adolescents and young adults, therefore HCPs identified the role a **smartphone app** could play in providing this awareness. This would allow patients to access confidential information regarding risky behaviours, allowing them to make a more informed choice about whether or not they want to engage in such behaviours in light of the consequences.

Firstly an intervention needs to **target HCPs** to provide them with awareness regarding risky behaviours, HCPs will then be able to provide this awareness to patients.

The research identified that awareness is not always enough to prevent the initiation or aid the cessation of risky behaviours within the CF population. Therefore HCPs identified the need to have **screening tools** embedded within CF care on regular occasions (e.g. during annual reviews) to identify patients who may be vulnerable to engaging in such behaviours. It is believed that these screening tools should focus upon psychological distress and avoidance of CF, to help individuals cope with these aspects of their lives which in turn has the potential to reduce the occurrence of risky behaviours within the CF population.

A screening tool would also be helpful to identify individuals engaging in risky behaviours. A new screening tool would be able to focus on new risky behaviours present within the general population (e.g. the use of vaping).

The first phase of data collection within this doctoral research involved the researcher conducting qualitative interviews with adult CF patients, to gain insight into their reasons as to why they do or do not engage in risky behaviours. This phase of data collection did successfully highlight a variety of reasons as to why some individuals with CF engage in risky behaviours, and do not engage in health-promoting behaviours, demonstrating the need for more effective health promotion measures, to reduce the occurrence of such behaviours. The participants' narratives were retrospective which provided a time dimension to the data, and created a more comfortable environment for participants to disclose sensitive and embarrassing information, when they were more distanced from the event (De Vaus, 2006).

Importantly, phase one data collection highlighted that risky behaviour initiation, and the engagement of non-adherence commonly occurs during adolescence. The researcher therefore deemed it necessary for a second phase of data collection to be conducted within the paediatric CF population, before work on an intervention commenced. This second phase of data collection was both current and prospective, exploring paediatric participants' knowledge, beliefs and attitudes towards risky behaviours, at an age commonly associated with initiation. There were a number of common findings within these two phases of data collection.

Within both phases of data collection it was clear to see how many individuals with CF are not defined by their CF, instead they view themselves to be a "normal" person, engaging in "normal" activities. With many placing emphasis on their desire for normalcy, it was not surprising that many adult and paediatric participants discussed the challenge of disclosing their CF status to others, due to them not wanting their illness identity to be visible to society. In order to possess a normal identity and to appear normal in front of others, many participants within both phases of data collection explained how non-adherence and the engagement in normalised risky behaviours can provide them with a sense of normalcy. In terms of barriers and enablers to adherence, it was clear that many adult and paediatric participants favour less time-consuming treatments, with time-consuming treatments preventing individuals engaging in normal activities. Many adult participants explained how they would engage in occasional non-adherence in order to engage in normal activities that they did not want to miss out on, demonstrating their life-orientated illness perspective. This was also demonstrated within the paediatric population, with many participants explaining how they wish they could engage in normal activities instead of adhering to their complex and time-consuming medical regimens. Within both phases of data collection it was highlighted how ill health can result in periods of poor adherence or non-adherence, due to the individual not having the required energy to complete their medical regimens, with this

predominantly impacting on physiotherapy regimens. In addition, psychological distress also reduces an individual's motivation to adhere to their medical regimens in both populations.

In terms of risky behaviours, participants within both phases of data collection spoke about how important awareness is regarding the adverse health effects of risky behaviours, to help patients understand why they cannot engage in such behaviours. This awareness originated from a number of sources. Both adult and paediatric participants explained that this awareness can be provided by their families, with participants often stating that their family have made them aware of the adverse health effects, and they are also aware that their family would discipline them if they engaged in such behaviours. It was also clear within both phases of data collection that when an individual has disclosed their CF status to their friends, their friends often work to prevent the individual initiating in a risky behaviour, with their peers' efforts often being successful. However, families and friends do not always provide this support, with some participants explaining how their family and friends have normalised risky behaviour engagement, with participants in phase one data collection demonstrating how normalisation can result in initiation, often due to a desire for normalcy. Participants did point out that when they had been provided awareness regarding the CF-specific adverse health effects of risky behaviours and accepted that awareness, they did not engage in risky behaviours despite this normalisation. Therefore, with the data demonstrating that the support an individual receives in their private life varies between individuals, the importance of awareness originating from HCPs on the CF-specific adverse health effects of risky behaviours was emphasised within both phases of data collection. It was clear that the adult and paediatric CF population receive awareness regarding risky behaviours from HCPs on an individualised basis, with some participants explaining that they have not received this awareness. This highlights the need for standardised interventions to be implemented into CF care to provide patients with awareness on risky behaviours on a regular proactive basis, regardless of an individual's personal condition.

Within both phases of data collection it was clear that awareness is not always enough to prevent an individual initiating in a risky behaviour. Psychological distress can result in an individual engaging in a risky behaviour, to alleviate their feelings of stress and anxiety despite their awareness regarding associated risks. Adult participants provided several examples of this, with paediatric participants highlighting the role of psychological distress through talking in the third person. In addition, some participants within phase one data collection, and one participant within phase two data collection, demonstrated compensatory health beliefs enabling their engagement in risky behaviours to continue, despite their awareness that these behaviours can be harmful towards their health. Some participants also demonstrated the role affective beliefs can have in influencing their

engagement in risky behaviours, with adult participants highlighting how enjoyment of a "risky" behaviour often results in continuation of that behaviour, regardless of an individual's awareness of the risks. Within the paediatric population it was clear that when interventions produced a strong negative affect within an individual, it resulted in the individual having negative views towards that behaviour, and not desiring initiation. Information regarding a risky behaviour needs to be accurate, clear and not over fearful. Participants within phase one data collection explained that when the experience of risky behaviour experimentation was not as bad as they had been told, they mistrusted and did not believe all other information they had been given, resulting in the continuation of their behaviour despite the awareness they had been provided.

With many participants reporting a lack of awareness regarding the adverse health effects of risky behaviours provided by HCPs, the researcher deemed it essential to talk with HCPs regarding what awareness they provide patients with, and which patients receive this awareness. The researcher recruited CF Specialist Nurses for phase three data collection, due to participants within both phases of data collection describing Nurses to be the most approachable member of the MDT, disclosing more information to Nurses than other HCPs. Therefore it was believed Nurses would be well placed to offer valuable insights into the issue of risky behaviours and effective interventions. The telephone interviews with Nurses did generate an in-depth understanding on how Nurses perceive the issue of risky behaviours within the CF population, and what interventions they believe would work. Before work started on creating an intervention the researcher did identify the importance of speaking to, and collaborating with other HCPs, in order for the research to have "real world" impact in the practice of health care. The final phase of data collection allowed the researcher to disseminate the research findings, allowing HCPs to critique these findings and offer suggestions regarding what interventions would work in reality. Phase three and phase four data collection both provide recommendations for how a new intervention should look within the CF population, to reduce the occurrence of risky behaviours, highlighting the practical applications of this research.

Recommendations

While all CF units contacted reported having procedures in place if a patient engages in a risky behaviour, a common finding highlighted within the transition evaluation, and by HCPs within phase three and phase four data collection, is the lack of proactive awareness CF patients are provided with regarding the CF-specific adverse health effects of risky behaviours. Without this awareness patients are not able to make an informed choice as to whether or not they wish to engage in such behaviours, which are commonly normalised

within their environment. HCPs identified that risky behaviours are a missed area within CF care, with awareness regarding risky behaviours not being embedded within practice. Consequently it was identified that individuals with CF often seek awareness regarding such behaviours from elsewhere, such as the internet, where inaccurate information can be displayed. It was evident within this doctoral research that the issue of risky behaviours is approached on an individualised basis, with different patients (within the first two phases of data collection) at the same CF unit not always having the same awareness regarding risky behaviours. This research therefore highlights the need for proactive interventions to be integrated into CF care in order to reduce the occurrence of risky behaviours.

In order to provide awareness, HCPs within phase three and phase four data collection identified that they firstly require some form of staff training, to raise their awareness as to what risky behaviours are current within the general population, what impact they can have upon CF patients, and how HCPs should approach the issue of risky behaviours, whilst being in line with safeguarding and confidentiality policies. The need for staff training was also raised by the adult CF population, with some participants expressing their beliefs that HCPs are naive and are not aware of what risky behaviours are present within the general population. In terms of providing awareness to CF patients, all phases of data collection, along with the transition evaluation demonstrate that this awareness needs to go beyond verbal awareness, in order to provide standardised information to all patients regardless of their personal condition. HCPs identified that verbal information could be implemented on a reactive basis, where the information does need to be individualised, whereas technology could administer a proactive intervention.

HCPs identified the role smart-phone apps could play in presenting such information, with this intervention having the potential to reach hard to reach groups (e.g. those who do not attend clinic appointments, who HCPs suspect engage in risky behaviours), and fostering the communication style used by individuals at an age where initiation in risky behaviours commonly occurs. The use of technology would allow individuals with CF to seek accurate information regarding risky behaviours in a confidential way, with this doctoral research indicating that such awareness needs to be administered to individuals from the age of 12 years and above. It was also highlighted that this awareness needs to be revisited on several occasions, with patients within phase one and phase two data collection often remembering that the provision of awareness was implemented into their care, but not being able to recall what awareness was provided. In order to revisit such information HCPs identified a role for the annual review. As well as awareness implemented into one's care by their CF unit, proactive awareness could be provided online via the CF Trust, which currently

does not offer any awareness regarding smoking or illicit drug use, and only distributes minimal awareness regarding excessive alcohol consumption.

All phases of data collection highlight how awareness administered to patients would need to be revised on regular occasions due to the emergence of new risky behaviours, in order to accurately document to patients what behaviours are risky for the CF population, and what impact they can have upon their CF. For instance, a new risky behaviour that has emerged is the use of e-cigarettes, with paediatric participants explaining how some individuals engage in this behaviour despite never smoking conventional cigarettes. Research is required to investigate the respiratory complications associated with this behaviour, to see whether or not this could have an impact upon one's CF. Quantitative research would also be useful to investigate the incidence and prevalence of "vaping" within a CF population, to investigate whether an intervention does need to specifically focus upon this new "risky behaviour".

As well as this doctoral research highlighting the need for proactive awareness to be embedded within CF care regarding the adverse health effects of risky behaviours, this research did also highlight factors that can influence engagement in such behaviours. All phases of data collection highlighted the role psychology can play within an intervention, in terms of screening patients for these "potential predictors". Adult and paediatric participants identified the role psychological distress, avoidance of CF and negative family interactions can play in influencing engagement in such behaviours, with HCPs also identifying these factors as influential within risky behaviour engagement. Consequently a screening tool could be created to identify these "at risk" groups; with HCPs then having the opportunity to help such patients cope with these aspects of their lives, in order to attempt to reduce the occurrence of risky behaviours within the CF population. In terms of avoidance of one's CF, a proactive intervention could be introduced which would encourage all individuals with CF to take ownership of their CF, by highlighting CF's true nature whilst instilling a sense of hope and optimism within patients. In terms of highlighting CF's true nature to individuals, this should focus upon the practicalities of their condition, and what that means for their life. For example, with adolescent patients this could involve providing awareness on what behaviours an individual can and cannot (or should not) engage in, in order to protect their health. It is acknowledged that making individuals aware of the fatal nature of CF is not always advantageous, therefore as explored within previous chapters, awareness within this intervention should just focus upon the practical aspects of the condition. HCPs also identified the role mentoring could play as a way to reduce the occurrence of risky behaviours within the CF population, by offering patients online support from individuals who truly understand their condition, reducing feelings of isolation.

Limitations

Overall, this research has highlighted to CF HCPs within the Midlands a missed area which could have detrimental impacts upon some patients. This research provides practical insight into policy change for the prevention and reduction of risky behaviours within the CF population, by informing current advice and practice. Nonetheless, limitations of this research do need to be acknowledged. For the majority of the research two CF units were used (Birmingham Heartlands Hospital and the Royal Stoke University Hospital); whilst qualitative research does not aim to generalise findings to the wider population, the aim of this research is to create an intervention to reduce the occurrence of risky behaviours within the UK CF population, in part by providing standardised information across all UK CF units. However an individual's attitudes and beliefs regarding risky behaviours is likely to partly be influenced by their environment, with research acknowledging that economic distress can play a big role in the initiation of risky behaviours within the general population (Board on Children, Youth and Families, 2011). Therefore the effectiveness of an intervention is likely to vary depending upon the location of the CF unit, and potentially would need to be modified depending upon that area to maximise its effectiveness. Consequently further research could be conducted to gain an insight into the incidence and prevalence of risky behaviours (smoking, excessive alcohol consumption and illicit drug use) across all UK CF units, to identify where emphasis needs to be more thoroughly placed.

Limitations of data collection methods also need to be acknowledged. Within the first phase of data collection retrospective interviews were used. While this study design enables participants to assess the influence a situation had upon their identity and experiences, when they are more distanced from it (Taylor, 2008; Yates et al., 2010), it is not without its limitations, and can contain several sources of bias. Retrospective interviews can result in selective memory, where the participant remembers, or does not remember, certain events which happened in their past which could have been an influential factor affecting their initiation in risky behaviours (Witrock & Foraker, 2001). Retrospective interviews can also result in telescoping, where an individual recalls an event that happened at one time, as if it happened at another time e.g. recalling that suicidal thoughts occurred prior to initiation, whereas in reality such thoughts occurred after the individual had initiated in risky behaviours (Johnson & Schultz, 2005). Attribution is also an issue within retrospective accounts, where individuals will attribute positive events to one's own agency, but attribute negative events to external forces (Aguinis & Edwards, 2014). Furthermore, exaggeration is another form of bias which can occur during retrospective accounts, where an individual represents outcomes as more significant than reality (Aguinis & Edwards, 2014).

Nonetheless, while these limitations do need to be acknowledged, the whole purpose of qualitative research is to recognise what is important to each individual participant, rather than establish honesty, reliability and validity, therefore this research did accept what participants said during the interviews as their stories, with all participants offering great insight into their lives with CF and their decisions regarding risky behaviour engagement.

During the retrospective interviews it was deemed necessary to conduct prospective interviews in the following phase of data collection with adolescent CF patients, to explore their knowledge, awareness and attitudes towards risky behaviours at an age commonly associated with initiation. Prospective interviews can work to overcome the above mentioned biases with retrospective accounts, allowing the research to examine participants' attitudes and beliefs towards risky behaviours in real time (Lally, 2007). However, again this phase of data collection is not without its limitations. Firstly, during five interviews guardians were present for the entire interview, with it being accepted that their presence will have had an impact on what information was disclosed during the interview; adolescents were unlikely to disclose experimentation with risky behaviours while their legal guardians were present (Economic and Social Research Council, 2017). Even in the absence of legal guardians, a limitation of prospective interviews is the likelihood of social desirability bias. The researcher was aware that participants were unlikely to report current experimentation or engagement in risky behaviours to the researcher regardless of whether or not their guardians were present, due to participants being likely to believe that these behaviours are "undesirable" (Schwarz, 2004), despite the researcher's effort to generate rapport and demonstrate a non-judgemental approach. For this reason, the research was not investigating engagement with risky behaviours within this phase of data collection, instead it was focusing upon one's attitudes, beliefs and awareness towards risky behaviours, with the researcher paying attention to the discourse of participants to try and identify accounts that had been influenced by social desirability bias.

Another data collection limitation that should be highlighted is the use of telephone interviewing within phase three data collection. With few qualitative studies employing telephone interviews (Sturges & Hanrahan, 2004), literature has reported that it can be viewed as "the less attractive" alternative to face-to-face interviewing (Novick, 2008). It is argued that the absence of visual cues via telephone results in a loss of contextual and nonverbal data, and can also influence the rapport generated during the interview, and the researcher's ability to probe and truly interpret the responses of participants (Garbett & McCormack, 2001; Novick, 2008; Smith, 2005; Sturges & Hanrahan, 2004). Whilst this data collection method does not contain nonverbal information, it does have to be acknowledged that this data is not always essential, with nonverbal cues not always being used extensively

in analyses that heavily rely on transcripts rather than field notes (Novick, 2008). In addition there is always the possibility that nonverbal data has been misinterpreted (Burnard, 1994; Chapple, 1999; Sturges & Hanrahan, 2004). The researcher did consider these limitations, however valued the anonymous nature of telephone interviewing, believing that it would allow the Nurses to relax and feel able to disclose sensitive information about their CF unit's practice (Sweet, 2002). This data collection method also decreased the travel required by the researcher, allowing this research to reach geographically dispersed participants (Novick, 2008).

Conclusions

Overall this research does provide practical insight into policy change for the prevention and reduction of risky behaviours within the CF population nationally and internationally, by informing current advice and practice. Throughout this research HCPs have acknowledged that they require awareness and tools around risky behaviours, with the provision of awareness regarding risky behaviours not appearing to be implemented into CF care on a proactive basis. Standardised, easily implemented and evidence-based practice is therefore required throughout UK CF centres, to provide awareness to patients from the age of 12-years, with this awareness needing to be revisited on several occasions. This research identifies a role for technology in administering this awareness. Awareness regarding risky behaviours would allow individuals with CF to make a more informed choice on engagement with such behaviours. However, as discussed, an intervention needs to go beyond providing awareness, with this research making a useful contribution to literature in highlighting factors that influence the engagement in risky behaviours within the CF population.

Consequently, as explored in previous chapters, an intervention firstly needs to inform HCPs regarding risky behaviours; both in terms of why patients may engage in such behaviours, along with the CF-specific adverse health effects these behaviours can have upon CF patients. It is then identified the intervention needs to focus upon patients. This research demonstrates the need for an intervention to screen for psychological distress and avoidance of CF as influential factors affecting initiation in risky behaviours, as well as identifying those who have negative relationships within their lives. Identified patients should then be offered assistance to cope with these aspects of their lives, which in turn would have the potential to reduce the occurrence of risky behaviours within the CF population, potentially through encouraging such patients to develop emotional sobriety (Sweet & Miller, 2016). This support could in part involve the use of patient advisory groups, or mentoring, which have been successfully set up within the USA to allow CF patients to communicate and encourage positive health behaviours amongst one another (Moog, 2016).

In addition, this doctoral research points out that all patients should be informed on the adverse health effects of risky behaviours regardless of their personal condition, and this awareness should be administered on a proactive basis, through the use of technology. It is therefore believed that the researcher now needs to take this research further afield, to ensure an intervention would be welcomed into all UK CF units. In terms of designing the intervention, the researcher proposes to collaborate with patients, HCPs, as well as the UK CF Trust, providing the possibility of impact at national and international levels by dissemination of findings and reporting standardised practices.

References

- Abbott, J. (2003). Coping with cystic fibrosis. *Journal of the Royal Society of Medicine*, 96, 42–50. Retrieved on 24/10/2014 from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1308787/pdf/12906325.pdf>
- Abbott, J. (2011). Nottingham in smoke-free play areas move. *Horticulture Week*. Retrieved on 23/10/2014 from: <http://www.hortweek.com/nottingham-smoke-free-play-areas-move/parks-and-gardens/article/1104228>
- Abbott, J., Dodd, M., Bilton, D., & Webb, A.K. (1994). Treatment compliance in adults with cystic fibrosis. *THORAX*, 49, 115-120. doi: 10.1136/thx.49.2.115
- Abbott, J., Dodd, M., & Webb, A.K. (1996). Health perceptions and treatment adherence in adults with cystic fibrosis. *THORAX*, 51, 1233-1238. doi: 10.1136/thx.51.12.1233
- Abbott, J., Hart, A., Morton, A., Gee, L., & Conway, S. (2008). Health-related quality of life in adults with cystic fibrosis: the role of coping. *Journal of Psychosomatic Research*, 64, 149-157. doi: 10.1016/j.jpsychores.2007.08.017
- Abbott, J., Havermans, T., & Hart, A. (2009). Adherence to the medical regimen: clinical implications of new findings. *Current Opinion in Pulmonary Medicine*, 15, 597-603. doi: 10.1097/MCP.0b013e3283310859
- Addaction. (2015). *Addaction*. Retrieved 30/01/2017 from: <http://www.addaction.org.uk/>
- Aguinis, H., & Edwards, J.R. (2014). Methodological wishes for the next decade and how to make wishes come true. *Journal of Management Studies*, 51, 143-174. doi: 10.1111/joms.12058
- Ajzen, I. (1988). *Attitudes, personality and behaviour*. Chicago, IL: Dorsey Press.
- Ajzen, I., & Madden, T.J. (1986). Prediction of goal-directed behaviour: attitudes, intentions, and perceived behavioural control. *Journal of Experimental Social Psychology*, 22, 453-474. doi: 10.1016/0022-1031(86)90045-4
- Alcoholics Anonymous. (2017). *Alcoholics anonymous; great britain*. Retrieved on 30/01/2017 from: <http://www.alcoholics-anonymous.org.uk/>
- Amos, A., & Hastings, G. (2009). A review of young people and smoking in England. *Public Health Research Consortium*. Retrieved on 30/05/2017 from: http://webcache.googleusercontent.com/search?q=cache:K4d_zzlohZIJ:phrc.lshtm.ac.uk/papers/PHRC_A7-08_Final_Report.pdf+&cd=4&hl=en&ct=clnk&gl=uk

- Anderson, P., de Bruijn, A., Angus, K., Gordon, R., & Hastings, G. (2009). Impact of alcohol advertising and media exposure on adolescent alcohol use: a systematic review of longitudinal studies. *Alcohol and Alcoholism*, *44*, 229-243. doi: 10.1093/alcalc/agn115
- Antos, N.J., Quintero, D.R., Walsh-Kelly, C.M., Noe, J.E., & Schechter, M.S. (2014). Improving inpatient cystic fibrosis pulmonary exacerbation care: two success stories. *British Medical Journal Quality and Safety*, *23*, 33-41. doi: 10.1136/bmjqs-2013-002367
- ASH. (2016a). Smoking statistics, illness and death. *Action on Smoking and Health Fact Sheet*. Retrieved on 30/01/2017 from: <http://ash.org.uk/category/information-and-resources/fact-sheets/>
- ASH. (2016b). Electronic cigarettes. *Action on Smoking and Health*. Retrieved on 29/06/2016 from: http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=8&ved=0ahUKEwjT9ZKxMzNAhWMJsAKHZXVBgAQFghLMAC&url=http%3A%2F%2Fwww.ash.org.uk%2Ffiles%2Fdocuments%2FASH_715.pdf&usg=AFQjCNH0GvGoar-xNkC7WYpygi9J4N4Ucw
- Ashton, S. (2014). Researcher or nurse? Difficulties of undertaking semi-structured interviews on sensitive topics. *Nursing Researcher*, *22*, 27031. doi: 10.7748/nr.22.1.27.e1255.
- Auduly, A., Asplund, K., & Norbergh, K.G. (2010). The influence of illness perspectives on self-management of chronic disease. *Journal of Nursing and Healthcare of Chronic Illness*, *3*, 109-118. doi: 10.1111/j.1752-9824.2011.01087.x
- Aujoulat, I., Marcolongo, R., Bonadiman, L., & Deccache, A. (2008). Reconsidering patient empowerment in chronic illness: a critique of models of self-efficacy and bodily control. *Social Science and Medicine*, *66*, 1228–1239. doi: 10.1016/j.socscimed.2007.11.034
- Aurora, P., Carby, M., & Sweet, S. (2008). Selection of cystic fibrosis patients for lung transplantation. *Current Opinion in Pulmonary Medicine*, *14*, 589–594. doi: 10.1097/MCP.0b013e328313e3d4
- Aveyard, P., & Raw, M. (2011). Improving smoking cessation approaches at the individual level. *Tobacco Control*, *21*, 252-257. doi: 10.1136/tobaccocontrol-2011-050348
- Backström-Eriksson, L., Sorjonen, K., Bergsten-Brucefors, A., Hjelte, L., & Melin, B. (2015). Anxiety and depression in adults with cystic fibrosis: a comparison between patients and the general population in Sweden and three other European countries. *BioMed Central Pulmonary Medicine*, *15*, 121. doi: 10.1186/s12890-015-0117-9

- Ball, R., Southern, K.W., McCormack, P., Duff, A.J.A., Brownlee, K.G., & McNamara, P.S. (2013). Adherence to nebulised therapies in adolescents with cystic fibrosis is best on week-days during school term-time. *Journal of Cystic Fibrosis*, *12*, 440-444. doi: 10.1016/j.jcf.2012.12.012
- Barber, N. (1995). What constitutes good prescribing. *British Medical Journal*, *310*, 923-925. doi: 10.1136/bmj.310.6984.923
- Barker, D.H., Driscoll, K.A., Modi, A.C., Light, M.J., & Quittner, A.L. (2012). Supporting cystic fibrosis disease management during adolescence: the role of family and friends. *Child: Care, Health and Development*, *38*, 497-504. doi: 10.1111/j.1365-2214.2011.01286.x
- Barrett, A.E. (2000). Marital trajectories and mental health. *Journal of Health and Social Behaviour*, *41*, 451-464. doi: 10.2307/2676297
- Bava, S., & Tapert, S.F. (2010). Adolescent brain development and the risk for alcohol and other drug problems. *Neuropsychology Review*, *20*, 398-413. doi: 10.1007/s11065-010-9146-6
- BBC. (2016). Nottingham is UK's second city to launch smoke-free zones. *BBC News Nottingham*. Retrieved on 29/11/2016 from: <http://www.bbc.co.uk/news/uk-england-nottinghamshire-35414972>
- Bennett, A.V., Patrick, D.L., Lymp, J.F., Edwards, T.C., & Goss, C.H. (2010). Comparison of 7-day and repeated 24-hour recall of symptoms of cystic fibrosis. *Journal of Cystic Fibrosis*, *9*, 419-424. doi: 10.1016/j.jcf.2010.08.008
- Bernhard, T. (2014). The extra burdens faced by young people with chronic illness. *Psychology Today*. Retrieved on 21/10/2014 from: <http://www.psychologytoday.com/blog/turning-straw-gold/201403/the-extra-burdens-faced-young-people-chronic-illness>
- Bilton, D. (2015). Preventing lung damage. *The UK Cystic Fibrosis Conference; Fighting for a Life Unlimited*. Retrieved on 12/1/2016 from: <https://www.youtube.com/watch?v=QVz8mCR6rtU>
- Bissett, S., Wood, S., Cox, R., Scott, D., & Cassell, J. (2011). Calculating alcohol risk in a visualisation tool for promoting healthy behaviour. *AI and Health Communication*. Retrieved on 13/10/2014 from: <http://www.sussex.ac.uk/Users/sharonw/papers/BissettWoodCoxScottCassellAIHC2011.pdf>
- Board on Children, Youth and Families. (2011). *The science of adolescent risk taking*. Washington, USA: National Academy of Sciences.

