# Adapting the Essen Climate Evaluation Schema (EssenCES) for use in Forensic Intellectual Developmental Disorder (IDD) Services

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Natalie Sarah Bell

School of Psychology

Faculty of Business, Law and Social Sciences

Birmingham City University

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**Abstract**

Social climate is a crucial aspect of the treatment environment in forensic settings. However, the majority of social climate questionnaires have limited evidence to support their reliability and validity in Intellectual Developmental Disorder (IDD) populations. Furthermore, concerns have been raised regarding the suitability of using these non-IDD specific questionnaires with IDD populations. Consequently, understanding of the social climate of forensic IDD settings remains limited. This thesis aimed to develop a pilot version of the Essen Climate Evaluation Schema (EssenCES) for individuals with IDD. The perspectives of 80 staff working in forensic IDD settings were sought via an online questionnaire, interviews, and focus groups to develop an understanding of the difficulties that individuals with IDD may experience when completing the EssenCES, and to establish how the questionnaire could be amended to improve its suitability for this specialist population. Participants highlighted potential difficulties and made suggestions for amendments in the areas of the layout, linguistic content and response format of the EssenCES, along with drawing attention to ways in which the administration of the questionnaire could be improved. This feedback was used to develop the initial pilot version of the EssenCES for individuals with IDD (the EssenCES-IDD). Six individuals with IDD from one UK prison wing participated in individual interviews and seven staff members participated in focus groups to provide feedback on the initial pilot version of the EssenCES-IDD. A specialist Speech and Language Therapist and two social climate experts also provided free-text qualitative feedback. Following this, further adaptations (in terms of the layout, time-frame, cover sheets, linguistic content, response format, and administration) were made and the updated pilot version of the EssenCES-IDD was developed. Findings indicated that the current version of the EssenCES is not suitable for use in IDD populations and that a specifically adapted version is required. The EssenCES-IDD has the potential to measure social climate of IDD settings in a more accurate and reliable way, and to further develop understanding of IDD social climate and its relationship with other clinical and organisational outcomes. The addition of gathering qualitative feedback is likely to enable social climate data to be utilised in a more clinically meaningful way. It is envisaged that the EssenCES-IDD will lead to significant developments in terms of IDD social climate research;

resulting in services developing ways in which to promote a more positive social climate and ultimately enhancing rehabilitative outcomes for offenders with IDD.

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# Chapter 1: An Introduction to Measuring Social Climate in Forensic Settings

## 1.1 The Social Climate of Forensic Settings

Forensic mental health services encompass prison, hospital and community services and are for mentally disordered individuals who pose, or have posed, a risk to others, usually associated with their mental disorder (Centre for Mental Health, 2011; Joint Commissioning Panel for Mental Health, 2013). The primary aim of these services is to assess and treat mental disorder and reduce offending behaviour (Joint Commissioning Panel for Mental Health, 2013). Significant developments have occurred across forensic mental health services over the last two decades, with increased emphasis on patient-centred care; considering the needs and preferences of residents in relation to their treatment and the treatment environment (Livingston et al., 2012). Whilst much effort has been focused on developing rehabilitation programmes and evaluating the success of such programmes, it is also of importance to consider the environment in which these programmes are being delivered and the environment as a whole in which mentally disordered offenders reside (Blagden et al., 2016). There is a clear need for such services to provide an environment conducive to rehabilitative gain; however, services are faced with the challenge of delivering rehabilitative programmes within an environment that, by necessity, also provides a suitable level of physical, procedural, and relational security to manage resident risks (Doyle et al., 2017; Mann et al., 2014). Clearly, devising a mechanism that ensures the attainment of both of these, somewhat contradictory, goals is not straightforward (Doyle et al., 2017).

The literature has, unsurprisingly, concluded that more positive prison and forensic hospital environments improve the outcomes of rehabilitation programmes delivered within such settings (e.g., Day et al., 2012; Harding, 2014; Long, Langford, et al., 2011). This knowledge has been used within prison services to develop democratic therapeutic communities and, more recently, psychologically informed planned environments (PIPEs), both of which promote a safe environment for residents and staff in which therapeutic programmes can be undertaken (Haigh, 2013). Preliminary research has evaluated the social climate of these settings with, for example, Turley et al. (2013) exploring the social climate of prison units before and after the PIPE model was introduced. Findings indicated that the units were

perceived as being significantly more supportive, safe, and cohesive following introduction of the PIPE model. These findings are encouraging and indicate that PIPEs have the potential to provide an improved environment for offender rehabilitation.[1] In light of these developments, the need for mainstream prison units to focus more on the units' therapeutic aspects has also been recognised within recent research (e.g., Reading & Ross, 2020). This is clearly an area requiring much attention given that it is reported that up to 90% of prisoners have mental health issues (House of Commons, 2017), meaning that the majority of offenders experiencing mental health issues currently reside within mainstream prison units as opposed to specialised prison mental health units or forensic hospital settings.

Forensic hospital settings are designed to be of a therapeutic nature. However, they often experience similar challenges to prison settings in terms of their ability to provide a secure environment that is also conducive to the rehabilitative process (Doyle et al., 2017). Recent literature highlights that physical security measures (such as high fences and locked doors), the clinical nature of the hospital environment, and the fact that most residents are detained under the Mental Health Act (and are, therefore, not undertaking treatment on a voluntary basis), can contradict the environment required for effective therapeutic progress (Doyle et al., 2017). Higher levels of security evidently require more of a focus on physical and procedural security, as opposed to conditions of lower security where relational security in terms of care and treatment has a greater role (Kennedy, 2002). It is, therefore, encouraging that consideration of the environment of forensic hospital settings has also attracted attention over recent years, exploring ways in which a more therapeutic environment can be established (e.g., Livingston et al., 2012; Marshall & Adams, 2018).

Whilst practical developments, such as those described above, have taken place across UK and international forensic settings, researchers have also been working alongside this to examine the environment of forensic settings with the aim of understanding the mechanisms by which the environment links to a wide variety of rehabilitative outcomes. The environment of psychiatric settings was first discussed in the literature in the 1960s by Rudolf Moos (e.g., Moos, 1968; Moos & Houts, 1968) who considered that, in order to fully

[1] Of note is that a more comprehensive evaluation of PIPEs is required.

understand behaviour, there was a requirement to examine both internal factors (such as personality) and external factors (such as the environment). Moos (1968) identified that the majority of previous research examining behaviour had only considered internal factors and that, therefore, it was important that future research identified a way in which it could also incorporate the consideration of these external, environmental, factors, particularly as Murray (1938) had acknowledged an interactive relationship between these factors. Moos and Houts (1968) highlighted previous research findings which had identified that individuals, environments, and interactions between the individual and the environment all contributed to individuals' behaviour, and initially used the terms 'ward atmosphere' and 'social climate' to refer to these environmental factors and the impact of the environment on the individual within forensic settings. Following subsequent research in this area, Moos (1989) defined forensic social climate as the specific way in which the material, social, and emotional conditions of an institutional setting interact. A variety of terms to describe forensic social climate have emerged since such as therapeutic milieu (Livingston et al., 2012), psychosocial atmosphere (Moos, 1989) and therapeutic climate (Day et al., 2012), all of which broadly encompass the same components which are believed to underpin the socio-cultural environment of forensic settings and which highlight the multifactorial nature of the social climate construct. For the purpose of this thesis, however, the definition of social climate is based specifically on the work of Schalast et al. (2008) who proposed that the key characteristics of forensic social climate encompass how safe residents and staff feel from the threat of aggression and violence, and how supportive the unit is perceived to be of therapeutic gain and of the physical and psychological needs of residents. Schalast and Groenwold (2009) suggested that these key characteristics may influence the well-being, behaviour, and self-concept of both residents and staff within secure units.

### 1.2 The Benefits of Measuring Social Climate

There are many benefits to measuring forensic social climate. Longitudinal monitoring can evaluate changes in social climate over time and cross-sectional monitoring can evaluate the effect of an intervention or change in physical environment (Tonkin & Howells, 2011). Furthermore, as social climate is measured in numerous forensic settings, comparisons across units and levels of security are possible (Howells et al., 2009).

The importance of social climate is underscored by a multitude of research that has shown climate to relate to many important clinical and organisational outcomes within psychiatric and forensic settings. Social climate has been shown to be positively associated with resident satisfaction and resident experiences of their therapeutic relationships with staff (Bressington et al., 2011), staff satisfaction and staff perceptions of their working conditions (Bressington et al., 2011; Røssberg & Friis, 2004), enhanced staff morale and performance, and reductions in staff stress, burnout, and turnover (Moos & Schaefer, 1987; Rose, 1993; Rose et al., 2013; Thompson & Rose, 2011). A more positive social climate has also been associated with improved therapeutic alliance and treatment readiness (Gaab et al., 2020; Johansson & Eklund, 2004; Long, Anagnostakis, et al., 2011), reductions in levels of institutional violence (Friis & Helldin, 1994; Ros et al., 2013) and improved treatment outcomes for patients (Beech & Hamilton-Giachritsis, 2005; Long, Anagnostakis, et al., 2011; Moos et al., 1973). Relatively few studies have reported on the relationship between social climate and reoffending despite this possibly being one of the more overarching measures of treatment outcomes within forensic settings, reportedly as a result of this being a difficult relationship to measure (Auty & Liebling, 2020). However, within prison settings, Auty and Liebling (2020) demonstrated a link between higher moral social climate and improved prisoner outcomes on release from custody, and both Marshall (1997) and Taylor (2000) provided preliminary evidence that individuals who have participated in therapeutic community prison programmes are less likely to reoffend.

Throughout the aforementioned studies, the complexity of measuring social climate as a whole and the challenges in exploring its relationship with other variables is acknowledged. Social climate is a multifactorial construct (Tonkin, 2016), with various suggestions proposed as to exactly which components contribute to it (Doyle et al., 2017). Additionally, the relationships between social climate and other variables may not be straightforward, and can be mediated by other factors, for example, resident aggression (Robinson et al., 2018) and community connection, the wider system, attitudes to diversity, and cultural and gender issues (Doyle et al., 2017). Despite differences in how the above studies have defined social climate and the social climate measures used, there is a clear consensus that a more positive social climate is associated with more positive outcomes for residents. These relationships have been reported in prison and forensic hospital settings across a

variety of countries and underscore the influence of a positive social climate on successful offender rehabilitation. In order for organisations and researchers to address how settings perceived as having a poorer social climate can implement positive changes that will improve the social climate and, subsequently, result in more successful rehabilitation of offenders, it is evident that a reliable and valid measure of social climate is required.

### 1.3 Self-Report Questionnaire Measures of Social Climate

A range of questionnaire-based measures exist to assess social climate and related constructs (see Tonkin, 2016, for a review), but the most widely used measures are the Ward Atmosphere Scale (WAS; Moos, 1974), the Correctional Institutions Environment Scale (CIES; Moos, 1987), the Measuring the Quality of Prison Life survey (MQPL; see Liebling et al., 2011), and the Essen Climate Evaluation Schema (EssenCES; Schalast et al., 2008). Alternative – less commonly used – questionnaires include the Prison Preference Inventory (PPI; Toch, 1977) and the Prison Environment Inventory (PEI; Wright, 1985), along with newer questionnaires including the Forensic Satisfaction Scale (FSS; MacInnes et al., 2010) and the Prison Group Climate Inventory (PGCI; van der Helm et al., 2011). Limits on space preclude a detailed review of these measures; however, the aforementioned references provide a useful overview.

### 1.4 The Essen Climate Evaluation Schema (EssenCES)

The EssenCES was developed by Schalast et al. (2008) in an attempt to overcome some of the limitations of the WAS and CIES, and consists of two unscored and 15 scored items across three subscales (five items per subscale). Originally written in German, and later translated to English, it is reportedly the most widely used measure of social climate in UK forensic settings (Chester et al., 2015). Two slightly different versions of the questionnaire exist: one for use within forensic hospital settings and the other for use in prison settings with small variations in terminology across the two versions (see Appendices 1 and 2). The forensic hospital subscales are named therapeutic hold, patient cohesion, and experienced safety, and the prison subscales are named hold and support, inmate cohesion, and experienced safety; reflecting the differences between the terminology required, and goals,

of these different types of establishments (Schalast & Tonkin, 2016). Further information regarding the EssenCES can be found in Appendix 3.

The English version of the EssenCES has received considerable empirical support with studies supporting the proposed factor structure and psychometric properties within both forensic hospital and prison settings (e.g., Howells et al., 2009; Tonkin et al., 2012) and, in a recent German study, the utility and psychometric properties of the EssenCES were largely confirmed on general psychiatric wards (Siess & Schalast, 2017). Construct validity has been demonstrated with significant relationships identified between the EssenCES and a number of important clinical and organisational outcomes (e.g., Day et al., 2012; Tonkin et al., 2012) and content validity has also been established with studies reporting clear correlations between EssenCES scores and those of other social climate measures, such as the CIES (Schalast & Groenewald, 2009), along with measures of the ward environment such as the Working Environment Scale and the Good Milieu Index. Furthermore, the questionnaire has demonstrated the ability to differentiate between different security levels and perceptions of residents and staff (e.g., Day et al., 2012; Long, Anagnostakis, et al., 2011; Milsom et al., 2014).

### 1.5 Limitations of Existing Questionnaire-Based Measures of Social Climate

Despite the wide variety of different social climate measures available, many of the aforementioned questionnaires do, however, present certain limitations. Some of these questionnaires have only been designed for use within either forensic hospital or prison settings (e.g., the PPI = prison settings and the FSS = forensic hospital settings) and some have only been designed for completion by residents but not staff (e.g., the FSS and PGCI). Furthermore, some can be considered outdated (e.g., the WAS and CIES); however, more recently developed questionnaires may lack broad empirical support (e.g., the FSS). Resident and staff perceptions have been taken into consideration during development of some of the above measures (e.g., the PPI and FSS) in an attempt to ensure that the questionnaires examine aspects of social climate that are important to forensic residents and staff, and that appropriate terminology is used within the questionnaire items. However, it is apparent that both residents and staff need to be provided with more

opportunities for involvement in development of social climate measures as, undoubtedly, these individuals are those best placed to provide meaningful contributions to such measures. Additionally, recent research conducted by Robinson et al. (2018) has also identified a pressing need for qualitative research to be conducted in this area, proposing that this would be a beneficial way of gathering more in-depth information relating to both resident and staff experiences of social climate.

Although all of the above limitations are of great relevance to the current research, that of most importance is clearly that there is limited evidence to support the reliability and validity of any current social climate measures across the entirety of the forensic population, with women's, adolescent's, neurorehabilitation and IDD services being either not considered at all or being severely under-represented (Bell et al., 2018). None of the above questionnaires have been validated for use across the full range of forensic IDD settings, with most not validated within any forensic IDD settings. This is a significant limitation given the high prevalence of IDD in forensic settings and previous recommendations that social climate be regularly monitored in all UK forensic hospital IDD services (Royal College of Psychiatrists, 2013). Consequently, concerns have been raised regarding generalisation of the above results to these populations (Alderman & Groucott, 2012; Bell et al., 2018; Tonkin, 2016). It is important that research considers whether existing measures of social climate are suitable for use with IDD populations as, without exploration of this, any attempts to monitor the social climate of forensic IDD settings will be, at best, meaningless and, at worst, misleading.

# Chapter 2: Measuring Social Climate in Forensic IDD Settings: An Introduction and Literature Review

## 2.1 Defining Intellectual Developmental Disorder

Intellectual Developmental Disorder (IDD) is a diagnosis which includes significant impairments in intelligence (Intelligence Quotient [IQ] <70) and deficits in adaptive functioning that present before adulthood (18 years) and that have a lasting effect on development (American Psychiatric Association, 2013). According to The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; *DSM-5*; American Psychological Association, 2013), the following three criteria must be met for a diagnosis of IDD to be made:

1. Deficits in intellectual functions, such as reasoning, problem-solving, planning, abstract thinking, judgment, academic learning, learning from experience, and practical understanding.
2. Deficits in adaptive functioning resulting in a failure to meet developmental and societal standards for independence and social responsibility across conceptual, social, and practical domains.
3. The onset of the intellectual and adaptive deficits mentioned above must occur during the developmental period.

IQ scores were previously used to determine the severity levels of IDD (i.e., IQ 50-69 - mild, IQ 36-49 - moderate, IQ 20-35 - severe, and IQ <20 - profound). However, DSM-5 instead proposed using the individual's adaptive functioning level across conceptual, social, and practical skills to guide clinical judgment in determining the severity level of IDD. Historically it was the norm for individuals with IDD who required intensive support to be housed within institutional-style settings (Department of Health, 2001). However, over recent years, initiatives have been pushing for a shift towards enhanced community provision to prevent unnecessary admissions and to ensure that individuals are supported in the least restrictive setting (Department of Health, 2012). Admission to hospital settings is, however, a necessity for a small minority of individuals with IDD, particularly for those who present with complex mental health difficulties and who are deemed to present a risk to

themselves or others (Morrissey et al., 2017). Individuals with IDD may also be placed within secure forensic hospital settings if warranted by their level of risk, with a high proportion of individuals with IDD who are admitted to such settings having been convicted of committing criminal offences and presenting with complex clinical needs (Morrissey et al., 2017). Individuals convicted of offences can also be detained within prison settings (Royal College of Psychiatrists, 2014). It is estimated that there are approximately 3,000 forensic beds for individuals with IDD in England (Royal College of Psychiatrists, 2013) and that approximately 24,500 prisoners across England and Wales have IDD or borderline IDD (Mottram, 2007). It is, therefore, evident that forensic settings cater for a high number of individuals with IDD.

### 2.2 Measuring the Social Climate in Forensic IDD Settings

Although knowledge and understanding of the social climate construct have developed considerably since Moos' early research in the 1960s, little attention has been paid to the social climate of specialist forensic settings, including IDD settings (Tonkin, 2016). Social climate literature for this specialist population is, therefore, sparse. No empirical studies have considered how the social climate of IDD settings is constructed and, although a small number of studies have used social climate measures with IDD individuals in order to examine the social climate of a given environment (see review below), there are surprisingly few studies examining the relationships between social climate and outcome variables, such as resident and staff satisfaction, institutional violence, staff morale and stress, or treatment engagement and outcomes, in forensic IDD settings (Bell et al., 2018). There has been some consideration of social climate and associated constructs within qualitative research, such as that conducted by Fish and Culshaw (2005) and Wood et al. (2008); however, again, this remains sparse.

A small number of studies have examined the social climate of forensic IDD settings using the WAS or CIES. McGee and Woods (1978) used a modified version of the WAS to measure the social climate in a residential adolescent IDD service, with findings highlighting significant differences between staff and resident perceptions of social climate. The authors clearly appreciated the necessity of adapting the WAS for IDD populations. However, as the reliability and validity of the modified WAS were not examined, their findings may need to

be interpreted with caution. Langdon et al. (2006) used the CIES to compare the social climate of medium and low secure forensic IDD units, and staff and resident perceptions of social climate. Their findings indicated that residents across both medium and low secure units rated the units significantly higher than staff on the involvement, support, personal problem orientation, and staff control subscales. However, they rated the units significantly lower than staff on the practical orientation subscale. Additionally, the low secure unit was rated significantly higher on the practical orientation and personal problem orientation subscales by both staff and residents. The authors concluded that their findings provided some support for the use of the CIES in IDD populations; however, remarked that a lack of normative data for IDD settings made it difficult to contextualise their results. Whilst it is encouraging that some research has utilised the WAS and CIES with forensic IDD populations, it should also be noted that the WAS is intended for use in general psychiatric units rather than forensic units. It is therefore unclear how this may have impacted on the study's findings and, consequently, how much credence should be given to the results. It is also important to highlight that the study conducted by Langdon et al. (2006) only included male residents and that McGee and Woods (1978) did not specify the sex of participating residents. Furthermore, both studies included small resident samples (10 and 18 residents respectively) within individual forensic establishments. This raises questions as to whether the results of these studies would be generalisable to the broader forensic IDD population.