- Bock, B.C., Becker, B., Monteiro, R., Partridge, R., Fisher, S., & Spencer, J. (2001). Physician intervention and patient risk perception among smokers with acute respiratory illness in the emergency department. *Preventive Medicine, 32*, 175–181. doi: 10.1006/pmed.2000.0799
- Boden, J.M., & Fergusson, D.M. (2011). Alcohol and depression. *Addiction, 106*, 906-914. doi: 10.1111/j.1360-0443.2010.03351.x
- Bollinger, C.T., Zellweger, J.P., Danielsson, T., von Biljon, X., Robidou, A., Westin, A., Perruchoud, A.P., & Sawe, U. (2000). Smoking reduction with oral nicotine inhalers: double blind, randomised clinical trial of efficacy and safety. *The British Medical Journal, 321*, 329–33. doi: 10.1136/bmj.321.7257.329
- Borrelli, B., Bartlett, Y.K., Tooley, E., Armitage, C.J., & Wearden, A. (2015). Prevalence and frequency of mHealth and eHealth use among US and UK smokers and differences by motivation to quit. *Journal of medical internet research, 17*. doi: 10.2196/jmir.4420
- Borrelli, B., Hayes, R.B., Dunsiger, S., & Fava, J.L. (2010). Risk perception and smoking behaviour in medically ill smokers: a prospective study. *Addiction, 105*, 1100-1108. doi: 10.1111/j.1360-0443.2010.02900.x
- Borschuk, A.P., Everhart, R.S., Eakin, M.N., Ridge, A., Green, A., & Riekert, K.A. (2014). Characteristics associated with disease disclosure in older adolescents and adults with cystic fibrosis. *Pediatric Pulmonology, 49*, 442-443. doi: 10.1002/ppul.23108
- Boyle, I.R., di Saint, A.P.A., Sack, S., Millican, F., & Kulczycki, L.L. (1976). Emotional adjustment of adolescents and young adults with cystic fibrosis. *Journal of Paediatrics, 88*, 318-326. Retrieved on 21/10/2014 from: <http://www.ncbi.nlm.nih.gov/pubmed/1249700>
- Bradley, E., McSherry, W., & McSherry, R. (2010). The dissemination of healthcare research: utilising joint posts. *Nursing Times, 106*, 44. Retrieved on 29/03/2016 from: <http://www.nursingtimes.net/roles/nurse-managers/disseminating-research-how-joint-nhs-and-university-posts-can-support-this-process/5021440.fullarticle>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101. doi: 10.1191/1478088706qp063oa
- Braun, V., & Clarke, V. (2013). *Successful qualitative research; a practical guide for beginners*. London, UK: SAGE.

- Bregnballe, V., Schiotz, P.O., Boisen, K.A., Pressler, T., & Thastum, M. (2011). Barriers to adherence in adolescents and young adults with cystic fibrosis: a questionnaire study in young patients and their parents. *Patient Preference and Adherence*, 5, 507-515. doi: 10.2147/PPA.S25308
- Brendel, E., & Jager, C. (2005). *Contextualisms in epistemology*. The Netherlands: Springer.
- Breslau, N., Kilbey, M., & Andreski, P. (1992). Nicotine withdrawal symptoms and psychiatric disorders: findings from an epidemiological study of young adults. *American Journal of Psychiatry*, 149, 464-469. doi: 10.1176/ajp.149.4.464
- Brinkmann, S. (2016). Methodological breaching experiments: Steps toward theorizing the qualitative interview. *Culture & Psychology*, 22, 520-533. doi: 10.1177/1354067X16650816
- Britto, M.T., Daeschner, C.W., Dugliss, M.A.J., Garrett, J.M., Johnson, C.A., & Konrad, T.R. (1998). Risky behaviour in teens with cystic fibrosis or sickle cell disease: a multicenter study. *Pediatrics*, 101, 250 - 256. doi: 10.1542/peds.101.2.250
- Britton, J., & Bogdanovica, I. (2014). *Electronic cigarettes: A report commissioned by Public Health England*. London: Public Health England.
- Bryon, M. (2015). Adolescent motivation - neurological and emotional. *The UK Cystic Fibrosis Conference; Fighting for a Life Unlimited*. Retrieved on 11/1/2016 from: <https://www.youtube.com/watch?v=a8lQ-CEprJQ>
- Buller, D.B., Borland, R., Woodall, W.G., Hall, J.R., Burris-Woodall, P., & Voeks, J.H. (2003). Understanding factors that influence smoking uptake. *Tobacco Control*, 12, 16-25. Retrieved on 29/10/2014 from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1766136/pdf/v012p0iv16.pdf>
- Burker, E.J., Kazukauskas, K.A., & Williams, L.W. (2012). Maximising quality of life in adults with cystic fibrosis: the critical role of certified rehabilitation counsellors. *The Journal of Rehabilitation*, 78, 20-26. Retrieved on 24/10/2014 from: <http://ezproxy.bcu.ac.uk:2144/ps/i.do?action=interpret&ty=as&v=2.1&lm=&u=uce&it=search&s=RELEVANCE&authCount=1&p=SPJ.SP00&qt=TI~Maximizing+Quality+of+Life+in+Adults+with+Cystic+Fibrosis+The+Critical+Role+of+Certified+Rehabilitation+Counselors~~SP~20~~IU~3~~SN~0022-4154~~VO~78&sw=w&selfRedirect=true>
- Burnard, P. (1994). The telephone interview as a data collection method. *Nurse Education Today*, 14, 67-72. doi: 10.1016/0260-6917(94)90060-4

- Burr, V. (1995). *An introduction to social constructionism*. Routledge: UK.
- CF News Today. (2016). *Ivacaftor/Lumacaftor (Orkambi)*. Retrieved on 12/09/2016 from:
<http://cysticfibrosisnewstoday.com/orkambi-lumacaftor-ivacaftor-vertex/>
- Change4Life. (2017). *Change4Life; eat well; move more; live longer*. Retrieved on 27/01/2017 from:
<http://www.nhs.uk/change4life/pages/alcohol-drink-swaps.aspx>
- Chapple, A. (1999). The use of telephone interviewing for qualitative research. *Nurse Researcher*, 6, 85-93. doi: 10.7748/nr1999.04.6.3.85.c6090
- Charlton, A. (1984). Children's opinion about smoking. *Journal of the Royal College of General Practitioners*, 34, 483-467. Retrieved on 12/07/2015 from:
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1959674/?page=1>
- Charlton, A., & Blair, V. (1989). Predicting the onset of smoking in boys and girls. *Social Science and Medicine*, 29, 813-818. doi: 10.1016/0277-9536(89)90080-4
- Charmaz, K. (2002) Qualitative interviewing and grounded theory analysis. In Gubrium, J.F., & Holstein, J.A. (2002). *Handbook of interview research: context & method*. Thousand Oaks, CA: SAGE.
- Chatwin, J., Povey, A., Kennedy, A., Frank, T., Firth, A., Booton, R., Barber, P., & Sanders, C. (2014). The mediation of social influences on smoking cessation and awareness of the early signs of lung cancer. *BMC Public Health*, 14, 1-11. doi: 10.1186/1471-2458-14-1043
- Chowdry, H., Kelly, E., & Rasul, I. (2013). Reducing risky behaviour through the provision of information, research report. *Department for Education*. Retrieved on 14/12/2016 from:
<https://www.gov.uk/government/publications/reducing-risky-behaviour-through-the-provision-of-information>
- Clarke, V., Kitzinger, C., & Potter, J. (2004). Kids are just cruel anyway: lesbian and gay parents' talk about homophobic bullying. *British Journal of Social Psychology*, 43, 531-550. doi: 10.1348/0144666042565362
- Cohen, S., David, A.J., Tyrrell, M.D., & Smith, A.P. (1991). Psychological stress and susceptibility to the common cold. *The New England Journal of Medicine*, 325, 606-612. doi: 10.1056/NEJM199108293250903
- Cohn, L.D., Macfarlane, S., Yanez, C., & Imai, W.K. (1995). Risk-perception: differences between adolescents and adults. *Health Psychology*, 14, 217-222. doi: 10.1037/0278-6133.14.3.217

- Cole, J., Watkins, C., & Kleine, D. (2016). Health advice from internet discussion forums: how bad is dangerous? *Journal of Medical Internet Research*, 18. doi: 10.2196/jmir.5051
- Coleman, L., & Glenn, F. (2009). *When couples part: understanding the consequences for adults and children*. United Kingdom: OnePlusOne
- Collins, S. (2015). Good communication helps to build a therapeutic relationship. *Nursing Times*. Retrieved on 29/04/2016 from: <http://www.nursingtimes.net/roles/nurse-educators/good-communication-helps-to-build-a-therapeutic-relationship/5003004.fullarticle>
- Cooley, S.J., Holland, M.J.G., Cumming, J., Novakovic, E.G., & Burns, V.E. (2014). Introducing the use of a semi-structured video diary room to investigate students' learning experiences during an outdoor adventure education group work skills course. *Higher Education*, 67, 105-121. doi: 10.1007/s10734-013-9645-
- Cooley, M.E., Lundin, R., & Murray, L. (2009). Smoking cessation interventions in cancer care: opportunities for oncology nurses and nurse scientists. *Annual Review of Nursing Research*, 27, 243-272. doi: 10.1891/0739-6686.27.243
- Coon, J. (2015). Increasing self-management of cystic fibrosis through the use of smartphone app technology. *Senior Honors Theses*. Retrieved on 31/08/2016 from: <http://commons.emich.edu/honors>
- Cooper, C. (2013). In Newcombe, T. (2013). Stress and presenteeism "sapping UK productivity", says research. *HR*. Retrieved on 27/12/2014 from <http://www.hr magazine.co.uk/hro/news/1077290/stress-presenteeism-sapping-uk-productivity-research>
- Cory, M., Edwards, L., Sevinson, H., & Knowles, M. (1990). Longitudinal analysis of pulmonary function decline in patients with cystic fibrosis. *The Journal of Pediatrics*, 131, 809-814. doi: 10.1016/S0022-3476(97)70025-8
- Couce, M., O'Brien, T.D., Moran, A., Roche, P.C., & Butler, P.C. (1996). Diabetes mellitus in cystic fibrosis is characterized by islet amyloidosis. *The Journal of Clinical Endocrinology & Metabolism*, 81, 1267-1272. doi: 10.1210/jc.81.3.1267
- Cox, K. (2015). Cystic Fibrosis in the changing NHS. *The UK Cystic Fibrosis Conference; Fighting for a Life Unlimited*. Retrieved on 12/1/2016 from: <https://www.youtube.com/watch?v=QVz8mCR6rtU>

- Cystic Fibrosis. (2015). *Cystic Fibrosis and Vaping*. Retrieved on 27/06/2016 from:
https://www.reddit.com/r/CysticFibrosis/comments/3h3zos/cf_and_vaping/
- Daneman, D. (2006). Type 1 diabetes. *Lancet*, 367, 847-858. doi: 10.1016/S0140-6736(06)68341-4
- Daniels, T., Goodacre, L., Sutton, C., Pollard, K., Conway, S., & Peckham, D. (2011). Accurate assessment of adherence: self-report and clinician report vs electronic monitoring of nebulizers. *Chest*, 140, 425-432. doi: 10.1378/chest.09-3074
- Das, S.K. (2003). Harmful health effects of cigarette smoking. *Molecular and cellular biochemistry*, 253, 158. doi: 10.1023/A:1026024829294
- Day, S. (2012). A reflexive lens: exploring dilemmas of qualitative methodology through the concept of reflexivity. *Qualitative Sociology Review*, 8. Retrieved on 17/12/2014 from:
http://www.qualitativesociologyreview.org/ENG/index_eng.php
- De Ridder, D., Fournier, M., & Bensing, J. (2004). Does optimism affect symptom report in chronic disease? What are its consequences for self-care behaviour and physical functioning? *Journal of Psychosomatic Research*, 56, 341-359. doi: 10.1016/S0022-3999(03)00034-5
- De Vaus, D. (2006). Retrospective study. *The SAGE Dictionary of Social Research Methods*. doi: 10.4135/9780857020116
- Deci, E.L., & Ryan, R.M. (1985). *Intrinsic motivation and self-determination in human behaviour*. New York, USA: Plenum.
- Deci, E.L., & Ryan, R.M. (2000). The “what” and “why” of goal pursuits: human needs and the self-determination of behaviour. *Psychological Inquiry: An International Journal for the Advancement of Psychological Theory*, 11, 227-268. doi: 10.1207/S15327965PLI1104_01
- Del Piero, L.B., Saxbe, D.E., & Margolin, G. (2016). Basic emotion processing and the adolescent brain: task demands, analytic approaches, and trajectories of changes. *Developmental cognitive neuroscience*, 19, 174-189. doi: 10.1016/j.dcn.2016.03.005
- Denscombe, M. (2014). *The good research guide*. (5th ed.). Berkshire, England: Open University Press.
- Denzin, N.K., & Lincoln, Y.S.E. (2000). Introduction: The discipline and practice of qualitative research. In Denzin, N.K., & Lincoln, Y.S.E. (2000). *Handbook of qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.

- Department of Health. (2015a). *Smoking in vehicles*. Retrieved on 29/05/2016 from: <https://www.gov.uk/government/news/smoking-in-vehicles>
- Department of Health. (2015b). *Health matters: smoking and quitting in England*. Retrieved on 29/06/2016 from: <https://www.gov.uk/government/publications/health-matters-smoking-and-quitting-in-england/smoking-and-quitting-in-england>
- Department of Health. (2015c). *Policy, reducing harmful drinking*. Retrieved on 30/01/2017 from: <https://www.gov.uk/government/policies/reducing-harmful-drinking>
- Department of Health. (2016). *Policy, reducing drugs misuse and dependence*. Retrieved on 30/01/2017 from: <https://www.gov.uk/government/policies/reducing-drugs-misuse-and-dependence>
- Derman, U., Demir, G., & Akan, P. (1995). Is awareness of its risk enough to stop people from smoking? *Journal of Cancer Education*, 10, 68-70. doi: 10.1080/08858199509528337
- Dillard, A.J., Midboe, A.M., & Klein, W.M.P. (2009). The dark side of optimism: unrealistic optimism about problems with alcohol predicts subsequent negative event experiences. *Personality and Social Psychology Bulletin*, 35, 1540-1550. doi: 10.1177/0146167209343124
- Dishion, T.J., Nelson, S.E., Kavanagh, K. (2003). The family check-up with high-risk young adolescents: preventing early-onset substance use by parents monitoring. *Behaviour Therapy*, 34, 553-571. doi: 10.1016/S0005-7894(03)80035-7
- Drugwise. (2016). *Promoting evidence-based information on drugs, alcohol and tobacco*. Retrieved on 30/01/2017 from: <http://www.drugwise.org.uk/how-many-people-use-drugs/>
- Duff, A.J.A., & Latchford, G.J. (2010). Motivational interviewing for adherence problems in cystic fibrosis. *Pediatric Pulmonology*, 45, 211–220. doi: 10.1002/ppul.21103
- Eakin, M.N., Bilderback, A., Boyle, M.P., Mogayzel, P.J., & Riekert, K.A. (2011). Longitudinal association between medication adherence and lung health in people with cystic fibrosis. *Journal of Cystic Fibrosis*, 10, 258-264. doi: 10.1016/j.jcf.2011.03.005
- Economic and Social Research Council. (2017). *Research with children and young people*. Retrieved on 5/6/2017 from: <http://www.esrc.ac.uk/funding/guidance-for-applicants/research-ethics/frequently-raised-topics/research-with-children-and-young-people/>
- Elborn, S., (2016). Cystic fibrosis. *The Lancet*, 388, 19-25. doi: 10.1016/S0140-6736(16)00576-6

- Engstrom, M., & Forsberg, A. (2011). Wishing for deburdening through a sustainable control after bariatric surgery. *International Journal of Qualitative Studies on Health and Well-being*, 6, 1-13. doi: <http://dx.doi.org/10.3402/qhw.v6i1.5901>
- Entwistle, V. A., & Watt, I. S. (1998). Disseminating information about health care effectiveness: a survey of consumer health information services. *Quality in Health Care*, 7, 124–129. Retrieved on 14/01/2016 from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2483600/>
- Erikson, E. (1964). *Insight and responsibility: lectures on the ethical implications of psychoanalytic insight*. New York, USA: Norton.
- Ernst, M.M., Johnson, M.C., & Stark, L.J. (2011). Developmental and psychosocial issues in cf. *Child & Adolescent Psychiatric Clinics of North America*, 19, 263-283. doi: 10.1016/j.chc.2010.01.004
- Fajac, I., & De Boeck, K. (2017). New horizons for cystic fibrosis treatment. *Pharmacology & Therapeutics*, 170, 205-211. doi: 10.1016/j.pharmthera.2016.11.009
- Festinger, L. (1954). A theory of social comparison processes. *Human Relations*, 7, 117-140. doi: 10.1177/001872675400700202
- Festinger, L. (1957). *A Theory of cognitive dissonance*. Stanford, CA: Stanford University Press.
- Fielden, A.L., Sillence, E., & Little, L. (2011). Children's understanding's of obesity, a thematic analysis. *International Journal of Qualitative Studies on Health and Wellbeing*, 6, 1-14. doi: 10.3402/qhw.v6i3.7170
- Fielding, N., & Thomas, H. (2008). Qualitative interviewing. In Gilbert, N. (2008). *Researching social life*. London, UK: SAGE.
- Filigino, S. S., Brannon, E. E., Chamberlin, L. A., Sullivan, S. M., Barnett, K. A., & Powers, S. W. (2012). Qualitative analysis of parent experiences with achieving cystic fibrosis nutrition recommendations. *Journal of Cystic Fibrosis*, 11, 125-130. doi: 10.1016/j.jcf.2011.10.006
- Fishbein, M. (1967). *Readings in attitude theory and measurement*. New York: Wiley.
- Fishbein, M., & Ajzen, I. (1975). *Belief, attitude, intention, and behaviour: an introduction to theory and research*. Reading, MA: Addison-Wesley.
- Flay, B.R. (1999). Understanding environmental, situational and intrapersonal risk and protective factors for youth tobacco use: the theory of triadic influence. *Nicotine & Tobacco Research*, 1, 111-114. doi: 10.1080/14622299050011911

- Fore, A.M., Karvonen-Gutierrez, C.A., Talsma, A.N., & Duffy, S.A. (2014). Nurses' delivery of the tobacco tactics intervention at a veterans affairs medical center. *Journal of Clinical Nursing*, 23, 2162-2169. doi: 10.1111/jocn.12460
- Frank. (2009). *Cannabis. Find out the Facts*. Retrieved on 7/3/2016 from:
<http://www.talktofrank.com/sites/default/files/Cannabis%20Find%20Out%20The%20Facts.pdf>
- Frank. (2017). *The highs, the lows and everything in between*. Retrieved on 30/01/2017 from:
<http://www.talktofrank.com/>
- Freemantle, N., & Watt, I. (1994). Dissemination: implementing the findings of research. *Health Libraries Review*, 11, 133-137. doi: 10.1046/j.1365-2532.1994.1120133
- Galvani, S. (2015). Drugs and relationships don't work: children's and young people's views of substance use and intimate relationships. *Child Abuse Review*, 24, 440-451. doi: 10.1002/car/2292
- Garbett, R., & McCormack, B. (2001). The experience of practice development: An exploratory telephone interview study. *Journal of Clinical Nursing*, 10, 94–102. doi: 10.1046/j.1365-2702.2001.00455.x
- Gee, L., Abbott, J., Conway, S.P., Etherington, C., & Webb, A.K. (2000). Development of a disease specific health related quality of life measure for adults and adolescents with cystic fibrosis. *Thorax*, 55, 946-954. doi: 10.1136/thorax.55.11.946
- Gibson, R.L., Burns, J.L., & Ramsey, B.W. (2003). Pathophysiology and management of pulmonary infections in cystic fibrosis. *American Journal of Respiratory and Critical Care Medicine*, 168, 918-951. doi: 10.1164/rccm.200304-505SO
- Gidlof, K., Holmberg, N., & Sandberg, H. (2012). The use of eye-tracking and retrospective interviews to study teenagers' exposure to online advertising. *Visual Communication*, 11, 329-345. doi: 10.1177/1470357212446412
- Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Methods of data collection in qualitative research: interviews and focus groups. *British Dental Journal*, 204, 291-295. doi: 10.1038/bdj.2008.192
- Giroud, C., de Cesare, M., Berthet, A., Varlet, V., Concha-Lozano, N., & Favrat, B. (2015). E-Cigarettes: A review of new trends in cannabis use. *International Journal of Environmental Research and Public Health*, 12, 9988-10008. doi: 10.3390/ijerph120809988

- Glassroth, J., Adams, G.D., & Schnoll, S. (1987). The impact of substance abuse on the respiratory system. *Chest*, *91*, 596-602. doi: 10.1378/chest.91.4.596
- Gloucestershire Confidentiality Policy. (2005). *Confidentiality policy and working guidelines for those working with young people*. Retrieved on 26/02/2016 from: http://www.gloucestershire.gov.uk/media/adobe_acrobat/e/5/confidentiality_document.pdf.
- Goodwin, N., Curry, N., Naylor, C., Ross, S., & Duldig, W. (2010). *Managing people with long-term conditions*. UK: The Kings Fund.
- Goss, C.H., Edwards, T.C., Ramsey, B.W., Aitken, M.L., & Patrick, D.L. (2009). Patient-reported respiratory symptoms in cystic fibrosis. *Journal of Cystic Fibrosis*, *8*, 245-252. doi: 10.1016/j.jcf.2009.04.003
- Götz, I., & Götz, M. (2000). Cystic fibrosis psychological issues. *Paediatric Respiratory Reviews*, *1*, 121-127. doi: 10.1053/prrv.2000.0033.
- Graham, H. (1987). Women's smoking and family health. *Social Sciences and Medicine*, *25*, 47-56. doi: 10.1016/0277-9536(87)90206-1
- Great Ormond Street Hospital for Children. (2017). *Transition to adult services*. Retrieved on 29/05/2017 from: <http://www.gosh.nhs.uk/parents-and-visitors/advice-when-you-leave/transition-adult-services>
- Guion, L.A., Diehl, D.C., & McDonald, D. (2011). Triangulation: establishing the validity of qualitative studies. *University of Florida IFAS Extension*. Retrieved on 17/12/2014 from: <http://edis.ifas.ufl.edu/pdf/files/FY/FY39400.pdf>
- Gutman, L.M., Eccles, J.S., Peck, S., & Malancuk, O. (2011). The influence of family relations on trajectories of cigarette and alcohol use from early to late adolescence. *Journal of Adolescence*, *34*, 119-128. doi: 10.1016/j.adolescence.2010.01.005
- Haire-Joshu, D., Glasgow, R.E., & Tibbs, T.L. (2004). American diabetes association; smoking and diabetes. *Diabetes Care*, *27*, 74-75. doi: 10.2337/diacare.27.2007.S74
- Hajek, P., Etter, J.F., Benowitz, N., Eissenberg, T., & McRobbie, H. (2014). Electronic cigarettes: review of use, content, safety, effects on smokers and potential for harm and benefit. *Addiction*, *109*, 1801-1810. doi: 10.1111/add.12659.
- Hall, S., Munoz, R., & Reus, V. (1994). Cognitive behaviour intervention increases abstinence rates for depressive-history smokers. *Journal of Consulting and Clinical Psychology*, *62*, 141-146. doi: 10.1037/0022-006X.62.1.141