It is also of importance to note that Langdon et al. (2006) did not modify the CIES for use within their study nor did they comment on the ability of individuals with IDD to understand this measure. The CIES has not been validated for use with IDD populations, meaning questions ought to be raised with regards to the validity of this study's findings. This is of particular concern given that, in 2012, Bakken et al. conducted a study investigating whether individuals with IDD can reliably complete the WAS and, as the CIES is a corrections-modified version of the WAS, their findings are of clear relevance. Their study included 17 patients with mild and moderate IDD and 21 members of staff, with all participants being asked to complete the revised WAS-R (a shortened form of the WAS comprised of 82 items rated on a four-point scale). Only two patients completed the WAS without help, with the authors reporting that most patients were not comfortable with self-reporting, and that they expressed finding the questions too difficult to answer and

highlighted that they had no experience with answering written questions. Following receipt of this feedback from the first five patients, the WAS-R was presented verbally for most of the patients, with the interviewer reformulating difficult phrases and questions containing double negatives, along with explaining the content of some of the questions to patients. Despite the above adjustments, the authors reported that nine of the patients found more than half of the questions too difficult to answer without extensive help from the interviewer and that one patient left more than half of the questions blank. This was more prevalent in individuals with moderate IDD, with the authors concluding that, in their opinion, participants with moderate IDD were unable to reliably rate the WAS. This was also reflected in measures of internal consistency, with this being satisfactory for five subscales for patients with mild IDD but only for two of the six subscales for those with moderate IDD. The potential bias introduced as a result of patients being provided with help to complete the WAS was also discussed, with the authors perceiving that such bias was likely to have occurred, although stating that further research would need to be conducted to determine the nature and direction of this bias. When reflecting on their findings, the authors concluded that, as their patient sample was comprised of individuals with IDD and mental illness whereas those of McGee and Woods (1978) and of Langdon et al. (2006) were comprised of individuals with 'only' IDD, the combination of moderate IDD and mental illness may explain the low levels of internal consistency found within their study. However, this reflection may be incorrect given that Langdon et al. (2006) conducted their study within forensic hospital settings, of which mental illness is a prerequisite for admission. It is possible that geographical differences in terminology surrounding forensic hospital settings may be responsible for this discrepancy. Regardless, it is, however, apparent that there are identified issues surrounding using both the WAS and the CIES in a clinically meaningful way within forensic IDD populations with the aforementioned studies clearly emphasising the need for further research to be conducted in this area, incorporating a broad sample of male and female residents across a variety of international forensic IDD settings.

The Group Climate Instrument (GCI; van der Helm et al., 2011) is a variation of the PGCI, and is designed specifically for non-prison populations. The concept of group climate is somewhat different to that of social climate and, therefore, this measure of climate differs from questionnaires that measure social climate as all items are relevant to the context of

residents living in groups. The concept of living in groups is more prevalent in adolescent prisons and secure residential hospitals, in comparison to adult prisons where inmates often spend a lot of time in their cells (van der Helm et al., 2011). However, it was considered relevant to provide a brief overview of the study conducted by Neimeijer et al. (2018) who examined the psychometric properties of a modified version of the GCI in forensic IDD settings. Participants consisted of 189 male residents; 44% with mild IDD (IQ 50–69) and 56% with borderline IDD. All residents had additional psychiatric co-morbidities and were placed within the service under criminal or civil law. The authors adapted the GCI for the IDD and borderline IDD population, reviewing the original GCI for clarity, comprehensiveness, understanding, sensitivity, and practical relevance with 10 young adults with IDD and borderline IDD. Based on this review, the adapted GCI contained 29 items instead of the original 36 items, and the incorporation of simpler wording and reformulation of some of the items was also undertaken. The authors also reported that the majority of residents were supported to complete the questionnaire, with questions and response options being provided verbally. Alternative scripted phrases were also provided to enable questions to be explained to residents in a different way and as a means of checking participant understanding. Furthermore, this also helped to limit administration biases which could occur if those administering the questionnaire reworded the questions in their own way, which could result in them projecting their own interpretation of the questions on to participants. Findings confirmed the proposed four-factor structure of the GCI, and reliability coefficients for all four scales were satisfactory. The authors also commented upon the potential biases that may have been encountered during the study, providing some clear justifications as to why they perceived that these biases had not impacted on their findings. The authors noted that there were no participants who dropped out of the study and that all participants completed all questions on the questionnaire, commenting that this would suggest that participants understood the questions (as one would expect missing data or dropouts should participants experience the questionnaire as too difficult). The authors also drew attention to participant consistency in patterns of responding, stating that patterns of responding that would be indicative of response biases were not present and, given that the questionnaire contained both positively and negatively worded items, this would suggest participant understanding. Finally, the authors highlighted that those interviewing the participants were not involved in the participants' treatment, suggesting

that socially desirable responding was minimised. Although the findings from this study appear encouraging, and it is clear that the authors maintained an awareness of the potential biases that could be present when conducting questionnaires with this participant group, it is evident that further, large scale, studies are required in order to provide further support for this modified version of the GCI in forensic IDD populations. Further research also needs to be undertaken to establish the relationship between social climate and group living climate. De Vries et al. (2018) made a tentative step forward in this area when they examined the correlation between the GCI-r (a more recent, unvalidated, version of the GCI) and the EssenCES, with their results suggesting that the two questionnaires do measure related constructs.

Following the above, Neimeijer et al. (2021) conducted a qualitative study which explored how individuals with mild-borderline IDD (IQ 50-85) perceive the group climate of forensic IDD settings and aimed to develop a more in-depth understanding of the experiences, challenges, and needs of individuals with IDD within such settings. Twelve patients participated in semi-structured interviews which covered the four sub-scales of the GCI (support, growth, atmosphere, and repression). Five over-arching themes were identified; autonomy, uniformity, recognition, competence, and dignity, with the authors commenting that these themes all interact with one another and are of relevance across all four of the GCI subscales. It was evident that participants had differing needs, and that requirements for support varied dependent on the individual. The authors concluded that provision of a group climate that is optimal for all patients would, therefore, be difficult to achieve. Importantly, this study demonstrated that individuals with IDD are able to engage in discussions surrounding the climate of their ward. It has also begun to draw attention to aspects of group climate that are important to individuals with IDD, which is an area that had not been explored previously. The authors did, however, highlight that their study solely focused on exploration of the GCI subscales and noted that, if an alternative measure of group climate had been used, results may have been quite different. Furthermore, they identified the need to conduct future research in this area to seek the views of ward staff.

A small number of studies have reported on use of the EssenCES in forensic IDD populations. In 2012 Quinn et al. explored the psychometric properties of the EssenCES in a sample of 37

male and 14 female residents (mean IQ 63.21) in a UK medium and low secure IDD service. Their findings indicated acceptable reliability. Construct validity was examined through comparison of resident scores on the medium and low secure units and, although residents on the low secure unit reported significantly higher levels of experienced safety, no significant differences were found on the therapeutic hold or patient cohesion subscales. The authors concluded that it is unclear whether the EssenCES is a valid measure in this population. Willets et al. (2014) used the EssenCES to examine social climate across 64 male residents and 73 staff in one establishments' IDD and non-IDD medium and low secure services. One aspect of their study compared the scores of residents with IDD across medium and low secure units and, similar to the findings of Quinn et al. (2012), they reported that although there was a statistically significant difference on the experienced safety subscale, no differences reached significance on the remaining subscales. These findings lead to the question of whether the patient cohesion and therapeutic hold subscales are measuring the constructs they intend to measure in IDD populations as, in line with previous research using the EssenCES in non-IDD populations, it would be expected that units of a higher level of security would be rated as less cohesive and less supportive than units of a lower level of security (Howells et al., 2009; Schalast et al., 2008; Tonkin et al., 2012). Additional studies have utilised the EssenCES with IDD populations but do not appear to have explored the psychometric properties of the questionnaire within this specialist group as a part of their work (e.g., Annesley et al., 2020).

One study has also been undertaken using the EssenCES with adolescents with IDD. In 2018 Glennon and Sher examined the utility of the EssenCES within low secure and locked rehabilitation Child and Adolescent Mental Health Service (CAMHS) Units for adolescents with neurodevelopmental and mental health difficulties. Although participants did not all have a diagnosis of IDD, with diagnoses also including autism, foetal alcohol syndrome, and developmental trauma, it can perhaps be considered that this is a reflection of the diagnostic make up of such units and that, therefore, there are clinical benefits to including a broader range of individuals within the study. Fourteen out of a total of 59 patients were deemed appropriate to participate in the study (seven male and seven female), with the majority of the remaining patients being considered to lack capacity to consent to

participation and three patients being excluded due to their low levels of cognitive functioning and comprehension. Forty-five staff members also participated. Patients were supported to complete the EssenCES by a staff member with whom they were familiar; however, their completed questionnaires were otherwise anonymous. The authors were precluded from conducting a thorough statistical analysis due to low participant numbers; however, results did highlight an inverse relationship between level of security and social climate, with lower total mean scores (comprised of patient and staff scores) for the low secure unit compared with the locked rehabilitation unit, thus providing some evidence of construct validity. Differences between patient and staff perceptions of social climate across both units were also found. The authors commented on the limitations of their study, including reporting that some degree of socially desirable responding may have occurred as a result of the patient questionnaires being administered by a staff member and that not all patients were considered able to participate. They also drew attention to the social climate construct within adolescent settings, highlighting that the EssenCES was not developed for adolescents and that, therefore, it may not tap into the aspects of social climate that are relevant to adolescent populations. Recommendations for future research were made, with the authors stating that adapting the EssenCES for forensic IDD populations was a necessity, and suggesting that the incorporation of visual images and communication mats ought to be considered, particularly for adolescent IDD populations.

Of note is that the studies conducted by Quinn et al. (2012) and Willetts et al. (2014) included mainly male participants within medium and low secure units in individual establishments. Similarly, although the study conducted by Glennon and Sher (2018) included both male and female participants, it was only conducted within one establishment. This results in difficulties generalising the above findings to broader IDD populations. It is also important to recognise that two of the above studies did not comment on the method of administering the measure, and that none of the studies commented on any difficulties experienced by participants during completion. Furthermore, only Quinn et al. (2012) commented on the participants' IQ range, and only Glennon and Sher (2018) reported whether or not any participants were excluded due to cognitive difficulties. Clearly difficulties completing questionnaire measures are more apparent in individuals with more moderate IDD, and it is therefore imperative to identify the IQ range of participants and

highlight whether or not all individuals on the units were included in the studies. It is of importance for the above points to be addressed when conducting research in IDD settings, with Bakken et al. (2012) providing a positive example of this; resulting in a much clearer picture of the participant group and difficulties experienced by different sub-groups of participants (mild and moderate IDD) being provided.

Despite very recent studies using the EssenCES with IDD populations (e.g., Annesley et al., 2020), emerging research has begun to question the suitability of the EssenCES for IDD populations. Chester et al. (2015) investigated clinician experiences of using the EssenCES in forensic IDD settings, with participants being seven clinicians currently working, or who had previously worked, within the Psychology discipline in one UK forensic IDD service. The results raised a number of concerns across all items of the scale. Concerns included residents' difficulties understanding the language used in the measure (e.g., complex words such as "progress" and abstract concepts such as "atmosphere") and difficulties when residents were required to comment on the views and experiences of other residents and staff. Results also highlighted that some residents required support to understand the Likert scale response format. These difficulties often resulted in clinicians providing further explanations or using pictorial aids. This can create problems as clinicians may interpret and explain the questions in different ways or use different pictorial aids, potentially changing the meaning of the questions and resulting in reduced validity and reliability of the questionnaire.

In 2012 Alderman and Groucott examined the suitability of the EssenCES for use in a UK neurobehavioural rehabilitation setting, including 76 staff and 38 resident participants. Although not conducted in IDD settings, there are a number of commonalities in the cognitive difficulties experienced by individuals with IDD and those affected by acquired brain injury (ABI). For example, both individuals with ABI and IDD often experience difficulties with comprehension and expression of language, short-term memory problems, and reduced information processing abilities (Healthcare Improvement Scotland, 2013; Royal College of Physicians and British Society of Rehabilitation Medicine, 2003). Findings were similar to those obtained by Howells et al. (2009) and Tonkin et al. (2012) in terms of supporting the existing factor structure of the EssenCES and demonstrating satisfactory

internal consistency. Convergent validity was also demonstrated through statistically significant relationships between the EssenCES and other measures of social climate. However, the authors also undertook a Rasch Analysis to test the assumption that the EssenCES can be classed as a true interval-scale measurement tool. Their findings highlighted erratic and unpredictable response patterns along with category redundancy and disordered thresholds (suggesting that the subscales are not functioning as intended) across all items, mainly within the resident responses. They concluded that the EssenCES is unlikely to be a reliable and valid measure in neurobehavioural settings, with comments echoing those of Chester et al. (2015) including that some items are too complicated for those with cognitive impairments to understand, and that there are difficulties with the use of a five-point Likert scale.

Recent studies have, however, begun to explore adapting the EssenCES to improve its suitability for the IDD population. Robinson and Craig (2019) conducted a small-scale study investigating the relationship between social climate and aggression within one UK service offering low secure, locked rehabilitation, and step-down services for individuals with IDD. Exploration of the association between social climate and other constructs has been limited within IDD settings, undoubtedly in part as a result of difficulties in sourcing an appropriate measure of social climate to use with this specialist population. The authors obviously appreciated this, and conducted a staff focus group to elicit staff perspectives as to how the EssenCES could be amended so as to be more accessible for the IDD population. Following this, consultation with a Speech and Language Therapist was undertaken in order to make the amendments suggested by focus group members. Amendments made included increasing the font size on the questionnaire and adding pictorial aids to assist patient understanding of the items. The wording of the items was not changed; however, a glossary of alternative words was produced, with this being used as a way of providing a standardised way of explaining the meaning of particular words or of rewording questions should a patient experience any difficulties in understanding the items. This process resulted in the development of an adapted version of the EssenCES; the EssenCES-A. The authors initially piloted this new measure with three patients from the step-down service; however, no further changes to the EssenCES-A were made following this. Thirteen male patients then completed the EssenCES-A, with results showing no significant associations

between the EssenCES-A scores and incidents of aggression. Similarly, no correlation was found between the EssenCES-A scores and level of security. The authors concluded that these findings were likely a result of the very limited number of participants included within the study, but also commented that difficulties experienced by patients in relation to their understanding of the wording of some of the EssenCES-A items, along with difficulties in processing the meaning of the items and selecting their chosen response option, may have meant that the EssenCES-A remained too cognitively taxing. They also identified difficulties in sourcing appropriate visual images to portray the items included on the questionnaire, noting that the visual images they used may have been interpreted differently by each individual or that the inclusion of such images may have changed the meaning of the items, and that difficulties were also faced with regards to sourcing appropriate alternative words for inclusion within the glossary. The authors suggested that further attempts to adapt the EssenCES for IDD populations would benefit from consideration of amendments to the wording of the items so as to provide simple, short sentences phrased in the positive tense, and that providing three response options as opposed to five may also aid patient completion.

In 2020 Barker et al. modified the EssenCES for a low secure IDD population and explored the psychometric properties of the modified measure using a sample of 227/271/276[2] residents from UK low secure IDD services. The majority of participants were male (70%) and tested IQ ranged between 50-69. The modified EssenCES was developed by the Lead Consultant Clinical Psychologist from the IDD service, with input from Speech and Language Therapists. The modified EssenCES contained simplified wording, pictures, and bullet point information. However, the authors did not provide any further information regarding the nature of the modifications (e.g., copies of the modified items or pictures). Furthermore, they did not provide information regarding any reviews that had been undertaken to ascertain whether the modified items retained the meanings of the items on the original EssenCES, nor did they discuss having checked how the pictures were interpreted by individuals with IDD (i.e., whether individuals with IDD interpreted the pictures in the way in which they were intended). Individuals with IDD completed the modified EssenCES with

[2] Different sample sizes are reported in the paper, with it being unclear which is correct.

support from assistant psychologists who read out the questions, provided additional, neutral prompts, and pointed to the images as required to aid understanding. Their findings indicated that the modified EssenCES retained the original three-factor structure and demonstrated satisfactory internal consistency once one item from the therapeutic hold subscale had been removed ("Often, staff seem not to care whether patients succeed or fail in treatment" [Item 13]). The authors noted that the therapeutic hold subscale had the lowest internal consistency of the three EssenCES subscales. They queried whether individuals with IDD may have experienced difficulties with items on this subscale which require them to consider the perspectives of staff. The authors concluded that their findings provide preliminary support for use of their modified EssenCES for individuals with IDD in low secure settings. They did acknowledge that it was unclear whether administrators were able to remain impartial during completion of the questionnaire and noted that future research should consider standardising administration of questionnaire measures for IDD populations. However, of concern is that there is no information provided regarding whether the authors explored whether the reworded items retained the meaning of the original EssenCES items, or whether the pictures that were included were interpreted by individuals with IDD in the way in which they were intended. Thus, one will need to exercise some caution when interpreting these findings.

Despite the paucity of research exploring use of the EssenCES in IDD settings, there are significant questions regarding the suitability of the original version of the EssenCES for this specialist population. Additional difficulties are also apparent in that a large number of individuals with IDD have been deemed to lack capacity to consent to participation in studies attempting to examine social climate in IDD settings. For example, Robinson and Craig (2019) reported that 22 out of 36 potential participants were deemed unsuitable to take part in the study as a result of the severity of their IDD and, in some cases, further impairments due to chronic mental illness. Of note, however, is that other studies have failed to report on any assessment of capacity to consent or on the proportion of individuals with IDD who were excluded from the study (e.g., Barker et al, 2020; Neimeijer et al., 2018; Willets et al., 2014), meaning it is impossible to ascertain how many individuals with IDD were not included within their studies. This has clear implications as to how their findings can be interpreted, as it may mean that some individuals were included but did not have

capacity to understand the questionnaire, or that some individuals were classed as not having capacity to participate and that, therefore, their findings are not reflective of the entirety of the IDD population, in particular those with lower cognitive abilities. This is compounded by the authors of the EssenCES stating that a minimum level of intelligence and understanding of language is deemed necessary in order to complete the measure (Schalast & Tonkin, 2016). This is of particular concern as the Royal College of Psychiatrists (2013) previously recommended regular monitoring of social climate using the EssenCES in all UK inpatient IDD services as part of routine outcome monitoring. Yet, without a reliable and valid measure, this seems futile. In the wake of the Winterbourne View scandal (which involved the abuse of detained patients with IDD) and in line with relevant government strategies (e.g., Department of Health, 2001, 2009), it is vital that this lack of research is addressed to ensure that individuals with IDD are provided with the opportunity to express their opinions regarding the social climate of their units in a more independent manner, ultimately enhancing inclusion. The achievement of this aim, however, relies on the existence of reliable and valid questionnaires to measure the social climate in IDD settings. As highlighted by Bell et al. (2018), development of an IDD-specific measure of social climate, that is applicable across both prison and hospital forensic IDD settings, would fill a gap in the IDD social climate literature through improving current understanding of the social climate construct within IDD settings, facilitating examination of the relationships between social climate and other important clinical and organisational outcomes in IDD settings, and extending knowledge of the aspects of social climate important to individuals with IDD. Additionally, an IDD-specific measure would promote active involvement of individuals with IDD in outcome monitoring and service evaluation through enabling individuals to provide feedback on the social climate of the wards or units on which they reside.

There are already a number of questionnaires that have been developed to measure social climate, as mentioned in Section 1.3. Therefore, when considering developing a social climate measure for IDD populations, it would appear logical to start (initially at least) by adapting an existing questionnaire rather than developing a new questionnaire. This approach would also allow for comparison of social climate across IDD and non-IDD units using the IDD and non-IDD versions, which would clearly be of benefit. Given that the

EssenCES appears to have received the most consistent empirical support to date and is widely used across UK and international forensic IDD settings (see Section 1.4), adapting this questionnaire for use in forensic IDD settings would appear to provide the best opportunity of not only developing a questionnaire that is more accessible for individuals with IDD, but that is also more likely to provide reliable and valid social climate data.

The next part of the review will consider the features of IDD and the potential impact that the cognitive profile associated with IDD may have on the ability of individuals with IDD to reliably complete the EssenCES.