- Hall, S., Munoz, R., Reus, V., & Sees, K. (1993). Nicotine, negative affect and depression. *Journal of Consulting and Clinical Psychology, 61*, 761-767. doi: 10.1037/0022-006X.61.5.761
- Halpern-Felsher, B.L., Biehl, M., Kropp, R.Y., & Rubinstein, M.L. (2004). Perceived risks and benefits of smoking: differences among adolescents with different smoking experiences and intentions. *Preventive Medicine, 39*, 559–567. doi: 10.1016/j.ypmed.2004.02.017
- Halpern-Felsher, B.L., & Cauffman, E. (2001). Costs and benefits of a decision: decision-making competence in adolescents and adults. *Journal of Applied Developmental Psychology, 22*, 257-273. doi: 10.1016/S0193-3973(01)00083-1
- Harness-Brumley, C.L., Elliott, A.C., Rosenbluth, D.B., Raghavan, D., & Jain, R. (2014). Gender differences in outcomes of patients with cystic fibrosis. *Journal of Women's Health, 23*, 1012-1020. doi: 10.1089/jwh.2014.4985
- Hathaway, A.D. (2004). Cannabis users' informal rules for managing stigma and risk. *Deviant Behavior, 25*, 559–577. doi 10.1080/01639620490484095
- Hathaway, A.D., Comeau, N.C., Erickson, P.G. (2011). Cannabis normalization and stigma: contemporary practices of moral regulation. *Criminology & Criminal Justice, 11*, 451-469. doi: 10.1177/1748895811415345
- Hathaway, A.D., & Erickson, P.G. (2003). Drug reform principles and policy debates: harm reduction prospects for cannabis in canada. *Journal of Drug Issues 33*, 467–496. doi: 10.1177/002204260303300209
- Hawkins, S.S., Cole, T.J., & Law, C. (2011). Examining smoking behaviours among parents from the UK millennium cohort study after the smoke-free legislation in Scotland. *Tobacco Control, 20*, 112-118. doi: 10.1136/tc.2010.037028
- Hay, J.L., Ostroff, J., Burkhalter, J., Li, Y., Quiles, Z., & Moadel, A. (2007). Changes in cancer-related risk perception and smoking across time in newly-diagnosed cancer patients. *Journal of Behavioral Medicine, 30*, 131–142. doi: 10.1007/s10865-007-9094-7
- Heale, R., & Forbes, D. (2014). Understanding triangulation in research. *Evidence Based Nursing, 4*, 98. doi: 10.1136/eb-2013-101494
- Health and Safety Executive. (2016). *Work related stress, anxiety and depression statistics in great britain 2016*. Retrieved on 30/01/2017 from: www.hse.gov.uk/statistics/
- Health and Social Care Information Centre. (2012). *Statistics on smoking – England, 2012. National Statistics*. Retrieved on 19/9/2014 from: <http://www.hscic.gov.uk/catalogue/PUB07019>

- Health and Social Care Information Centre. (2016). *Statistics on drug misuse*. Retrieved on 30/05/2017 from:
<http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=3&ved=0ahUKEwibheLGk5fUAhUKAcAKHZEKA3oQFggzMAI&url=http%3A%2F%2Fcontent.digital.nhs.uk%2Fcatalogue%2FPUB21159%2Fdrug-misu-eng-2016-rep.pdf&usq=AFQjCNGcgrFyUQUuSuzZQanAltSvibkyqg>
- Heath, C., & Hindmarsh, J. (2002). *Analysing interaction: video, ethnography and situated conduct*. In May, T. (2002). *Qualitative research in practice*. London, UK: SAGE.
- Hennink, M., Hutter, I., & Bailey, A. (2011). *Qualitative research methods*. UK: SAGE.
- Henriksen, K., Battles, J.B., Marks, E.S., & Lewin, D.I. (2005). *Advances in patient safety from research to implementation; volume 4: programs, tools, and products*. Rockville, US: Agency for Healthcare Research and Quality.
- Henson, J.M., Carey, M.P., Carey, K.B., & Maisto, S.A. (2006). Associations among health behaviors and time perspective in young adults: model testing with boot-strapping replication. *Journal of Behavioural Medicine*, 29, 127-137. doi: 10.1007/s10865-005-9027-2
- Higham, L., Ahmed, S., & Ahmed, M. (2013). Hoping to live a “normal” life whilst living with unpredictable health and fear of death: impact of cystic fibrosis on young adults. *Journal of Genetic Counselling*, 22, 374-383. doi: 10.1007/s10897-012-9555-1
- Hilliard, M.E., Eakin, M.N., Borrelli, B., Green, A., & Riekert, K.A. (2015). Medication beliefs mediate between depressive symptoms and medication adherence in cystic fibrosis. *Health Psychology*, 34, 496-504. doi: 10.1037/hea0000136.
- Hilliard, M.E., Hahn, A., Ridge, A.K., Eakin, M.N., & Riekert, K.A. (2014). User preferences and design recommendations for an mHealth app to promote Cystic Fibrosis self-management. *JMIR Mhealth and Uhealth*, 2, 44. doi: 10.2196/mhealth.3599.
- Hofer, S.E., Rosenbauer, J., Grulich-Henn, J., Naeke, A., Frohlich-Reiterer, E., Holl, R.W., & Wiss, D.P.V. (2009). Smoking and metabolic control in adolescents with type 1 diabetes. *The Journal of Pediatric*, 154, 20-23. doi: 10.1016/j.jpeds.2008.07.052
- Holohan, C.J., & Moos, R.H. (1987). Personal and contextual determinants of coping strategies. *Journal of Personality and Social Psychology*, 52, 946–55. doi: 10.1037/0022-3514.52.5.946
- Horky, S. (2014). Psychosocial challenges related to significant health improvements in cystic fibrosis. *Pediatric Pulmonology*, 49, 434. doi: 10.1002/ppul.23108

- Horne, R. (2000). Assessing perceptions of medications: psychological perspectives. In: McGavock, H. (2000). *Handbook of drug research methodology*. Newcastle upon Tyne, United Kingdom: Drug Utilisation Research Group.
- Horne, R., Weinman, J., Barber, N., Elliott, R.A., & Morgan, M. (2006). *Concordance, adherence and compliance in medicine taking: a conceptual map and research priorities*. Brighton, UK: National Co-ordinating Centre for NHS Service Delivery and Organisation R&D.
- Houston, S. (2001). Beyond social constructionism: critical realism and social work. *The British Journal of Social Work*, 31, 845-861. doi: 10.1093/bjsw/31.6.845
- Howitt, D. (2013). *Introduction to qualitative methods in psychology (2nd ed.)*. Harlow, UK: Pearson.
- Humphrey, C. (2014). Qualitative research: mixed emotions. *Qualitative Research in Accounting & Management*, 11, 51-70. doi: 10.1108/QRAM-03-2014-0024
- Huq, S., Sureshkumar, S., Kalidindi, S., Chandramouli, S., Greenwood, J., & Walshaw, M.J. (2011). Smoking, alcohol and drug use in cystic fibrosis patients. *Journal of Cystic Fibrosis*, 10, 98. doi: 10.1016/S1569-1993(11)60397-4
- Informal Communication. (2015). *The Cystic Fibrosis Nursing Association Study Day*. Birmingham, UK.
- Jacks, J.Z., & Cameron, K.A. (2003). Strategies for resisting persuasion. *Basic and Applied Social Psychology*, 25, 145-161. doi: 10.1207/S15324834BASP2502_5
- Jackson, R., & Pencharz, P.B. (2003). Cystic fibrosis. *Best Practice and Research Clinical Gastroenterology*, 17, 212-235. doi: 10.1053/ybega.2003.370.
- Jacobson, A.M., Hauser, S.T., Powers, S., & Noam, G. (1982). Ego development in diabetics: a longitudinal study. In: Pacaud, D., & Yale, J.F. (2005). Exploring a black hole: transition from paediatric to adult care services for youth with diabetes. *Paediatrics & Child Health*, 10, 31-34. doi: 10.1093/pch/10.1.31
- Jaén, C.R., Stange, K. C., Tumiel, L. M., & Nutting, P. (1997). Missed opportunities for prevention: smoking cessation counseling and the competing demands of practice. *The Journal of Family Practice*. 45, 348-354. Retrieved on 14/01/2016 from: <http://go.galegroup.com/ps/anonymous?id=GALE%7CA20097070&sid=googleScholar&v=2.1&it=r&linkaccess=fulltext&issn=00943509&p=AONE&sw=w&authCount=1&isAnonymousEntry=true>

- Jamner, L.D., Whalen, C.K., Loughlin, S.E., Mermelstein, R., Audrain-McGoven, J., Krishnan-Sarin, S., Worden, J.K., & Leslie, F.M. (2003). Tobacco use across the formative years: a road map to developmental vulnerabilities. *Nicotine & Tobacco Research, 5*, 71-87. doi: 10.1080/14622200310001625573
- Jeppe, C.Y., Szabo, C.P., & Smith, M.D. (2015). Chronic pancreatitis, depression and substance use disorders: A not uncommon combination. *South African Medical Journal, 105*, 179-180. doi: 10.7196/samj.8885
- Johnson, E.O., & Schultz, L. (2005). Forward telescoping bias in reported age of onset: an example from cigarette smoking. *International Journal of methods in Psychiatric Research, 14*, 19-29. doi: 10.1002/mpr.2
- Kamerow, D. (2015). Teenagers, smoking, and vaping. *The British Medical Journal, 350*, 2110. doi: 10.1136/bmj.h2110
- Karamanidou, C., Weinman, J., & Horne, R. (2008). Improving haemodialysis patients' understanding of phosphate-binding medication: a pilot study of psycho-educational intervention designed to change patients' perceptions of the problem and treatment. *British Journal of Health Psychology, 13*, 205-214. doi: 10.1348/135910708X288792
- Kassel, J.D., Stroud, I.R., & Paronis, C.A. (2003). Smoking, stress and negative affect: correlation, causation, and context across stages of smoking. *Psychological Bulletin, 129*, 270-304. doi: 10.1037/0033-2909.129.2.270
- Kavanagh, D., Klein, B., Austin, D., Proudfoot, J., Kay-Lambkin, F., Connor, J., Young, R., Connolly, J.M., White, A., & Kyrios, M. (2011). Evaluating online psychological interventions for alcohol and depression. *Australian Professional Society on Alcohol and other Drugs Conference, 2011*, 48-49. doi: 10.1111/j.1465-3362.2011.00355.x
- Kelley, J.M., Kraft-Todd, G., Schapira, L., Kossowsky, J., & Riess, H. (2014). The influence of the patient-clinician relationship on healthcare outcomes: a systematic review and meta-analysis of randomized controlled trials. *PLoS One, 9*, doi: 10.1371/journal.pone.0094207
- Kelly, M. (1992). Self, identity and radical surgery. *Sociology of Health and Illness, 14*, 390-415. doi: 10.1111/1467-9566.ep11357507
- Kerem, B., Rommens, J.M., Buchanan, J.A., Markiewicz, D., Cox, T.K., Chakravarti, A., Buchwald, M., & Tsui, L.C. (1989). Identification of the cystic fibrosis gene: genetic analysis. *Science, 245*, 1073-1080. doi: 10.1126/science.2570460

- Kettler, L.J., Sawyer, S.M., Winefield, H.R., & Greville, H.W. (2002). Determinants of adherence in adults with cystic fibrosis. *An International Journal of Respiratory Medicine; THORAX*, 57, 459-464. doi: 10.1136/thorax.57.5.459
- Keyte, R., Beswick, L., Rayner, O., Bryon, M., Carr, S.B., & Medhurst, N. (2017a). Orkambi: the expectations of benefit for people in the UK with cystic fibrosis. *Journal of Cystic Fibrosis*, 16, S77. doi: 10.1016/S1569-1993(17)30416-2
- Keyte, R., Beswick, L., Rayner, O., Bryon, M., Carr, S.B., & Medhurst, N. (2017b). Self-reported motivators to treatment adherence in adults with cystic fibrosis in the UK. *Journal of Cystic Fibrosis*, 16, S62. doi: 10.1016/S1569-1993(17)30365-X
- Keyte, R., Egan, H., Jackson, C., Nash, E., Regan, A., & Mantzios, M. (2017c). A weekend / weekday comparison in adherence to daily treatment regimens for adults with cystic fibrosis. *Health Psychology Report* [Under Review].
- Kilbourne, A.M. (2005). Depression linked to inadequate medication adherence. *Diabetic Microvascular Complications Today*. Retrieved on 5/6/2015 from: http://www.diabeticmctoday.com/HtmlPages/DMC0505/PDFs/DMC_Kilbourne.pdf
- King, J. (2015). Moving mountains. *The UK Cystic Fibrosis Conference; Fighting for a Life Unlimited*. Retrieved 12/1/2016 from: <https://www.youtube.com/watch?v=QVz8mCR6rtU>
- Knoll, L.J., Magis-Weinberg, L., Speekenbrink, M., & Blakemore, S.J. (2015). Social influence on risk perception during adolescence. *Psychological Science*, 26, 1-10. doi: 10.1177/0956797615569578
- Kriemler, S., Radtke, T., Christen, G., Kerstan-Huber, M., & Hebestreit, H. (2016). Short-term effect of different physical exercises and physiotherapy combinations on sputum expectoration, oxygen saturation, and lung function in young patients with cystic fibrosis. *Lung*, 194, 659-664. doi: 10.1007/s00408-016-9888-x
- Krumpal, I. (2013). Determinants of social desirability bias in sensitive surveys: a literature review. *Quality and Quantity*, 4, 2025-2047. doi: 10.1007/s11135-011-9640-9
- Kubler-Ross, E. (1969). In Carey, R.G. (1974). Emotional adjustment in terminal patients: a quantitative approach. *Journal of Counselling Psychology*, 21, 433-439. doi: 10.1037/h0037084
- Kuhn, D. (2006). Do cognitive changes accompany developments in the adolescent brain? *Perspectives on psychological science*, 1, 59-67. doi: 10.1111/j.1745-6924.2006.t01-2-.x

- Kulich, M., Rosenfeld, M., Gross, C.H., & Wilmott, R. (2003). Improved survival among young patients with cystic fibrosis. *The Journal of Pediatrics*, *142*, 631-636. doi: 10.1067/mpd.2003.197
- Kvale, S., Brinkmann, S. (2009). *Interviews: learning the craft of qualitative research interviewing*. Thousand Oaks, CA: SAGE.
- Lader, D., & Matherson, J. (1991). *Smoking among secondary school children in England (1990). An enquiry carried out by the social survey division of OPCS*. London: HMSO.
- Lakhanpaul, M., Bird, D., Culley, L., Hudson, N., Robertson, N., Johal, N., McFeeters, M., Hamlyn-Williams, C., & Johnson, M. (2014). The use of a collaborative structured methodology for the development of a multifaceted intervention programme for the management of asthma (the MIA project), tailored to the needs of children and families of South Asian origin: a community-based, participatory study. *Health Services and Delivery Research*, *2*, 1-256. doi: 10.3310/hsdr02280
- Lally, P. (2007). Identity and athletic retirement: A prospective study. *Psychology of Sport and Exercise*, *8*, 85-99. doi: <https://doi.org/10.1016/j.psychsport.2006.03.003>
- Lamas, D.J. (2013). Cystic Fibrosis patients losing a connection. *Boston Globe*. Retrieved on 29/04/2016 from: <https://www.bostonglobe.com/lifestyle/health-wellness/2013/11/18/cystic-fibrosis-patients-losing-connection/vl06v1Je4Dil5CLjNLMrMP/story.html>
- Lamb, C.S., & Crano, W.D. (2014). Parents' beliefs and children's marijuana use: evidence for a self-fulfilling prophecy effect. *Addictive Behaviours*, *39*, 127-132. doi: 10.1016/j.addbeh.2013.09.009
- Lamberts, R. (2010). A letter from a doctor to those with chronic diseases. Read it: it's so valuable! *Degos Disease*. Retrieved on 29/04/2016 from: <http://www.degosdisease.com/patients/stories/letter-doctor-those-chronic-diseases-read-it-its-so-valuable>
- Lancaster, T., Stead, L., Silagy, C., & Sowden, A. (2000). Effectiveness of intervention to help people stop smoking: findings from the cochrane library. *The British Medical Journal*, *321*, 355-8. doi: 10.1136/bmj.321.7257.355
- Latchford, G., Duff, A., Quinn, J., Conway, S., & Conner, M. (2009). Adherence to nebulised antibiotics in cystic fibrosis. *Journal of Cystic Fibrosis*, *75*, 141-144. doi:10.1016/j.pec.2008.08.027

- Lawler, R.H., Nakielny, W., & Wright, N.A. (1966). Psychological implications of cystic fibrosis. *Canadian Medical Association Journal*, *94*, 1043 – 1046. Retrieved on 29/9/2014 from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1935422/?page=1>
- Lawrence, R.S., Appleton Gootman, J.A., Sim, L.J. (2009). *Adolescent health service*. Washington DC, USA: National Academics Press.
- Laws, M.B., Rose, G.S., Bezreh, T., Beach, M.C., Taubin, T., Kogelman, L., Gethers, M., & Wilson, I.B. (2012). Treatment acceptance and adherence in HIV disease: patient identity and the perceived impact of physician-patient communication. *Patient Preference and Adherence*, *6*, 893-903. doi: 10.2147/PPA.S36912
- Lawton, R., Conner, M., & McEachan, R. (2009). Desire or reason: predicting health behaviours from affective and cognitive attitudes. *Health Psychology*, *28*, 56-65. doi: 10.1037/a0013424
- Lazarus, R.S. (1966). *Psychological stress and the coping process*. New York: Magraw-Hill.
- Lee, T.J., Cameron, L.D., Wunsche, B., & Stevens, C. (2011). A randomized trial of computer-based communications using imagery and text information to alter representations of heart disease risk and motivate protective behaviour. *British Journal of Health Psychology*, *16*, 72-91. doi: 10.1348/135910710X511709
- Leventhal, H., Benyamini, Y., & Shafer, C. (2007a). Lay beliefs about health and illness. In: Ayers, S. (2007). *Cambridge handbook of psychology, health and medicine*. Cambridge, UK: Cambridge University Press
- Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger. *Medical Psychology*, *2*, 7-30. Retrieved on 4/3/2014 from: http://www.academia.edu/259452/The_Common_Sense_Representation_of_Illness_Danger
- Leventhal, H., & Nerenz, D. (1985). The assessment of illness cognition. In: Karoly, P. (1985). *Measurement strategies in health psychology*. New York, USA: Wiley.
- Leventhal, H., Weinman, J., Leventhal, E.A., & Phillips, L.A. (2007b). Health psychology: the search for pathways between behaviour and health. *Annual Review of Psychology*, *59*, 1-29. doi: 10.1146/annurev.psych.59.103006.093643
- Lippitt, M., Masterson, A.R., Sierra, A., Davis, A.B., & White, M.A. (2014). An exploration of social desirability bias in measurement of attitudes toward breastfeeding in public. *Journal of Human Lactation*, *30*, 358-366. doi: 10.1177/0890334414529020

- Little, P., Griffin, S., Kelly, J., Dickson, N., & Sadler, C. (1998). Effect of education leaflets and questions on knowledge of contraception in women taking the combined contraceptive pill: randomised controlled trial. *British Medical Journal*, *316*, 1948–1952. doi: 10.1136/bmj.316.7149.1948
- Ma, X., Hancock, J., & Naaman, M. (2016). Anonymity, intimacy and self disclosure in social media. *Proceedings of the 2016 CHI conference on human factors in computing systems*. doi: 10.1145/2858036.2858414
- MacFarlane, J., Holmes, W., Gard, P., Thornhill, D., Macfarlane, R., & Hubbard, R. (2002). Reducing antibiotic use for acute bronchitis in primary care: blinded, randomised controlled trial of a patient information leaflet. *British Medical Journal*, *324*, 1–6. doi: 10.1136/bmj.324.7329.91
- Mackay, D.F., Nelson, S.M., Haw, S.J., & Pell, J.P. (2012). Impact of Scotland's smoke-free legislation on pregnancy complications: retrospective cohort study. *PLoS Medicine*, *9*. doi: 10.1371/journal.pmed.1001175
- Mann, C., & Fiona, S. (2000). Internet communication and qualitative research. London, UK: Sage
- Marteau, T.M., Thorne, J., Aveyard, P., Hirst, J., & Sokal, R. (2013). Financial incentives for smoking cessation in pregnancy: protocol for a single arm intervention study. *BioMedCentral Pregnancy and Birth*, *13*, 66. doi: 10.1186/1471-2393-13-66
- Martinic, M. & Measham, F. (2008). *Swimming with crocodiles: the culture of extreme drinking*. New York: Routledge.
- Massey-Chase, R. (2016). Preparing for living a healthy adult life with CF. *UK CF Conference 2016; putting the person in personalised medicine*. East Midlands, UK: The Cystic Fibrosis Trust. Retrieved on 13/09/2016 from: <https://www.cysticfibrosis.org.uk/get-involved/conference-and-meetings/ukcfc>
- Mathieu, I. (2011). What is emotional sobriety? *Psychology Today*. Retrieved on 27/04/2016 from: <https://www.psychologytoday.com/blog/emotional-sobriety/201107/what-is-emotional-sobriety>
- Maxwell, J.A. (2012). *A realist approach for qualitative research*. UK: Sage Publications Inc.

- Mays, D., Streisand, R., Walker, L.R., Prokhorov, A.V., & Tercyak, K.P. (2012). Cigarette smoking among adolescents with type 1 diabetes: strategies for behavioural prevention and intervention. *Journal of Diabetes and its Complications*, 26, 148-153. doi: 10.1016/j.jdiacomp.2012.03.005
- McCarthy, M. (2015). Teens who use e-cigarettes are more likely to take up smoking, US study finds. *The British Medical Journal*, 351, 4471. doi: 10.1136/bmj.h4471
- McEwan, F.A., Hodson, M.E., & Simmonds, N.J. (2012). The prevalence of "risky behaviour" in adults with cystic fibrosis. *Journal of Cystic Fibrosis*, 11, 56-58. doi: 10.1016/j.jcf.2011.09.002
- McHugh, R., McFeeters, D., Boyda, D., O'Neill, S. (2016). Coping styles in adults with cystic fibrosis: implications for emotional and social quality of life. *Psychology, Health & Medicine*, 21, 102-112. doi: 10.1080/13548506.2015.1020317
- McNamara, P.S., McCormack, P., McDonald, A.J., Heaf, L., & Southern, K.W. (2009). Open adherence monitoring using routine data download from an adaptive aerosol delivery nebuliser in children with cystic fibrosis. *Journal of Cystic Fibrosis*, 8, 258-263. doi: 10.1016/j.jcf.2009.04.006
- McSherry, R., & McSherry, W. (2001). Putting research into practice. *Nursing Times*, 23, 36- 37. Retrieved on 29/03/2016 from: <http://www.nursingtimes.net/putting-research-into-practice/200887.fullarticle>
- Mercken, L., Candel, M., van Osch, L., & de Vries, H. (2011). No smoke without fire: the impact of future friends on adolescents smoking behaviour. *British Journal of Health Psychology*, 16, 170-188. doi: 10.1348/135910710X531608.
- Metse, A.P., Bowmann, J.A., Wye, P., Stocklings, E., Adams, M., Clancy, R., Terry, M., Wolfenden, L., Freund, M., Allan, J., Prochaska, J.J., & Wiggers, J. (2014). Evaluating the efficacy of an integrated smoking cessation intervention for mental health patients: study protocol for a randomised controlled trial. *Trials Journal*, 15, 1-7. doi: 10.1186/1745-6215-15-266

- Michaud, P.A., Suris, J.C., & Viner, R. (2007). The adolescent with a chronic condition, epidemiology, developmental issues and health care provision. *Department of Child and Adolescent Health and Development, WHO*. Retrieved on 30/05/2017 from: http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0ahUKEwiGu7lpZfUAhWqKMAKHTjJA0YQFggiMAA&url=http%3A%2F%2Fwhqlibdoc.who.int%2Fpublications%2F2007%2F9789241595704_eng.pdf&usg=AFQjCNGL_1YjUf5vQ3uYYWI7vm3_Wu5zEw
- Miller, S.M., & Mangan, C.E. (1983). Interacting effects of information and coping style in adapting to gynecologic stress: should the doctor tell all? *Journal of Personality and Social Psychology, 45*, 223–6. doi: 10.1037/0022-3514.45.1.223
- Minai, O.A., & Budev, M.M. (2005). Referral for lung transplantation: a moving target. *Chest, 127*, 705–707. doi: 10.1378/chest.127.3.705
- Mitchell, A.J., & Selmes, T. (2007). Why don't patients take their medicine? Reasons and solutions in psychiatry. *Advances in Psychiatric Treatment, 13*, 336-346. doi: 10.1192/apt.bp.106.003194
- Modi, A.C., Lim, C.S., Yu, N., Geller, D., Wagner, M.H., & Quittner, A.L. (2006). A multi-method assessment of treatment adherence for children with cystic fibrosis. *Journal of Cystic Fibrosis, 5*, 177-185. doi: 10.1016/j.jcf.2006.03.002
- Moodie, C., Mackintosh, A.M., & Hastings, G. (2013). Adolescents' response to pictorial warning on the reverse panel of cigarette packs: a repeat cross-sectional study. *Tobacco Control, 24*, 1-5. doi: 10.1136/tobaccocontrol-2013-050999
- Moog, A. (2016). Transition mentor program: Connecting adolescents with adults. *Pediatric Pulmonology, the 30th Annual North American Cystic Fibrosis Conference, 27-29 October 2016*. doi: 10.1002/ppul.23573
- Moola, F.J. (2012). "This is the best fatal illness that you can have": Contrasting and comparing the experiences of parenting youth with Cystic Fibrosis and Congenital Heart Disease. *Qualitative Health Research, 22*, 212-225. doi: 10.1177/1049732311421486

- Moos, R.H., & Schaefer, J.A. (1993). Coping resources and processes: current concepts and measures. In: Goldberger, L., & Breznitz, S. (1993). *Handbook of stress: theoretical and clinical aspects* (2nd ed.). New York, USA: Free Press.
- National Institute on Alcohol and Alcoholism. (2017). *Alcohol's effects on the body*. Retrieved on 27/05/2017 from: <http://www.niaaa.nih.gov/alcohol-health/alcohols-effects-body>
- Newcombe, T. (2013). Stress and presenteeism “sapping UK productivity”, says research. *HR*. Retrieved on 27/2/2014 from <http://www.hrmagazine.co.uk/hro/news/1077290/stress-presenteeism-sapping-uk-productivity-research>
- NHS. (2015). Acute pancreatitis. *NHS Choices; Your health, your choice*. Retrieved on 30/01/2017 from: <http://www.nhs.uk/conditions/pancreatitis/pages/introduction.aspx>
- NHS. (2016a). Symptoms of cystic fibrosis. *NHS Choices; your health, your choices*. Retrieved on 30/01/2017 from: <http://www.nhs.uk/Conditions/cystic-fibrosis/Pages/Symptoms.aspx>
- NHS. (2016b). Treating cystic fibrosis. *NHS Choices; your health, your choices*. Retrieved on 30/01/2017 from: <http://www.nhs.uk/Conditions/cystic-fibrosis/Pages/Treatment.aspx>
- NHS. (2016c). The risks of drinking too much. *NHS Choices; Your health, your choice*. Retrieved on 30/01/2017 from: <http://www.nhs.uk/Livewell/alcohol/Pages/Effectsofalcohol.aspx>
- NHS. (2016d). Alcohol support. *NHS Choices; Your health, your choice*. Retrieved on 30/01/2017 from: <http://www.nhs.uk/Livewell/alcohol/Pages/Alcoholsupport.aspx>
- NHS Choices. (2015). *Transition planning for disabled young people*. Retrieved on 29/05/2017 from: <http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/transition-planning-disabled-young-people.aspx>
- NHS Choices. (2016). *Diagnosing cystic fibrosis*. Retrieved on 30/05/2017 from: <http://www.nhs.uk/Conditions/cystic-fibrosis/Pages/Diagnosis.aspx>
- NHS Choices. (2017). *Your health, your choices*. Retrieved on 12/06/2017 from: <http://www.nhs.uk/pages/home.aspx>
- NHS Digital. (2016). *Statistics on Alcohol, England, 2016*. Retrieved on 30/06/2017 from: <http://content.digital.nhs.uk/catalogue/PUB20999>
- NHS Health Check. (2017). *Free nhs health check; helping you prevent heart disease, stroke, diabetes, kidney disease and dementia*. Retrieved on 30/01/2017 from: <http://www.healthcheck.nhs.uk/>

- NHS Institute for Innovation and Improvement. (2010). *Knowledge improvement and research*. Retrieved on 29/03/2016 from: http://www.institute.nhs.uk/nhs_alert/knowledge_improvement_and_research/knowledge_improvement_and_research.html
- NIDA. (2016). Marijuana. *The Science Behind Drug Abuse*. Retrieved on 9/3/2016 from: <http://teens.drugabuse.gov/drug-facts/marijuana>
- Novick, G. (2008). Is there a bias against telephone interviews in qualitative research? *Research in Nursing & Health*, 31, 391-398. doi: 10.1002/nur.20259
- NSPCC. (2013). *Conducting safe and ethical research with children*. Retrieved on 26/02/2016 from: <https://www.nspcc.org.uk/globalassets/documents/information-service/factsheet-conducting-safe-ethical-research-children.pdf>.
- O'Brien, K.S., Caputi, P., Minto, R., Peoples, G., Hooper, C., Kell, S., & Sawley, E. (2009). Upward and downward physical appearance comparisons: development of scales and examination of predictive qualities. *Body Image*, 6, 201-206. doi: 10.1016/j.bodyim.2009.03.003
- O'Reilly, K. (2012). Ethnographic returning, qualitative longitudinal research and the reflexive analysis of social practice. *The Sociological Review*, 60, 518-536. doi: 10.1111/j.1467-954X.2012.02097.x
- Office for National Statistics. (2011). *General lifestyle survey*. Retrieved on 15/07/2014 from: <http://www.ons.gov.uk/ons/rel/ghs/general-lifestyle-survey/2011/index.html>
- Office for National Statistics. (2012). *Opinions and lifestyle survey*. Retrieved on 13/10/2014 from: <http://www.ons.gov.uk/ons/rel/ghs/opinions-and-lifestyle-survey/index.html>
- Office for National Statistics. (2013). *Integrated household survey, January to December 2013*. Retrieved on 12/10/2014 from: <http://www.ons.gov.uk/ons/rel/integrated-household-survey/integrated-household-survey/index.html>
- Ogden, J. (2012). *Health psychology; a text book*. (5th ed.). Berkshire, UK: Open University Press.
- Ong, T., Schechter, M.S., Yang, J., Peng, L., Emerson, J., Gibson, R.L., Morgan, W., & Rosenfeld, M. (2017). Socioeconomic status, smoke exposure, and health outcomes in young children with cystic fibrosis. *Pediatrics*, 139, 1-11. doi: 10.1542/peds.2016-2730

- Orens, J.B., Estenne, M., Arcasoy, S., Conte, J.V., Corris, P., Egan, J.J., Egan, T., Keshavjee, S., Knoop, C., Kotloff, R., Martinex, F.J., Nathan, S., Palmer, S., Patterson, A., Singer, L., Snell, G., Studer, S., Vachieri, J.L., & Glanville, A.R. (2006). International guidelines for the selection of lung transplant candidates: 2006 update—a consensus report from the pulmonary scientific council of the international society for heart and lung transplantation. *Journal of Heart and Lung Transplantation*, *25*, 745–755. doi: 10.1016/j.healun.2006.03.011
- Orenstein, D.M. (2004). *Cystic fibrosis: a guide for patient and family (3rd ed.)*. Philadelphia, USA: Lippincott Williams & Williams.
- Orr, D.P., Weller, S.C., Satterwhite, B., & Pless. I.B. (1984). Psychosocial implications of chronic illness in adolescence. *Journal of Paediatrics*, *104*, 152-157. doi: 10.1016/S0022-3476(84)80616-2
- Owen, E. (2016). Putting people with CF at the heart of everything we do. *UK CF Conference 2016; putting the person in personalised medicine*. East Midlands, UK: The Cystic Fibrosis Trust. Retrieved on 13/09/2016 from: <https://www.cysticfibrosis.org.uk/get-involved/conference-and-meetings/ukcfc/video-gallery>
- Pacaud, D., & Yale, J.F. (2005). Exploring a black hole: transition from paediatric to adult care services for youth with diabetes. *Paediatrics & Child Health*, *10*, 31-34. doi: 10.1093/pch/10.1.31
- Parker, I. (1998). *Social constructionism, discourse and realism*. London, UK: SAGE Publications Ltd.
- Parker, H., Williams, L., & Aldridge, J. (2002) The normalisation of sensible recreational drug use: further evidence from the north west longitudinal study. *Sociology*, *36*, 941-964. doi: 10.1177/003803850203600408
- Patterson, J.M., Wall, M., Berge, J., & Milla, C. (2008). Gender differences in treatment adherence among youth with cystic fibrosis: Development of a new questionnaire. *Journal of Cystic Fibrosis*, *7*, 154-164. doi: 10.1016/j.jcf.2007.07.008
- Patton, M.Q. (2015). *Qualitative evaluation and research methods (4th ed.)*. UK: Sage.
- Peacock, L., & Sanghan, R. (2014). Teenagers more confident talking to each other via smartphones than face-to-face - study. *The Telegraph*. Retrieved on 28/11/2016 from: <http://www.telegraph.co.uk/women/mother-tongue/10793984/Teenagers-more-confident-talking-to-each-other-via-smartphones-than-face-to-face-study.html>

- Pellecchia, L.G. (1999). Dissemination of research findings: conference presentations and journal publications. *Topics in Geriatric Rehabilitation, 14*, 67-79. doi: 10.1097/00013614-199903000-00010
- Perkins, K.A., Karelitz, J.L., Giedgowd, G.E., Conklin, C.A., & Sayette, M.A. (2010). Acute negative affect relief from smoking depends on the affect situation and measure but not on nicotine. *Biological Psychiatry, 67*, 707-714. doi: 10.1016/j.biopsych.2009.12.017
- Pinkerton, K. (2013). Cystic fibrosis life expectancy statistics. *Disabled World*. Retrieved on 8/4/2014 from: <http://www.disabled-world.com/health/respiratory/cystic-fibrosis/life-expectancy.php>
- Pisinger, C., & Døssing, M. (2014). A systematic review of health effects of electronic cigarettes. *Preventive Medicine, 69*, 248-260. doi: <http://doi.org.ezproxy.bcu.ac.uk/10.1016/j.ypmed.2014.10.009>
- Price, S. (2011). To what extent has recreational drug use become normalised amongst the student population at university? *Internet Journal of Criminology*. Retrieved on 14/1/2015 from: http://www.internetjournalofcriminology.com/Price_Recreational_Drug_Use_Amongst_the_Student_Population_IJC_July_2011.pdf
- Pritchard, K., & Whiting, R. (2012). Autopilot?: a reflexive review of the piloting process in qualitative e-research. *Qualitative research in organizations and management, 7*, 338-353. doi: 10.1108/17465641211279798
- Prochaska, J.O., & DiClemente, C.C. (1982). Transtheoretical therapy: toward a more integrative model of change. *Psychotherapy: Theory Research and Practice, 19*, 276-288. doi: 10.1037/h0088437
- Quicke, J., & Winter, C. (1994). Labeling and learning: an interactionist perspective. *Support for Learning, 9*, 16-21. doi: 10.1111/j.1467-9604.1994.tb00150.x
- Quittner, A.L., Goldbeck, L., Abbott, J., Duff, A., Lambrecht, P., Solé, A., Tibosch, M., Brucefors, A.B., Yüksel, H., Catastini, P., Blackwell, L., & Burker, D. (2014). Prevalence of depression and anxiety in patients with cystic fibrosis and parent caregivers: results of the international depression epidemiological study across nine countries. *Thorax, 69*, 1090-1097. doi: 10.1136/thoraxjnl-2014-205983
- Quittner, A., Modi, A.C., Lemanek, K.L., Ievers-Landis, C.E., & Rapoff, M.A. (2008). Evidence-based assessment of adherence to medical treatments in pediatric psychology. *Journal of Pediatric Psychology, 33*, 916-936. doi: 10.1093/jpepsy/jsm064

- Quittner, A.L., Zhang, J., Marynchenko, M., Chopra, P.A., Signorovitch, J., Yushkina, Y., & Riekert, K.A. (2014). Pulmonary medication adherence and health-care use in cystic fibrosis. *Chest*, *146*, 142-151. doi: 10.1378/chest.13-1926
- Rabiau, M., Knauper, B., & Miquelon, P. (2006). The eternal quest for optimal balance between maximizing pleasure and minimizing harm: the compensatory health benefits model. *British Journal of Health Psychology*, *11*, 139-153. doi: 10.1348/135910705X52237
- Radtke, T., Scholz, U., & Keller, R. (2011). Smoking specific compensatory health beliefs and the readiness to stop smoking in adolescents. *British Journal of Health Psychology*, *16*, 610-625. doi: 10.1348/2044-8287.002001
- Raynor, D.K., & Knapp, P. (2000). Do patients see, read and retain the new mandatory medicines information leaflets? *The Pharmaceutical Journal*, *264*, 268-270. doi: 10.1211/ijpp.15.3.0008
- Raynor, D.K., Silcock, J., Knapp, P., & Edmondson, H. (2007). *International Journal of Pharmacy Practice*, *15*, 209-218. doi: 10.1211/ijpp.15.3.0008
- Read, A.M., & Mayberry, J.F. (2000). Doctor or nurse? The patients' choice. *Postgraduate Medical Journal*, *76*, 212-214. doi: 10.1136/pmj.76.894.212
- Reddit. (2015). *CF and Vaping*. Retrieved on 29/06/2016 from: https://www.reddit.com/r/CysticFibrosis/comments/3h3zos/cf_and_vaping/
- Rhodes, R.E., Fiala, B., & Conner, M. (2010). A review and meta-analysis of affective judgements and physical activity in adult populations. *Annals of Behavioural Medicine*, *38*, 180-204. doi: 10.1007/s12160-009-9147-y.
- Rhys, S. (2011). Helping cystic fibrosis patients: a nurse's account. *The Trauma and Mental Health Report*. Retrieved on 13/05/2016 from: <http://trauma.blog.yorku.ca/2011/05/helping-cystic-fibrosis-patients-a-nurses-account/>
- Richards, T. (2015). A parent perspective. *The UK Cystic Fibrosis Conference; Fighting for a Life Unlimited*. Retrieved on 12/1/2016 from: <https://www.youtube.com/watch?v=a8lQ-CEprJQ>
- Richmond. (2014). Risky behaviour training programme. *Children's workforce development*. Retrieved on 23/10/2014 from: http://www.richmond.gov.uk/risky_behaviour_programme
- Roesch, S.C., & Weiner, B. (2001). A meta-analytic review of coping with illness. Do causal attributions matter? *Journal of Psychosomatic Research*, *50*, 205-19. doi: 10.1016/S0022-3999(01)00188-X

- Rosen, D.S. (1991). Pubertal growth and sexual maturation for adolescents with chronic illness or disability. *Pediatrician*, *18*, 105-120. Retrieved on 21/10/2014 from: <http://psycnet.apa.org/psycinfo/1991-33278-001>
- Rosenfeld, M., Davis, R., Simmons, S., Pepe, M., & Ramsey, B. (1997). Gender gap in cystic fibrosis mortality. *American Journal of Epidemiology*, *145*, 794-803. doi: 10.1093/oxfordjournals.aje.a009172
- Ross-Durow, P.L., Veliz, P.T., McCabe, S.E., & Boyd, C.J. (2015). *Drug and Alcohol Dependence*, *146*, 83-84. doi: 10.1016/j.drugalcdep.2014.09.596
- Roth, S., & Cohen, L.J. (1986). Approach, avoidance, and coping with stress. *American Psychologist*, *41*, 813–9. doi: 10.1037/0003-066X.41.7.813
- Royal College of General Practitioners. (2011). *Confidentiality and young people toolkit; improving teenagers' uptake of sexual and other health advice*. UK: RCGP.
- Rubin, H.J., & Rubin, I.S. (1995). *Qualitative interviewing: the art of hearing data*. Thousand Oaks, CA: SAGE.
- Sakiani, S., Chernick, M.S., Zhao, X., Eccleston, J.L., Hoofnagle, J., Koh, C., & Heller, T. (2017). Cystic fibrosis liver disease - development of a novel criteria to identify a second wave of liver disease in adults. *Gastroenterology*, *146*, 929. doi: 10.1016/S0016-5085(14)63376-X
- Saldana, P.S., & Pomeranz, J.L. (2012). Cystic fibrosis and the workplace: a review of the literature. *Work*, *42*, 185-193. doi: 10.3233/WOR-2012-1353
- Santrock, J.W. (1995). Erikson's theory. In: Santrock, J.W. (1995). *Life-span development* (5th ed.). Dubuque: Brown and Benchmark.
- Sanzone, L.A., Lee, J.Y., Divaris, K., DeWalt, D.A., Baker, A.D., Vann, W.F. (2013). A cross sectional study examining social desirability bias in caregiver reporting of children's oral health behaviours. *BMC Oral Health*, *1*, 24-33. doi: 10.1186/1472-6831-13-24
- Sarna, L., Bialous, S.A., Zou, A.N., Hong, J., Chan, S., Wells, M.J., & Brook, J. (2016). Helping smokers quit: behaviours and attitudes of chinese registered nurses. *Journal of Advanced Nursing*, *72*, 107-117. doi: 10.1111/jan.12811
- Sawicki, G.S., Heller, K.S., Demars, N., & Robinson, W.M. (2015). Motivating adherence among adolescents with cystic fibrosis: youth and parent perspectives. *Pediatric Pulmonology*, *50*, 127-136. doi: 10.1002/ppul.23017

- Scheier, M.F., & Carver, C.S. (1985). Optimism, coping and health: assessment and implications of generalised outcome expectancies. *Health Psychology, 4*, 219–47. doi: 10.1037//0278-6133.4.3.219
- Schwartz, B. (2016). Using storytelling to shape the way we do medicine - how can physicians use 'narrative medicine' to provide better care for the cystic fibrosis community? *The UK CF Conference; putting the person in personalised medicine*. Retrieved on 10/10/2016 from: https://www.cysticfibrosis.org.uk/get-involved/conference-and-meetings/ukcfc?gclid=Cj0KEQIAtqHEBRCNrdC6rYq9_oYBEiQAejvRI3b08F6hB-KFJxWct0QYaQT45JvsTfx3FRwomFCOzMlaAi6k8P8HAQ
- Schwarz, N. (2004). *Retrospective and concurrent self-reports: the rationale for real-time data capture*. From: Stone, A., Shiffman, S.S., Atienza, A., & Nebeling, L. (2007). *The science of real-time data capture: self-reports in health research* (pp. 11-26). New York, USA: Oxford University Press.
- Scott, K., & McSherry, R. (2009). Evidence-based nursing: clarifying the concepts for nurses in practice. *Journal of Clinical Nursing, 8*, 1085-1095. doi: 10.1111/j.1365-2702.2008.02588
- Seaman, P., & Ikegquonu, T. (2010). Drinking to belong; understanding young adults' alcohol use within social networks. *Joseph Rowntree Foundation*. Retrieved on 14/1/2015 from: <http://www.jrf.org.uk/sites/files/jrf/alcohol-young-adults-full.pdf>
- Shaw, C., Brady, L.M., & Davey, C. (2011). *Guidelines for research with children and young people*. London, UK: NCB Research Centre.
- Shepherd, A., Sanders, C., Doyle, M., & Shaw, J. (2017). Using social media for support and feedback by mental health service users: thematic analysis of a twitter conversation. *Biomed Central Psychiatry, 19*, 15-29. doi: 10.1186/s12888-015-0408-y.
- Sherman, D.A.K., Nelson, L.D., & Steele, C.M. (2000). Do messages about health risks threaten the self? Increasing the acceptance of threatening health messages via self-affirmation. *Personality and Social Psychology Bulletin, 26*, 1046-1059. doi: 10.1177/01461672002611003
- Sims, M., Maxwell, R., Bauld, L., & Gilmore, A. (2010). Short term impact of smoke-free legislation in England: retrospective analysis of hospital admission for myocardial infarction. *British Medical Journal, 340*, 2161. doi: 10.1136/bmj.c2161

- Sims-Schouten, W., Riley, S.C.E., & Willig, C. (2007). A presentation of a systematic method of analysis using women's talk of motherhood, childcare and female employment as an example. *Theory & Psychology, 7*, 101-124. doi: 10.1177/0959354307073153
- Sinaasappel, M., Stern, M., Littlewood, J., Wolfe, S., Steinkamp, G., Heijerman, H.G.M., Robberecht, E., & Doring, G. (2002). Nutrition in patients with cystic fibrosis. *Journal of Cystic Fibrosis, 1*, 51-75. doi: 10.1016/S1569-1993(02)00032
- Singhal, A., Thomas, P., Cook, R., Wierenga, K., & Serjeant, G. (1994). Delayed adolescent growth in homozygous sickle cell disease. *Archives of Disease in Childhood, 71*, 404-408. doi: 10.1136/adc.71.5.404
- Skånfors, L. (2009). Ethics in child research: children's agency and researchers' ethical radar. *Childhoods Today, 3*, 1-22. Retrieved on 26/02/2016 from: <http://www.childhoodstoday.org/download.php?id=40>.
- Smedley, J., Jancey, J.M., Dhaliwal, S., Zhao, Y., Monteiro, M.D.R., & Howat, P. (2015). Women's reported health behaviours before and during pregnancy: A retrospective study. *Health Education Journal, 73*, 28-40. doi: 10.1177/0017896912469570
- Smith, A. (2013). *Smartphone ownership-2013 update*. Washington DC, USA: Pew Research Center. Retrieved on 20/11/2015 from [http://boletines.prisadigital.com/IPIP_Smartphone_adoption_2013 .pdf](http://boletines.prisadigital.com/IPIP_Smartphone_adoption_2013.pdf)
- Smith, E.M. (2005). Telephone interviewing in healthcare research: A summary of the evidence. *Nurse Researcher, 12*, 32-41. doi: 10.7748/nr2005.01.12.3.32.c5946
- Smith, A., & Gouick, L. (2015). 30 day challenge - using social media to support adult CF patients to exercise in the adult CF service Dundee. *Journal of Cystic Fibrosis; Abstracts of the European Cystic Fibrosis Conference, Brussels, Belgium, 10-13 June 2015*. doi: 10.1016/S1569-1993(15)30028-X
- Smoking in England. (2016). *Providing the latest information on smoking and smoking cessation in England*. Retrieved on 29/06/2016 from: <http://www.smokinginengland.info/>
- Smyth, A. (2016). Treatment of pulmonary exacerbations in cystic fibrosis - could do better? *Paediatric Respiratory Reviews, 20*, 6-7. doi: 10.1016/j.prrv.2016.06.004
- Smyth, A., O'Hea, U., Williams, G., Smyth, R., & Heaf, D. (1994). Passive smoking and impaired lung function in cystic fibrosis. *Archives of Disease in Childhood, 71*, 353-4. doi: 10.1136/adc.71.4.353

- Snipes, D.J., & Benotsch, E.G. (2013). High-risk cocktails and high-risk sex: examining the relation between alcohol mixed with energy drink consumption, sexual behaviour, and drug use in college students. *Addictive Behaviours*, *38*, 1418-1423. doi: 10.1016/j.addbeh.2012.07.011
- Solberg, L.I., Desai, J.R., O'Connor, P.J., Bishop, D.B., & Devlin, H.M. (2004). Diabetic patients who smoke: are they different? *Annals of Family Medicine*, *2*, 26-32. doi: 10.1370/afm.36
- Stoltz, D.A., Meyerholz, D.K., & Welsh, M.J. (2015). Origins of cystic fibrosis lung disease. *The New England Journal of Medicine*, *372*, 351-362. doi: 10.1056/NEJMra1300109
- Sturges, J.E., & Hanrahan, K.J. (2004). Comparing telephone and face-to-face qualitative interviewing: A research note. *Qualitative Research*, *4*, 107–118. doi: 10.1177/1468794104041110
- Sundbom, L.T., & Bingefors, K. (2013). The influence of symptoms of anxiety and depression on medication non adherence and its causes: a population based survey of prescription drug users in sweden. *Patient Preference and Adherence*, *7*, 805-811. doi: 10.2147/PPA.S50055
- Super, M. (2003). Cystic fibrosis newborn screen and detection of carriers. *Archives of disease in childhood- fetal and neonatal edition*, *88*. doi: 10.1136/fn.88.6.F448
- Suris, J.C., & Parera, N. (2005). Sex, drugs and chronic illness: health behaviours among chronically ill youth. *European Journal of Public Health*, *15*, 484–488. doi: 10.1093/eurpub/cki001
- Sweet, L. (2002). Telephone interviewing: Is it compatible with interpretive phenomenological research? *Contemporary Nurse*, *12*, 58–63. doi: 10.5172/conu.12.1.58
- Sweet, A.D., & Miller, I.S. (2016). Bingeing on sobriety: white holes, black holes and time;s arrow in the intra-psychic worlds of addicted and substance abusing patients. *British Journal of Psychotherapy*, *32*, 159-174. doi: 10.1111/bjp.12207
- Tan, A. (2015). Study reveals e-cig vapor compromises lung immune response. *Lung Disease News*. Retrieved on 29/11/2016 from: <https://lungdiseaseneews.com/2015/02/06/study-reveals-e-cig-vapor-compromises-lung-immune-response/>
- Targett, K., Bourke, S., Nash, E., Murphy, E., Ayres, J., & Devereux, G. (2014). Employment in adults with cystic fibrosis. *Occupational Medicine*, *64*, 87-94. doi: 10.1093/occmed/kqt140

- Tashkin, D.P. (1990). Pulmonary complications of smoked substance abuse. *The Western Journal of Medicine*, 152, 525-530. Retrieved on 25/11/2014 from:
http://scholar.google.co.uk/scholar_url?hl=en&q=http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1002405/pdf/westjmed00117-0063.pdf&sa=X&scisig=AAGBfm3BsSFVyRNhSeKAx0uB7t-X7VicVA&oi=scholar&ei=TmJ0VI3zFZevaaT5gPgC&ved=0CCEQgAMoADAA
- Taylor, S.E. (1989). *Positive illusions: creative self deception and the healthy mind*. New York, USA: Harper Collins.
- Taylor, S. (2008). Combining qualitative and quantitative methods in researching the dynamics of childhood poverty. *ENQUIRE*, 1, 1-13. Retrieved on 17/12/2014 from:
<http://www.nottingham.ac.uk/sociology/prospective/postgraduate/enquire/enquire-pdfs/taylorsarah.pdf>
- Taylor, L., Tsang, A., & Drabble, A. (2006). Transition of transplant patients with cystic fibrosis to adult care: today's challenges. *Progress in Transplantation*, 16, 329–335. doi: 10.1177/152692480601600408
- Telford, K., Kralik, D., & Koch, T. (2005). Acceptance and denial: implications for people adapting to chronic illness: literature review. *Journal of Advanced Nursing*, 55, 457 – 464. doi: 10.1111/j.1365-2648.2006.03942.x
- Tercyak, K.P. (2004). Personal and social correlates of tobacco use among adolescents with diabetes. *Children's Health Care*, 33, 109-122. doi: 10.1207/s15326888chc3302_2
- Tercyak, K.P., Beville, K.W., Walker, L.R., Prahlad, S., Cogen, F.R., Sobel, D.O., & Streisand, R. (2005). Health attitudes, beliefs, and risk behaviours among adolescents and young adults with type 1 diabetes. *Children's Health Care*, 34, 165-180. doi: 10.1207/s15326888chc3403_1
- Tercyak, K.P., Britto, M.T., Hanna, K.M., Hollen, P.J., & Hudson, M.M. (2008). Prevention of tobacco use among medically at risk children and adolescents: clinical and research opportunities in the interest of public health. *Journal of Pediatric Psychology*, 33, 119-132. doi: 10.1093/jpepsy/jsm132