## 2.3 IDD and the EssenCES Questionnaire

It is widely accepted that individuals with IDD can present with a complex range of difficulties that can impact upon their ability to self-report in a reliable and valid way, with many of these reported difficulties being highly relevant to measures of social climate, including the EssenCES (Bell et al., 2018). As demonstrated above, a number of studies that have utilised the EssenCES with IDD populations over recent years have highlighted this. Research has also been conducted that has specifically explored the difficulties individuals with IDD may face when completing the EssenCES with, for example, Bell et al. (2018) and Chester et al. (2015) concluding that the EssenCES may not be suitable for use in IDD settings in its current form. Indeed, the authors of the EssenCES have also commented that, although the questionnaire was developed with the lower-than-average intellectual abilities of the forensic population in mind, it does require a minimum level of general intelligence and comprehension of language (Schalast & Tonkin, 2016). This section will explore the specific difficulties that are likely to be encountered by individuals with IDD in relation to completion of the EssenCES; utilising existing literature, accessible information guidelines, and research pertaining to use of the EssenCES in IDD populations. An overview is also provided in Bell et al. (2018).

### 2.3.1 Cognitive Difficulties

Individuals with IDD can exhibit difficulties sustaining attention, with this becoming more pronounced when tasks place increased demands on encoding and memory abilities (Tomporowski & Hager, 1992). The EssenCES is a relatively short questionnaire (17 items) in comparison to some of the other existing measures of social climate (e.g., the WAS [100 items] and CIES [90 items]). Clearly, lengthy measures will present more challenges for individuals with IDD due to difficulties maintaining attention, particularly if these measures are more complex or if the individuals do not perceive the questionnaire to be of interest (Bell et al., 2018). The EssenCES could, therefore, be considered to be a more suitable length for individuals with IDD. Individuals with IDD can, however, take longer than non-IDD individuals to process information (van der Molen et al., 2007) meaning that, although the EssenCES is relatively short, completion could still be time consuming. Indeed, Robinson and Craig (2019) reported that, within their study, individuals with IDD were allocated a time period of one hour to complete their adapted EssenCES and that breaks were offered throughout completion. This appears to highlight the demands that even a version of the EssenCES that has been specifically adapted for individuals with IDD can place on individuals' processing abilities and attention. One also needs to consider the impact that a questionnaire that places too many cognitive demands on individuals with IDD could have on their completion. Individuals may fail to complete the questionnaire or may not even start. Similarly, a questionnaire that is too time consuming may also result in individuals dropping out. The EssenCES has been described as cognitively taxing for individuals with IDD (Robinson, 2017) meaning these issues would likely impact upon individuals with IDD when completing the EssenCES.

Memory deficits can also be apparent in individuals with IDD, with difficulties retaining information in short-term memory and accessing information stored in long-term memory (Kells, 2011). The EssenCES requires respondents to retain both the item and the five different response choices in their short-term memory, and to organise and recall this information to provide a response (Bell et al., 2018). Clearly, this places a large demand on their short-term memory. If individuals with IDD are unable to accurately remember the item or response choices then it is more than likely that they will provide an inaccurate response.

Completion of the EssenCES also relies on the ability of respondents to interpret the broader meaning of the experiences or situations referred to within the items, and to relate this to experiences or situations that have occurred. For example, Item 3 ("Really threatening situations can occur here") requires respondents to not only understand that the item is enquiring as to their perception of the prevalence of threatening situations, but to be able to recall previous experiences that they may consider threatening and to use these experiences to gauge an overall estimation of the prevalence of such incidents. This is a complex process involving multiple levels of processing and could present challenges for individuals with IDD. The EssenCES also requires respondents to indicate what "usually" happens on the ward or unit, or how they feel about situations on a "general" basis (Bell et al., 2018); however, these types of questions can also be difficult for individuals with IDD as they can struggle to aggregate specific instances and to use this information to form a general evaluation (Finlay & Lyons, 2001).

Recollection of experiences and situations that have occurred previously can be problematic in itself due to difficulties individuals with IDD can experience in terms of their ability to recall information (Clare & Gudjonsson, 1993), and the ability to summarise these experiences in order to provide a response clearly poses further challenges. Furthermore, although Tonkin and Howells (2011) state that questionnaire measures of social climate can be used for both longitudinal and cross-sectional monitoring, the EssenCES manual does not stipulate whether the questionnaire should be completed in relation to a particular time period (e.g., the previous week, month, or longer). Clearly this will be dependent on the reason for administering the questionnaire; however, this lack of explicit guidelines will likely result in individuals with IDD struggling to understand exactly what time period is being referred to and which previous experiences and situations are in fact relevant to their responses (Bell et al., 2018). Additionally, individuals with IDD can often struggle to understand the concept of time and to recall whether something occurred this week or last week, or one month or three months ago (Sharp et al., 2001). Therefore, presenting them with a time period to which the items relate may not necessarily solve the problem.

### 2.3.2 Linguistic Difficulties

The EssenCES is intended to be completed independently by respondents. It, therefore, requires respondents to possess the ability to read the items and response choices. Individuals with IDD generally have a below average reading ability, with Petty et al. (2013) reporting that average literacy levels of individuals with IDD in forensic settings equate to approximately those of a 6-7 year old. Given that the Flesch-Kincaid grade level scores for the EssenCES suggest the questionnaire requires respondents to possess the reading ability of an 11-12 year old, the ability of individuals with IDD to actually read the EssenCES form is questionable. Additionally, the small font size used within the EssenCES has also been highlighted as problematic within previous research pertaining to the use of the EssenCES in IDD populations (Robinson, 2017). Furthermore, it is reported that individuals with IDD are more likely to have additional difficulties such as visual impairments (Kinnear et al., 2018) which may have the potential to impact upon their ability to read the EssenCES form. If individuals with IDD are not able to read the form, then the provision of inaccurate responses is unavoidable.

Some of the language used in the EssenCES could be viewed as unsuitable for individuals with IDD due to the use of abstract concepts and generalised terms. For example, Item 1 ("This ward has a homely atmosphere") and Item 5 ("Even the weakest patient finds support from his fellow patients") include words of an abstract nature which could easily be misunderstood by individuals with IDD (Bell et al., 2018). When communicating with individuals with IDD it is recommended that the present tense is used where possible (Gentile & Gillig, 2012). Although different measures of social climate phrase their items in different tenses (e.g., the PEI uses a combination of present and future tense, and the CIES uses only the future tense), a beneficial aspect of the EssenCES is that it uses only the present tense, thus individuals with IDD may have less difficulty responding to questions on the EssenCES in this regard. However, there are potential issues that could arise as a result of using the present tense as this means the items are enquiring as to only the "here and now". Items such as "There are some really aggressive patients on this ward" (Item 6) could, therefore, be interpreted as enquiring whether any patients on the ward are behaving in an

aggressive manner at this exact point in time. This could markedly narrow the overall perspective of the ward or unit which the questionnaire is attempting to elicit.

When communicating with individuals with IDD it is also recommended that first person pronouns are used (Mencap, 2002). The EssenCES is written in the third person and uses terms such as “inmates” and “patients”. This may reflect the fact that the EssenCES is designed to be completed by both residents and staff; however, this can result in difficulties for individuals with IDD as, for example, they could interpret the term inmates as meaning themselves, themselves and other inmates, or only other inmates, which would impact upon the meaning of the questions (Bell et al., 2018). The PGCI is written in the first person and could, therefore, be considered to be more suitable for individuals with IDD. However, it is important to note that social climate is a group construct and that, therefore, it is important that items retain use of terms such as inmates and patients to ensure the items enquire about the perceptions of the group of patients, prisoners, or staff as a whole, as opposed to seeking individual perceptions.

The EssenCES contains a number of items which could be considered complex, for example, “Some patients are so excitable that one deals very cautiously with them” (Item 15). Complex items are also present in other measures of social climate (e.g., the CIES and PGCI). Complex items may pose difficulties for individuals with IDD (Prosser & Bromley, 2012), resulting in them responding based on single words contained in the item rather than to the item as a whole (Zetlin et al., 1985). The EssenCES also includes items that are phrased in the negative tense, for example “Often, staff seem not to care if patients succeed or fail in treatment” (Item 13). Again, this is consistent with other existing measures of social climate (e.g., the CIES and PGCI). However, individuals with IDD can find negatively phrased items more difficult to respond to as they are constructed in a more complicated way and often include modifiers (single words or clauses that change the meaning of the items). Individuals with IDD will, at times, ignore the modifier and respond to the item as if it is phrased in the positive (Finlay & Lyons, 2001). It has also been noted that individuals with IDD may be less likely to provide criticism, preferring to respond to more positive items (Lowe & de Paiva, 1988).

The EssenCES contains items whereby respondents are required to comment on the views of others, for example “At times, members of staff are afraid of some of the patients” (Item 12). This type of item draws on theory of mind skills (the ability to attribute mental states to oneself and others) and can pose problems for individuals with IDD due to a limited ability to reflect on and understand the views and experiences of others (Jolliffe & Farrington, 2004). Diagnoses such as autism, which is present in approximately 30-40% of patients in forensic IDD services (Esan et al., 2015), can further exacerbate these difficulties due to additional theory of mind deficits. The inclusion of these items within the EssenCES has the potential to lead to confusion amongst individuals with IDD or to lead to individuals feeling unable to provide a response as a result of them feeling unable to comment on the views or experiences of other residents or of staff. This could result in missing data, particularly in relation to the therapeutic hold/hold and support subscale as this subscale contains three items of this nature. If an individual finds this type of item too challenging and is, therefore, unable to respond, this could result in the inability to calculate a score for this subscale as the authors state that a subscale score should not be calculated if more than one item from the subscale is missing (Schalast & Tonkin, 2016).

Lastly, items that include more than one clause and, therefore, more than one question can also be difficult for individuals with IDD to understand (Beail & Jahoda, 2012). Items included in the EssenCES such as “Staff know patients and their personal histories very well” (Item 16) may, therefore, be challenging for individuals with IDD (Bell et al., 2018).

### 2.3.3 Response Biases, Response Format Difficulties, and Questionnaire Administration

Response biases are common amongst individuals with IDD, with Likert scales being cited as a format more vulnerable to these biases as a result of their complexity (Kells, 2011). There is a multitude of research that has examined response biases when using questionnaire measures in IDD populations, with it evident that response biases such as acquiescence (the tendency to say yes to questions regardless of content), recency bias (the tendency to select the last option mentioned in multiple-choice questions, irrespective of one’s true opinion), nay-saying (saying no to every question), and suggestibility are more prevalent in IDD populations (Emerson et al. 2013; Kells, 2011). These response biases are more likely to

occur when complex questions are asked and can severely reduce the reliability and validity of questionnaire measures in individuals with IDD (Kells, 2011). It is also important to note that individuals with IDD are more likely to have questionnaires presented orally rather than in a written format (Finlay & Lyons, 2001). This poses a number of difficulties. Firstly, oral presentation of questionnaires with multiple response options places pressure on short term memory (Kabzems, 1985). Secondly, the resulting reduction in anonymity of responses can increase the likelihood of nay-saying or socially desirable responding when individuals are asked questions regarding prohibited behaviour or the quality of their care (Finlay & Lyons, 2001). Lastly, it has been suggested that oral presentation of questionnaire measures can lead to administrating staff providing further explanation of the questions, resulting in concerns surrounding staff projecting their own interpretation of a question on to individuals (Chester et al., 2015).

The response format used in the EssenCES is a five-point Likert scale. The PGCI also uses a five-point Likert scale, the PEI a four-point Likert scale, and the CIES a forced-choice scale (true/false). The use of a four or five-point Likert scale is likely to compound the difficulties mentioned above as, although some studies have found that the number of response options does not affect response rate (Hartley & Maclean, 2006), individuals with IDD have repeatedly been shown to struggle to respond effectively to four and five-point Likert scales, with evidence suggesting that a three-point scale is more appropriate (Fang et al., 2011; Sentell & Ratcliff-Baird, 2003). The response scale used in the EssenCES could, therefore, be considered unsuitable for individuals with IDD.

The response format of the EssenCES is designed to depict how much respondents agree with the items, as opposed to the prevalence or frequency of which the experiences or situations occur. This has the potential to be particularly confusing for individuals with IDD, as it involves additional cognitive processes. The agreement nature of the response format is only highlighted at the top of the page above the response option headings and, therefore, may be unclear. It is likely that there will be a tendency for individuals with IDD to only consider the item and the response options, rather than considering the agreement aspect. For example, with regards to the item “Really threatening situations can occur here” (Item 3), individuals are likely to interpret the response option of “quite a lot” as relating to

frequency (i.e., that quite a lot of really threatening situations occur), as opposed to comprehending that "quite a lot" actually pertains to their level of agreement, and in selecting that response option they are stating they agree quite a lot with the statement that really threatening situations occur. Although this may appear to be a minute detail, it does have the potential to mean that individuals are not reporting how much they agree with the item, but are reporting perceived frequency of the situations referred to in the items instead. Clearly this could have a marked impact upon their responses.

The response option headings contained within the EssenCES also requires consideration as a result of the complexity of language used, an issue which was discussed earlier. Terms such as "somewhat" are not likely to be familiar to individuals with IDD and may lead to individuals possessing a limited understanding of the meaning of some of the response options.

An additional point which ought to be considered is that the EssenCES, along with all other questionnaire measures of social climate, is intended to be completed independently by respondents, with Moos (1975) recommending that individuals are afforded anonymity when completing measures of social climate so as to increase honesty of responses. However, studies using the EssenCES (and other social climate measures) in IDD populations have, at times, reported provision of staff support during completion (e.g., Barker et al., 2020; Langdon et al., 2006; Robinson & Craig, 2019). Furthermore, one author (Robinson, 2017) also suggested the need for development of a glossary of terms and administration of the EssenCES by staff. Evidently, supportive strategies such as these prevent complete anonymity of responses and would, therefore, have the potential to impact upon data gathered.

### 2.3.4 Summary

It is evident that individuals with IDD can present with a complex range of difficulties that impact upon their ability to self-report in a reliable and valid way. As a result of the difficulties detailed above, it is clear that many individuals with IDD will struggle when completing the EssenCES and, similarly, other questionnaire measures of social climate.

Although these difficulties will vary between severity of IDD, and different measures, items, and methods of administration, they can be expected to impact on the reliability and validity of such measures. These difficulties span multiple areas and have the potential to result in the collection of self-report data that is not only inaccurate, but that may also be meaningless. It could be considered better to collect no data at all than to collect data that provides an unreliable account of the views of individuals with IDD, and that leads to decisions and changes being made which are unnecessary, time consuming and, concerningly, have the potential to have a more negative impact (as change in itself can be difficult for individuals with IDD). Based on the above, it is also necessary to question the findings of studies that have used both the EssenCES and other measures of social climate with IDD populations, as results may not accurately represent this population's views. Self-report measures, including measures of social climate, can be adapted to better suit the IDD population, and the next section of the review will discuss these methods.

### 2.4 Adapting the EssenCES for Individuals with IDD

Given the heterogeneity in cognitive ability seen within the IDD population (Finlay & Lyons, 2001), it is unrealistic to expect that any self-report measure of social climate can be adapted in a way that would make it accessible to *all* individuals with IDD (Bell et al., 2018). Although in an ideal world one would hope to be able to develop a measure of social climate that would be accessible to all individuals with IDD, it is arguably very unlikely that this would be achievable given the broad range of difficulties experienced by individuals with IDD and the more severe difficulties experienced by those who, prior to the publication of DSM-5 (American Psychological Association, 2013), would have been diagnosed with severe or profound IDD. A more realistic approach would be to adapt social climate measures such that they can be completed by the majority of individuals with IDD and, whilst this approach may result in the exclusion of some, it appears this is the most inclusive way of gathering self-report data from IDD populations at present (Bell et al., 2018). Moreover, such an approach is clearly preferable to making no changes at all (Emerson et al., 2013).

This method has been successfully achieved for a variety of other measures for individuals with IDD with studies showing that the adaptations have resulted in reliable and valid measurement tools (e.g., the Clinical Outcome Routine Evaluation-Learning Disabilities 30-Item [CORE-LD30]; Barrowcliff et al., 2018, the Social Intimacy Scale [SIS] and the Victim Empathy Distortion Scale [QVES]; Keeling et al., 2007; the Glasgow Anxiety Scale for People with an Intellectual Disability [GAS-ID]; Mindham & Espie, 2003; and the Modified Worker Loneliness Questionnaire [MWLQ]; Stancliffe et al., 2014). This evidences that a large number of those with IDD can reliably complete self-report measures regarding subjective states when appropriate adaptations are made, suggesting that it is not unrealistic to expect that social climate measures can be successfully adapted for individuals with IDD (Bell et al., 2018).

As mentioned earlier, some studies have begun to explore adapting existing measures of social climate for IDD settings. Neimeijer et al. (2018) adapted the GCI for individuals with IDD. They shortened the questionnaire from 36 to 29 items, incorporated simpler wording and rephrased some of the items. Questions and response options were provided verbally and alternative scripted phrases were provided to enable questions to be explained to residents in a different way if required. Their results confirmed the proposed four-factor structure of the GCI and reliability coefficients for all four sub-scales of the questionnaire were satisfactory. Robinson and Craig (2019) adapted the EssenCES for individuals with IDD; making amendments which included increasing the font size on the questionnaire and adding pictorial aids to assist understanding of the items. A glossary of alternative words was produced, with this being used as a way of providing a standardised way of explaining the meaning of particular words or of rewording questions should a patient experience any difficulties in understanding the items. However, the authors did not find any evidence of construct validity and no correlation was found between the scores on the adapted EssenCES and level of security. Furthermore, Barker et al. (2020) modified the EssenCES for use in low secure forensic hospital settings. They simplified the wording, added pictures, and provided support throughout completion. They concluded that the three-factor structure of the original EssenCES had been maintained within their modified EssenCES and that internal consistency was satisfactory. There is, therefore, a clear rationale for research

to further consider how the EssenCES can be adapted so as to ensure reliable and valid data pertaining to social climate can be collected from the IDD population.

When considering adaptations that may be required in order to increase the suitability of the EssenCES for individuals with IDD, it is important to draw upon previous research that has highlighted difficulties experienced by individuals with IDD when completing both self-report measures in general (e.g., Buell, 2017; Emerson et al., 2013; Finlay & Lyons, 2002; Hartley & Maclean, 2006) and when completing the EssenCES specifically (e.g., Bell et al, 2018; Chester et al, 2015; Glennon & Sher, 2018; Robinson & Craig, 2019). It is also important to consider previous studies (such as those mentioned earlier within the current section) that have successfully adapted self-report measures for this population. Finally, it is necessary to consider published accessible information standards and recommended guidelines for presenting information to individuals with IDD (e.g., Department of Health, 2010; Mencap, 2002).

An overview of the difficulties that are likely relevant to the EssenCES in IDD populations, along with suggestions for adaptations that could be made to improve its accessibility, are presented in Table 2A.

**Table 2A**

*Summary of Difficulties and Possible Adaptations*

| Area of difficulty | Possible adaptation |
|---|---|
| Attention and memory | Shorten both the questionnaire and the length of items. |
| | Simplify the item content. |
| | Inform respondents of the time-frame that the items relate to and include anchor events. |
| | If the questionnaire is administered in an interview-style format, ensure respondents can see a copy of the questionnaire and associated materials. |
| Linguistic content | Simplify complex items. |
| | Use the present tense and ensure that all items are written in the first person. |
| | Do not use contractions. |
| | Do not use items containing more than one clause. |
| | Replace abstract concepts with more concrete concepts where possible. |
| | Remove negatively phrased items and items that require respondents to make direct comparisons. |
| | Remove items that require respondents to comment on the views of others. |
| | Replace generalised items with items that relate to a specific situation or time-point. |
| | Involve individuals with IDD in the questionnaire development process to gain an understanding of appropriate and familiar terminology. |
| Response biases and response format | Use three-point Likert scales instead of four or five-point Likert scales. |
| | Include pre-test screening when using Likert-scales. |
| | Include a response option of "I don't know" when using forced-choice scales. |
| | Include visual representations of the response choices. |
| Administration | Consider the layout of the questionnaire and the type and size of font used. |
| | Include an explanation of the purpose of the questionnaire. |
| | Use scripted phrasing of items and include alternatively worded scripted phrases or a glossary of alternative terms. |
| | Consider whether the questionnaire should be completed individually or with support and, if support is provided, how this may impact upon anonymity of responses. |

From July 2016 onwards it is a legal requirement for all UK organisations that provide National Health Service (NHS) or publicly funded adult social care to conform to the Accessible Information Standards (National Health Service England; 2017). Although this remains a relatively under-researched area, meaning suggestions regarding the most appropriate way of developing IDD-specific questionnaires and associated administration guidelines are few, some authors have highlighted ways of improving both questionnaires and their administration in IDD populations which are of relevance to measures of social climate (Bell et al., 2018). Existing literature in conjunction with relevant accessible information guidelines should be used to form a basis for exploring how the EssenCES can be adapted for IDD populations. The inter-relations between the different over-arching areas of difficulty described in Table 2A also need to be taken into account as any adaptations made within one area will most likely impact upon other areas and, therefore, adaptations need to be considered as a whole and not as separate entities.

Furthermore, it is important to consider how any adaptations made to the EssenCES would impact upon the ability to compare data gathered using this adapted version with existing or future data gathered using the original EssenCES. There are obvious benefits to being able to compare data from both versions, such as enabling services to compare IDD and non-IDD wards or units within their service and being able to merge data from the adapted version with the original version within service evaluation reports. However, this should not be the overriding aim of developing an adapted measure as, if too much effort is given to ensuring an adapted version is comparable to the existing version, it is most probable that this will detract from adaptations being made that are necessary for the IDD population; resulting in development of a questionnaire which is neither reliable nor valid. It would also be worthwhile to consider whether one adapted version of the EssenCES would be sufficient, given the heterogeneity of the IDD population. Although it appears that most questionnaires adapted for individuals with IDD have been able to utilise only one adapted version, this does not necessarily mean the same will be true for the EssenCES.

## 2.5 The Aims of This Thesis

The current chapter has drawn attention to the paucity of research examining social climate within forensic IDD settings and the lack of a reliable and valid tool for measuring social climate in this specialist population. Therefore, understanding of the social climate of forensic IDD settings remains limited. Research has highlighted the necessity of involving individuals with IDD in service evaluation for some time and, following events such as the Winterbourne View scandal, this need has become more apparent. As discussed within the current chapter, individuals with IDD can experience difficulties in completing self-report measures, meaning that gaining their perspectives surrounding the social climate of their ward or unit can be challenging, particularly for those with more severe deficits. However, other questionnaires adapted specifically for IDD populations have evidenced that it is indeed possible for questionnaires to be adapted in such a way that they are more accessible for individuals with IDD and are, therefore, able to gather reliable and valid data.

The aims of the current research are to:

1. Ascertain whether the current version of the EssenCES is suitable for use with individuals with IDD;
2. Identify what adaptations need to be made to improve the suitability of the EssenCES for individuals with IDD;
3. Develop a pilot version of an adapted EssenCES for individuals with IDD (the EssenCES-IDD); and
4. Conduct a preliminary exploration of how individuals with IDD interpret the concepts that underpin forensic social climate.

Chapter 3 aims to explore whether the EssenCES is suitable for use with individuals with IDD through conducting two studies consisting of questionnaires, interviews, and focus groups with those working in forensic IDD settings. These two studies will also aim to identify difficulties experienced by individuals with IDD when completing the EssenCES and adaptations that may be required. This will provide an enhanced understanding of where individuals with IDD are likely to struggle during completion of the questionnaire and why

these difficulties arise. The views of those working in forensic IDD settings will also be sought as to the adaptations they perceive will be necessary to improve the suitability of the questionnaire for individuals with IDD.

Chapter 4 will develop an initial pilot version of the adapted EssenCES for individuals with IDD (The EssenCES-IDD), drawing on the findings described in Chapter 3, as well as the wider research literature. Existing questionnaires that have been successfully adapted for IDD populations and relevant accessible information guidelines will also be considered.

Chapter 5 will gather feedback regarding the initial pilot version of the EssenCES-IDD through interviews and focus groups with those working with individuals with IDD and individuals with IDD themselves. Feedback from Social Climate experts will also be sought. The different constructs that are covered within the EssenCES (experienced safety, therapeutic hold/hold and support, and patient/inmate cohesion) will also be explored with forensic residents with IDD, allowing for initial consideration of how individuals with IDD interpret these constructs.

Chapter 6 will develop an updated version of the EssenCES-IDD, drawing on the data described in Chapter 5.

Finally, Chapter 7 will provide a summary of the implications of this thesis for theory, policy, clinical practice and, most importantly, for individuals with IDD. The limitations of the current research will be discussed and suggestions for future research directions proposed.

The development of the pilot version of the EssenCES-IDD is an important initial step towards improved understanding of the social climate construct within forensic IDD settings and of the aspects of social climate important to those with IDD. Future validation of the EssenCES-IDD will enable examination of the relationships between social climate and other important clinical and organisational outcomes in forensic IDD settings, and enable the provision of preliminary normative data across different security levels in forensic IDD settings. Ultimately, this will allow forensic IDD services to explore how a more positive social climate might be fostered, benefitting individuals with IDD and staff members, the

services themselves, and, most importantly, contributing to improved treatment outcomes for individuals with IDD.

# Chapter 3: Measuring Social Climate Using the EssenCES in Forensic IDD Populations: Staff Experiences and Perspectives

## 3.1 Introduction

As discussed within Chapter 1, there are many benefits associated with using either longitudinal or cross-sectional monitoring to measure the social climate of forensic settings. The EssenCES is a questionnaire-based measure of social climate that is widely used within UK forensic settings. However, limited research has been undertaken using the EssenCES (or, indeed, any measure of social climate) to explore the social climate of forensic IDD settings. Reasons for this include the lack of a suitable measurement tool.

Section 2.3 highlighted the difficulties that individuals with IDD can encounter when completing the EssenCES. It is often necessary for tools to be developed, or for existing tools to be adapted, specifically for this population. A number of self-report measures exist that measure subjective states within IDD populations, with many of these measures demonstrating a good standard of reliability and validity (e.g., the SIS and GAS-ID). Many of these measures have been developed or adapted specifically for IDD populations. This evidences that the development of an accessible tool to measure social climate in forensic IDD settings is most likely achievable.

Given the success of previously adapted measures for IDD populations and the importance of ensuring individuals with IDD are provided with appropriate opportunities for involvement in evaluation of the services in which they reside, this chapter considers how the EssenCES can be adapted for individuals with IDD through exploring the perspectives of staff members working in forensic IDD settings. The two studies reported in this chapter sought to gather data surrounding both the difficulties individuals with IDD experience when completing the EssenCES and suggestions for potential adaptations.

Previous studies exploring staff perspectives regarding the suitability of the EssenCES for IDD populations have, to date, only been conducted in UK forensic hospital settings (Barker et al., 2020; Chester et al., 2015; Robinson & Craig, 2019) and, therefore, the perspectives of

staff working within international settings or UK prison settings have not been sought. Furthermore, two of the aforementioned studies were only conducted in individual establishments (Chester et al., 2015 & Robinson & Craig, 2019), and one only included low secure services (Barker et al., 2020). Therefore, the studies included within this chapter provided the opportunity to compile data from a broader range of staff working across UK and international forensic hospital and prison settings. It was envisaged that this would provide a clearer understanding of both the difficulties with, and adaptations suggested for, the EssenCES in IDD settings, thus enabling it to be adapted in a way that is appropriate for individuals with IDD across a wider range of forensic IDD settings.

## 3.2 Aims of the Current Chapter

This chapter is comprised of two studies, both of which aimed to explore staff perceptions of the suitability of the EssenCES for individuals with IDD and difficulties that may be encountered by individuals with IDD when completing the EssenCES, and to develop an understanding of the adaptations that staff perceive necessary in order to improve its suitability for individuals with IDD. Study 1 was comprised of an online questionnaire and Study 2 of interviews and focus groups. The rationale for the design of the studies is described within Section 3.3.3.

## 3.3 Methodology

### 3.3.1 Participants

#### *3.3.1.1 Study 1*

A purposive sampling technique was used to select particular forensic IDD services to approach for participation in this study. This approach was necessary so as to ensure that participants working across the full range of forensic IDD settings were included in the study, and was of particular importance in relation to services such as high secure forensic hospital settings and prison based therapeutic communities due to there being only a small number of these services that provide specific units for individuals with IDD. The participant

information sheet (Appendix 4) and a link to the online questionnaire (Appendix 5) were sent to participating services via email for distribution to staff working in a variety of UK and international forensic IDD settings. Time-periods for participation were agreed individually with each service and varied from two weeks to eight weeks. Potential participants were able to choose whether to volunteer to participate in the study and could complete the online questionnaire at any point within the agreed time-period. All participants had direct clinical contact with forensic IDD residents. Thus, it was expected that participants had an understanding of the cognitive difficulties experienced by such individuals. Some familiarity with the EssenCES was considered advantageous, but not a necessity. Staff who did not have regular clinical contact with forensic IDD individuals, or who did not feel able to comment on the cognitive difficulties experienced by them, were not included. The questionnaires were mainly of a qualitative nature and, therefore, the sample size was not fixed. Instead, the aim was that a broad sample of staff working across different clinical disciplines and levels of security, and who had varied professional experiences, would be recruited.

This resulted in a sample of 80 staff members who participated in the study. Participants worked in forensic IDD settings in Australia (51%), the UK (42%) and New Zealand (6%), and across a variety of disciplines; Psychologists, Therapists and Intervention Facilitators (34%), Healthcare Assistants (29%), Nurses (8%), Social Workers (5%), Psychiatrists (4%), Occupational Therapists (2%), Speech and Language Therapists (2%), and Prison Officers (2%). The remaining participants' job roles included management, research and training (14%). Participants worked across various settings; prison (13%), high secure healthcare (14%), medium secure healthcare (21%), low secure healthcare (11%), locked rehabilitation (30%), and residential forensic services (10%). Participants' length of experience working within forensic IDD settings was diverse; less than one year (15%), 1-5 years (33%), 5-10 years (25%) and over 10 years (26%). Participants were male (50%) and female (50%). Out of 79 participants (one participant did not answer this question) only 18% had used the EssenCES in clinical practice and only 16% had used the current version with individuals with IDD.[3] It is postulated that this low percentage was due to the variety of professionals

[3] Participants were provided with a copy of the EssenCES and, therefore, findings were not affected in any way as a result of participants being unfamiliar with the questionnaire.

working within different job roles that completed the questionnaire as it is likely that services that do use the EssenCES allocate this data collection to particular groups of healthcare professionals within their service. However, it is also acknowledged that this could be a result of a number of services included in the research not currently monitoring social climate.

Although 80 staff completed the questionnaire, issues were noted across one subset of questions. Here, qualitative responses clearly identified that some participants had misinterpreted some of the questions. This occurred solely in relation to questions enquiring about the suitability of each of the individual EssenCES items for individuals with IDD. These questions provided participants with each of the EssenCES items and asked "Is this item suitable for use with individuals with Learning Disabilities?". Participants were given the option of answering either "yes" or "no" and the option to discuss the reasons for their choice of response. The difficulties that arose were a result of some participants providing direct responses to the EssenCES items and discussing the social climate of the setting in which they work as opposed to discussing whether they felt that the items were suitable for individuals with IDD. The qualitative feedback provided clearly evidenced where participants had misinterpreted the questions and, subsequently, any responses where the researcher identified that this had occurred were removed from the analysis. This was based on participant responses to each question individually as some participants had answered the questions posed on some occasions but not others. Should a blanket exclusion have been applied to those participants, then important data would have been unnecessarily removed.

This decision resulted in all questions in this subset being excluded for 15 participants. A further six participants' responses to some of the questions in this subset were also excluded. On further examination of the data, it was observed that some participants had responded only to the multiple-choice aspect of this subset, and had not provided any qualitative feedback. It was, therefore, unclear whether these participants had understood the questions. Basic statistical analysis was conducted to examine the percentages of the aforementioned participants that had answered "yes" and "no" to these questions. These percentages were compared to those for the group of participants who had clearly evidenced that they had understood the questions and the group of participants who had

clearly evidenced that they had not understood the questions. This identified that the pattern of responses to the multiple-choice questions by this group of participants more closely resembled the pattern of responses provided by those who had clearly evidenced that they had not understood the questions, as opposed to those who had clearly evidenced that they had answered the questions posed. For this reason, it was decided to also exclude the responses of these participants, resulting in exclusion of a further 10 participants' responses across this subset. Fifty-five participants' responses were, therefore, included across this subset, and a further six participants' responses were included for some of the questions within this subset.

#### *3.3.1.2 Study 2*

Staff that participated in Study 1 were provided with a summary of Study 2 at the end of the online questionnaire. They were asked to provide their email address if they wished to be contacted regarding participation in Study 2. Participant information sheets (Appendix 6) were sent to potential participants and they were then asked to confirm whether they wished to participate. Inclusion criteria were identical to the criteria for participation in Study 1. Due to the qualitative nature of this study, only a small sample of staff was required in order to gather more in-depth perspectives from staff working across different clinical disciplines and levels of security who had varied professional experiences.

This resulted in a sample of 25 staff from the UK that participated in the study; three participants engaged in individual interviews and 22 in focus groups. Two of the interview participants worked in forensic hospital settings and one in a prison setting. Five focus groups were held, two within forensic hospital settings (six participants in focus group one and five in focus group two) and three within prison settings (two participants in focus group three, five in focus group four, and four in focus group five). Sixteen participants were female and nine were male.

### 3.3.2 Materials and Measures

#### *3.3.2.1 Study 1*

Online questionnaire: Developed using Bristol Online Surveys, the online questionnaire covered a variety of aspects of the EssenCES, including the nature and wording of the items, the format and presentation of the questionnaire, the Likert response scale, and administration of the questionnaire. The questions reflected points raised within the literature regarding the use of self-report measures with individuals with IDD and measuring social climate in forensic IDD settings. A copy of the questionnaire can be found in Appendix 5.

#### *3.3.2.2 Study 2*

Interview and focus group schedule: This utilised a semi-structured approach and introduced broad topic areas for discussion, including experiences of using and the suitability of, the EssenCES in IDD settings, and adaptations that may improve its accessibility and clinical utility in the IDD population. The topic areas were based around points raised within the literature regarding the use of self-report measures with individuals with IDD and measuring social climate in forensic IDD settings, and on the data gathered through the online questionnaires in Study 1. Participants in Study 1 identified various areas of the EssenCES which they considered unsuitable for individuals with IDD. However, explanations regarding the reasons for this were rarely provided or were only of a brief nature. The interview schedule, therefore, was designed to develop an understanding of these reasons and to enquire how these particular areas could be amended to improve their suitability for the IDD population. Participants in Study 1 also provided a number of suggestions regarding how individual EssenCES items could be reworded to improve their suitability for individuals with IDD. Therefore, the interview schedule also enquired about participants' perspectives of the reworded items that had been suggested and provided an opportunity for participants to explore the advantages and disadvantages of a variety of ways of rewording the items and to discuss their rationale for any further rewordings which they suggested. A copy of the interview and focus group schedule can be found in Appendix 7.

### 3.3.3 Procedure

#### *3.3.3.1 Study 1*

This study utilised a mixed-methods approach, gathering both quantitative and qualitative data. A questionnaire design was chosen as it enabled participation from a broad range of staff working across a variety of forensic IDD settings in the UK, Australia and New Zealand. The use of an online platform also enabled ease of completion by participants. The questionnaire included both structured Likert-style and open-ended questions. It also asked participants whether they had used the EssenCES in forensic IDD settings and, if so, requested feedback regarding its suitability for this population. For those who had not used the EssenCES in clinical practice, a copy of the EssenCES was provided and participants were asked for feedback regarding its applicability to the forensic IDD populations with which they worked. Some demographic questions were also included.

A further copy of the information sheet (Appendix 4) was provided via the link to the online questionnaire. Consent was obtained through an online consent form (Appendix 8), following which participants completed and submitted the questionnaire anonymously online.

#### *3.3.3.2 Study 2*

This study utilised a qualitative approach, gathering data through interviews and focus groups. This approach has been used within other studies that have adapted questionnaires for IDD populations (e.g., Keeling et al., 2007; Robinson & Craig, 2019) and was chosen in order to provide an opportunity to gather more detailed perspectives regarding the suitability of the EssenCES for forensic IDD populations and to complement the data gathered through Study 1. The focus group design provided an opportunity for participants to share their individual perspectives and to work collaboratively to develop suggestions regarding possible adaptations to the EssenCES. Utilising this approach also enabled a number of adaptations to be made before discussing the adapted questionnaire with individuals with IDD, therefore reducing the demands on this vulnerable population.

The interviews and focus groups lasted approximately one hour and were held at the relevant establishments to facilitate ease of involvement for participants. The rooms used were away from the ward or unit to ensure that disruptions were minimised. Interviews were also offered in telephone format to provide increased flexibility. All interviews and focus groups were recorded using a Dictaphone and the recordings later transcribed verbatim.

Information sheets (Appendix 6) were provided to participants in advance of the interviews and focus groups. Consent forms (Appendix 9) were provided and completed immediately prior to the interview or focus group commencing.

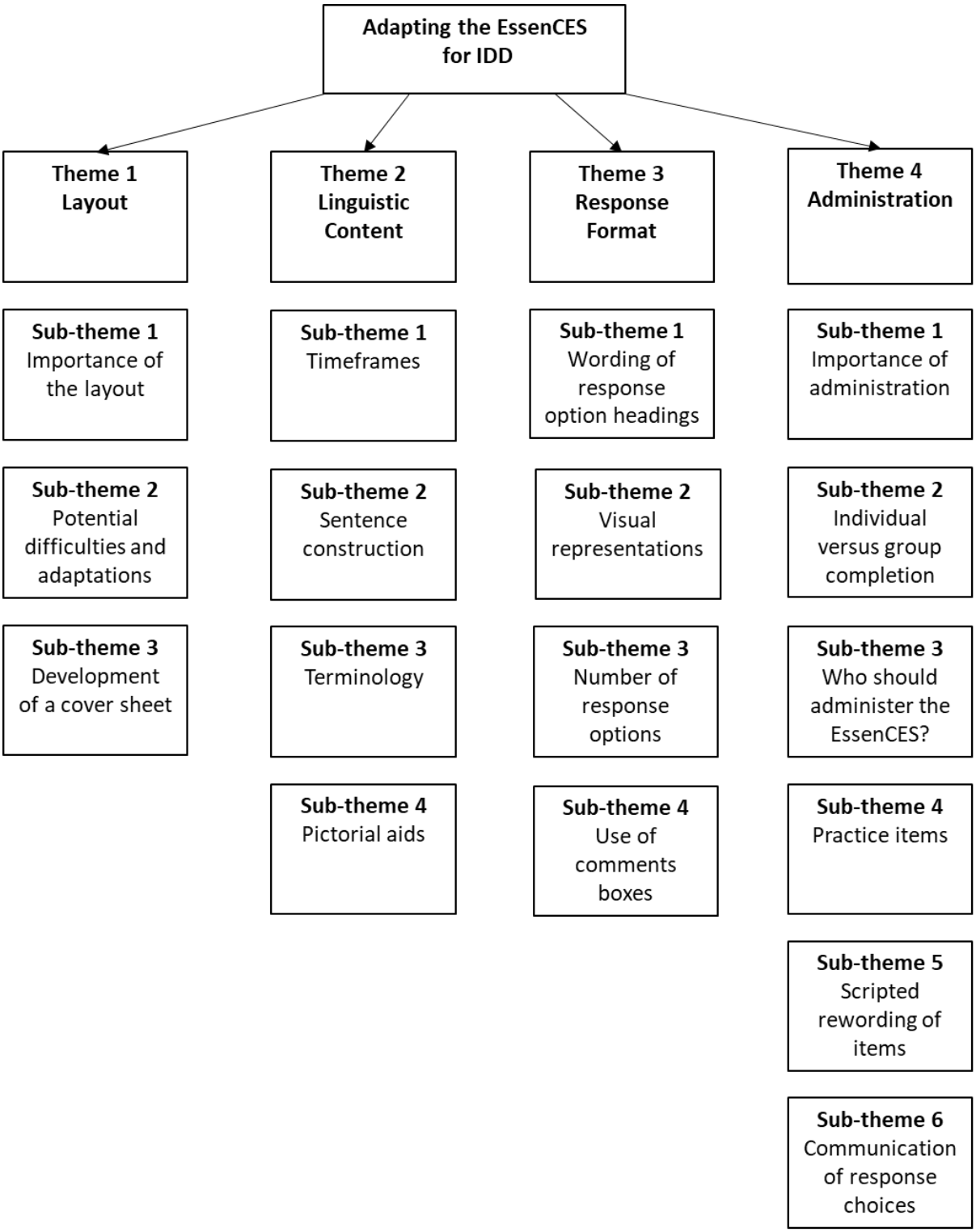
### 3.4 Analysis

Questionnaire data was downloaded from the Bristol Online Survey Form platform. Quantitative data were transferred into a database and qualitative data were transferred into Word documents on the researcher's computer. The audio-recordings of interviews and focus groups were downloaded onto the researcher's computer and transcribed verbatim into Word documents with pseudonyms used to ensure confidentiality. Thematic analysis was used to describe and interpret qualitative data gathered through the questionnaire and interviews and focus groups following the six-phase analysis process described by Braun and Clarke (2006). Demographic information was used at times to help contextualise the viewpoints and experiences of participants, and basic statistical analysis was conducted to analyse quantitative data gathered through the questionnaire. When conducting the thematic analysis, a list of codes was generated. Twenty-four initial codes were identified including broad topics such as "inclusion of individuals with IDD", "diversity of the IDD population", and "motivation for engagement", along with codes that specifically related to adapting the EssenCES for individuals with IDD such as "time-frames", "scripted rewording of items", and "number of response options provided". To ensure that the analysis remained focused on the key areas that specifically related to adapting the EssenCES for individuals with IDD, the codes were reassigned within four themes: layout, linguistic content, response format, and administration (see Figure 3A).