- The Cystic Fibrosis Trust. (2010). *Nutrition: A guide for adults with cystic fibrosis*. Retrieved on 14/12/2016 from:
<https://webcache.googleusercontent.com/search?q=cache:LNqvq5lZDfMJ:https://www.cysticfibrosis.org.uk/~media/documents/life-with-cf/publications/factsheet-nutrition-for-adults.ashx%3Fla%3Den+&cd=1&hl=en&ct=clnk&gl=uk>
- The Cystic Fibrosis Trust. (2013a). Cystic fibrosis-related diabetes factsheet. *Cystic Fibrosis; our focus*. Retrieved on 13/10/2014 from:
http://www.cysticfibrosis.org.uk/media/127524/FS_Related_Diabetes_Mar_13.pdf
- The Cystic Fibrosis Trust. (2013b). *Peer review report; Birmingham Heartlands Hospital West Midlands Regional Adult CF Centre*. Retrieved on 6/01/2016 from:
<http://heartlandscf.org/index.php?id=315>
- The Cystic Fibrosis Trust. (2013c). *Peer review report: North West Midlands Cystic Fibrosis Centre Adult*. Retrieved on 6/1/2016 from: <https://www.cysticfibrosis.org.uk/media/430940/CC10-B%20-%20NWM%20Adult%20Peer%20Review%20-%20V2.pdf>
- The Cystic Fibrosis Trust. (2014). UK specialist cystic fibrosis centres. *Cystic Fibrosis what, exactly?* Retrieved on 17/12/2014 from: <http://www.cysticfibrosis.org.uk/about-cf/cystic-fibrosis-care/uk-specialist-cf-centres>
- The Cystic Fibrosis Trust. (2015). A CF adolescent perspective (film). *The UK Cystic Fibrosis Conference; Fighting for a Life Unlimited*. Retrieved on 12/1/2016 from:
<https://www.youtube.com/watch?v=a8lQ-CEprJQ>
- The Cystic Fibrosis Trust. (2016a). *Let's get personal*. Retrieved on 23/11/2016 from:
<https://www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/lets-get-personal>
- The Cystic Fibrosis Trust. (2016b). Thinking of starting a family? A guide for adults with cystic fibrosis and their partners. *Cystic Fibrosis supporting your decisions*. Retrieved on 29/04/2016 from: <https://www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/fertility>
- The Cystic Fibrosis Trust. (2017a). *How is cystic fibrosis diagnosed?* Retrieved on 12/06/2017 from:
<https://www.cysticfibrosis.org.uk/en/what%20is%20cystic%20fibrosis/diagnosis>
- The Cystic Fibrosis Trust. (2017b). Transplants in cystic fibrosis. *Cystic Fibrosis what, exactly?* Retrieved on 30/01/2017 from: <http://www.cysticfibrosis.org.uk/about-cf/living-with-cystic-fibrosis/transplants-in-cf>

- The Cystic Fibrosis Trust. (2017c). *Personalised healthcare*. Retrieved on 30/05/2017 from:
<https://www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/cystic-fibrosis-care/personalised-healthcare>
- The Cystic Fibrosis Trust. (2017d). *Adult specialist CF centres in the United Kingdom*. Retrieved on 29/05/2017 from
<https://webcache.googleusercontent.com/search?q=cache:Bc1Z3W9A4nQJ:https://www.cysticfibrosis.org.uk/~media/documents/life-with-cf/care-and-treatment/adult-cf-specialist-centres.ashx%3Fla%3Den+&cd=1&hl=en&ct=clnk&gl=uk>
- The Cystic Fibrosis Trust. (2017e). *Paediatric specialist CF centres in the United Kingdom*. Retrieved on 29/05/2017 from:
<https://webcache.googleusercontent.com/search?q=cache:pD76wxn8Ut4J:https://www.cysticfibrosis.org.uk/~media/documents/life-with-cf/care-and-treatment/paediatric-cf-specialist-centres.ashx%3Fla%3Den+&cd=1&hl=en&ct=clnk&gl=uk>
- The Foundation of Nursing Studies.(2010). *Developing practice subscribers areas*. Retrieved on 29/03/2016 from: <http://www.fons.org/>
- The Telegraph. (2014). *Paris bans smoking in park playgrounds*. Retrieved on 23/10/2014 from:
<http://www.telegraph.co.uk/news/worldnews/europe/france/11172518/Paris-bans-smoking-in-park-playgrounds.html>
- The UK CF Conference. (2016). *Putting the person in personalised medicine*. East Midlands: The CF Trust. Retrieved on 15/09/2016 from: https://www.cysticfibrosis.org.uk/get-involved/conference-and-meetings/ukcfc?gclid=Cj0KEQIAtqHEBRCNrdC6rYq9_oYBEiQAejvRI3b08F6hB-KFJxWct0QYaQT45JvsTfx3FRwomFCOzMlaAi6k8P8HAQ
- Thurmond, V. (2001). The point of triangulation. *Journal of Nursing Scholarship*, 33, 254–256. doi: 10.1111/j.1547-5069.2001.00253.x
- Tierney, S. (2012). Body image and cystic fibrosis: a critical review. *Body Image*, 9, 12-19. doi: 10.1016/j.bodyim.2011.09.001
- Tomashefski, J.F. (2004). The pulmonary pathology of illicit drug and substance abuse. *Current Diagnostic Pathology*, 10, 413-426. doi: 10.1016/j.cdip.2004.04.009
- Toth, C. (2016). "You wouldn't know I have CF": Social isolation and connection among young adults with Cystic Fibrosis. *Paediatric Pulmonology, the 30th annual North American Cystic Fibrosis Conference*, 45, 446.

- Turkel, S., & Pao, M. (2007). Late consequences of pediatric chronic illness. *Psychiatric Clinics of North America*, 30, 819-835. doi: 10.1016/j.psc.2007.07.009
- Tuten, T.L., & Neidermeyer, P.E. (2004). Performance, satisfaction and turnover in call centres: the effects of stress and optimism. *Journal of Business Research*, 57, 26-34. doi: 10.1016/S0148-2963(02)00281-3
- Tyas, S.L., & Pederson, L.L. (1998). Psychosocial factors related to adolescent smoking: a critical review of the literature. *Tobacco Control*, 7, 409-420. doi: 10.1136/tc.7.4.409
- Tyc, V.L., & Belzer, L.T. (2006). Smoking rates and the state of smoking interventions for children and adolescents with chronic illness. *Pediatrics*, 118, 471-487. doi: 10.1542/peds.2004-2413
- University Hospital Southampton. (2014). *Transition to adult care: ready steady go*. Retrieved on 28/11/2016 from: <http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx>
- University Hospital of South Manchester. (2014). *Transitions*. Manchester, United Kingdom: The Manchester Adult Cystic Fibrosis Centre, Wythenshawe Hospital.
- Valentine, C. (2007). Methodological reflections: attending and tending to the role of the researcher in the construction of bereavement narratives. *Qualitative Social Work*, 6, 159-176. doi: 10.1177/1473325007077237
- Van den Heever, A.E., Poggenpoel, M., & Myburgh, C.P.H. (2015). Nurses' perceptions of facilitating genuineness in a nurse-patient relationship. *Health SA Gesondheid*, 20, 109-117. doi: 10.1016/j.hsag.2015.02.003
- Verma, A., Clough, D., McKenna, D., Dodd, M., & Webb, A.K. (2001). Smoking and cystic fibrosis. *Journal of the Royal Society of Medicine*, 94, 29-34. Retrieved on 22/5/2014 from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1310584/pdf/11601162.pdf>
- Viner, R. (1999). Transition from paediatric to adult care; bridging the gaps or passing the buck? *Archives of Disease in Childhood*, 81, 271-275. doi: 10.1136/ad.81.3.271
- Viner, R., & Macfarlane, A. (2005). Health promotion. *British Medical Journal*, 330, 527-529. doi: 10.1136/bmj.330.7490.527
- Visse, M., Abma, T., Oever, H.V.D., Prins, Y., & Gulmans, V. (2013). Perceptions of hospital admission in patients with cystic fibrosis. *Journal of Hospital Administration*, 2, 54-65. doi: 10.5430/jha.v2n3p54

- Vos, T., Barker, B., Stanley, L., & Lopez, A. (2007). *The burden of disease and injury in aboriginal and torres strait islander peoples 2003*. Brisbane: The University of Queensland.
- Wadwa, R.P. (2006). Cardiovascular disease risk in youth with diabetes mellitus. *Reviews in Endocrine & Metabolic Disorders*, 7, 197-204. doi: 10.1007/s11154-006-9016-y
- Weinstein, N. D. (1980). Unrealistic optimism about future life events. *Journal of Personality and Social Psychology*, 39, 806-820. doi: 10.1037/0022-3514.39.5.806
- Weinstein, N.D. (1983). Reducing unrealistic optimism about illness susceptibility. *Health Psychology*, 2, 11-20. doi: 10.1037/0278-6133.2.1.11
- Weinstein, N.D. (1988). The precaution adoption process. *Health Psychology*, 7, 355–386. Retrieved on 13/10/2014 from: <http://psandman.com/articles/PAPM.pdf>
- Weinstein, N.D. (1999). What does it mean to understand a risk? evaluating risk comprehension. *Journal of the National Cancer Institute*, 25, 15–20. doi: 10.1093/oxfordjournals.jncimonographs.a024192
- Weinstein, N.D., Marcus, S.E., & Moser, R.P. (2005). Smokers' unrealistic optimism about their risk. *Tobacco Control*, 14, 55-59. doi: 10.1136/tc.2004.008375
- Wiener, L.S., & Battles, H.B. (2006). Untangling the web: a close look at diagnosis disclosure among HIV-infected adolescents. *Journal of Adolescent Health*, 38, 307-309. doi: 10.1016/j.jadohealth.2005.03.024
- Wilderman, M. (2015). Motivational Interviewing. *North West Midlands Cystic Fibrosis Centre Regional Meeting*.
- Wiles, R., Crow, G., Heath, S., & Charles, V. (2006). *Anonymity and confidentiality*. Retrieved on 26/2/2016 from: http://www.sociology.soton.ac.uk/proj/informed_consent/index.htm
- Willig, C. (1999). Beyond appearances: a critical realist approach to social constructionism. In Nightingale, D.J., & Cromby, J. (1999). *Social constructionist psychology: a critical analysis of theory and practice*. Open University Press: UK.
- Winefield, T., Montgomery, B., Gault, U., Muller, J., O'Gorman, J., Reser, J., & Roland, D. (2000). The psychology of work and unemployment. *The Australian Psychological Society Ltd*. doi: 10.1080/00050060210001706606
- Withers, A.L. (2012). Management issues for adolescents with cystic fibrosis. *Pulmonary Medicine*, 1, 1-10. doi:10.1155/2012/134132

Wittrock, D.A., & Foraker, S.L. (2001). Tension-type headache and stressful events: the role of selective memory in the reporting of stressors. *Headache*, 41, 482-493. doi: 10.1046/j.1526-4610.2001.01086.x

Yates, L., Bond, L., Dixon, M., Drew, S., Ferguson, P., Hay, T., Moss, J., St Leger, P., Walker, H., & White, J. (2010). *Identity, social connection and education for young people living with chronic illness; keeping connected, young people, identity and schooling*. Melbourne: Melbourne Graduate School of Education.

Appendix A

Extracts from the Researcher's Reflexive Diary

The researcher presented this research (aims and methodology to begin with and then findings as they emerged) at the following conferences and research meetings: The North American Cystic Fibrosis Conference 2014, RESCON14, The National Cystic Fibrosis Nursing Association Study Day 2015, The European Cystic Fibrosis Conference 2015, BLSS Faculty Research Conference 2015, The North West Midlands Cystic Fibrosis Regional Meetings 2015, 2016; RESCON 15; Birmingham Heartlands Hospital CF Multi-Disciplinary Team Meeting 2016; The International CF Conference 2016; Well-Being Conference 2016; The North American CF Conference 2016; RESCON 17; The European Cystic Fibrosis Conference 2017.

Through presenting this research the researcher was able to reflect and act upon points made by fellow academics and HCPs:

Postgraduate Certificate in Research Practice:

During a presentation as part of the PgCert in Research course the researcher was asked two questions:

1) Are "risky behaviours" a negative thing or are they just a normal process within adolescence?

2) Can you prevent "risky behaviours"

The researcher reflected upon these questions and concluded (as taken from the researcher's reflexive diary and incorporated into the literature review) that:

"Adolescence is a time characterised by the experimentation of risky behaviours (Suris & Parera, 2005). However despite literature acknowledging that risky behaviours within adolescence is quite common, there is a line which causes these normal experimental behaviours to escalate to behaviours that put the individual at risk (Richmond, 2014) e.g. smoking for adolescents in the general population may be viewed as just an experimental behaviour, however for an adolescent with CF it is an extremely risky behaviour. In addition it is considered normal in the general population for adolescents to go out and socialise with alcohol after the age of 18 years, but for a CF patient there is the risk of hypoglycaemia and pancreatitis.

Furthermore the existing discussion on adherence has accepted that increasing adherence (and decreasing risky behaviours) is a positive outcome (Abbott et al., 1996), without acknowledging that avoidance of regimens and the initiation in risky behaviours may be rational and represent an active choice (Mitchell & Selmen, 2007) which should be respected. However patients cannot make a rational choice if they have not been presented with enough information on the consequences of such behaviours (as found in the transition evaluation).

By providing patients with information on risky behaviours it would not necessarily prevent the initiation of these behaviours, but it would allow CF patients to make a more informed choice on whether or not they want to engage in those behaviours in light of their knowledge of the consequences."

Cystic Fibrosis Nursing Association Study Day 2015:

Through speaking to Nurses about the transition process at different CF regional units the researcher was provided with some very interesting feedback (taken from the researchers reflexive diary). The researcher presented the transition proforma that a UK Hospital stated they use to guide the conversation that HCPs have with patients, including a discussion on risky behaviours. However a Nurse from the same hospital informed the researcher that he had never seen that document, indicating that in best practice the hospital uses this document to guide the conversation, but in reality the document is not used.

European Cystic Fibrosis Conference 2015:

[Taken from the researchers reflexive diary]

"It was a really valuable experience to attend the European Cystic Fibrosis Conference in Brussels. My supervisor and I agreed that there is a gap within the current research within CF where my research can sit. Whilst there is research focusing upon the psychological implications of this disease, there is virtually no mention of risky behaviours within the current research. I was delighted to receive the Young Investigator Award during the closing ceremony. This is a fantastic recognition for my work and demonstrates that my work is both current and relevant."

UK Cystic Fibrosis Conference 2015:

[Taken from the researchers reflexive diary]

"This was a fantastic experience for me to network with professionals within the field of CF, and to have an insight into the most current research being conducted within this area. I was particularly pleased to see an emphasis on adolescence by Dr Bryon and the behaviours they may engage in to seek 'rewards'. However no solutions were provided on how to overcome this issue - this is something my PhD research will hopefully provide".

North West Midlands Cystic Fibrosis Regional Meeting:

[Taken from the researcher's reflexive diary]

The researcher presented the preliminary findings from phase one data collection to the MDT at their regional meeting, allowing the researcher to reflect upon the MDT's views on these findings:

"It was stated that the aim of the intervention should not be to prevent risky behaviours, but to provide more education. I agree with this (and should change the discourse of this) as it has to be acknowledged that the engagement in such behaviours is an active choice which may be rational and should be respected - however patients should have enough information to make a more informed choice on their engagement."

Support from Participants and HCPs:

[Taken from the researcher's reflexive diary]

"Participants have also acknowledged the need for my research, with participant 11 (phase one data collection) stating that my information sheet made sense - it made sense that someone should investigate this. Furthermore, participant 9 (phase one data collection) stated that my research was great and that more people should look into CF to raise awareness for the condition.

As well as patients seeing the relevance of my research, HCPs have also been very supportive. HCPs have encouraged me during the research process, and state that the interviews (both adult and paediatric interviews) have been a success as I am an approachable individual. They also stated that my interviews are useful to help patients

acknowledge the reasons behind their behaviours. Again the reactions from staff and patients illustrate the relevance of my research".

North American Cystic Fibrosis Conference 2016:

[Taken from the researchers reflexive diary]

"I attended the NACFC in Orlando, Florida and presented my research as a poster presentation. This was a fantastic opportunity and I was pleased that my poster generated a large amount of interest with a lot of researchers / practitioners questioning me regarding the research. Everyone was very supportive of my research and findings, acknowledging its practical applications, increasing the validity of these findings.

In addition, I was asked during my time at the conference if I would be interested in conducting a qualitative analysis for the UK Cystic Fibrosis Trust. This involved me analysing open ended responses from the patient preference response survey, and I got the opportunity to present these findings at the European Cystic Fibrosis Conference 2017 in Seville."

Appendix B

Adult Interview Schedule

Ice Breakers Question's:

- Thank you for taking part
- What were your first thoughts when you were asked to take part in this research?
- Did you have any hesitations about agreeing to take part?
- So to begin with, can you tell me a bit about your life?
 - What do you do in your spare time?
 - Do you work / study?
 - Live with your family?

Impact of Cystic Fibrosis on the patient's personal life:

- Could you tell me about some of the challenges in terms of living with Cystic Fibrosis?
- Has it always been this, or were other aspects / things more difficult to cope with when you were younger?
- How do you find it sticking to your treatment regimen? Are there any aspects that are more difficult?
- Has this changed over time / circumstances?
- What treatments do you tend to "miss out"?
- At the end of the day if you have missed a treatment how does it make you feel?
- When you wake up in a morning do you plan to do all your treatments?
- Are there some days when you wake up and you know you're just not going to do everything?

Barriers to Adherence:

- What things make it difficult to stick to the regimen?
Areas for further elaboration may include:
 - Not enough time in the day with their job etc
 - The belief that the medical regimen is not benefitting them
 - The fear of antibiotic resistance
 - Are they self-prescribing according to their symptoms
 - Ask whether this is of a weekday / weekend
- Are there any situations where you are less likely to take your medication / complete your physiotherapy?

Areas for further elaboration may include:

- At college / work
- At a friend's house

- What makes it harder to complete your regimen in these situations?
 - An area for further exploration may include the identity the medical regimen provides them with

Risky Health Behaviours:

- Are there things that you think are “not good” for your health?
Examples may include:
 - Smoking
 - Drugs
 - Drinking alcohol
- Do you feel that these behaviours have an impact on your Cystic Fibrosis?
- Is there anything else in your life that you may not do if you were being "really healthy"?

Smoking (CAN BE ADAPTED TO ANY RISKY BEHAVIOUR):

- Did you think about Cystic Fibrosis when you started smoking?
- About how old were you when you started smoking?
- Can you remember why you started smoking, what were the triggers, what did you think about at the time? What was happening?
- Some people with health problems say that they engage in behaviours that are not good for their health because these behaviours give them a sense of being “normal”. What do you think about that?
- Have you ever tried to stop smoking? Why? How did you find it?
- What do you hope for your future in terms of smoking?

Family and Friends:

- Are you open with family and friends about your smoking? What do they think about it? What is their reaction?
- “Other” may include:
 - Parents
 - Siblings
 - Partner
- Are you open with your friends about your Cystic Fibrosis? What do they think about your Cystic Fibrosis? What is their reaction?
- Who do you go to with any concerns regarding your Cystic Fibrosis?
Example may be:
 - Consultants
 - Family

- Friends
- Online forums
- Do you speak to Cystic Fibrosis patients face to face?

Conclusion:

- What would you want to tell a young patient with Cystic Fibrosis?
- What would you tell a family who had just had a child with Cystic Fibrosis, or who have a young adult with Cystic Fibrosis?
- Honestly if you were to have this discussion with another person who has Cystic Fibrosis, outside of this research, would this conversation be the same?
- Do you have anything else to add?

Title of study: The role of health beliefs in predicting and explaining lifestyle choices within Cystic Fibrosis patients

Researchers: Rebecca Keyte, Dr Helen Egan, Dr Anna Regan, Dr Angela McGowan.

What is the research about?

We are investigating Cystic Fibrosis (CF) patients' views about their current or past lifestyle choices. We are interested in your personal views and experiences about your lifestyle choices, and how they impact upon your health and wellbeing (both in a positive way or negative way).

What are lifestyle choices?

We are interested in hearing **your** experiences of living with CF; and hearing about choices you have made both in the past and now around smoking, drinking alcohol and taking drugs.

Who can take part?

Anybody who has CF and is 18 years or over can take part in this research. It does not matter if you have never smoked, drank alcohol or taken drugs, we would still like to talk to you and hear **your** experiences of living with CF and the reasons why you made decisions about certain lifestyle choices.

What will this research involve?

It is completely up to yourself whether or not you want to take part in this research. If you do decide to take part, you will be interviewed by Rebecca Keyte to investigate **your** personal views and experiences about your lifestyle choices. This interview will be audio recorded so the researcher can listen back over the interview again and analyse the material; this recording will not be listened to by anyone outside of the research team. This interview will take a maximum of 60 minutes and will take place at Birmingham Heartlands Hospital on a date suitable for yourself. None of the information collected about you during this study will be seen by anyone including the staff treating you. You do not have to answer any questions that you do not want to during the interview, and you can leave the interview at any time without providing a reason. You will be given the opportunity to read through your interview and ask for anything to be taken out if you wish to do so.

ADULT CONSENT TO CONTACT FORM

Title of Study: The role of health beliefs in predicting and explaining lifestyle choices within Cystic Fibrosis patients.

Name of Researcher: Rebecca Keyte

Please complete this form if you are happy for the researcher to contact you to discuss this study.

Please initial the box

- 1. I confirm that I have read the research information sheet for the above study.
- 2. I agree that my care co-ordinator can inform the above researcher of my medical condition in order to assess my eligibility to participate in the above study.
- 3. I understand that my personal contact details below will be stored securely, in line with the data protection act.
- 4. I agree that the researcher can contact me to discuss my participation in the above study using my contact details below.

Full Name: _____

Address: _____

Telephone: _____ Mobile: _____

Email: _____

Preferred Time to be contacted: Morning Afternoon Evening (please circle)

Preferred Method of contact: Home Mobile Email (please circle)

Many thanks for expressing interest in this study. You will be contacted, as per your stated preferences within 24-48 hours to discuss the research further. As previously explained, there is no obligation to commit to the study at this time and whether you participate or not, this will not affect the care or treatment you receive under normal routine care.

Appendix E

Adult Information Sheet and Consent Form



Title of study: The role of health beliefs in predicting and explaining lifestyle choices within Cystic Fibrosis patients

You are being invited to participate in a research study. Before you make a decision on whether to take part, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and discuss it with others if you wish. Please feel free to ask us any questions if there is anything that is not clear or you would like more information on before you decide whether to participate or not. Thank you for reading.

Introduction to the research and invitation to take part

This study aims to investigate Cystic Fibrosis (CF) patients' views about their current or past lifestyle choices. Participants are being recruited from the West Midlands Adult Cystic Fibrosis Centre at Heartlands Hospital, and at the North West Midlands Adult Cystic Fibrosis Centre at the Royal Stoke University Hospital. You are identified as potentially suitable to take part in this study. The members of the research team are: Rebecca Keyte (Psychology Graduate), Dr Helen Egan (Health Psychologist), Dr Anna Regan (Clinical Psychologist) and Dr Angela McGowan (Consultant Respiratory Physician).

What is the purpose of the study?

We are interested in your personal views and experiences about your lifestyle choices, and how they impact on your health and wellbeing. There is very little research which asks people with CF directly how they feel about their choices and about what factors might influence the health choices that they make. The findings from this research will be useful for health professionals to help support people with CF, particularly young people who are

beginning to make independent decisions around their own health and lifestyle. If we understand more about why people make choices that may not be good for their health, we can offer more effective support to encourage positive health and lifestyle choices.

Do I have to take part?

It is up to you whether to take part or not. You will be approached, and will complete this study in a private room at your Cystic Fibrosis Centre; you will not be expected to complete any part of this study in the public waiting room. To help you decide if you want to participate, we will first describe the study and if you express an interest, we will give you this information sheet. If after reading this sheet and having any questions answered, you are still keen to participate, we will ask you to sign the consent form. You are free to withdraw from this research at any time without giving a reason. This would not affect the care that you receive in any way.

Why have I been asked to participate?

You have been asked to consider participating in this study because you have Cystic Fibrosis, and are cared for either at the West Midlands Adult Cystic Fibrosis Centre or the North West Midlands Adult Cystic Fibrosis Centre.

What will I have to do if I participate?

If you decide to participate, you will be interviewed by Rebecca Keyte to investigate your personal views and experiences about your lifestyle choices, and how they impact on your health and wellbeing both positively and negatively. This interview will be audio recorded so the researcher can listen back over the interview again and analyse the material; this recording will not be listened to by anyone outside of the research team. This interview will take a maximum of 60 minutes. None of the information collected about you during this study will be seen by anyone including the staff treating you. We will also record your latest lung function results from your medical notes.