It is of note that the researcher conducting these studies has previously worked within forensic IDD settings and also has experience of using the EssenCES with this population. Consequently, they possessed their own perspectives regarding the difficulties that individuals with IDD may experience when completing the EssenCES and the adaptations they felt may be beneficial. It is acknowledged that it is not possible for researchers to remain completely objective when conducting qualitative research. However, it was important that the researcher's own views were kept separate from the studies. Therefore, the researcher ensured that the questions posed within the online questionnaire, interviews, and focus groups were based solely on the literature, relevant accessible information guidelines and, for the interviews and focus groups, on the online questionnaire feedback. This prevented the researcher's own opinions from precluding objectivity and ensured that questions asked did not lead participants towards a particular conclusion.

**Figure 3A**

*Questionnaire and Interview Data Analysis - Themes and Sub-Themes*



## 3.5 Ethical Considerations

Ethical approval was granted by Birmingham City University's Business, Law and Social Sciences Ethics Committee prior to the studies being conducted (Appendix 10).

Additional UK approvals were granted by:

- The NHS; and
- The National Offender Management Service.

Local approvals were granted by:

- NHS Lothian;
- A New Zealand District Health Board; and
- Two Australian Disability Service departments.

It was agreed that a summary report detailing the main findings across both studies would be sent to all organisations involved for dissemination to participants.

Informed consent from all participants was recorded in writing. Questionnaires, interviews, and focus groups did not include any topics of a sensitive nature and all participants were reminded beforehand that they were not to refer to any residents by name. The questionnaire responses were encrypted upon participant submission. Quantitative data (Study 1) remained anonymous throughout, and qualitative data (both studies) was anonymised immediately following transcription, with digital recordings being destroyed at this point. Data were kept in a secure manner to ensure no individuals other than the researcher and their supervisors had access. No identifiable participant information has been included in the dissemination of research findings.

## 3.6 Results

A summary of the amendments suggested by participants is provided in Table 3A, with suggestions grouped by the over-arching theme to which they relate. Four over-arching themes were identified.

**Table 3A**

*Summary of Amendments to the EssenCES Suggested by Participants*

| Layout | Response Format |
|---|---|
| Use size 14+ font.<br>Use a clear style of font.<br>Include more "white space".<br>Improve accessibility of the layout in order to retain use of a single page or, alternatively, split the questionnaire over multiple pages.<br>Provide cover sheets for staff and for individuals with IDD. | Simplify response option headings.<br>Provide visual representations of the response options using histogram style images.<br>Provide optional comment boxes within the response format. |
| **Linguistic Content** | **Administration** |
| Provide either a "here and now" or a one-week time-frame.<br>Shorten sentences, remove qualifying words and use simple punctuation.<br>Ensure only one question is asked per item.<br>Rephrase items as questions.<br>Use the terms "patient" and "ward" for the patient version, and "prisoner" and "wing" for the prison version.<br>Remove complex words and simplify complex concepts where possible.<br>Remove negative wording of items but retain negative concepts.<br>Retain wording of items in the third person, but enable addition of the prefix "I think" or "do you think" for items enquiring as to the perceptions of staff.<br>Do not add pictorial aids.<br>Staff and individuals with IDD should complete the same version of the questionnaire. | Individuals with IDD must be able to see the questionnaire.<br>The questionnaire should be administered on an individual basis.<br>It is currently unclear who is best placed to administer the questionnaire.<br>There are pros and cons for using three, four and five response options.<br>Practice items should not be included.<br>An "I don't know" response option could be included.<br>Use the cut-off points identified by Schalast and Tonkin (2016) to determine whether sub-scale scores can be calculated.<br>Provide scripted rewording of the items on a separate page.<br>Provide an administration pack. |

This section aims to discuss each of the themes in detail, using quotations from participants and drawing on relevant literature that contextualises participants' perspectives.

### 3.6.1 Theme 1: Layout

This theme describes the main difficulties that participants raised with regards to how the information contained in the original EssenCES is configured, and how these difficulties could impact on the motivation of individuals with IDD not only to complete the EssenCES, but to provide genuine responses. This could subsequently affect the reliability of the responses provided by individuals with IDD, impacting on the ability of clinicians and researchers to gain an accurate understanding of the social climate construct within IDD settings. Suggestions regarding potential adaptations to the layout of the questionnaire were also discussed.

Data gathered were allocated to three sub-themes: (1) the importance of the layout of the EssenCES, (2) potential difficulties and suggested amendments to the layout of the EssenCES, and (3) the development of a cover sheet for the EssenCES. These themes are discussed below.

#### *3.6.1.1 Sub-Theme 1: The Importance of the Layout of the EssenCES*

Questionnaire participants provided mixed feedback with regards to the suitability of the layout of the EssenCES for individuals with IDD, as summarised in Table 3B.

**Table 3B**

*Questionnaire Feedback Regarding the Layout of the EssenCES*

| Response | Not at all | Little | Somewhat | Quite a lot | Very much |
|---|---|---|---|---|---|
| The way that the questionnaire is set out on the page is appropriate for individuals with IDD | 24% | 25% | 26% | 22% | 2% |
| The type and size of font is appropriate for individuals with IDD | 16% | 16% | 30% | 27% | 10% |
| The length of questionnaire is appropriate for individuals with IDD | 14% | 11% | 35% | 34% | 6% |

The majority of questionnaire and interview participants reported that an IDD version of the EssenCES should be completed collaboratively in an interview-style format with support from an administrator (see Section 3.6.4.2). However, despite this, they stated that individuals should be able to see a copy of the EssenCES during completion and that, therefore, the layout of the EssenCES was still important.

Participants were keen to advocate the importance of individuals taking ownership of their completion of the EssenCES. This includes being provided with the opportunity to actively engage with completion, particularly in light of the restrictive nature of forensic settings, with one participant stating “I think people like to tick it off themselves as well … even if you’re guiding them through it … people still like to do it coz then it’s not like you’re quizzing them” (Participant 4, Focus Group 2).

Participants highlighted the need for transparency and openness, and discussed how providing individuals with a copy of the EssenCES would promote far more inclusive and transparent practice along with opportunities for learning:

> What's not showing people going to add in terms of the value? It's going to make people more suspicious and, and they might be able to find out "well this word I don't understand" and, and they can see it for themselves. It's, it's just being far more inclusive, it's doing it with them rather than to them which I think is generally a lot more preferable. (Participant 2, Focus Group 2)

Participants also discussed how, in light of levels of suspiciousness that can be present amongst forensic populations, individuals would likely be more trusting of written information and that, therefore, any additional resources (e.g., cover sheet, separate response option sheet, scripted rewordings) should also be developed in an accessible format and shared with individuals.

This feedback demonstrates that, regardless of the method of administration, the layout of the EssenCES is still an area which requires careful consideration.

#### *3.6.1.2 Sub-Theme 2: Potential Difficulties and Suggested Amendments to the Layout of the EssenCES*

Participants discussed the length of the EssenCES (17 items). The majority agreed that the length was appropriate for individuals with IDD. This was also highlighted as a positive of the EssenCES by Chester et al. (2015). Only one participant raised concerns in this area, expressing concern regarding a loss of motivation due to the number of items and commenting that this could impact on the reliability of responses (Participant 5, Focus Group 4).

There was not a clear consensus with regards to the whether the EssenCES items should be presented on a single page, or whether the items should be split across multiple pages.

Some participants commented that a single page would increase the response rate as this can make the questionnaire appear shorter and can, therefore, be more appealing:

> I think it's good visually that it fits on to one page… I think that's one thing I notice with patients, they're like "How many pages is it? How long is it?" and they'll very much stop at the end of the page even if there's like four questions on the next one … so I do think if you have it on the same page that's good because as soon as you turn over you've lost them because they've probably got it in their head that they're gonna stop at the end of that page. (Participant 3, Focus Group 1)

However, participants noted that the EssenCES currently contains a lot of information, with a large amount of text on the page and the inclusion of numerous check-boxes for provision of responses. Concerns were also raised with regards to a lack of space between items and a failure to use lines to distinguish between the different items and the different response options. Participants expressed that this can make the questionnaire appear cluttered, and noted that this can "put some people off" (Interview 2).

Whilst participants appreciated the benefit of the EssenCES being presented on a single page, many also acknowledged the challenges that this can present, stressing that splitting the questionnaire across multiple pages would enable use of a larger font, inclusion of pictures, symbols or comment boxes if required, greater spacing between items, and the inclusion of fewer items per page, all of which would contribute to a reduction in cognitive processing demands:

> If I do a questionnaire it's, it looks right rather than it fits on one page … if it does go on to five pages people think "oh, I've got to do all that, that's a lot" but it's over so quickly they're like "oh that was quick". (Interview 2)

These suggestions are also supported by previous research (e.g., Buell, 2017) and accessible information guidelines (e.g., Department of Health, 2010; Mencap, 2002), which state that it is important to ensure that there is not too much information presented on a single page,

and highlight the necessity of having an increased amount of white space (space between text) within documents designed for individuals with IDD.

One participant was keen to stress the importance of using a size and style of font that was appropriate for individuals with IDD, stating that the use of a minimum font size of 14 and the use of clear fonts (such as the Century Gothic font style) was supported by recent research conducted by Buell (2017). This participant explained their understanding of the reasoning for this, stating "the reason why that [century gothic font] is better is the way that the letters are spaced out … they're evenly spaced out and the letters are quite different from each other" (Interview 2). The National Offender Management Service (NOMS) easy-read guidelines (2014) also provide support for this, recommending that font size of at least 14, and font styles such as Arial (or similar), should be utilised as they are clear and do not contain any complicated letters or shapes, thereby making them more accessible.

However, participants in one focus group pointed out that it was important not to make too many changes to the layout, commenting "one of the reasons I think they responded fairly well to the EssenCES, coz they knew the other mainstream units do it … so there is benefit in making sure it doesn't look too different" (Participant 3, Focus Group 4).

Participants also acknowledged that resources that are presented in an accessible format can, at times, appear patronising:

> [They are] very attuned to the fact that people might be dumbing something down and they seemed to be really really attuned to that … they can spot that from a mile off … so if you're getting something that looks like it's meant to be one way and then suddenly got something that looks out of place… (Participant 5, Focus Group 4)

However, another participant expressed that individuals did not seem to be discouraged from completing questionnaires which were presented in a more accessible manner, stating "even with guys who are quite, well, borderline really … most of them don't go 'I'm not filling this out because it looks childish'" (Participant 2, Focus Group 2). This highlights the

necessity of striking a balance; promoting accessibility whilst also ensuring that adaptations do not alienate individuals with IDD.

Participants were also aware that the original EssenCES is completed by both residents and staff. There was discussion surrounding the layout of the EssenCES in relation to staff completion, particularly how some of the layout amendments suggested for individuals with IDD may not be of benefit in relation to staff. Participants highlighted that, although an amended version of the EssenCES for individuals with IDD would benefit from being split across multiple pages, this would likely not be the best approach for staff and that presentation of the EssenCES on a single page may enhance motivation for staff completion. It would obviously be beneficial for there to be a single adapted version of the EssenCES that could be completed by individuals with IDD and staff as this would enable direct comparison of resident and staff responses; however, further consideration of the practicalities of this is required.

On an overall level, findings indicated that the EssenCES should either be split across multiple pages, or that the layout of the single page version should be amended so as to incorporate more white space, and that a larger font size is required. However, the impact of such changes on staff completion must be acknowledged.

#### *3.6.1.3 Sub-Theme 3: Development of a Cover Sheet for the EssenCES*

Participants emphasised the importance of a cover sheet for the EssenCES. They stated that this would need to include information relating to the purpose of the questionnaire (such as an explanation of social climate and the importance of measuring it), information regarding how the information gathered through the questionnaire will be used, a statement concerning anonymity of responses and the importance of providing honest responses, and a space for the name of the ward or unit so as to ensure individuals are aware of the environment in which the questionnaire is asking their opinions about.

Participants stated that the purpose of the original EssenCES is not explained on the questionnaire, and that this could lead to confusion as individuals may not be clear what

topic area they are being asked about or why. Participants identified potential challenges that could be faced when explaining the purpose of the EssenCES to individuals with IDD, acknowledging that any explanation would likely need to include a summary of the concept of social climate, which is a difficult concept to comprehend: “Climate is abstract, it’s taking safety, relationships, four, five different things and then kind of clumping them together and making something called climate, and asking someone to talk about that abstract thing called climate” (Participant 5, Focus Group 4). It is apparent that any explanation of social climate, and its importance, needs to be accessible, with attention being afforded to how this complex concept can be captured in a more concrete way.

One participant suggested that a written explanation of the purpose of the questionnaire could be utilised as a springboard to engage individuals in a discussion regarding the purpose of the questionnaire (Interview 2). This discussion would enable administrators to ascertain whether the individual has understood the questionnaire’s purpose, and would also allow an opportunity for them to ask any questions surrounding this. Given that both of these points are important aspects of gaining informed consent, it would appear a necessity to include them. However, any discussion facilitated by those administering the EssenCES would clearly require that the administrators themselves understand the concept of social climate. This would ensure that any explanation they provided would be consistent across administrators within different services. Thus, as far as practically possible, all individuals would receive the same information and, therefore, gain a similar understanding of the concept of social climate and the purpose of the questionnaire. Concerningly, participants drew attention to their own difficulties in understanding the concept of social climate, with one participant commenting “what is the understanding of social climate if you were to break it down simply, coz I, I’m not sure I completely…” (Participant 5, Focus Group 4). It may, therefore, be beneficial to provide a summary of the concept of social climate, and its importance, for those administering the EssenCES. This would enhance their own understanding and enable them to answer any questions individuals with IDD may have in as consistent a manner as possible. This could be included with the administration guidelines which are discussed in more detail within Section 3.6.4.

Participants also discussed the need for provision of information explaining how responses to the EssenCES will be utilised both on an individual service level and from a broader evaluative perspective. Participants highlighted the necessity of explaining to both individuals with IDD and staff why the feedback they provide through the EssenCES is important, and how this could potentially increase motivation to engage:

> They have to do loads of questionnaires … I think they get a bit bored of them but if they knew … "we're getting your opinion about the ward, what it's like to live on it, we're hoping to achieve this from it" they might be more inclined to do it, I think. (Interview 2)

Participants discussed the necessity of individuals with IDD being aware that their responses to the EssenCES are going to be utilised for more than just statistical outcome measures:

> If I were to sit down with a patient and go "I want you to fill this out then your score … a large part of your score … there'll be an average and then the data will be reported, we want to know for the next eighteen months", they're gonna go "I don't want to do it". (Participant 2, Focus Group 2)

Participants acknowledged that more in-depth data gathered, such as through the provision of qualitative feedback (see Section 3.6.3.4), could be incredibly beneficial in providing individuals with an additional means of providing feedback, and in effecting change on a clinical level which should be, at the core, the purpose of collecting data via the EssenCES.

Participants also expressed that it would be important to inform staff who were completing the EssenCES how their responses would be utilised, and that it is just as important for staff to have a clear understanding of this as it is for individuals with IDD:

> "You keep asking me about this but as, as an organisation what're you going to do about this to help?". So, I mean it's not to do with the questionnaire but it's about the sort of, erm, best practice use of it in context isn't it? And the service being clear about … where the results are going to go and who's going to look at them and what

> we're going to do and the feedback people are going to get. (Participant 3, Focus Group 2)

Clearly, consideration needs to be given as to how this can be explained, within the cover sheet, to both individuals with IDD and staff. However, there needs to be a degree of acknowledgment that, on a practical basis, some services may not have the resources to devote to utilising the EssenCES data to bring about any changes within the service. Furthermore, some services may only be utilising the EssenCES to collect outcome measure data or due to contractual requirements. Attention must also be drawn to the responsibilities of both the questionnaire developers and individual services. Due to there being various reasons for using the EssenCES, it would be impossible for the current research to develop a cover sheet that provides a summary that would be relevant across all services. Therefore, a brief cover sheet that provides an overview of the questionnaire and that does not make any promises regarding changes being implemented as a result of collection of EssenCES data appears to be all that warrants inclusion. Should individual services wish to provide further information for individuals with IDD and staff within their service, it is likely that they would be best placed to develop this themselves.

Some participants, based in prison services, also discussed the need for the cover sheet to explain how responses would not have any bearing, either positively or negatively, on individuals' treatment programme or prison sentence. These participants related this to the important role of anonymity, perceiving that the opportunity to anonymously respond to the EssenCES would encourage individuals with IDD and staff to provide more open and honest and, therefore, more reliable, responses. Due to the nature of the EssenCES, and that the EssenCES items enquire about perceptions of how safe individuals feel on the ward or unit, peer relationships, and relationships with staff, participants perceived that both individuals with IDD and staff would require reassurance that their responses could not be linked back to them and, should they provide negative feedback regarding the ward or unit, or staff, they would not suffer any negative repercussions. One participant commented on how they perceived prisoners would question this, stating "…'some people won't like me if I say… officers, will they get to know about it?'. Like if they say that the wing's not nice and

the support isn't good are the officers gonna get to know about it and will they then be treated differently?" (Participant 2, Focus Group 3).

Other participants were aware that, due to the diverse nature of the IDD population, some individuals would be more able to provide open and honest responses than others:

> You know the preamble around how you support people to be as open and truthful, it, it to me is quite key as well in terms of getting the best out of this because … some people who … are perhaps sort of assertive anyway would sit down and would, would be able to say "right, there are some questions about this, this is a really good opportunity for me to say what I think" … and then there'd be other people that are, part of … who they are is, is less assertive, more acquiescent. (Participant 3, Focus Group 2)

It is apparent that anonymity in terms of responses is vital, and that this needs to be clearly explained within the cover sheet. However, of note is that one would need to consider how the EssenCES would be best administered with individuals with IDD as, if administered by a staff member, this would have a clear impact on the anonymity of responses. This will be discussed in further detail within Section 3.6.4.3.

Finally, participants stated that it would be beneficial for there to be a space on the cover sheet in which either the individual or administrator could write the name of the ward or unit on which the individual is currently residing. Participants suggested that this would clarify the environment to which the EssenCES items pertain.

It is evident that a cover sheet would be beneficial as a way of explaining the purpose of the EssenCES and the environment in which the EssenCES items relate to, how feedback will be utilised, and that responses will be anonymous; all of which will also help to ensure that informed consent is provided by both individuals with IDD and staff.