What are the possible risks of participating?

There are no risks from participating in this study as the information that you provide in this research will be strictly confidential. The information will be anonymised, which means that all identifying information will be removed and will not be seen by anyone including the staff treating you.

Are there any possible benefits?

There are likely to be no direct benefits to you by participating in this study. The findings from this research will be useful for health professionals to help support people with CF, particularly young people who are beginning to make independent decisions around their own health and lifestyle.

If you do become distressed during the interview you will be referred to Dr Anna Regan (Clinical Psychologist at Heartlands Hospital) or Dr Angela McGowan (Consultant at the Royal Stoke University Hospital).

What do I do now?

Once you have read this information sheet and have had any questions answered to your satisfaction, we will ask you if you are still keen to participate in the study. If so, we will ask you to sign a consent form, and arrange a date / time of when we will conduct the interview (possibly on the same day as you consenting depending on your availability). We will also obtain the information about your lung function from your medical notes.

What if there are any problems?

We do not anticipate there to be any problems in taking part in this study. Participants will be given the option of results feedback with the researcher to talk through any issues raised during this research.

What if I have a complaint?

In the unlikely event of you having any complaints about any aspects of the study, we will do our best to answer these complaints. If you would prefer to speak to someone independent of the research team about your complaint then you can contact your local Patient Advice Liaison Service (PALS) Team:

Heartlands Hospital: Telephone 0121 424 1212 or email pals@heartofengland.nhs.uk

Royal Stoke University Hospital: Telephone 01782 676450 or 01782 676455 or email patient.advice@uhns.nhs.uk

However, we do not expect any harm to come to you during the course of this study. If you are harmed by taking part in this research project there are no special compensation arrangements outside that of the NHS.

Will my taking part in the study be kept confidential?

Yes, we will follow ethical and legal practice and all information about you will be handed in confidence. However if you were to disclose some information within the interview that indicated the potential harm to either yourself or others then the researcher may have to report this information to a suitable authority.

What happens at the end of the study?

Throughout the study, and when it ends, your hospital Doctor and General Practitioner will continue to monitor you as usual.

What happens if I have more questions?

If you do not understand something in this leaflet, or have further questions you may ask the researcher now. Or you can contact the researcher via email or telephone on:

Rebecca.Keyte@mail.bcu.ac.uk / 07957157974; or Dr Helen Egan on:

Helen.Egan@bcu.ac.uk ; or Dr Anna Regan on: anna.regan@heartofengland.nhs.uk ; or Dr

Angela McGowan on: Angela.McGowan@uhns.nhs.uk

What happens now if I decide to participate?

If you decide to participate you will be asked to read, sign and date the written consent form attached to this sheet. By signing it you acknowledge that you have understood the aims of the research, and what you are being asked to do.

Will my General Practitioner (GP) be informed?

We do not plan to inform your GP about your participation in the study, but can do if you wish.

What happens if I change my mind during the study?

You are free to withdraw your participation at any time, and it will not affect your future care.

Who is organising and funding the study?

The study has been organised by Rebecca Keyte, Dr Helen Egan, Dr Anna Regan and Dr Angela McGowan at Birmingham Heartlands Hospital and The Royal Stoke University Hospital. These will not be paid for including you in this study. In addition unfortunately we are unable to pay for travel expenses.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion.

Who can I contact about the study?

In the first instance any concerns or questions should be addressed to Rebecca Keyte (Rebecca.Keyte@mail.bcu.ac.uk / 07957157974) or Dr Helen Egan (Helen.Egan@bcu.ac.uk) or Dr Anna Regan (anna.regan@heartofengalnd.nhs.uk) or Dr

Angela McGowan (Angela.McGowan@uhns.nhs.uk). If you have further concerns you can contact your Patient Advice Liaison Service (PALS)

Heartlands Hospital: Telephone 0121 424 1212 or email pals@heartofengland.nhs.uk

Royal Stoke University Hospital: Telephone 01782 676450 or 01782 676455 or email patient.advice@uhns.nhs.uk



REC Number: 14/EM/1183

Enrolment Number:

Title: The role of health beliefs in predicting and explaining lifestyle choices within Cystic Fibrosis patients

I (Name in BLOCK CAPITALS)

Initials

1. Have read the attached information concerning my participation in this study and have had the opportunity to discuss it and ask any questions. All my questions have been answered in a satisfactory way.

2. Understand my participation is voluntary and I will not be paid for my participation.

3. Know that at any time, and without giving a reason, I can withdraw my participation in the study and that my future care and management will not be affected.

4. Understand that audio-taping will be used to record my interview which will only be listened to by members of the research team.

5. Understand that I will have a copy of this patient information leaflet and written consent to keep.

6. Understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

7. Understand that the researcher will not identify me by name in any reports using information obtained from this study, and that my confidentiality as a participant in this study will remain secure.

8. Understand that if I were to disclose some information during the interview which indicated the potential harm to either myself or others then the researcher may have to report this information to a suitable authority.

I hereby give my consent to take part in this study.

My SignatureDate

Name Printed Signature of Researcher

Appendix F

Adult Debriefing Sheet



Dear Participant ,

The purpose of this study was to investigate your views behind your lifestyle choices. This study was conducted due to research indicating that some lifestyle choices have a negative impact upon a CF patient's health. It is hoped that this research will identify ways to prevent CF patients from engaging in risky behaviours; which in turn will benefit patients as it will contribute to increasing their health, as they will not be engaging in a behaviour that can compromise their health.

The information that was collected about you during the course of this study will be kept strictly anonymous and will be destroyed when the study is completed. If you require any further help or discussion after taking part in the study; or if you would like to know anything about the results or information of the study then please feel free to contact me: - (Rebecca.Keyte@mail.bcu.ac.uk / 07957157974), or Dr Helen Egan on:- Helen.Egan@bcu.ac.uk , or Dr Regan on:- anna.regan@heartofengland.nhs.uk , or Dr Angela McGowan on:- Angela.McGowan@uhns.nhs.uk

Thank you again for participating in this study.

Appendix G

Results Feedback

Thank you for taking part

I conducted 24 interviews with adults with Cystic Fibrosis. During these interviews we spoke about what life is really like with Cystic Fibrosis, and I listened to your reasons about why you make certain lifestyle choices. We are really grateful to all of you who contributed to this research and I was pleased to hear that so many of you valued the research, saying things such as:

- *"It made sense that someone should investigate this"*
- *"It is great, more people should look into CF to raise awareness for the condition"*

The results of the research do indicate that some adults with Cystic Fibrosis do engage in certain behaviours like smoking, drinking excessive amounts of alcohol, and drug use, despite these behaviours being negative for their health. Individuals provided a variety of reasons for engaging in such behaviours.

By understanding why some adults with Cystic Fibrosis do engage in these "risky behaviours", Health Care Professionals will now be able to identify adults who may be at risk of engaging in these behaviours to try and prevent their engagement. As many individuals emphasised the need for more information to be provided to patients about the negative health effects of these behaviours, we will work to create a way of providing patients with this information at an age where they may be considering engagement in such behaviours.

All of this would not be possible without yourselves giving up your time to contribute to this research, so again I would like to say a big thank you to you all.

Rebecca Keyte

Appendix H

Revising the Codes

Taken from the Researchers Reflexive Diary:

3rd March 2016:

After a supervision meeting where we looked at my themes and accompanying codes I have made some slight changes.

❖ **Occupational Identity:**

Firstly I have incorporated a new code “occupational identity” into the “**Identity**” theme. The material was represented already within my analysis, however we acknowledged that the identity provided to an individual through employment and education is very important and therefore needed to be more clearly signposted within my analysis.

EXAMPLE:

Participant 3 [F, 32years]: “I wasn’t going out with any of my holiday repping friends (.) it [drug use] wasn’t re:eally (.) the sa:ame (.) sort of night”

❖ Within my new code “Occupational Identity” I decided that the data would be better represented if this code was separated into two distinct codes:

- **The impact Employment / Education has upon an individual’s Identity with CF** which explores both positive and negative impacts employment and education can have upon a CF patient's identity
- **The relationship between an Occupational Identity and Risky Behaviours** which represents how the workplace / educational institute can encourage a CF patient to engage in normalised risky behaviours

4th March 2016:

Based upon my supervision meeting I decided to include an additional three codes within the theme focusing upon “**Acceptance and Awareness**” to indicate patients' awareness regarding adherence and risky health behaviours which had originated from HCPs. Firstly there was the code:

❖ **Lack of Awareness from HCPs regarding the need for adherence**

This included data which had predominantly originated within the theme that focuses upon “Support from Others” and still features within that theme. This data highlights how HCPs can provide a lack of awareness regarding the need for adherence despite the data documenting that awareness / acceptance can result in adherence.

EXAMPLE:

Participant 19 [M, 23years]: "I think a lot is re:ally underrated ## when I come to hospital [...] they ask (.) o:oh have you done much exercise # o:oh maybe try and do some more # [...] there should be mo:ore than taking medication # they're hot on giving you medication (.) but not on lifestyle choices [...] there's mo:ore value than is being lead on to in hospitals anyway (.) fo:or exercise"

Secondly there was the code:

❖ Lack of awareness from HCPs regarding risky health behaviours

This included data which had predominantly originated within the theme that focuses upon “Support from Others” and still features within that theme. This data highlights how HCPs can provide a lack of awareness regarding the adverse effects of risky health behaviours to their patients despite the data documenting that awareness of such adverse effects can prevent initiation / aid cessation

EXAMPLE:

Participant 11 [F, 29years]: "I'm pa:artial to a glass when I # you know (.) if I've had a bad day at work (.) o:or:r just of a weekend [...] they've [HCP] never said (.) don't (.) drink # but they've also said # obviously don't ## no they've never told me not to drink"

Thirdly there is the code:

❖ Awareness provided by HCPs regarding risky health behaviours

This included data which had predominantly originated within the theme that focuses upon “Support from Others” and still features within that theme. This data highlights the information HCPs had provided participants with regarding risky health behaviours.

EXAMPLE:

Participant 9 [M, 25years]: "It weren't until I got to # he:ere [Hospital name] [...] as an adult they explained mo:ore [about alcohol] # crunch down on you # that's the effect it had on it then ## I realised what it's doing [...] when you're not having your drugs and your drinking as well ## or:r (.) not having your creon right (.) your bowels are everywhere ## your lungs hurt"

7th March 2016:

Support from Others:

Within the theme that focuses upon "**Support from Others**" I created a new code to indicate the importance of friendship from participants' perspectives. The new code is:

- ❖ "The importance of friendship, providing patients with a sense of belonging"

This data was already displayed within this theme, however the new code better displays the role of friendship alongside the existing codes illustrating the support or lack of support participants receive from their friends, and the influence such friendships have upon the engagement in risky behaviours.

EXAMPLE:

Participant 1 [M, 19 years]: "It's good that I have mates that care [...] I haven't got a (.) strong (.) relationship with my family like (.) so my friends are all I've got to be honest"

In addition within the theme that focuses upon "**Support from Others**" I also added more data under the code "Society has a lack of awareness regarding CF" to illustrate the impact of this lack of awareness.

EXAMPLE:

Participant 11 [F, 29years]: "A lot of people go # °I've heard that° # but nobody knows wha:at it is:s [...] it's ve:ery hard then when you have to explain to someone (.) it's ve:ery tricky # be:ecause ## I don't even know where to start [...] >don't go home and google it< [laughs] (.) because it looks # on paper (.) it's horrendous [...] can you just look at the re:eality in front of you"

Finally, within the theme that focuses upon "**Support from Others**" I combined the codes "Lack of support from work / University" and "Work / University as a source of support" as both codes did not have a lot of data under them, and all the data was representing the same thing. The new code was called:

- ❖ The support a patient receives from work / university

Appendix I

Example Theme

Theme: "Why should I let Cystic Fibrosis completely dominate my life?"

Codes:

- Not defined by a CF identity
- Normalcy / normal identity provided through non-adherence
- Normalcy / normal identity provided through risky health behaviour engagement
- Normalcy / normal identity provided by engaging in normal activities
- Desire to fit in
- Adherence allows normalcy / normal identity
- Adherence prevents normalcy
- Response to the CF identity
- The invisible impairment allows normalcy
- The invisible impairment causes ignorance off others
- Life-orientated illness perspective
- Risky health behaviours were normalised by friends
- A change in friendship group resulting in cessation
- Peer pressure and risky health behaviours
- Risky health behaviours were normalised by friends
- Risky health behaviours were not normalised, thus preventing initiation
- Risky health behaviours were normalised by the environment
- Risky health behaviours were normalised by educational and employment experiences
- The impact employment / education has upon an individual's identity with CF
- The relationship between an occupational identity and risky health behaviours
- Illness identity physically on display
- The impact of the illness identity being on display
- Hiding the illness identity to provide oneself with a normal identity
- Incorporated CF into their identity
- Non-disclosure to partner
- Non-disclosure to hide the illness identity
- Non-disclosure to escape sympathy
- Disclosure of CF

Appendix J

Approval from the Paediatric CF MDTs at the Royal Stoke University Hospital and Birmingham Heartlands Hospital

[Taken from the Researcher's Reflexive Diary]

The Royal Stoke University Hospital:

"I did an oral presentation on the aims of my current and proposed research within the CF population (Investigating the role of health beliefs in predicting lifestyle choices). It was great to receive feedback from professionals within the field. The paediatric team stated that the inclusion criteria should be from 12 - 18 years to coincide with secondary school, and because literature states that individuals start to contemplate risky behaviour engagement at that age (11+ years). In addition the paediatric Clinical Psychologist stated I should look at patients awareness / beliefs about their life expectancy as this can influence risky behaviours (she suspects). Furthermore it was stated that the aim of the intervention should not be to prevent risky behaviours, but to provide more education. I agree with this (and should change this / the discourse I use) as it has to be acknowledged that the engagement in such behaviours is an active choice which may be rational and should be respected - however patients should have enough information to make a more informed choice on their engagement.

After my talk the paediatric team stated that they want to be involved in my research. The team seemed very keen to be on board. This is fantastic news as I have struggled to recruit research sites. However now I can progress with phase two data collection!!

Overall this indicates that professionals within the field of Cystic Fibrosis see my research to be relevant and valuable; believing it has the potential to have an impact upon NHS practice."

Birmingham Heartlands Hospital:

"I presented my research proposal for phase two data collection to the CF MDT at Birmingham Heartlands Hospital. The presentation went well with the paediatric team stating they are keen to be involved within the research. The team have ten patients at the moment aged 12 years and above and are happy to start handing out consent to contact forms (I am just waiting for R&D approval).

Through my discussions with the paediatric CF MDT it did indicate that risky health behaviours are a missed area - patients are provided a booklet on drugs etc but there is no

discussion encouraged. The CF MDT stated that they are aware the booklet ends up under the patients bed etc. The CF MDT also stated how they ask if patients smoke but not about alcohol or drug use.

The CF MDT suspect that the majority of patients will not have engaged in any risky health behaviours, however they did say they may be naive to believe that! We did discuss about confidentiality and at what point I would need to break that (e.g. what is risky? - Is one cigarette risky? Is parental smoking risky? Is drinking with family risky? Is under-aged sex risky?). This is something I need to discuss with my supervisors before I conduct my first interview.

Hopefully I should be starting data collection again shortly"

Appendix K

Paediatric Interview Schedule

Ice Breakers Question's:

- Thank you for taking part
- What were your first thoughts when you were asked to take part in this research?
- Did you have any hesitations about agreeing to take part?
- So to begin with, can you describe what you do in a typical day?
 - Weekday / Weekend difference
 - Spare time

Impact of Cystic Fibrosis on the patient's personal life:

- Could you tell me what it is like to live with Cystic Fibrosis
 - Discuss the challenges of living with Cystic Fibrosis
 - Has it always been this or were other aspects / things more difficult to cope with when you was younger?
- Do you tell others about your Cystic Fibrosis?
 - Who do you tell?
 - What do you tell them?
 - How do you find telling others about your Cystic Fibrosis?
 - Why don't you tell others about your Cystic Fibrosis?
- How do you find it sticking to your treatment regimen?
 - Does anyone help you stick to your regimen? (Who?)
 - Are there any aspects that are more difficult to stick to?
 - Has this changed over time?
 - Does it change depending on the situation / circumstances?
 - Are there any treatments you tend to "miss out"?
 - Are there any treatments you wish you could "miss out"?
 - How do you think it would make you feel if you did miss those treatments out?

Barriers to Adherence:

- What things make it difficult to stick to the regimen?
Areas for further elaboration may include:
 - Not enough time in the day with school etc
 - The belief that the medical regimen is not benefitting them
 - Are they self-prescribing according to their symptoms?

- Weekday / weekend difference
- Are there any situations where you are less likely to take your medication / complete your e.g. physiotherapy?

Areas for further elaboration may include:

- At school
- At a friend's house
- What makes it harder to complete your regimen in these situations?
 - An area for further exploration may include the identity the medical regimen provides them with

Risky Health Behaviours:

- When I say "risky behaviours" what does that make you think of?
- Do you think that some things are more risky for you because of your Cystic Fibrosis?
- What things would "not be good" for your health?
Examples may include:
 - Smoking
 - Drugs
 - Drinking alcohol
- Do you feel that these behaviours would have an impact on your Cystic Fibrosis?
- Have you ever been told that any of these behaviours would be bad for your Cystic Fibrosis?
 - Who has provided you with this awareness?
 - How does it make you feel towards these behaviours?
- Do you know anyone who takes part in these behaviours?
 - Who?
 - How does that make you feel?
- Have you / would you ever be motivated to try one of these behaviours?
 - What would motivate you?
 - What would stop you?
- Why do you think people do engage in these behaviours?
- Do you think any Cystic Fibrosis patients engage in risky behaviours?

- Why do you think a Cystic Fibrosis patient would engage in these behaviours?
- Why do you think a Cystic Fibrosis patient would not engage in these behaviours?

Family and Friends:

- If you did (e.g. smoke) would you be open with family and friends about your (e.g. smoking?) What do you think they would think about it? What would their reaction be?
- “Other” may include:
 - Parents
 - Siblings
 - Partner
- Who do you go to with any concerns regarding your Cystic Fibrosis?
Examples may be:
 - Consultants
 - Family
 - Friends
 - Online forums
- Do you ever speak to any other Cystic Fibrosis patients?
 - Is this online?
 - Is this face to face?

Conclusion:

- What would you want to tell a younger patient with Cystic Fibrosis?
 - e.g. about going to school with Cystic Fibrosis
 - e.g. about telling others about their Cystic Fibrosis
- What would you tell a family who had just had a child with Cystic Fibrosis?
- Honestly if you were to have this discussion with another person (e.g. someone who has Cystic Fibrosis), outside of this research, would this conversation be the same?
- Do you have anything else to add?

Appendix L - Paediatric Handout

Title of study: The role of health beliefs in predicting and explaining lifestyle choices within Cystic Fibrosis patients

Researcher: Rebecca Keyte

Contact Details: Rebecca.Keyte@mail.bcu.ac.uk; 07957157974

About the Researcher:

I am PhD student in the Psychology department at Birmingham City University. I have recently completed a piece of research with adult Cystic Fibrosis patients (at Birmingham Heartlands Hospital and the Royal Stoke University Hospital) which was looking at their lifestyle choices. Now I would like to conduct a similar piece of research with paediatric Cystic Fibrosis patients.

What is the research about?

I am interested in hearing your experiences of living with Cystic Fibrosis and hearing your thoughts about the lifestyle choices made by you and by other people. These lifestyle choices may include smoking, drinking alcohol and taking drugs.

I would like you to take part in this research as you are aged 12 years or above. It does not matter if you have never smoked, drank alcohol or taken drugs, I would still like to talk to you and hear your experiences of living with Cystic Fibrosis.

What will the research involve?

It is completely up to yourself whether or not you want to take part in this research. If you do decide to take part, you will be interviewed by Rebecca Keyte to investigate your personal views and experiences about your lifestyle choices. This interview will be audio recorded so the researcher can listen back over the interview again and analyse the material; this recording will not be listened to by anyone outside of the research team. This interview will take a maximum of 60 minutes and will take place at Birmingham Heartlands Hospital on a date suitable for yourself. None of the information collected about you during this study will be seen by anyone else including the staff treating you. You do not have to answer any questions that you do not want to during the interview, and you can leave the interview at any time without providing a reason. However, if you were to tell the researcher some information during the interview which indicated the potential harm to either yourself or others then the researcher may have to report this information to a suitable authority.

PAEDIATRIC CONSENT TO CONTACT FORM

Title of Study: The role of health beliefs in predicting and explaining lifestyle choices within Cystic Fibrosis patients.

Name of Researcher: Rebecca Keyte

Please complete this form if you are happy for the researcher to contact you to discuss this study.

- | | Please initial
the box |
|--|-----------------------------------|
| 1. I confirm that my son/daughter has read the research information sheet for the above study. | <input type="checkbox"/> |
| 2. I agree that my son/daughter's care co-ordinator can inform the above researcher of their medical condition in order to assess their eligibility to participate in the above study. | <input type="checkbox"/> |
| 3. I understand that my personal contact details below will be stored securely, in line with the data protection act. | <input type="checkbox"/> |
| 4. I agree that the researcher can contact me to discuss my son/daughter's participation in the above study using my contact details below. | <input type="checkbox"/> |

Full Name: _____

Address: _____

Telephone: _____ Mobile: _____

Email: _____

Preferred Time to be contacted: Morning Afternoon Evening (please circle)

Preferred Method of contact: Home Mobile Email (please circle)

Many thanks for expressing interest in this study. You will be contacted, as per your stated preferences within 24-48 hours to discuss the research further. As previously explained, there is no obligation to commit to the study at this time and whether you participate or not, this will not affect the care or treatment you receive under normal routine care.

Appendix N

Parental Information Sheet and Consent Form



Title of study: The role of health beliefs in predicting and explaining lifestyle choices within Cystic Fibrosis

Researchers: Rebecca Keyte, Dr Helen Egan, Dr Anna Regan, Dr Angela McGowan.

Institutions name and location: Birmingham City University, School of Social Sciences

Birmingham City University, Perry Barr, Birmingham B42 2SU

Email: Rebecca.Keyte@mail.bcu.ac.uk (07957157974)

Introduction to the research and invitation for your son / daughter to take part

We are researchers at Birmingham City University carrying out a research project investigating what adolescents with Cystic Fibrosis think about “risky” health behaviours (e.g. smoking, excessive alcohol consumption, illicit drug use). This study is interested in adolescents' personal views about risky health behaviours and the impact they believe they have upon an individual's life. The findings of these interviews, alongside interviews with adult Cystic Fibrosis patients, will highlight to professionals why some individuals with Cystic Fibrosis do engage in risky health behaviours, and what could be done to motivate patients to not engage in these behaviours to improve their health status. Participants are being recruited from Birmingham Heartlands Hospital and the Royal Stoke University Hospital.

Does your son / daughter have to take part?

It is up to you whether or not you want your son / daughter to participate in this research. Cystic Fibrosis patients aged 12 years and above are being recruited for this research. Your son / daughter will complete this study in a private room at their hospital; they will not be expected to complete any part of this study in the public waiting room. To help you and your

son / daughter to decide about participation, we will first describe the study and if you both express an interest we will give you both an information sheet. If after reading your information sheets and having any questions answered, you are both still keen on participation, we will ask you both to sign a consent form. Your son / daughter would be free to withdraw from this research at any time without giving a reason, this would not affect the care they receive in any way.

What will your son / daughter have to do if they participate?

If you and your son / daughter decide to provide written consent, your son / daughter will participate in a semi-structured interview conducted by Rebecca Keyte to investigate their views towards risky health behaviours, and their views on why some adolescents engage in risky health behaviours. The interview will take place in a private room at their hospital. The interview will be audio recorded so the researcher can listen back over the interview again and analyse the material; this recording will not be listened to by anyone else outside of the research team. The interview will take a maximum of 60 minutes, but can be stopped earlier if your son / daughter wishes this to be the case. None of the information collected about your son / daughter during this study will be seen by anyone else including the staff at their hospital, and the interview data (including recordings) will be destroyed at the end of the study. However, if your son / daughter were to tell the researcher some information during the interview which indicated the potential harm to either themselves or others then the researcher may have to report this information to a suitable authority. We will also record your son / daughters latest lung function results from their medical notes. The interviews are designed to be independent, however if your son / daughter wishes you to be present this can be arranged.

What are the possible risks of participating?

There are no risks from participating in this study as the information that your son / daughter provides in this research will be strictly confidential. The information will be anonymised, which means that all identifying information will be removed and will not be seen by anyone including the staff at your son / daughter's hospital. I want to assure you that I have had a full criminal record check done and this is clear, a copy of which can be produced upon request. If you have any questions regarding this research then please feel free to contact me using the information given above.

Are there any possible benefits?

There are likely to be no direct benefits to your son / daughter by participating in this study. It is not expected for your son / daughter to become distressed during the interview, however if this was to happen your son / daughter will be referred to Dr Anna Regan or Dr Francis Gilchrist.

The findings from this research will highlight to professionals ways to encourage CF patients not to engage in risky behaviours; which in turn will benefit patients as it will contribute to increasing their health, as they will not be engaging in a behaviour that can compromise their health status.

What do I do now?

Once you have read this information sheet and have had any questions answered to your satisfaction, if you are still keen for your son / daughter to participate in the study we ask you to sign the attached consent form. If your son / daughter also consents to participating in this study we will arrange a date / time of when we will conduct the interview (possibly on the same day as you and your son / daughter consenting depending on your availability). We will also obtain the information about your son / daughters lung function from their medical notes.

What if I have a complaint?

In the unlikely event of you having any complaints about any aspects of the study, we will do our best to answer these complaints. If you would prefer to speak to someone independent of the research team about your complaint then you can contact your local Patient Advice Liaison Service (PALS) Team:

Heartlands Hospital: Telephone 0121 424 1212 or email pals@heartofengland.nhs.uk

Royal Stoke University Hospital: Telephone 01782 676450 or 01782 676455 or email patient.advice@uhns.nhs.uk

Will my son / daughters taking part in the study be kept confidential?

Yes, we will follow ethical and legal practice and all information about your son / daughter will be handled in confidence.

What happens at the end of the study?

Throughout the study, and when it ends, your son / daughters hospital Doctor and General Practitioner will continue to monitor them as usual.

What happens if I have more questions?

If you do not understand something in this leaflet, or have further questions you may ask the researcher now. Or you can contact the researcher via email or telephone on the contact details provided above.

What happens now if I decide my son / daughter should participate?

If you decide to allow your son / daughter to participate you will be asked to read, sign and date the written consent form attached to this sheet. By signing it you acknowledge that you have understood the aims of the research, and what your son / daughter is being asked to do. Your son / daughter will then be asked to read, sign and date a separate consent form if they wish to participate.

Will my son / daughters General Practitioner (GP) be informed?

We do not plan to inform your son / daughters GP about their participation in the study, but can do if you wish.

What happens if my son / daughter changes their mind during the study?

Your son / daughter is free to withdraw their participation at any time without providing a reason.

Who is organising and funding the study?

The study has been organised by Rebecca Keyte and Dr Helen Egan at Birmingham City University. These will not be paid for including your son / daughter in this study. In addition your travel expenses will not be paid.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by NRES Committee East Midlands - Leicester.

Who can I contact about the study?

In the first instance any concerns or questions should be addressed to Rebecca Keyte (see above for contact details). If you have further concerns you can contact your Patient Advice Liaison Service (PALS) team:

Heartlands Hospital: Telephone 0121 424 1212 or email pals@heartofengland.nhs.uk

Royal Stoke University Hospital: Telephone 01782 676450 or 01782 676455 or email patient.advice@uhns.nhs.uk

REC Reference: 14/EM/1183

Enrolment Number:

Title: The role of health beliefs in predicting and explaining lifestyle choices within Cystic Fibrosis

- | I | (Name of parent / guardian) | Initials |
|---------|---|--------------------------|
| 1. | Have read the attached information sheet (Version 2; 26/1/2016) concerning my son / daughters participation in this study and have had the opportunity to ask any questions. All my questions have been answered in a satisfactory way. | <input type="checkbox"/> |
| 2. | Understand my son / daughters participation is voluntary and they will not be paid for their participation. | <input type="checkbox"/> |
| 3. | Know that at any time, and without giving a reason, my son / daughter can withdraw their participation in the study. | <input type="checkbox"/> |
| 4. | Understand that audio-taping will be used to record the interview which will only be listened to by members of the research team. | <input type="checkbox"/> |
| 5. | Understand that I will have a copy of this patient information leaflet to keep. | <input type="checkbox"/> |
| 6. | Understand that relevant sections of my son / daughters medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my son / daughters taking part in this research. I give permission for these individuals to have access to my son / daughters records. | <input type="checkbox"/> |
| 7. | Understand that the researcher will not identify my son / daughter by name in any reports using information obtained from this study, and that their confidentiality as a participant in this study will remain secure. | <input type="checkbox"/> |
| 8. | Understand that if I my son / daughter was to disclose some information during the interview which indicated the potential harm to either themselves or others then the researcher may have to report this information to a suitable authority. | <input type="checkbox"/> |

I hereby give my consent for my son / daughter to take part in this study.

My SignatureDate

Name PrintedSignature of the Researcher

Appendix O

Paediatric Information Sheet



Title of study: The role of health beliefs in predicting and explaining lifestyle choices within Cystic Fibrosis patients

Researchers: Rebecca Keyte, Dr Helen Egan, Dr Anna Regan and Dr Angela McGowan.

What is the research about?

We are investigating Cystic Fibrosis (CF) patients views about their lifestyle choices. We are interested in what **you** think about lifestyle choices made by you and by other people, and how **you** think they impact upon your health and wellbeing (both in a positive way or negative way).

What are lifestyle choices?

We are interested in hearing **your** experiences of living with CF; and hearing your thoughts around smoking, drinking alcohol and taking drugs.

Who can take part?

Anybody who has CF and is 12 years or over can take part in this research. It does not matter if you have never smoked, drank alcohol or taken drugs, we would still like to talk to you and hear **your** experiences of living with CF and the reasons why you make decisions about certain lifestyle choices.

What will this research involve?

It is completely up to yourself whether or not you want to take part in this research. You will not be paid for taking part in the research. If you do decide to take part, you will be interviewed by Rebecca Keyte to investigate **your** personal views and experiences about your lifestyle choices. This interview will be audio recorded so the researcher can listen back over the interview again and analyse the material; this recording will not be listened to by anyone else outside of the research team. This interview will take a maximum of 60 minutes and will take place in a private room at your Cystic Fibrosis Centre on a date suitable for

yourself. None of the information collected about you during this study will be seen by anyone else including the staff treating you, and the interview data (including recordings) will be destroyed at the end of the study. However, if you were to tell the researcher some information during the interview which indicated the potential harm to either yourself or others then the researcher may have to report this information to a suitable authority. You do not have to answer any questions that you do not want to during the interview, and you can leave the interview at any time without providing a reason. It is not expected that you will get upset during the interview, however if you was to get upset you will be referred to Dr Anna Regan (Clinical Psychologist at Heartlands Hospital) or Dr Francis Gilchrist (Consultant at the Royal Stoke University Hospital). The researcher will also take a record of your latest lung function result.

What happens if I have more questions?

If you do not understand something, or have further questions you may contact the researcher via email or telephone on: Rebecca.Keyte@mail.bcu.ac.uk (07957157974).

If you have further concerns you can contact your local Patient Advice Liaison Service (PALS) on:

Heartlands Hospital: Telephone 0121 424 1212 or email pals@heartofengland.nhs.uk

Royal Stoke University Hospital: Telephone 01782 676450 or 01782 676455 or email patient.advice@uhns.nhs.uk

Appendix P

Paediatric Assent Form



REC Reference: 14/EM/1183

Enrolment Number:

Title: The role of health beliefs in predicting and explaining lifestyle choices within Cystic Fibrosis

I (Name in BLOCK CAPITALS)

Initials

1. Have read the information sheet (Version 2; 26/1/2016) about taking part in this study and have had the chance to ask any questions about this study. All my questions have been answered.

2. Understand that I do not have to take part in this study if I do not want to and that I will not be paid for taking part.

3. Know that I can quit the study at any time, and I do not have to give a reason for this.

4. Understand that audio-taping will be used to record the interview which will only be listened to by members of the research team.

5. Understand that I will have a copy of this patient information leaflet to keep.

6. Understand that my medical notes will be looked at by the researcher to record my lung function.

7. Understand that the researcher will not write my name in any reports written about the study, so that only the researcher will know what I said during the study.

8. Understand that if I were to tell the researcher some information which indicated that myself or others may be at risk of harm, then the researcher may have to report this information to a suitable authority.

I would like to take part in this study:

My SignatureMy Name

DateSignature of Researcher

Appendix Q

Paediatric Consent Form



REC Reference: 14/EM/1183

Enrolment Number:

Title: The role of health beliefs in predicting and explaining lifestyle choices within Cystic Fibrosis

I (Name in BLOCK CAPITALS)

Initials

1. Have read the information sheet (Version 2; 26/1/2016) about taking part in this study and have had the opportunity to discuss it and ask any questions. All my questions have been answered.
2. Understand that I do not have to take part in this study if I do not want to and that I will not be paid for taking part.
3. Know that at any time, and without giving a reason, I can quit the study.
4. Understand that audio-taping will be used to record the interview which will only be listened to by members of the research team.
5. Understand that I will have a copy of this patient information leaflet to keep.
6. Understand that my medical notes will be looked at by the researcher to record my latest lung function result.
7. Understand that the researcher will not identify me by name in any reports of this study, and that my confidentiality as a participant in this study will remain secure.
8. Understand that if I were to tell the researcher some information during the interview which indicated the potential harm to either myself or others then the researcher may have to report this information to a suitable authority.

I hereby give my consent to take part in this study.

My SignatureDate

Name Printed Signature of Researcher

Appendix R

Paediatric Debriefing Sheet



Dear Participant,

The purpose of this study was to investigate your views on risky health behaviours (e.g. smoking), and your views on why some individuals with Cystic Fibrosis smoke etc. It is hoped that this research will identify ways to stop Cystic Fibrosis patients engaging in these behaviours; which in turn will benefit patients as it will increase their health status.

The information that was collected about you during this study will be kept strictly anonymous which means that no one (other than the researchers) will know what you said during your interview. If you have any questions after taking part in the study; or if you would like to know anything about the results then please feel free to contact me: - (Rebecca.Keyte@mail.bcu.ac.uk; 07957157974).

Thank you again for participating in this study.

Appendix S

Paediatric Results Feedback

Thank you for taking part

I conducted 10 interviews with adolescents with Cystic Fibrosis. During these interviews we spoke about what life is really like with Cystic Fibrosis, and I listened to participants' beliefs about certain lifestyle choices. We are really grateful to all of you (parents and adolescents) who contributed to this research.

The results of the research indicate the attitudes and beliefs that some adolescents with Cystic Fibrosis have regarding engagement in certain behaviours like non-adherence, smoking, drinking excessive amounts of alcohol, and drug use. Individuals provided a variety of reasons for why some individuals with Cystic Fibrosis may engage in such behaviours.

By understanding the factors that may influence engagement in these "risky behaviours", Health Care Professionals will now be able to identify patients who may be at risk of engaging in these behaviours to try and prevent their engagement. As many participants emphasised the need for more information to be provided to patients about the negative health effects of these behaviours, we will work to create a way of providing patients with this information at an age where they may be considering engagement in such behaviours.

All of this would not be possible without yourselves giving up your time to contribute to this research, so again I would like to say a big thank you to you all.

Rebecca Keyte

Appendix T

Breaking Confidentiality in Paediatric Participants

In regards to this research ("The role of health beliefs in predicting and explaining risky behaviours within the paediatric Cystic Fibrosis population"), the researcher has created this document to clearly illustrate when confidentiality should be broken.

The researcher would have no option to break confidentiality if:

[In brief] it is deemed that the risks to the participants (or others) health, safety or welfare, outweigh the participants right to confidentiality (RCGP, 2011).

Specifically this means that confidentiality would have to be broken if:

- The participant discloses being the victim of a unreported crime (Wiles et al., 2006)
- The researcher feels the participant is at risk of harm (Wiles et al., 2006); such harm usually surrounds issues such as that from crime, suicidal attempts / thoughts, or self-harm (but includes both physical and psychological harm)
- The researcher feels others are at risk of harm e.g. through criminal activities (includes both physical and psychological harm) (Wiles et al., 2006)
- The participant disclosed that they (or others) was in, or could be in a life threatening situation (e.g. self-harm, suicidal attempts) (Gloucestershire Confidentiality Policy, 2005)
- The participant was being threatened by an abuser (Gloucestershire Confidentiality Policy, 2005)
- The participant requested the release of information themselves (the researcher would get written evidence of this)
- There were court orders for confidential information
- It appeared that the participant had not provided consent for sexual activities (e.g. they were being coerced) (RCGP, 2011) (this would also be the case if the participant was under the influence of drugs or alcohol)
- The participant was under the age of sixteen years and engaging in sexual activity with an individual significantly above the age of sixteen years, the RCGP (2011) states that researchers should be alert if there is a power imbalance indicated by an age gap of more than five years
- The participant was engaging in substance use (e.g. smoking, excessive alcohol consumption, illicit drug use) and had not provided consent to engage in such behaviours (e.g. peer pressure)

The procedure which would be followed if confidentiality needed to be broken:

[Devised through discussions with the researcher's supervisory team]

- 1) Identify the dilemma of concern: Is it ethical, legal, or moral?
- 2) Identify potential issues: evaluate rights and responsibilities of all involved (researcher, participant, parents, healthcare team)
- 3) Look at the relevant ethics code for guidance
- 4) Consider applicable laws
- 5) Consult others with experience
- 6) Brainstorm various courses of action before doing anything
- 7) Identify the consequences of each action for all parties
- 8) Decide on the best possible course of action bearing above process in mind.

Specifically in regards to this research, if the researcher felt that confidentiality needed to be broken (after completing the above checklist), the following actions would be taken:

- 1) The researcher would discuss with the participant the benefits of disclosing such information to their HCPs, in the hope of gaining the participants consent to break confidentiality
- 2) The researcher would ask the participant if there was a member of staff at their CF centre they would prefer the researcher to talk to first; if the participant had no preference the researcher would discuss the issue with the Consultant at the CF centre.

However if the participant refused to allow disclosure of such information to their HCPs the researcher would:

- 1) Consult the research supervisory team in order to decide whether or not disclosure without consent was justified
- 2) The participant would be informed before disclosure was made, if this was the decision (RCGP, 2011).

The researcher would have discussions with the research supervisory team if:

- The participant had reported engagement in risky behaviours (e.g. smoking, excessive alcohol consumption, illicit drug use, risky sexual behaviour) but the

researcher had not broken confidentiality, the researcher would discuss the case with the research supervisory team and record her decision and reasons for not disclosing such information.

Appendix U

Revising the Codes

Taken from the Researchers Reflexive Diary

5th August 2016

Upon completion of my initial codes, I left my data for one month until revising the codes in order to allow me to look at the codes with "fresh eyes". I have made some slight changes to the codes within each of the four themes.

Identity Theme

Within the theme focusing upon **identity** I added four new codes. Firstly, there was the code:

- ❖ **Illness identity on display aids adherence**

This code includes data which had originated within that theme, within the code "Illness identity on display due to acceptance", however by representing this data within another code it clearly outlined the impact displaying an illness identity can have upon one's adherence to medical regimens.

EXAMPLE:

Participant 3 [F, 12 years]: "Sister: when you're out with your friends an you don't mi:ind taking your tablets (.) an stuff like that

Participant: Yeah # I don't mi:ind [...] they just ask (.) what's that"

Secondly, two new codes were added to support the code "desires normalcy". The first codes was:

- ❖ **A desire for normalcy can result in non-adherence**

This code included data which had originated within that theme, within the code "desires normalcy", however by representing this data within the new code it clearly outlines the impact a desire for normalcy can have upon one's adherence to medical regimens.

EXAMPLE:

Participant 3 [F, 12 years]: “Researcher: Is there any other treatments that you think o::oh (.) I don't wana do this toda:ay

Participant: ## E::er:r # dna:ase [...] because like # I go to school (.) and when I get back I've got to do it like stra:aight away # but sometimes they sa:ay # my friends ask me to >go the park< or something (.) but I ca:an't # I've got to do that fi:irst”

The second code was:

- ❖ **A desire for normalcy can result in risky behaviour engagement**

This code included data which had originated within that theme, within the code "desires normalcy", however by representing this data within the new code it clearly outlines the impact a desire for normalcy can have upon one's engagement with risky health behaviours.

EXAMPLE:

Participant 6 [M, 18 years]: “I just see drinking alcoho:ol (.) a:as:s # you do it fo:or fun [...] I just see it a:as # you go out an ha:ave fun an do it”

Thirdly, one new code was added to support the code "disclosure of illness identity":

- ❖ **Disclosure of illness identity assists with adherence:**

This code includes data which had originated within that theme, within the code "disclosure of illness identity", however by representing this data within the new code it clearly outlines the impact disclosure of one's illness identity has upon their adherence.

EXAMPLE:

Participant 5 [F, 12 years]: “Someti:imes like # at scho:ool (.) so:ome people come up to me an a:ask (.) <wh:hy I'm ta:aking # mediaca:ation> # like ta:ablets [...] I don't mi:ind telling them # I don't mi:ind people kno:owing about it”

In addition to adding new codes to this theme, I also renamed two codes to better represent the data embedded within these codes. Firstly I renamed the code "peers can result in individuals engaging in risky health behaviours" to:

- ❖ **Group norms can result in risky health behaviours**

The reason for this change in name is because the data represented by this code demonstrates how the normalisation of a risky health behaviour by an individual's social group can result in initiation, in an attempt to conform to the group norms and to be accepted within that group.

Secondly, I renamed the code "awareness of adverse health effects can prevent the influence peer pressure has upon the engagement of risky health behaviours" to:

- ❖ Awareness of adverse health effects can prevent the engagement in risky health behaviours despite group norms

The reason for this change in name is because the data represented by this code does not just refer to peer pressure, it also outlines how some individuals' social group has normalised the engagement in risky health behaviours. Therefore this code outlines how awareness of the adverse health effects of risky behaviours can prevent individuals conforming to their group norms (whether or not such conformity is influenced by peer pressure).

Adherence

Within the theme focusing upon adherence I deleted 9 codes:

1) I deleted the code:

- ❖ Adherence is boring

The reason for deleting this code is because it only contained one quote which could be represented by another code within the same theme: "Adherence requires willpower", as the participant was explaining how difficult it is to adhere to their medical regimens due to how boring their treatments are, therefore such adherence requires willpower.

2) I deleted the code:

- ❖ Adherence is more difficult during weekends

The reason for deleting this code is because it only contained one quote which could be represented by another code within the same theme: "Adherence stops the participant engaging in normal activities", as the participant was explaining how during weekends he wants to be lazy (engage in normal activities) as opposed to waking up early to adhere to his medical regimens.

3) I deleted the code:

- ❖ Adherence is more difficult during the mornings

The reason for deleting this code is because it only contained one quote which could be represented by another code within the same theme: "Adherence is time consuming", as the participant was explaining how she has to wake up early to complete her time consuming treatments which is difficult due to tiredness etc.

4) I deleted the code:

- ❖ Hospital stays prevent the participant engaging in normal activities

The reason for deleting this code is because it only contained one quote which could be represented by another code within the same theme: "Adherence stops the participant engaging in normal activities", as the participant was discussing the impact IV antibiotics has upon her life, with hospital admissions being an additional form of adherence.

5) I deleted the code:

- ❖ Patient and parents perspective on independence vary

The reason for deleting this code is because it only contained one quote which could be represented by another code within the same theme: "Participant is independent with adherence", as the participant was explaining that he feels he is independent, however his Father disagreed, suggesting that a patients perspective of independence may not be accurate, with some participants' responses potentially being influenced by social desirability bias.

6) In terms of independence, I also deleted the code:

- ❖ Parents acknowledge independence will decrease adherence

The reason for deleting this code is because it only contained one quote which could be represented by another code within the same theme: "Independence will be a challenge", as the quote was from a Father who agrees that independence will be difficult, and that he expects that the participant will struggle with their adherence when they become independent.

7) I also deleted the code:

❖ Adherence due to support from others

The reason for deleting this code is because it only contained one quote which did not clearly illustrate the impact support from others has upon an individual's adherence efforts. This concept is more clearly outlined within the theme focusing upon **support from others**.

8) I also deleted the code:

❖ No routine results in non-adherence

The reason for deleting this code is because it only contained one quote which could be represented by another code within the same theme: "**Routine aids with adherence**", as the quote was illustrating how a structured routine can improve one's adherence efforts.

9) Finally, I deleted the code:

❖ Adheres despite illness identity

The reasons for deleting this code is because the data was all illustrating how patients had appeared to have accepted their illness identity (and were not afraid to display their illness identity) due to them having good awareness of their CF and the need for adherence, therefore the data was added to the code: "**Independence due to awareness**".

Awareness

Within the theme focusing upon one's **awareness** I deleted two codes. Firstly, I deleted the code:

❖ Lack of awareness regarding CF

The reason for deleting this code is because it only contained one quote which could be represented by another code within the same theme: "**Awareness regarding CF**", as it was indicating the impact a lack of awareness can have upon an individual's health behaviours, which will be opposite to the data represented within this code, and outline the imperative nature of awareness regarding one's illness to promote health keeping behaviours.

Secondly, I deleted the code:

❖ Awareness of the adverse effects of risky health behaviours does not always prevent initiation due to habit

The reason for deleting this code is because it only contained one quote which could be represented by another code within the same theme "**Awareness of adverse effects of risky health behaviours does not always prevent initiation**", as the quote was indicating how awareness alone cannot prevent an individual engaging in such behaviours due to a variety of reasons (in this case habit).

The role of others

Within the theme focusing upon **the role of others** I deleted six codes:

1) I deleted the code:

- ❖ **Friends do not normalise risky health behaviours**

The reason for deleting this code is because it only contained one quote which could be represented by another code within the same theme: "**Friends prevent the initiation of risky health behaviours**", as the participant was indicating that by their peers not normalising such behaviours it prevents their initiation as such engagement would not provide the individual with a normal identity.

2) I deleted the code:

- ❖ **Friends would not prevent the initiation in risky health behaviours**

The reason for deleting this code is because it only contained one quote which could be represented by another code within the same theme: "**Peer pressure can result in the initiation of risky health behaviours**", as the participant was indicating how their friends all smoke so their friends would not prevent the participants initiation, instead they may encourage such initiation (through peer pressure).

3) I deleted the code:

- ❖ **Awareness prevents the initiation of risky health behaviours despite peer pressure**

The reason for deleting this code is because it only contained one quote which could be represented by another code within the same theme: "**Awareness prevents the initiation of risky health behaviours despite normalisation**", as the participant was explaining that even if a friend was to have normalised a risky behaviour and told the participant to engage in that behaviour, her awareness of the adverse health effects would prevent such initiation.

4) I deleted the code:

- ❖ Hospital cannot prevent the engagement in risky health behaviours

The reason for deleting this code is because it only contained one quote which could be represented by another code within the same theme: "Hospital works to prevent the initiation of risky health behaviours", as although the participant was explaining how hospital cannot prevent such initiation, he did illustrate the hospitals effort to try and prevent such behaviours amongst patients.

5) I deleted the code:

- ❖ Cross Contamination rules have a negative impact upon a patient's life

The reason for deleting this code is because it only contained one quote which could be represented by another code within the same theme: "Cross Contamination rules are seen in a negative light", as the participant was explaining how he views such rules in a negative way due to the negative impact they have upon his life.

6) Finally, I deleted the code:

- ❖ Lack of support from school

The reason for deleting this code is because it only contained one quote which could be represented by another code within the same theme: "Support from school is important", as the participant was explaining how he has to manage his own adherence at school, which is difficult, due to a lack of support; highlighting the imperative nature of such support.

Appendix V

Example Theme

Theme: "I wish I did not have Cystic Fibrosis, that would be wicked"

Codes:

- CF is normal
- Disclosure of the illness identity
- Disclosure of the illness identity assists with adherence
- Disclosure due to necessity
- Disclosure provides patients with support off others
- Illness identity being on display is positive
- Illness identity being on display allows adherence
- Illness identity is on display due to acceptance
- Illness identity is on display due to society accepting the illness identity
- Non-disclosure to prevent illness identity being on display
- Desires normalcy
- A desire for normalcy can result in risky health behaviours
- A desire for normalcy can result in non-adherence
- Normalcy is provided through adherence
- Group norms can result in risky health behaviours
- Awareness of adverse health effects can prevent the engagement of risky health behaviours despite group norms
- Risky health behaviours are not normalised for the participant which results in negative views towards such behaviours
- Risky health behaviours are normalised for the participant
- Normalisation results in initiation
- Normalisation causes the participants to view the behaviour in a positive light
- Awareness of the adverse health effects prevents initiation in risky health behaviours despite normalisation of such behaviours

Appendix W

CF Specialist Nurses Interview Schedule

Ice Breakers Question's:

- Thank you for taking part
- What were your first thoughts when you were asked to take part in this research?
- Did you have any hesitations about agreeing to take part?

Working within the Cystic Fibrosis population:

- Could you tell me what it is like to work within the field of Cystic Fibrosis
 - Discuss the rewards of working within the field of Cystic Fibrosis
- Many Cystic Fibrosis patients I have spoken with have discussed some challenges in terms of living with Cystic Fibrosis, these include the deteriorating nature of Cystic Fibrosis and the uncertain future patients face, how do you find working within that environment?
 - How do you cope?
 - How do you help patients cope?
- Do you believe that patients tell you everything during their clinic appointments (are they truthful to their HCPs)?
 - Do you ever feel when a patient has left the room that they have not told you the truth / told you everything?
 - What do you think they are not truthful about?
 - What do you do if you suspect a patient is not being truthful?

Adherence:

- What are some of the barriers you are faced with in terms of successfully treating Cystic Fibrosis?
It is believed HCPs will identify the issue of adherence
 - Do you believe adherence is a major concern within the Cystic Fibrosis population?
 - What treatments do you believe patients find most difficult to adhere to?
 - Do you believe patients tell the truth regarding their adherence?
 - How do you help patients improve their adherence?
 - Is there anything else you could do / wish you could do to help patients improve their adherence?

Risky Health Behaviours:

- What procedures do you have in place to inform patients about risky health behaviours?
 - Which behaviours do you inform them about?
 - Do you think this is effective?
 - What else would you like to do to prevent these behaviours within the Cystic Fibrosis population?

- Do you believe many Cystic Fibrosis patients do engage in risky health behaviours?
 - What behaviours?
 - If a patient disclosed their engagement in that behaviour what would you do?
 - If you suspected a patient engaged in that behaviour what would you do?
 - Do you believe that this is effective?
 - Is there anything else you wish you could do if you had the time / resources?