#### *3.6.1.4 Summary*

Adaptations that have been proposed are:

1. The layout of the EssenCES needs to be adapted, regardless of whether it is administered by staff or completed independently.
2. An adapted version of the EssenCES should either be presented over multiple pages or the single page layout should be adapted based on the layout of pre-existing IDD specific questionnaires, to allow for a larger font to be used and to ensure adequate white space. Consideration should also be afforded to both the size and style of font used. However, one should be mindful of the diverse nature of the IDD population and ensure that the adapted version does not appear overly simplistic. Staff completion must also be considered to ensure that any changes made are not to the detriment of gathering staff data.
3. A cover sheet should be developed for individuals with IDD. This should explain the purpose of the EssenCES and the environment to which the EssenCES items relate, how feedback will be utilised, and that responses will be anonymous. A separate cover sheet may be required for staff to provide slightly more detailed explanations.
4. The layout of the EssenCES cannot be considered as a distinct entity. Subsequent themes discussed in this analysis (linguistic content, response format, and administration) will all impact upon the required adaptations to the layout of the EssenCES.

### 3.6.2 Theme 2: Linguistic Content

This theme describes the main difficulties that participants raised with regards to the general linguistic content of the EssenCES items, and specific difficulties pertaining to particular items which were considered to be most problematic for individuals with IDD. This theme highlights how these difficulties could impact on the ability of individuals to understand the EssenCES items and, therefore, to provide reliable and valid responses. The difficulties highlighted could also lead to administration bias as a result of administrators rewording items based on their own, individual, interpretation of the items' meanings.

Various suggestions regarding potential adaptations to the items were discussed, along with exploration of their meaning with a focus on ensuring the items retained their intended meanings.

Data gathered were allocated to four sub-themes: (1) time-frames, (2) sentence construction, (3) terminology, and (4) pictorial aids. These sub-themes are described below, followed by a more detailed description of the most commonly discussed items that participants felt would be problematic for individuals with IDD.

#### *3.6.2.1 Sub-Theme 1: Time-Frames*

Participants discussed the importance of specifying the time-frame to which the EssenCES items relate. The original EssenCES does not refer to a specific time-frame; however, due to some of the difficulties faced by the IDD population, participants suggested that the provision of a specific time-frame would be beneficial, although indicated that understanding of the concept of time varies, and can often be problematic.

Participants discussed how the presence of underlying cognitive difficulties can impact on the ability of individuals with IDD to understand the concept of time, with one participant commenting "some of them don't have any sequencing so like, for example, one of my patients tells me that he did something last week but actually it happened six months ago" (Interview 3). One participant also highlighted how memory and the ability to recall information can be inconsistent, stating "some … can remember quite far back … but they can't remember what they said ten seconds ago … but then they'll remember something else that happened thirty years ago and, and relay the conversation to you word for word" (Participant 4, Focus Group 4). These comments provide clear examples of the difficulties encountered by individuals with IDD in relation to understanding the concept of time, and are supported by previous research which also highlights the impact of cognitive deficits in the areas of memory, recall and sequencing abilities on the ability of individuals with IDD to understand time-frames (e.g., Owen & Wilson, 2006; Prosser & Bromley, 2012). Although participants identified that the provision of a time-frame for an adapted version of the EssenCES would be beneficial, it is evident that the aforementioned difficulties would

impact upon the ability of some individuals to comprehend this, perhaps more so those who are less cognitively able.

Participants had differing views with regards to the most appropriate time-frame to include for individuals with IDD. Some participants commented that a longer time-frame would be most suitable as they perceived that short time-frames could result in rigidity, with one participant commenting "once you do give a time-frame they get completely stuck on it … maybe if you said a month people might get less concrete, coz if you put it in weeks … but a month feels a little bit vaguer" (Participant 1, Focus Group 4). Others, however, perceived that individuals would struggle with longer time-frames as a result of being unable to draw on multiple, different, examples of situations that relate to the item in question and combine these different examples to form a single, overall, response. They noted that, within this context, more recent situations would be more memorable and could, therefore, bias their responses, stating "I'm not sure they've got the ability to, to form a true reflection … coz some of these answer'd [sic] be massively, err, tainted with what's happened in the last week or so" (Participant 4, Focus Group 5).

The potential of utilising a one-week time-frame was discussed, with some participants considering this would enable provision of a balanced view of the ward or unit's social climate. One participant commented "I think a week is a good length of time as it's enough time to have more of a broader view of how things are because if you use the last day it could have been like really unsettled or really settled and maybe out of the ordinary" (Participant 3, Focus Group 1).

Some participants suggested that, in order to aid understanding of this time-frame, an "anchor" could be used as a means of providing a clear point for the commencement of the one-week time-frame. One participant suggested how this could be used, stating "I suppose the more important thing is giving them some sort of anchor … so if something's happened you could say 'How's it been since X? How's it been since the last ward meeting?' or something" (Participant 2, Focus Group 1). Some participants suggested that this anchor could be identified in collaboration with the questionnaire administrator to ensure it was

relevant and comprehensible to each individual. This approach has also been utilised in other questionnaires developed specifically for individuals with IDD, such as the GAS-ID.

The purpose of utilising the EssenCES as a means of measuring social climate was also discussed, with participants acknowledging that the social climate of a particular ward or unit can change quickly and sharing their experiences of this occurring, such as "yesterday I went down a wing and it was fine and within thirty seconds something had happened [laughing] and the atmosphere had changed completely … because of what's going on" (Participant 2, Focus Group 3).

Participants discussed how using a "here and now" time-frame may be of benefit in relation to the EssenCES, noting that this would be in line with many other questionnaires used with IDD populations. They drew attention to how the EssenCES is intended to be a "snapshot" measure of the social climate at a given point in time, suggesting that using the "here and now" would provide a current perspective of the social climate of the ward or unit, and that this would also remove the impact of additional factors such as an individual's length of admission. However, some participants were keen to highlight that this may mean that all experiences relevant to the questions are not taken into consideration and that, therefore, the inclusion of important, relevant, information relating to the social climate could be missed, leading to the resulting data being misleading. One participant pointed out that this could impact upon the ability to utilise EssenCES data within a research context, stating that "in terms of a research point of view you could lose … doesn't capture perhaps the whole experience does it" (Participant 1, Focus Group 3). Clearly this is a valid point, and is one which could also be relevant to the use of EssenCES data on a clinical level. However, given the dynamic nature of social climate and the fact that a single administration of the EssenCES should not be used to measure social climate in a long-term manner, it would likely be impossible to use the EssenCES or, indeed, any measure of social climate, to capture the entirety of a ward or unit's social climate at every point in time. If the EssenCES is intended to provide a snapshot view of the social climate of a ward or unit then, inevitably, there needs to be some acceptance that this snapshot view will not capture everything.

The aforementioned findings evidence that utilising a one-week time-frame identified through the inclusion of anchor events would be most suitable. Importantly, this time-frame would be appropriate for use within the current scope of the EssenCES; either to measure social climate pre- and post-intervention, or to monitor the social climate of a setting on a regular basis over time. Additionally, this time-frame would be consistent with time-frames provided on other, IDD-specific, questionnaires such as the CORE-LD30 (Marshall & Willoughby-Booth, 2007).

#### *3.6.2.2 Sub-Theme 2: Sentence Construction*

Participants raised a number of concerns in relation to the sentence construction of the EssenCES items. This was also an issue identified by Chester et al. (2015). Participants highlighted that some of the sentences were confusing and would likely be overly complicated for individuals with IDD. They also expressed that many of the items were "too long" (Participant 4, Focus Group 1) and "too wordy" (Interview 3), and that this could pose problems due to the demands it would place on working memory. Participants made suggestions for how sentences could be shortened. They drew particular attention to the inclusion of various qualifying words, stating that they did not perceive that these words were required. For example, one participant commented on Item 6, stating "some really aggressive patients … it's too many qualifiers of the word patients. So, if I were to use just one qualifier … then we just say 'there are aggressive patients'" (Interview 1).

Participants stated that some of the EssenCES items were long and contained a large number of key words, and that this could pose difficulties:

> For example, you've got Number 4: "On this ward patients can openly talk to staff about their problems". You've got, for key words, you've got "ward", "patients", "openly talk", "staff", "about problems", so you've got seven key words there. So, if you've got a patient that can only retain three, already you've, you've lost them. (Interview 2)

Participants expressed that reducing the number of words, and key words, per sentence would be beneficial and would reduce demands on working memory.

Participants noted that various items included words such as “often” and “some” as a measure of frequency; however, they acknowledged that the response format already provided a measure of frequency and suggested that these additional words could be removed. These suggestions regarding reducing the length of sentences are in line with accessible information guidelines (e.g., Department of Health, 2010; Mencap, 2002), which recommend using fewer than 15 words within a sentence and ensuring that sentences are kept as short as possible.

Participants drew attention to the fact that some of the EssenCES items also include two separate questions, expressing that simplifying the sentences by including only one question would be beneficial:

> Number 17, the duplicity … “both patients and staff”, well ok, so they’ve gotta keep in their head “Both patients and staff are comfortable on this ward”. So, you, you would rephrase that, you’d ask two questions, you’d say “staff are comfortable on this ward, patients are comfortable on this ward” rather than trying to combine things. (Participant 6, Focus Group 1)

A number of the above points are explicitly addressed within accessible information guidelines (e.g., NOMS, 2014) which state that sentences should be short and clear, and should only include a single idea or point, meaning that an adapted version of the EssenCES should focus on including only one key point per item and shortening where possible. Participants did, however, note that difficulties can be encountered in trying to achieve this:

> If you change the, the sentence structure and you make the sentences shorter you lose a lot of key information as well so it’s a difficult balance to get the, the sentence structure right, make sure you’ve still got all the information in there you need and still make it make sense to patients … it’s not an easy task. (Interview 2)

Participants also noted that some of the EssenCES items contain more than one clause and, therefore, also include commas, and that this can be problematic. Similarly, participants expressed that individuals with IDD can also struggle with the use of apostrophes. Apostrophes are only used within one item on the EssenCES (Item 8); however, the sentence could be reworded to avoid this. These points, again, are supported by accessible information guidelines which state that simple punctuation should be used and that commas should be removed (Mencap, 2002).

One focus group highlighted that the EssenCES items are constructed as agreement statements, rather than as questions, and expressed that this could pose problems:

> Is there a reason why these are phrased as agreement statements and not just a question with a one to five tick, tick a number to gauge your response coz if there's lots of levels you have to kind of engage with on in terms of … with an agreement statement it's slightly more abstract than a, dunno, question. (Participant 5, Focus Group 4)

Participants mentioned the prevalence of suggestibility in IDD populations and suggested that the inclusion of agreement statements could magnify this. However, one participant expressed opposing views, stating that the use of agreement statements was appropriate for individuals with IDD within the context of this particular questionnaire:

> Patients don't really, erm, understand what question marks mean anyway … I think for this particular questionnaire the statements that you have suit the scale … better than questions do because if they were questions they'd say "yes" or "no" rather than using your scale, so I think having statements is probably better for them. (Interview 2)

This participant's view is supported by accessible information guidelines (Department of Health, 2010) which recommend avoiding the use of questions with individuals with IDD. However, many other questionnaires developed specifically for individuals with IDD do include questions. This is a point which would benefit from further consideration as

changing the items to questions would not necessitate drastic changes to the response format and may also reduce the suggestible or leading nature of some items.

#### *3.6.2.3 Sub-Theme 3: Terminology*

Participants discussed the terminology included within the EssenCES items. This was clearly one of their main areas of concern. Participants highlighted a multitude of issues, including the terminology used to describe individuals with IDD and their current place of residence, the inclusion of complex and abstract words, negatively worded items, items phrased in the third person, and theory of mind difficulties. However, participants did note that some of the EssenCES items pose far less difficulties and would, therefore, require either no, or minor, changes.

**Terminology used to describe individuals with IDD and their current place of residence.** Participants stated that consideration needed to be given to the appropriateness of the terms "patient", "inmate", "ward", and "unit"; noting that these terms may not be relevant for all individuals within forensic IDD settings. The option of leaving a blank space was discussed. This would enable different services to personalise the EssenCES for their particular setting by adding in the specific name of the ward or unit. As discussed earlier (see Section 3.6.1.3), the name of the specific ward or unit could also be added to the cover sheet, with this then being utilised as a reference point for the particular environment to which the EssenCES items pertain.

Participants within UK forensic hospital settings were generally in agreement that the terms "patient" and "ward" were suitable for their services. There was somewhat more discussion regarding the correct terminology to use within UK prison settings, with those who worked in therapeutic community settings stating that they would ordinarily utilise the terms "resident" and "community". These participants did, however, acknowledge that the terms "inmate", "prisoner", and "unit" would be understood by the individuals with IDD with whom they worked. Similarly, participants working within other UK prison settings agreed that the terms "prisoner" and "wing" would be appropriate, and would be in line with the official terminology currently utilised by the UK prison service. Participants from non-UK

forensic hospital settings stated that they would commonly utilise the terms “client” or “resident”, and “unit”.

Clearly, it is important to ensure that these basic terms of reference are applicable to as many forensic inpatient and prison settings as possible and that these terms would be understood by individuals with IDD. However, it is evident that a variety of terms are utilised across different settings. The authors of the EssenCES report that they have received numerous queries from services regarding which terms should be used, stating that their advice is for services to use the terms which best fit their service (M. Tonkin, personal communication, November 12, 2020). On this basis, it appears that developing a forensic hospital and a prison version using the terms suggested by participants above would be adequate. Services could adapt these terms as required and this could be documented in the administration guidelines.

**Complex and abstract words and concepts.** Participants highlighted that many of the EssenCES items contain complicated words, with commonly cited examples including “cautiously”, “peer”, “fellow”, and “genuine”. Participants suggested that replacing these words with simpler, more common words would be beneficial (e.g., replacing “fellow” with “other”, and replacing “genuine” with “real”). Participants also commented that there were a number of abstract words included (e.g., “atmosphere”, “weakest”, and “excitable”), and that these could also be problematic. These comments are also supported by previous research (e.g., Chester et al., 2015; Finlay & Lyons, 2001). Participants appeared to experience difficulties in suggesting appropriate alternative words. This may be a result of the fact that, due to the abstract nature of these words, it would be difficult to find an alternative, concrete, word with the same meaning. Suggestions, therefore, involved rewording the items so as to eliminate the need to include them (e.g., rewording Item 1 to read “This ward is a nice place to live” or “It’s good living here”).

Participants drew attention to the fact that the EssenCES items contain a number of abstract concepts (e.g., “progress” and “peer support”) which, again, can be problematic. The concept of peer support was highlighted on various occasions, with participants expressing that this is a particularly tricky concept for individuals with IDD to understand. Participants

discussed how this relates to the patient/inmate cohesion subscale of the EssenCES and how this can be a difficult area to broach within IDD populations. This is because there is a fine line between appropriate levels of peer support, and patients or prisoners providing each other with the type of support that should be provided by staff, which clearly is not appropriate. It is apparent that attention needs to be afforded to the way in which items on the patient/inmate cohesion subscale are worded, particularly given that individuals with IDD may find it more difficult than non-IDD individuals to understand what constitutes appropriate peer support and to understand how this is different to the support they would receive from staff.

**Negatively Worded Items**. Participants stated that negatively worded items can pose difficulties for individuals with IDD, particularly when combined with the Likert response scale which requires individuals to indicate how much they agree with the item. Participants drew attention to Item 13 ("Often, staff seem not to care if patients succeed or fail in treatment"), which is the only negatively worded item on the EssenCES, stating that this item, in conjunction with the style of response format, was verging on a double negative: "If you put 'staff don't listen to me' or 'don't care for me' then if you say 'not at all' that means that they do listen to you" (Participant 6, Focus Group 1). Participants proposed that it would be more straightforward if the item simply asked "How well do you feel staff care?" or stated "Staff care if we're doing well". However, some participants expressed that using positive wording for all items could also be problematic due to the fact that individuals with IDD can be more prone to acquiescence. Another participant pointed out that it is very difficult to find the balance between ensuring that the items are phrased in such a way that they are understandable by the majority of individuals with IDD, whilst also being aware of the suggestible nature of this population:

> So that people don't just go through it with the motion "yeah, yeah, everything's fine, everything's fine", they have to actually think about the question but I think when you do that, as you say, some of the population you might lose the question on them because you've changed it and it's very difficult to get it across, so in some senses it's better, as [name] says, just to give them the question so they understand the question. (Participant 6, Focus Group 1)

Previous research has highlighted that negative wording can be problematic for individuals with IDD, and that it should be avoided where possible (e.g., Buell, 2017). However, research has also drawn attention to the presence of suggestibility in IDD populations (e.g., Emerson et al., 2013), which would indicate that only including positively worded items could also be problematic. Although the EssenCES only contains one negatively worded item, it is worth noting that other items on the EssenCES include negative concepts. Participants indicated that some of these items may be leading in their nature (i.e., the implication that some patients or prisoners are "really aggressive" [Item 6] or are a "burden" [Item 10]), which could, similarly, result in biased responses through implying that respondents should agree with the item. Participants commented that these items, and others, draw on negative connotations and could be stigmatising due to their underlying assumptions regarding patients or prisoners being "weak", "aggressive", or a "burden", and that this could also have a negative impact on patient and prisoner responses. Clearly these points would also be applicable to non-IDD populations; however, it could be postulated that any negative impact may be more pronounced in IDD populations due to increased difficulties in understanding the context of the items and an increased prevalence in literal thinking. This point requires further consideration.

**Theory of Mind.** Numerous participants commented on the theory of mind difficulties present in individuals with IDD and noted that, due to this, individuals may have difficulties commenting on the views of others. The EssenCES contains items that require individuals to comment on the views of both staff and other patients or prisoners (e.g., "Inmates care about their fellow inmates' problems" [Item 8] and "At times, members of staff feel threatened by some of the inmates" [Item 12]). These items clearly have the potential to pose problems. Participants reported having encountered difficulties in this area when administering the original EssenCES with individuals with IDD, and noted that these difficulties can be more pronounced in individuals who also have a diagnosis of autism:

> For clients to depersonalise and look at the collective I think that, if they haven't got a well-formed sense of self then I think that's, that's quite a hard to think about, the, the others around them, and for people with autism as well … or levels of learning

> disability where that sort of cognitive insight … it's going to be quite a challenging concept to get some of these things out. (Participant 1, Focus Group 2)

These difficulties were also reported by Chester et al. (2015) who acknowledged that some individuals with IDD struggled to consider the views of others, and stated that the degree of difficulty can be impacted by autism, other psychiatric diagnoses, and level of insight.

Participants noted the importance of ensuring that the responses provided by individuals with IDD are accurate. They explained that asking individuals to provide what could essentially be their "best guess" as to the views of others would likely not result in reliable responses, suggesting that individuals would make comments such as "'probably staff do, probably staff do, it looks like they do, but how would I know?'" (Participant 3, Focus Group 2).

Some participants, however, discussed how they considered that the EssenCES items which require individuals to comment on the views of others are not seeking to identify whether or not individuals' perceptions of the views of other patients, prisoners, or staff are correct, but are seeking to identify their perception regardless:

> I think they still have a perception and whether that perception is a bit skewed because of what's going on for them … but I think it, it's still a question that's relevant to ask because I suppose it's about how they perceive other people treating them. (Interview 3)

Clearly, when measuring social climate, the purpose is to ascertain the perspectives of those living or working in that environment. This is regardless of, for example, whether or not staff take a personal interest in the progress of patients (Item 7). The key point is whether patients or prisoners *feel* that staff take an interest, not whether staff actually do take an interest, and it is these perceptions that will impact upon the social climate.

Participants appreciated the importance of the inclusion of items that pertain to the patient or prisoner group as whole, and to staff members, making some suggestions as to how these theory of mind difficulties could be reduced:

> When I've had questions, a similar sort of flavour on psychometrics, and it's been like "well I don't know how other people feel" … and you say "Well what do you think?" and then they're like "well I think it's this…" so that might be easier … "I think prisoners can talk to staff about their problems". It does make it, err, a longer sentence almost, but I think that would make it clearer. (Participant 1, Focus Group 3)

Utilising the phrase "I think" or "do you think" at the start of items that pertain to staff perspectives may help to reduce theory of mind difficulties. With regards to items that pertain to the perspectives of the patient or prisoner group as a whole, it was suggested by one participant that the same phrase could be used at the start of these items (Participant 1, Focus Group 3). However, this would result in every item on the EssenCES commencing with the phrase "I think" or "do you think". If this were to be required, it may be more appropriate for this to be made clear within the cover sheet or elsewhere on the questionnaire.

One participant also suggested there was a degree of disparity between the EssenCES items and the response format and commented that the response format asks how much individuals agree with each item (Participant 5, Focus Group 4). Another participant enquired "are they answering on behalf of everybody? Whereas that's not what … you want their opinion" (Participant 2, Focus Group 3). Clearly the EssenCES items intend to enquire as to the individual's perspective of the group of patients or prisoners; however, the response format requires individuals to rate how much they agree with each item. This makes the items more complicated, as it means the items are enquiring as to how much an individual agrees that the patient or inmate group think, for example, that some inmates are afraid of other inmates (Item 9).

Another common issue raised by participants was that the EssenCES items enquire as to the perspective of patients and inmates as opposed to enquiring about the individual's perspective. Many participants perceived that this could present difficulties and suggested that items could be rephrased using the first person. One participant commented "you're getting people to think about how other people are feeling and that might be quite complicated, so would it be better to have 'I am scared of other patients' or something?" (Participant 4, Focus Group 2). Although this suggestion is supported by accessible information guidelines (e.g., Mencap, 2002), participants noted that using first person terminology would mean that different versions of the questionnaire would need to be developed for individuals with IDD and for staff. They also drew attention to the fact that social climate is a group construct:

> I think that's what's difficult, you want to pick up that sense of how does it feel on, on the ward and does fear pop up, and as soon as you make it about "I" then you're changing what the EssenCES is. (Participant 2, Focus Group 2)

One participant was able to provide an example that demonstrated that individuals with IDD were able to recognise difficulties between other patients on the ward:

> There'd been a, a tension between two particular patients and the nurse was saying very clearly that they could tell that the other guys were, were picking up on that. So, I, I think the point behind the questions is that people can pick up a sense of tension between patients even if they're not involved and, and that sense of how people are managing that, even though they're not involved but they're sort of close to it is important for them. (Participant 3, Focus Group 2)

This highlights that some individuals with IDD are able to identify how others may be feeling. As this participant notes, it is important that the EssenCES items are phrased in such a way that they encourage individuals to consider the perspectives of the patient or prisoner group as a whole.

Some participants drew attention to the fact that phrasing items in the first person has the potential to mean that some individuals have difficulties in providing honest responses. In particular, this relates to items that pertain to how they feel about other patients or prisoners on the ward or unit. One participant commented on the responses they expected individuals may provide, stating "there'd be some people that you'd go 'well I'm not going to say it, anything at all because potentially I'm so afraid of them that I … keep really schtum'" (Participant 1, Focus Group 2). Participants considered that some individuals would be able to acknowledge certain feelings towards other patients or prisoners. However, being honest when responding to items that encompass their vulnerabilities could be difficult. Again, participants commented on how they perceived individuals may respond to this, with one participant stating "they might say 'yeah, actually I feel really angry with this person and I can admit feeling angry but I, but I can't admit to being afraid because that's too … vulnerable'" (Participant 2, Focus Group 2). However, participants acknowledged that there would be other individuals who would feel able to provide honest responses to these items. Participants suggested that utilising behavioural descriptors within the items as opposed to emotional descriptors may enable individuals to provide more honest responses. This may also support individuals to elicit meaning from the items through providing a more observable construct to relate to:

> Maybe something a bit more behavioural like "I avoid situations" or "I avoid things" or "I withdraw" rather than if you've got the actual internal feelings, coz that might make a bit more sense, but again you've got people that've got to recognise that they're avoiding situations which … is going to be problematic. (Participant 2, Focus group 2)

As this participant stated, however, this would require individuals to possess the ability to recognise their behaviours which, again, could be problematic.

Another participant queried whether individuals would include their own, individual, perspective when responding to items phrased in the third person:

> If you say “Are some patients afraid on this ward?” and they say “no” but when you ask “Are you afraid?” and they say “yes”, that means they didn’t include themselves when they were answering … even though they were afraid they didn’t say “yes, some are coz I know I am” but maybe their perception is that you’re talking about everybody else and not themselves. (Participant 6, Focus Group 1)

Some participants stated that keeping the items phrased in the third person had some advantages as it would remove the need for individuals to provide their own, individual, perspective. One participant commented that this “removes that personal responsibility, ‘some people are, some people are afraid of others … but not … not me’” (Participant 4, Focus group 1), meaning that individuals uncomfortable sharing their individual perspective would be able to essentially “hide” their perspective within that of the group.

It is evident that retaining use of the third person across all items would be preferable; however, providing the additional prefix of “I think” or “do you think” for items pertaining to the perspectives of staff could be beneficial. It may be that including this as an optional prefix would mean that it can be added as required to prevent unnecessarily increasing the length of these items.

**Over-Simplification.** Participants discussed various ways in which the items could be adapted to remove or reduce some of the linguistic difficulties. However, they also noted the broad similarities between the items included on each of the EssenCES subscales, in particular the patient/inmate cohesion subscale. Participants emphasised the need to avoid over-simplification of the items. They noted that this could result in the removal of some of the items’ nuances, potentially resulting in the different items on each of the subscales essentially becoming identical. When discussing Item 5 (“Even the weakest patient finds support from his fellow patients”), one participant observed that simplification of this item would result in this item becoming very similar to another item on the same subscale:

> There’s Question Number 14 says “good peer support” so I’m assuming it’s the idea of trying to word the same sort of thing differently? Which is where we’re struggling,

> coz to simplify it you're gonna end up, you could end up … with the same question. (Participant 3, Focus Group 1)

The need to strike a balance between simplifying the items and the potential for this to lead to a loss or reduction in the questionnaire's ability to collect meaningful data was also highlighted by one participant. They stated "if you make it too simple you're missing some of the … more meaty information. So, it's a balance between the quality of the data and … how replicable it will be" (Participant 4, Focus group 1). This is an interesting area that requires further consideration. Although the general literature and accessible information guidelines all point towards presenting information in as simple a way as possible, the potential consequences of over-simplification appear to have been afforded little, if any, attention. This is also of particular importance given the statistical issues that could occur as a result of over-simplification. Items on each subscale should correlate with one another; however, there should also be sufficient variance between items. Over-simplification of items has the potential to increase the inter-item correlation coefficients, meaning that the subscale is only capturing a small proportion of the construct it intends to measure.

Participants also drew attention to the fact that the original EssenCES is completed by staff and patients or prisoners. They commented that retaining this within an amended version of the EssenCES would be beneficial. However, they also noted that simplification of the linguistic content of the EssenCES, or the inclusion of symbols or pictures, could result in the questionnaire appearing inappropriate for staff completion. Participants expressed that, if staff complete an accessible version of the questionnaire, this could make it difficult for them to express their perspectives of the social climate. They made comments such as "they sort of then feel that they're not, it's not eliciting their true feelings … because they're slightly separated … from the process" (Participant 3, Focus Group 2). However, simplification of sentence construction and amending some of the terminology so that it is more appropriate for individuals with IDD is not likely to result in this version being inaccessible to staff members. Therefore, to prevent a loss of inclusivity, it appears important for both staff and individuals with IDD to complete the same version of the questionnaire.

#### *3.6.2.4 Sub-Theme 4: Pictorial Aids*

Many participants appreciated that the use of symbols or pictures as a means to support the explanation of words or sentences was common within IDD-specific resources. They suggested that this would be an appropriate way to improve the accessibility of the EssenCES:

> It breaks up the text, it makes it less intimidating … it can help keep people in with the kind of thing that the words are trying to ask even if they don't understand the words so I think that, yeah, I, I'm quite a big fan of doing that. Also, it fits within most LD services really … make easy read stuff. (Participant 2, Focus Group 2)

Participants noted that symbols or pictures could be particularly beneficial when sentences were long or when there were a higher number of key words included. This clearly reflects recent research and current accessible information guidelines, which advocate the use of pictures as a means to support written information for individuals with IDD (e.g., Mencap, 2002; NOMS, 2014).

One participant, however, considered that, at times, this could be unnecessary:

> I'm missing the picture thing. There's something I've read in manuals about LD and sometimes I'm trying to understand the link between, like, why? And, like, I get it, but sometimes I'm thinking what aim is it achieving and is it always, you know so if someone couldn't understand something written down is this just making it more simple to explain to them or is it just shove a picture up next to the word and some of them are going to get it? Sometimes I think it's a bit, almost a bit … prescriptive as if somehow now "oh I understand that now". (Participant 5, Focus Group 4)

It is clear that the decision regarding whether to include symbols or pictures would need careful consideration to ensure that any symbols or pictures actually aided understanding, rather than being included solely because previous research and accessible information guidelines dictate that this makes information more accessible.

Similar to the findings of Robinson and Craig (2019), participants also raised a variety of additional concerns with regards to the inclusion of symbols or pictures. They drew attention to the difficulties that could be encountered when attempting to select appropriate symbols or pictures to depict the items or concepts included within the EssenCES:

> Some of them are necessarily quite ambiguous coz you're trying to capture, say caring about each other, how on earth do you … capture caring about each other? And you've got the picture of an arm round someone and then you're saying you're supposed to be, sort of … not touching. (Participant 3, Focus Group 2)

Participants, again, commented that items on the individual subscales of the EssenCES were quite similar to each other, noting that this could be problematic when sourcing appropriate symbols or pictures. Participants also discussed how symbols or pictures in themselves can be difficult to interpret, and could be interpreted in different ways. Furthermore, some participants highlighted that the inclusion of symbols or pictures could impact negatively upon the layout of the EssenCES:

> Isn't it about just making this as simple as possible? … Simple words, a simple number scale, not having too many things going on on the page … If somebody shoved in a smiley face or a happy face it could be viewed as patronising but also it could just make the page super busy, and then you're trying, you don't know where to look. (Participant 5, Focus Group 4)

Some participants also stressed that inclusion of symbols or pictures could have the potential to appear patronising, potentially indicating that this could make the questionnaire appear overly-simplistic:

> Sometimes they react really badly to pictures coz they think that you're treating them like children … and they [name] went ballistic about it: "Argh, how dare you

> patronise us" … they, they can be hypersensitive to things being, erm, dumbed down. (Participant 3, Focus Group 4)

Participants perceived that, for some individuals, this could impact upon their motivation to engage. This point was supported by another participant who highlighted that the inclusion of symbols or pictures would likely only benefit a small minority, namely those who were of a lower level of functioning or those with a co-morbid diagnosis of autism (Interview 1).

It is apparent that there are both advantages and disadvantages to the inclusion of symbols or pictures within the EssenCES. Although recent research and accessible information guidelines report that pictorial representations can aid understanding of written information, participants suggested that this addition would only benefit a minority. Some participants queried whether two IDD versions of the EssenCES may be required; only one which includes pictorial aids. However, this would likely be confusing for administrators as guidelines would need to stipulate which version of the questionnaire should be used under which circumstances. Otherwise, administrators themselves would need to decide which version to use. Both alternatives clearly present issues. Additionally, as participants pointed out, identification of appropriate images would be challenging and their inclusion could result in some individuals perceiving the questionnaire to be overly simplistic. Recent research conducted by Hurtado et al. (2014) also identified that the inclusion of pictures can result in cognitive overload due to requiring an individual with IDD to spilt their attention between the text and the picture, meaning this could make the EssenCES more complicated as opposed to improving its accessibility. Therefore, symbols or pictures will not be included in the adapted version of the EssenCES developed in this research.

#### *3.6.2.5 Individual Item Feedback*

When asked specifically regarding the suitability of the linguistic content of each of the EssenCES items for individuals with IDD, participants' opinions varied widely. However, it was apparent that some items were generally rated as being less problematic, whilst other items were generally rated as posing more difficulties. Table 3C summarises the quantitative

questionnaire feedback gathered regarding the linguistic content of each of the EssenCES items.

**Table 3C**

*Questionnaire Feedback Regarding the Linguistic Content of the EssenCES Items*

| | EssenCES item | | Is this item suitable for individuals with IDD? | |
|---|---|---|---|---|
| **Item number** | **Hospital version** | **Prison version** | **Agree** | **Disagree** |
| 1. | This ward has a homely atmosphere | This unit has a liveable atmosphere | 23% | 77% |
| 2. | The patients care for each other | The inmates care for each other | 48% | 52% |
| 3. | Really threatening situations can occur here | Really threatening situations can occur here | 43% | 57% |
| 4. | On this ward, patients can openly talk to staff about all their problems | In this unit, inmates can openly talk to staff about all their problems | 64% | 36% |
| 5. | Even the weakest patient finds support from his fellow patients | Even the weakest inmate finds support from his/her fellow inmates | 11% | 89% |
| 6. | There are some really aggressive patients on this ward | There are some really aggressive inmates in this unit | 65% | 35% |
| 7. | Staff take a personal interest in the progress of patients | Staff take a personal interest in the progress of inmates | 40% | 60% |
| 8. | Patients care about their fellow patients' problems | Inmates care about their fellow inmates' problems | 42% | 58% |

| | EssenCES item | | Is this item suitable for individuals with IDD? | |
|---|---|---|---|---|
| **Item number** | **Hospital version** | **Prison version** | **Agree** | **Disagree** |
| 9. | Some patients are afraid of other patients | Some inmates are afraid of other inmates | 69% | 31% |
| 10. | Staff members take a lot of time to deal with patients | Staff members take a lot of time to deal with inmates | 49% | 51% |
| 11. | When a patient has a genuine concern, he finds support from his fellow patients | When inmates have a genuine concern, they find support from their fellow inmates | 27% | 73% |
| 12. | At times, members of staff are afraid of some of the patients | At times, members of staff feel threatened by some of the inmates | 53% | 47% |
| 13. | Often, staff seem not to care if patients succeed or fail in treatment | Often, staff seem not to care if inmates succeed or fail in the daily routine/program | 21% | 79% |
| 14. | There is good peer support among patients | There is good peer support among inmates | 50% | 50% |
| 15. | Some patients are so excitable that one deals very cautiously with them | Some inmates are so excitable that one deals very cautiously with them | 11% | 89% |
| 16. | Staff know patients and their personal histories very well | Staff know inmates and their personal histories very well | 59% | 41% |
| 17. | Both patients and staff are comfortable on this ward | Both inmates and staff are comfortable in this unit | 54% | 46% |

**Items Considered Less Problematic**. This included items 6 and 9.

*Item 6: There are some really aggressive patients on this ward/There are some really aggressive inmates on this unit*

Participants indicated that individuals with IDD tend to understand this item and that individuals are generally taught about the concept of aggression. Some participants, however, felt that small adaptations, such as shortening the sentence and replacing "aggressive" with "angry", may increase the suitability of this item.

*Item 9: Some patients are afraid of other patients/Some inmates are afraid of other inmates*

Participants expressed that the concepts included can be "easily understood" (Questionnaire Participant 6) and that on the whole it is "straightforward" (Questionnaire Participant 75). Some participants, again, highlighted small amendments that may be of benefit such as replacing "afraid" with "scared".

For both items 6 and 9, some participants highlighted that they felt these items were "speculative and leading" (Questionnaire Participant 51), and that the implication is "that there is something to be fearful of" (Questionnaire Participant 41). Clearly these comments are of value as they draw attention to the potentially leading nature of these items; however, it would be extremely difficult to make enquiries regarding aggressive behaviour and feelings of safety on a ward or unit without including items such as these.

**Items Considered More Problematic**. A number of items were considered more problematic for individuals with IDD. Some of these items are described in more detail below.

*Item 1: This ward has a homely atmosphere/This unit has a liveable atmosphere*

Participants raised concerns regarding the use of the terms "homely" and "liveable", stating that some individuals may have a limited understanding of these concepts as a result of having had difficult past experiences:

> If you think about our guys that might have come from, often come from foster homes and adoption and care system … might not even really know what a liveable atmosphere is I suppose … or their standard of liveable atmosphere … it could be very different to someone who's come from a home, a family home … you hear some stories of care homes and they say well this is much more preferable here to where they grew up. (Participant 2, Focus Group 3)

Clearly, these points would be applicable to both individuals with and without IDD. However, individuals with IDD may experience more difficulty with this item. They may have less of an understanding of what the terms liveable or homely are intended to mean, and a limited ability to draw upon experiences of others and consider what may constitute "home" outside of their own personal experience.

Participants queried whether a ward or unit should be homely; stating that it is the home of patients or prisoners for the duration of their admission or detention; however, this does not necessarily mean that the ward or unit should be homely. They also remarked that the terms homely, liveable, and atmosphere are not particularly common terms and can be complicated to understand as they are of an abstract and subjective nature.

Participants highlighted that this is the first item of the EssenCES, and its complexity could be off-putting. This could, therefore, impact on motivation to complete the remainder of the EssenCES items. One participant stated that, when they had used the EssenCES with individuals with IDD in clinical practice, they had, at times, missed out this item when individuals had struggled with it as they knew that this item was un-scored (Participant 2, Focus Group 2). Participants proposed that rearranging the order of the EssenCES items may reduce some of these difficulties. However, one participant noted that the rationale for this un-scored item being presented first may need to be considered:

> I suppose the, the scoring part of it is that, that would pick up a kind of like well that therapeuticness [sic] of the ward … and the safety as two parts of the scale so it

> should hopefully guide people in that way of thinking about safety and therapeutic hold of a, of a unit. (Participant 2, Focus Group 2)

Clearly, there is a rationale for this item being presented first, in that it is intended to be utilised as a means to guide individuals towards thinking about the whether the ward or unit feels safe and therapeutic, thus providing context for the subsequent items.

Participants discussed various ways in which this item could be reworded to improve its suitability. The term homely could be replaced with the term home (e.g., "This ward feels like home"). Other frequently mentioned alternatives included incorporating terms such as "comfort" or "safety", with participants suggesting that comfort and safety underpinned the concept of a homely or liveable environment. Other participants considered that inclusion of these descriptive terms would be unnecessary, stating that it may be simpler to say "This ward is a nice place to be".

*Item 5: Even the weakest patient finds support from his fellow patients/Even the weakest inmate finds support from his/her fellow inmates*

Multiple concerns were raised in relation to the complexity of this item. Participants stated that, in their experience of administering the EssenCES, individuals with IDD have struggled to understand both the terminology included within the item, and the underlying meaning it is attempting to elicit. Some participants also reported experiencing difficulties themselves in understanding its meaning.

Participants discussed inclusion of the word "fellow". Some participants considered that individuals would understand this word. Others thought that this word could be removed and that the term "peers" or "other patients/prisoners" would be more appropriate. One focus group also drew attention to the phrase "finds support", querying what this was intended to mean:

> Is it about the patient going and seeking support or they find themselves getting support? And that's a … confusing sort of … two sides of it, and myself, my sense is

> that it's more about patients feeling like other people give them support … rather than going out and getting. (Participant 3, Focus Group 2)

Almost all participants voiced concerns with regard to using the term "weakest" within forensic settings and when referring to vulnerable individuals. They suggested that this could be an inflammatory term for patients or prisoners due to the potential for it to be perceived in a derogatory way, commenting that they felt it to be "judgemental and deficit focused" (Questionnaire Participant 42) and that "it's got negative connotations … vulnerable, damaged people being called weak" (Participant 1, Focus Group 2). Some participants expressed that incorporation of the word weakest could lead to individuals trying to identify who they felt the weakest patient on their ward or unit was to make the item more concrete. One participant commented that "you almost have to say 'Who do you think is the weakest patient on your ward? Right, thinking of that person, do they get support?'" (Participant 6, Focus Group 1). Participants also acknowledged that this could feed into a hierarchical ideology stating "we would try to get away from that pecking order idea … and so it kind of reinforces it" (Participant 6, Focus Group 1).

Participants drew attention to the theory of mind abilities that this item requires. They noted that individuals are being asked to comment on the views of the weakest patient, and that this can pose problems. Many participants also felt that they would not understand what was meant by the term weakest in this context. They expressed that, in their experience, individuals have interpreted this in relation to physical weakness. Participants commented that administrators would need to explain what this term means to individuals. Some participants felt that this could be problematic due to their own lack of clarity regarding what the term weakest is intended to mean here. One participant commented "we'd be going into the territory of trying to explain what we mean by weakest and I don't feel clear on what we do mean" (Participant 3, Focus Group 1).