- Do you think a new intervention is required to prevent Cystic Fibrosis patients engaging in risky health behaviours?
 - What would you like this intervention to look like?

Conclusion:

- Do you think the intervention you have just described would work in reality?
 - What is preventing such intervention being implemented into Cystic Fibrosis care?
- Do you have anything else to add?

Appendix X

Handout provided to the Cystic Fibrosis Units

Title of study: The role of health beliefs in predicting and explaining lifestyle choices within Cystic Fibrosis patients

Researcher: Rebecca Keyte **Contact Details:** Rebecca.Keyte@mail.bcu.ac.uk; 07957157974

About the Researcher:

I am PhD student in the Psychology department at Birmingham City University. I have recently completed two pieces of research with adult and paediatric Cystic Fibrosis patients (at Birmingham Heartlands Hospital and the Royal Stoke University Hospital) which were investigating the factors associated with risky health behaviour engagement within the Cystic Fibrosis population

What is the research about?

I am interested in hearing the views of Cystic Fibrosis Specialist Nurses surrounding the issue of risky health behaviours. I am interested in hearing whether or not Cystic Fibrosis Specialist Nurses perceive risky health behaviours to be a major concern within the Cystic Fibrosis population, and whether or not they feel an intervention needs to be integrated into Cystic Fibrosis care to prevent the engagement of these behaviours.

What will the research involve?

If Cystic Fibrosis Nurses provide written consent, they will participate in a semi-structured interview conducted by Rebecca Keyte to investigate their views regarding whether or not risky health behaviours are a major concern within the Cystic Fibrosis population, and whether or not an intervention needs to be integrated into Cystic Fibrosis care. The interview will take place in a private room at the Cystic Fibrosis unit in which they work at, or will be conducted via telephone (depending on your preference / availability). The interview will be audio recorded so the researcher can listen back over the interview again and analyse the material; this recording will not be listened to by anyone else outside of the research team. The interview will take a maximum of 60 minutes, but can be stopped earlier if the Cystic Fibrosis Specialist Nurse wishes this to be the case. None of the information collected about the Nurses during this study will be seen by anyone else outside of the research team, and the interview data (including recordings) will be destroyed at the end of the study.

Appendix Y

Information Sheet and Consent Form



BIRMINGHAM CITY
University

Title of study: How Health Care Professionals perceive the issue of risky health behaviours within the Cystic Fibrosis population.

Researchers: Rebecca Keyte, Dr Helen Egan, Dr Michael Mantzios, Prof. Craig Jackson.

Institutions name and location: Birmingham City University, School of Social Sciences

Birmingham City University, Birmingham B4 7BD

Email: Rebecca.Keyte@mail.bcu.ac.uk (07957157974)

Introduction to the research and invitation for you to take part

We are researchers at Birmingham City University carrying out a research project investigating what predicts risky health behaviours (e.g. smoking, excessive alcohol consumption, illicit drug use, non-adherence) within the Cystic Fibrosis population. This study (phase three data collection) is interested in hearing the views of Specialist Nurses who work within the field of Cystic Fibrosis surrounding the issue of risky health behaviours. The researchers are interested in hearing whether or not Specialist Nurses perceive risky health behaviours to be a major concern within the Cystic Fibrosis population, and whether or not they feel an intervention needs to be integrated into Cystic Fibrosis care to prevent the engagement of these behaviours.

Do you have to take part?

It is up to you whether or not you want to participate in this research. Specialist Nurses who belong to a Cystic Fibrosis Multi-Disciplinary Team are being recruited. You will complete this study in a private room at the Cystic Fibrosis unit you work at, or via a telephone interview (depending on your preference / availability). To help you decide about

participation, we will first describe the study and if you express an interest we will give you an information sheet. If after reading your information sheet and having any questions answered, you are still keen on participation, we will ask you to sign a consent form. You would be free to withdraw from this research at any time without giving a reason.

What will you have to do if you participate?

If you decide to provide written consent, you will participate in a semi-structured interview conducted by Rebecca Keyte to investigate your views regarding whether or not risky health behaviours are a major concern within the Cystic Fibrosis population, and whether or not an intervention needs to be integrated into Cystic Fibrosis care. The interview will take place in a private room at the Cystic Fibrosis unit you work at, or will be conducted via telephone (depending on your preference / availability). The interview will be audio recorded so the researcher can listen back over the interview again and analyse the material; this recording will not be listened to by anyone else outside of the research team. The interview will take a maximum of 60 minutes, but can be stopped earlier if you wish this to be the case. None of the information collected about you during this study will be seen by anyone else outside of the research team, and the interview data (including recordings) will be destroyed at the end of the study.

What are the possible risks of participating?

There are no risks from participating in this study as the information that you provide in this research will be strictly confidential. The information will be anonymised, which means that all identifying information will be removed and will not be seen by anyone including the staff at the Cystic Fibrosis unit you work at. If you have any questions regarding this research then please feel free to contact me using the information given above.

Are there any possible benefits?

There are likely to be no direct benefits to you by participating in this study. However the findings from this research will highlight whether or not Specialist Nurses view risky health behaviours to be a major concern within the Cystic Fibrosis population, and will hopefully highlight potential interventions which could work in reality aimed to prevent the initiation and aid the cessation of such behaviours within the Cystic Fibrosis population.

What do I do now?

Once you have read this information sheet and have had any questions answered to your satisfaction, if you are still keen to participate in the study we ask you to sign the attached consent form. We will then arrange a date / time of when we will conduct the interview.

What if I have a complaint?

In the unlikely event of you having any complaints about any aspects of the study, we will do our best to answer these complaints. If you would prefer to speak to someone independent of the research team about your complaint then you can contact the relevant Research & Development Department [Insert contact details]:

Will my taking part in the study be kept confidential?

Yes, we will follow ethical and legal practice and all information about you will be handled in confidence.

What happens if I have more questions?

If you do not understand something in this leaflet, or have further questions you may ask the researcher now. Or you can contact the researcher via email or telephone on the contact details provided above.

What happens now if I decide to participate?

If you decide to participate you will be asked to read, sign and date the written consent form attached to this sheet. By signing it you acknowledge that you have understood the aims of the research, and what you are being asked to do.

What happens if I change my mind during the study?

You are free to withdraw your participation at any time without providing a reason.

Who is organising and funding the study?

The study has been organised by Rebecca Keyte, Dr Helen Egan, Dr Michael Mantzios and Prof. Craig Jackson at Birmingham City University. These will not be paid for including you in this study.

Who has reviewed the study?

This study has been provided favourable ethical opinion by Birmingham City University.

Enrolment Number:

Title: How Health Care Professionals perceive the issue of risky health behaviours within the Cystic Fibrosis population.

I (Name of participant)

1. Have read the attached information sheet concerning my participation in this study and have had the opportunity to ask any questions. All my questions have been answered in a satisfactory way.
2. Understand my participation is voluntary and I will not be paid for my participation.
3. Know that at any time, and without giving a reason, I can withdraw my participation in the study.
4. Understand that audio-taping will be used to record the interview which will only be listened to by members of the research team.
5. Understand that I will have a copy of this information leaflet to keep.
6. Understand that the researcher will not identify me by name in any reports using information obtained from this study, and that my confidentiality as a participant in this study will remain secure.

I hereby give my consent to take part in this study.

My SignatureDate

Name PrintedSignature of the Researcher

.....

Appendix Z

Debriefing sheet



BIRMINGHAM CITY
University

Dear Participant,

The purpose of this study was to investigate your views on whether or not risky health behaviours are a major concern within the Cystic Fibrosis population. This is in light of the two previous phases of data collection I have conducted, which have illustrated that some Cystic Fibrosis patients (predominately adults) engage in risky health behaviours, but do not disclose their engagement to their Health Care Professionals. It is hoped that all phases of this doctoral research will help in reducing the occurrence of risky health behaviours (e.g. smoking, excessive alcohol consumption, illicit drug use, non-adherence) within the Cystic Fibrosis population, by informing interventions aimed to prevent the initiation and aid the cessation of such behaviours, predominantly by increasing patient awareness regarding the adverse effects of such behaviours specific to Cystic Fibrosis.

The information that was collected about you during this study will be kept strictly confidential which means that no one (other than the researchers) will know what you said during your interview. If you have any questions after taking part in the study; or if you would like to know anything about the results then please feel free to contact me: - (Rebecca.Keyte@mail.bcu.ac.uk; 07957157974).

Thank you again for participating in this study.

Appendix AA

Results Feedback to CF Specialist Nurses

Thank you for taking part

I conducted nine interviews with Cystic Fibrosis Specialist Nurses to see how you perceive the issue of risky health behaviours within the Cystic Fibrosis population, and to gain an insight into how you would like to progress current interventions aimed to reduce the occurrence of risky behaviours.

Overall the majority of Nurses who I spoke to did acknowledge that risky health behaviours are becoming a major concern within the Cystic Fibrosis population, however you indicated that not all Cystic Fibrosis units address the issue of risky health behaviours. Some Nurses explained that it is only recently that their unit has started to address this issue, however Nurses often identified flaws within their unit's interventions. For instance it appeared that some units rely upon patients disclosing their engagement with risky health behaviours, or instigating a conversation before any awareness is provided. In addition, the majority of Cystic Fibrosis units who do provide awareness provide verbal information, with many Nurses stating that this now needs to be progressed to provide patients with accompanying written information, whether this is on paper or via technology. Furthermore, some Nurses expressed an interest in having some form of staff training to raise Health Care Professionals awareness as to what risky health behaviours are current within the general population, and how they may identify those within their patients.

Through conducting research within the adult and paediatric Cystic Fibrosis population to investigate patients' awareness and beliefs towards risky health behaviours, and by understanding how you perceive the issue of risky health behaviours within the Cystic Fibrosis population, I now aim to work with Health Care Professionals to design an intervention aimed to reduce the occurrence of such behaviours within this population. All of this would not be possible without yourselves giving up your time to contribute to this research, indicating what interventions would have practical applications to address the issue of risky health behaviours specifically within the Cystic Fibrosis population, so again I would like to say a big thank you to you all.

Rebecca Keyte

Appendix BB

Example Theme

Theme: Effective health promotion advice: What works?

Codes:

- No intervention to raise patients' awareness regarding CF's true nature
- Improve adherence through awareness on non-adherence
- Improve adherence through awareness via case studies
- Awareness does not always result in adherence
- Improve adherence through individualised care
- Do not blame patients for poor adherence
- Adherence interventions are now starting to use technology
- Future interventions for adherence could involve mentoring
- Time is key for any intervention
- Interventions for risky health behaviours are new
- Not all units have interventions for risky health behaviours
- No standardised interventions for risky health behaviours
- Risky health behaviour interventions often rely on patients instigating the conversation - reactive rather than proactive
- Risky health behaviour interventions and adherence interventions need to involve psychology
- Interventions need to allow patients to make an informed choice regarding risky health behaviours
- Interventions for risky health behaviours involve increasing a patients awareness through verbal information
- Intervention does not just use verbal information
- Interventions for risky health behaviours involve increasing a patients awareness (Ready, Steady, Go)
- Flaws with Ready, Steady, Go
- Awareness does not prevent initiation or aid cessation in all cases
- Intervention to encourage cessation is individualised
- Intervention to encourage disclosure is individualised
- Intervention encourages patients to disclose risky health behaviours to parents
- Interventions for risky health behaviours are revisited on several occasions
- Interventions are not successful when parents are present

- Verbal information needs to be progressed and accompanied by written information
- Verbal information needs to be progressed and accompanied by information via technology / online
- Future risky health behaviour interventions need to target the right age group
- Future risky health behaviour interventions need to target hard to reach group
- Future interventions need to be designed with patient input
- Future risky health behaviour interventions could involve mentorship
- Mentorship interventions would not just be for non-adherence and risky health behaviours
- Barriers to implementing a mentorship intervention
- Future interventions need to involve staff training
- Barriers to staff training intervention

Appendix CC

Dissemination Meeting Plan

- What would HCPs like to see in place to address the issue of risky behaviours within Cystic Fibrosis patients?
- Do HCPs currently use an intervention to address the issue of risky behaviours?
 - What does this involve e.g. Cystic Fibrosis specific risky behaviour material, input from psychologist?
 - Could this intervention be improved? If so, how?
- Do HCPs believe an intervention is required to address the issue of risky behaviours?
- What would be an "ideal" way to address the issue of risky behaviours in the Cystic Fibrosis population?
- What do HCPs believe would work in reality to address the issue of risky behaviours?
- Which members of the MDT should be involved in delivering an intervention to address the issue of risky behaviours?
- What are the potential benefits of the intervention HCPs have described?
- What are the practical applications of the intervention HCPs have described?
- What future events may help or hinder HCPs implementing such intervention to address the issue of risky behaviours?
- What barriers may HCPs face in implementing such intervention to address the issue of risky behaviours?
 - What suggestions do HCPs have for overcoming these potential barriers?

Appendix DD

Handout for the Dissemination Meetings

Title of study: Dissemination Meeting: What predicts risky health behaviours within the Cystic Fibrosis population.

Researcher: Rebecca Keyte

Contact Details: Rebecca.Keyte@mail.bcu.ac.uk; 07957157974

About the Researcher:

I am PhD student in the Psychology department at Birmingham City University. I have recently completed two pieces of research with adult and paediatric Cystic Fibrosis (CF) patients (at Birmingham Heartlands Hospital and the Royal Stoke University Hospital) which were investigating the factors associated with risky health behaviour engagement within the CF population. I have also conducted a piece of research with CF Specialist Nurses investigating their views towards risky health behaviours within the CF population.

What is the research about?

I aim to disseminate the research findings to Health Care Professionals (HCPs). I am interested in hearing the views of HCPs who work within the field of CF about the research findings. I want to hear which findings HCPs believe are relevant to practice, and ideas they have about an intervention which could work in reality aimed to prevent the initiation and aid the cessation of risky health behaviours within the CF population. HCPs are being recruited from both Birmingham Heartlands Hospital and the Royal Stoke University Hospital.

What will the research involve?

If HCPs provide verbal consent, they will participate in a dissemination meeting conducted by Rebecca Keyte to investigate their views regarding the research findings, and what interventions they believe could be integrated into CF care. The dissemination meeting will take place in a private room at the CF unit in which the HCPs work at. The meeting will be audio recorded so the researcher can listen back over the meeting again and analyse the material; this recording will not be listened to by anyone else outside of the research team. The dissemination meeting will take a maximum of 60 minutes, but can be stopped earlier if the HCPs wish this to be the case. None of the information collected about the HCPs during this study will be seen by anyone else outside of the research team, and the dissemination meeting data (including recordings) will be destroyed at the end of the study.

Appendix EE

Presentation used for the Dissemination Meetings

AN INVESTIGATION INTO RISKY HEALTH BEHAVIOURS IN CYSTIC FIBROSIS PATIENTS

Rebecca Keyte

Supervised by Dr Helen Egan, Dr Michail Mantzios & Prof. Craig Jackson



Risky health behaviours in the CF population

Within the CF population smoking, excessive alcohol consumption and illicit drug use are evident, with these behaviours having adverse health effects upon patients. Despite these adverse health effects, there is a lack of research indicating antecedents of these behaviours in the CF population, with previous research (McEwan, Hodson & Simmonds, 2012; Verma, Clough, McKenna, Dodd & Webb, 2001) focusing upon the incidence, prevalence and effects of these behaviours.

Transition Evaluation

- 19 Adult CF Units were contacted
- 12 Paediatric CF Units were contacted

Overall it was indicated that there are big variations across UK CF Units when addressing the issue of risky health behaviours during a patients transition to adult care.

First Phase of Data Collection

- 24 Semi-Structured Interviews with adult CF patients.
- Sex: (16 male participants; 8 female participants).
- Age Range: 19 – 66 years.
- 17 participants had engaged in risky health behaviours
 - Four of these participants were identified by HCPs as “non-risky”
- Seven participants had not engaged in risky health behaviours



“The role of Optimism, Pessimism and Psychological Distress in risky behaviours”

Risky health behaviours and psychological distress:

•[Male, 19years(1)]: “I think it [smoking marijuana] was more of a::a (.) way of self harming [...] I'd start it just to # take away the depression (.) and to sort of # shunt my life span a bit [...] I thought # forget about my CF [...] I'd rather live a short happy life # then a lo:ong # de:epressing [...] it crossed my mind that it would really damage me (.) now I can't remember if I wanted it to damage me # or I just didn't care about it damaging me”

“Denial and risky health behaviours”

Denial and risky health behaviours:

•[Male, 19years(1)]: "When I'd tried it [smoking] (.) I realised it didn't really affect me much # smoking's never made me ill"

Perceived beneficial effects:

•[Male, 23years]: "It [marijuana] can help in a lot of ways # there are certain benefits to it # it does actually (.) strangely enough (.) once you've had a bit it really (.) really settles your chest # it feels really (.) really clear"

Denial does not always result in risky behaviour initiation:

•[Male, 34years]: "I was in denial with my CF # cause I (.) I was re:really healthy # I was the sa:ame as everyone else [...] none of me mates smoked (.) no one in me family smokes # I've come from an environment where it's not done # I'm not exposed to it (.) I've no desire to do it"

“Support from Others”

Health Care Professionals awareness:

•[Male, 21years]: "I think they're [HCPs] naive to what you can get your hands on # I can get my hand on any drug # nobody in here would be saying (.) o:oh [name] don't do that (.) don't do that # they don't really expect that you could do that # I don't think half the people know what you can get your hands on (.) so they just don't assume that they have to tell you"

Awareness and initiation:

•[Male, 19years(2)]: "If I'd have known then what I know now it'd have gone a lot different # I'd have understood # I probably wouldn't have gone anywhere near a fag"

“Identity and risky health behaviours”

A desire for normalcy and “normalised risky behaviours”:

•[Male, 34years]: “It's nice just to be normal # for that day you're normal [drinking alcohol] # you feel like you're normal (.) you're not isolated (.) you're just a normal person that day (.) and the thousands of people around you they don't know any different”

Life-Orientated Illness Perspective:

•[Male, 19years(2)]: “My main priority (.) with a life threatening illness that's going to kill you (.) that should be living your life (.) doing what you want (.) ticking off your bucket list”

“Acceptance and risky health behaviours”

Psychological well-being and risky health behaviours:

•[Male, 19years(1)]: “Feeling a bit depressed (.) which is when I started [smoking] # before then I was proper no (.) like anti-smoke # I couldn't stand it # I knew it was risky (.) I always knew it was risky # when you get that low it's sort of like you don't care”

Initiation in a second risky health behaviour:

•[Female, 32years]: “I couldn't drink as much blue wickeds # it used to play havoc with my sto:omach [...] so that [drugs] would keep me on the same path as everybody else (.) like (.) up there (.) instead of me being the sober one [...] I didn't want to miss out # so I [laughs] went (.) skipped the alcohol and went straight for the drugs [laughs]”

•[Male, 19years(1)]: “I used to like # proper want to get drunk all the time (.) an then when I moved to weed (.) that stopped [...] there's no negative effects:s of weed [...] alcohol's worse at the end of the day”

Conclusions

The results from phase one data collection highlight the need for more effective health promotion measures to reduce the occurrence of risky health behaviours in the CF population.

Due to the initiation of risky health behaviours commonly occurring during adolescence it was deemed essential for the next phase of data collection to be conducted within the paediatric CF population.

Second Phase of Data Collection

- 10 Semi-Structured Interviews with paediatric CF patients.
- Sex: (5 male, 5 female).
- Age Range: 12 – 18 years.
- 1 participant had previously engaged in a risky health behaviour



“Adherence”

Psychological influence on adherence:

•[Female, 12years]:“I think I would be a bit mo:ore # re:elaxed (.) about thi:ings (.) and not ha:aving to worry as much [with non-adherence]”

Awareness does not prevent a desire for non-adherence:

•[Male, 13years]:“Researcher: Are there any treatments that you wi:ish you could miss out

Participant: Yeah # physio:o # that’s just the lo:ongest one

Researcher: And ho:ow do you think you’d feel if you didn’t do your physio:o (.) if you did miss it out # how would that make you feel

Participant: I’d feel a bit bad (.) because I kno:ow it could sta:art to make me ill

Researcher: Yeah # so although you wish you could miss it out (.) you think you may feel a bit # [...]”

“The role of others”

Awareness is reactive rather than proactive:

•[Male, 18years]:“I think it [smoking] ha:as been brought up befo:ore ## but # it’s mo:ore me # kind of # sa:aying (.) about it ## a:asking about it ## to be honest # in ho:ospitals they don’t ki:ind of # ta:alk about precautions of things # they’re mo:ore ta:alking about your treatments an stu:uff”

Awareness regarding risky health behaviours:

•[Female 12years]:“Researcher: Has anyone ever told you # anything (.) about drinking alcohol

Participant No:o

Researcher: No:o # what do you think of drinking alcohol (.) as a behaviour

Participant: ## I don’t get like # wha::at’s bad about it # I know it’s like alcho:ol (.) but # like wha:at’s # there’s something it in (.) o:or ## I dunno:o”

“CF and a paediatric’s identity”

Disclosure of the illness identity:

•[Male, 13years]: “Researcher: A:and # if people ask you # so say if someone did see you ta:aking your tablets (.) would you then tell them that you’ve got CF

Participant: Yeah

Researcher: And you’re fi:ine with telling them

Participant: Yeah”

Desire for normalcy:

•[Male 14 years (1)]: “Researcher: And wh:hy do you think your friend engages in that behaviour [smoking Shihsa]

Participant: Cause other boys in our year do it [...] they think they look good ## it’s bad”

•[Male, 13years]: “Researcher: Do you think anyone with CF smo:okes

Participant: I’d say probably quite a fe:ew people (.) like te:eenagers:s (.) and that # some adults:s might with CF # cause probably the a:area they’ve been brought up in # o:or some of the friends they have”

“CF and identity” Continued ...

[Male, 14years(2)]: “Researcher: Do you know anyo:one who does smo:oke

Participant: Most the people in my class does # it’s ridiculous

Researcher And ho:ow does that make you feel

Participant: I think they’re re:eally (.) stu:upid”

“Awareness and health behaviours”

Awareness and engagement in risky health behaviours:

•[Male, 14years(2)]:“Researcher: When I say the words (.) ri:isky (.) behaviours:s # what sort of behaviours would you think of

Participant: Smo:oking (.) drinking # that kind of thing

Researcher: Yeah # and what do you think about those so:ort of behaviours

Participant ## They’re stupid #

Researcher: Yeah # wh:hy do you think they’re stupid

Participant: It’s basically like cutting yourself ain’t it # it’s killi:ng yourself”

What are risky health behaviours?:

•[Male, 18years]:“Any ki:ind of behaviour that can affect your lu:ungs # even if it’s down to not doing treatments # I count that as a ri:isky behaviour”

Conclusion

Overall, this research highlights the juxtaposition between clinical recommendations, and personal life strategies undertaken by CF patients to support their identity, with this representing a challenge for patients, their families and HCPs alike. Understanding the dilemma highlighted within this research will help to inform existing interventions.

In order to shape the impact of this research, the third phase of data collection involved conducting semi-structured interviews with CF Specialist Nurses to investigate how they perceive the issue of risky health behaviours within the CF population, and to gain an insight into how they would progress current interventions.

Phase Three Data Collection

- 9 Semi-Structured telephone interviews with CF Specialist Nurses each from a different CF unit.
- 4 Nurses were from paediatric CF units, 5 Nurses were from adult CF units.
- Range of time in service: 11months – 23 years (mean: 15years)



Phase Three Preliminary Analysis

Acknowledgement of risky health behaviours:

•[Female, 4years, paediatric nurse]:“It’s a big issue (.) that’s probably a growing issue (.) risky behaviours # so there’s absolutely no reason why it won’t affect our CF patients”

Reactive rather than proactive discussion:

•[Female 8years, paediatric nurse]: “I don’t know if we need (.) something there just to highlight it # to make sure they are aware (.) so we do have a talk (.) before it starts even”

•[Female, 4years, paediatric nurse]:“With transition that [risky behaviours] becomes one of these areas we discuss (.) but # e:erm:m # no:ormally it’s them a:asking us (.) you know # o:or we hear they’ve been out dri:inking (.) so we have the conversation”

Staff training to raise awareness of risky health behaviours:

•[Female, 20years, paediatric nurse]:“Help u:us (.) as a tea:am # to understa:and (.) what risky behaviour i:is:s # ho:ow to identify it # and wa:avs in which (.) as a tea:am (.) we can manage it”

•[Female, 21 years, adult nurse]: “I think # it would be useful # for people # mo:ore knowledgeable than me (.) about what the current tre:endy things a:are # it’s tough enough to keep up to date on a:all the things that are changing # without having to read up on # the latest ecstasy # designer drug is [laughs]”

What happens next?

It is hoped that all three phases of data collection will improve knowledge and inform practice in reducing risky health behaviours within the CF population.

Therefore I would now like to hear your views on this research to gain clinical and practical insight into how these findings may be used to inform current advice and practice on risky health behaviours for people with CF.

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Appendix FF

Example Theme

Theme: HCPs ideas regarding future interventions to address the issue of risky health behaviours

Codes:

- Interventions are required to address risky health behaviours
- Staff training is required
- Awareness should be provided during annual reviews
- Interventions are required prior to adult care
- Interventions should be delivered in absence of parents
- Interventions for risky health behaviours need to emulate those used for non-adherence
- Interventions could provide awareness to adolescents via technology