When participants were asked directly about their interpretation of the term weakest within this item, it was clear that this varied. Most participants acknowledged that the term was likely to intend to reflect an individual who was struggling on the ward or unit; however, they were unclear as to the way in which that individual would be struggling. Some

participants suggested that using terms such as “quietest” or “least sociable” as opposed to the term weakest may be appropriate. However, they did acknowledge that these terms do not have the same meaning. Other participants felt that using the phrase “most unwell” may be more suitable as it is slightly more concrete in its nature. Participants felt that most individuals would understand that this was pertaining to mental, as opposed to physical, wellness.

Some participants felt that the inclusion of the phrase “even the weakest” was a way of querying whether all patients or prisoners receive support. A variety of similar suggestions were made about how the item could be reworded to encompass all patients or prisoners. Participants noted that this would result in the removal of the term weakest from the item, and that it would not require an alternative term to be found. However, of note is that participants were quick to point out that removing any reference to the weakest patient or prisoner, or the patient or prisoner who is struggling the most, would result in this item becoming very similar to other items on the patient/inmate cohesion subscale.

It is clear that there are intended to be small differences between all five items on the patient/inmate cohesion subscale (and, similarly, for the other two subscales). With regards to this item, it would appear that it is attempting to elicit whether the individual who is struggling the most receives support, as opposed to whether all individuals receive support. However, as the above participant acknowledged, simplifying this item to remove the need for inclusion of the phrase “even the weakest” would result in removal of the small nuances included in this item which differentiate it from other items on the subscale. It may be that inclusion of alternative terminology that was suggested such as “most unwell”, “less able”, or “residents who are having a difficult day” would be more appropriate. However, further consideration is required as to how this item can be simplified whilst retaining its intended meaning.

*Item 13: Often, staff seem not to care if patients succeed or fail in treatment/Often, staff seem not to care if inmates succeed or fail in the daily routine/program*

Participants commented that they felt that the word sequence and the general length of this item were problematic. One participant stated that the current wording of the item appeared to be a "wordy way [to ask the question]" (Questionnaire Participant 42). Participants felt that the clauses contained within the item "don't flow" (Questionnaire Participant 38) and that the sentence contains "several elements" (Questionnaire Participant 60), with one participant commenting "even I had to sit and think about that one" (Participant 1, Focus Group 3). This highlights that even staff participants found this item complex. Theory of mind abilities were also discussed, with participants highlighting that this item requires individuals to comment on whether or not staff care. The problematic nature of the negative wording of this item was also discussed. However, one participant felt that there may be benefits from including some negatively worded items. They stated that most items pertaining to individuals' opinions of staff were positively worded, which could, in itself, pose problems in terms of acquiescence (Interview 3).

Participants drew attention to inclusion of the word "often" at the start of the item, stating that they felt that this was a subjective term that could be interpreted differently by different individuals. They felt that inclusion of this word was unnecessary.
When discussing other items which started with a word denoting frequency, participants stated that these words were not required as the response format provides a means of denoting the frequency of agreement with the statements. The same principle can clearly be applied here.

Participants also discussed the inclusion of the phrase "succeed or fail". One participant asked "What does 'succeed or fail in treatment' mean?" (Participant 5, Focus Group 1). Other participants discussed feeling that this phrase was open to interpretation, asking "Is success or failure in the daily routine turning up to work … or sticking to the general rules … does it mean all of those things?" (Participant 1, Focus Group 3). Participants indicated that incorporation of both the terms succeed and fail increased the complexity of the item, and that it could be interpreted as asking two separate questions; one regarding success, the other failure. Participants suggested alternatives such as "Staff don't care if inmates do their sessions", "How well do you feel staff care?", and "Staff seem to care if we are doing ok", all of which focus solely on one aspect, either success or failure, but not both.

Participants working within prison settings also commented on the phrase "daily routine/program", which is included within the prison version of the EssenCES. Participants felt that it was unclear exactly what aspect of the prison routine or program this was referring to as the daily routine and prison program are two very different concepts. Participants suggested that these two concepts could be separated into two different questions. However, if the prison version of this item were to follow the hospital version which refers only to "treatment", then it would appear logical for this item to enquire only about the prison program rather than both the daily routine and program.

Various suggestions were made regarding how this item could be reworded, with suggestions including "Staff care if we're doing well", "Staff seem to care if we're doing ok", and "How well do you feel staff care?". All these suggestions are fairly similar in that they remove the negative wording and the initial frequency word ("often"). They also remove the reference to both the concepts of success and failure and simplify the wording of this to "doing ok" or "doing well", and remove any reference to treatment or daily routine or program.

*Item 15: Some patients/inmates are so excitable that one deals very cautiously with them*

This item was considered to be particularly problematic. Participants commented that it is "ridiculously complicated" (Questionnaire Participant 32) and is the "most problematic item on the EssenCES" (Questionnaire Participant 5). Participants also felt the item was "clunky" (Participant 3, Focus Group 2), "too wordy" (Questionnaire Participant 6), and that the sentence structure was "difficult to follow" (Questionnaire Participant 33). Another participant stated:

> They struggled a lot with that question. One, because they didn't understand what excitable meant, erm, but … as [name] says there's almost two parts to that aren't there? So, in both, there's excitable prisoners, whatever they are, but also because they're excitable … you are cautious. They really struggle with that one. (Participant 3, Focus Group 4)

Participants stated that they found it difficult to understand what the item was "getting at" (Questionnaire Participant 71), and one participant commented "I can guess but not sure exactly what this means myself" (Questionnaire Participant 4). This is obviously concerning and shows that the item is open to interpretation, even by staff. Participants noted that they have, therefore, experienced difficulties when attempting to explain this item to individuals with IDD with whom they work.

Participants drew attention to inclusion of the term "excitable", stating that individuals would have difficulties understanding this word and that they would also interpret it in a positive way: "Excitable implies happy which I don't think it's what it is getting at here" (Questionnaire Participant 71). Participants felt that the term "excitable" could be interpreted in numerous, very different, ways, with participants themselves having different interpretations of what the term "excitable" is intended to mean within this context. One participant enquired about whether this was intended to relate to "the ones that are just, well, bouncing off the walls or are you looking at the ones that're aggressive" (Participant 1, Focus Group 3). Another participant queried "Whether that relates to somebody being manic or is that just somebody … who's generally a bit happier than everybody else?" (Interview 3). A further participant explained "I think I understand it to be somebody who is very changeable in mood and kind of unpredictable" (Participant 1, Focus Group 5).

Participants also discussed the use of the term "excitable" within the general context of the item, with some participants expressing confusion as to how an excited patient or prisoner would evoke caution from others:

> If someone's excited it doesn't mean I'd be cautious. It just makes me, sometimes annoyed. I don't know, so it, it's presuming that when people are excitable people act with caution … which I'm not sure they'd necessarily do. That's what I struggle with. (Participant 5, Focus Group 4)

However, following discussions within the focus groups most participants did appear to generally agree that the term "excitable" was intended to refer to presentation or

behaviours that could highlight an increased risk of the occurrence of aggressive behaviour. However, participants noted that replacing the term “excitable” with “aggressive” would not be appropriate as this would alter the meaning of the item through removing the subtle difference gained from use of the term “excitable”. It would, therefore, make it very similar to other items contained within the experienced safety subscale.

Other participants drew upon the entirety of the item, and considered the intended meaning of the term “excitable” within the context of this. One participant stated “so almost unpredictable’s [sic] the word there that maybe, that they’re trying to get at, coz I can understand unpredictability evoking caution because you know, are they going to kick off or what” (Participant 5, Focus Group 4).

Considering this item falls on the experienced safety subscale, one would assume that it is not intended to relate to happiness or eagerness. However, when seeking to make this word more concrete, consideration needs to be given to whether it is meant to describe a more manic presentation, which may in fact also encompass unpredictable behaviour. It would appear that it is not solely intended to refer to aggression (as other items on the experienced safety subscale make clear references to aggression) meaning that it is obviously looking to incorporate a slightly different behavioural presentation. Participants highlighted the need for a concrete definition of this word to be provided.

Participants made some suggestions regarding alternative words or phrases that could be utilised in place of “excitable”. However, they noted that the use of an alternatives would be dependent on the intended meaning of the term excitable within this context. Suggested alternatives included “Some inmates mood changes so often” and “Some patients have risks”. Some participants suggested replacing the term “excitable” with “unpredictable”, and stated they thought this word would be easier to understand. However, other participants still perceived that the use of a direct term pertaining to aggressive behaviour would be more appropriate.

Participants also mentioned the inclusion of the phrase “one deals with”, stating that this is “not how patients talk” (Participant 6, Focus Group 1) and that this needs to be amended.

Participants also queried whether the word “one” was intended to refer to staff or to patients and prisoners. They suggested that inclusion of this word was unnecessary. Given that the word “one” is intended to refer to patients or prisoners if they are completing the questionnaire, and to staff if they are completing the questionnaire, further consideration is required regarding the most appropriate way of amending this.

Lastly, participants drew attention to the inclusion of the word “cautiously”, with the majority of participants stating that this was a difficult word for individuals with IDD to understand. Participants made various suggestions for alternative words that could be used, with many words suggested pertaining to the concept of safety. For example, “Are there prisoners that are so unpredictable they make where you live feel unsafe?”. Other participants did not use the word safe. However, the suggestions they made did relate to the concept of safety, for example “You have to be careful around them”, “You have to keep clear of them”, and “I avoid them”. Participants considered that using behavioural examples that depict the concept of caution would enable a more concrete understanding of this item’s meaning.

Clearly, when adapting this item, clarity of the intended meaning of the term “excitable” is needed so that it can be replaced with a simpler, more concrete word. Clarification is also required about to whom the word “one” is intended to refer. The inclusion of behavioural examples depicting caution would appear appropriate and more accessible rather than inclusion of the term “cautiously”.

#### *3.6.2.6 Summary*

Adaptations that have been proposed are:

1. A clearly defined one-week time-frame needs to be stated and identified through the inclusion of anchor events.
2. Sentence construction needs to be addressed. Sentences need to be:
    a. Short and simple; and
    b. Only contain one question.

Additionally;

a. All unnecessary and qualifying words need to be removed; and
b. Punctuation must be of a basic nature.

3. The terms patients and ward should be utilised within the UK hospital version of the EssenCES, and the terms prisoners and wing within the UK prison version. However, these terms can be adapted by individual services to reflect their local terminology.
4. Wherever possible complex and abstract words should be removed, and replaced, with words that are simple and more concrete.
5. Negatively worded items should be rephrased using the positive tense.
6. Items should remain in the third person. The possibility of including "I think" or "do you think" as a prefix to items pertaining to staff opinions needs further consideration.
7. Items need to be presented as questions as opposed to agreement statements.
8. Attention needs to be given to ensure items are not oversimplified, and that the nuances that differentiate between items on each of the three EssenCES subscales are retained.
9. Symbols or pictures should not be included in an attempt to provide a visual representation of the EssenCES items.
10. Staff and patients or prisoners should all complete the same version of the EssenCES.

### 3.6.3 Theme 3: Response Format

This theme describes the main difficulties that participants raised regarding the response options provided on the current EssenCES. It includes how these difficulties could impact on the ability of individuals with IDD to understand the different response options available and to select those options that accurately reflect their views. It is likely that this would not only impact upon whether individuals with IDD are able to complete the EssenCES, but also whether they are able to provide reliable and valid responses. Suggestions regarding potential adaptations to the response format were discussed, with participants keen to reflect on their experience of using different response formats with individuals with IDD, and to comment on the types of response formats that they considered most suitable for this population.

Data gathered were allocated to four sub-themes: (1) the wording of the response option headings, (2) the use of visual representations of response options, (3) the number of response options provided, and (4) the use of comment boxes. These themes are discussed below.

#### *3.6.3.1 Sub-Theme 1: The Wording of the Response Option Headings*

Most participants indicated that the wording of the response option headings is difficult for individuals with IDD to understand. Participants stressed the need to simplify them, replacing them with commonly used, concrete, words that individuals with IDD would be familiar with (e.g., "all the time" and "some of the time" or "agree a lot" and "agree a bit"). This clearly ties in with the earlier reported findings (see Section 3.6.2.3) and with recent research, also recommending using simple language when developing resources for individuals with IDD (e.g., Buell, 2017).

Some participants commented that, when they previously administered the EssenCES with individuals with IDD, at times they had to re-explain the meaning of the headings following each individual item. One participant reported that "every time you ask a question you then have to repeat the five scales … and explain what the difference between 'a little', 'somewhat' … and then their frustration will go up and you kind of lose them" (Participant 1, Focus Group 5). This demonstrates the impact that the difficult wording of these headings can have, and how this can result in frustration and disengagement; potentially meaning that those who are struggling to understand the wording may be less likely to complete the EssenCES, resulting in their feedback not being included.

Participants expressed concerns that individuals would struggle to differentiate between the different headings, with some participants commenting that even they would have difficulties with this. Some participants described methods that they had utilised when administering the EssenCES with individuals with IDD in an attempt to elicit a response from the individual that they could categorise under one of the current headings. This included providing examples to explain the difference between the headings and providing verbal

explanations of their interpretations of the meaning of the headings. Clearly it appears beneficial that staff who have previously administered the EssenCES with individuals with IDD have utilised strategies such as this; however, this approach could also be problematic. Such strategies involve the staff member using their own, individual, understanding of the meaning of the headings. As it is unlikely that all staff members would possess the same understanding of the wording or would differentiate between the different headings in the same way, this could result in a degree of administration bias. Additionally, depending on the words which staff have used to replace the headings, there is also the potential for the meaning of the headings to be altered. It is worth noting that this is a limitation of Likert-type questionnaires more generally as, even if individuals completed the EssenCES independently, they would be applying their own interpretation of the meaning of the headings.

Some participants discussed how the EssenCES items are currently worded as statements and that the current response format requires the respondent to indicate how much they agree with each of the statements. One participant felt that the complexity of this could pose problems, as it requires individuals to essentially add the pre-fix of "I agree" to each of the response option headings (Participant 5, Focus Group 1). There is also the need to have the ability to complete this process solely on a cognitive level, as this is not displayed in a simple way within the response format. Participants highlighted that this can be more confusing when responding to negatively worded items.

Participants also voiced concerns that, regardless of how the headings were reworded, some individuals would still struggle to select the appropriate word to match their response. The majority of participants, therefore, felt that the inclusion of visual representations of the response options would be essential. Participants were keen to stress that this should not replace the written response options, but should be provided in addition so as to provide individuals a choice regarding whether they utilise the written words, the visual representations, or both. One participant noted that the combination of written response options and visual representations can be particularly beneficial:

> If you have a sad face, they could just, that could mean, anyone could just interpret that in their own way. Whereas if you had the sad face and the, the writing underneath, the sad face is reinforcing the words and sort of adding or aiding understanding rather than … just … so if you took the words away then that's more that they're going to have to think about. (Interview 2)

This approach has been utilised in other questionnaires specifically adapted for individuals with IDD (e.g., the CORE-LD30). Research has reported that that this can support individuals with IDD to better distinguish between subtle differences among response choices (Hartley & Maclean, 2006) and has suggested that it can also result in an increased response rate (Heal & Sigelman, 1985; Sigelman et al., 1982).

#### *3.6.3.2 Sub-Theme 2: The use of Visual Representations of the Response Options*

Quantitative feedback gathered through the questionnaire demonstrated that the majority of participants (82%) felt that visual representations of the response format would be required. Some participants stated that, when using the current EssenCES with individuals with IDD, they had developed visual representations of the response format for the EssenCES by drawing out an adapted response format themselves or devising this within the staff team. However, the majority did not indicate where they had obtained these representations from. Whilst it would appear beneficial for staff to provide visual representations of the response format, this can pose problems in terms of the potential for introduction of administration and response bias in a similar way to staff rewording the response format headings (see Section 3.6.3.1).

Participants were keen to stress that there is a clear need for a balance between visual representations being an addition that would be beneficial and it leading to the response format appearing overly simplistic. When asked specifically how an appropriate balance could be achieved, one participant commented "we're still searching" (Participant 3, Focus Group 5), highlighting that this is a difficulty faced within clinical settings when working with individuals with IDD, and that there is probably no straightforward solution. Another

participant commented that an over-simplified response format could have a negative impact and has the potential to result in disengagement:

> I think when I first came here … I had an idea for one of the sessions. I thought "oh, we can do this picture thing" and I saw the stigma, I saw the reaction to, like you were saying about actually being very attuned to the fact that people might be dumbing something down, and they seemed to be really, really attuned to that … they can spot that from a mile off … give them a lollypop when they finish coz … they done well … a sticker [laugh], five stars. (Participant 5, Focus Group 4)

Accessible information guidelines such as Mencap (2002) recommend the inclusion of visual representations within resources developed for individuals with IDD. This approach has been used within a number of other, IDD specific questionnaires, including the adapted EssenCES developed by Robinson (2017). Previous research has suggested that inclusion of visual representations can increase engagement and understanding (e.g., Sigelman & Budd, 1986). However, the above comment highlights that there needs to be clear evidence as to how the addition of visual representations would aid explanation of the written response options as opposed to making the response format over-simplistic.

**Smiley Faces.** Participants discussed the potential use of smiley faces to depict the different response options, with many participants suggesting that this would be the most appropriate visual representation to include. Participants described having used smiley faces to depict different response options with individuals with IDD, and felt that they would be familiar with them.

Some participants noted that individuals who had a co-morbid diagnosis of autism may struggle to understand the meaning of the smiley faces and that they may struggle to recognise the images and to differentiate between them:

> I suppose my issue with it is, the scales you use, the face type system is … many years ago I remember doing it with someone and drew a smiley face and them going

> "that's the moon" and they couldn't recognise the fact it was a face. (Participant 2, Focus Group 2)

Another participant expressed concerns regarding the subtle differences in the facial expressions that would be required if smiley faces were used to depict a five-point response scale. They stated "if you had a five point [scale] and you were thinking about kind of presenting it … faces are confusing" (Participant 3, Focus Group 2).

Participants discussed some ways in which difficulties such as these could be overcome. One suggestion was the inclusion of colour as a way of providing an additional means to differentiate between the different response options. However, participants expressed that, despite their best efforts, some individuals may not be able to understand what the smiley faces are attempting to communicate, and that an alternative to this may be required:

> This isn't an easy task because we spend months trying to get people to understand some, some emojis and what things mean in terms of emotions and things like that, so you know to expect just to be able to do it for everybody it may be some people you just go "ok, this isn't going to work for them". (Participant 6, Focus Group 1)

Thus, it is evident that using smiley faces within the response format would be problematic.

**Traffic Lights.** Some participants discussed the use of traffic light based visual representations to depict the different response options; however, clear concerns were raised in relation to this. One participant stated "I think traffic lights suggest a knowledge around driving … the association of colours meaning green for good, you know … go … or red for not go" (Participant 1, Focus Group 2). One participant also drew attention to an individual with IDD that they had worked with, and the negative associations that this individual had in relation to the use of the red and green colours that would be utilised in this type of response format:

> Traffic lights have a lot of historical context and for LD services there always seemed to be like traffic scale systems for people's behaviour … one guy I used to work with

> used to be terrified of red lights because of, of that thing of "oh god, oh god I'm going to get a red light, I'm going to get a red light" because that's what he associated with actually being … quite negative consequences for that. (Participant 2, Focus Group 2)

Additionally, participants highlighted that using green to depict positive, and red negative, responses would not be appropriate for any negatively worded items. It is probable that the same would apply to items depicting negative concepts (i.e., aggression). It is, therefore, evident that there would be a number of difficulties if traffic light based visual representations were utilised and that a multitude of amendments would need to be made to the EssenCES items for this to be successful.

**Thumbs Up/Thumbs Down.** Some participants discussed having used visual representations incorporating thumbs up/thumbs down with individuals with IDD. They reported that this was a useful way of depicting different response options. Participants explained that the use of double thumbs up and double thumbs down at either end of a five-point response scale can lead to the scale being easier to interpret: "I use the one with the thumbs up, so for instance … the middle one would be like that [neutral thumb] and then it'd go single down, and then doubles at the ends and that one works quite well" (Participant 5, Focus Group 1). This approach was also mentioned by Chester et al. (2015), who reported that this helped to promote understanding of the Likert scale. Although this choice of visual representation was not discussed in great detail by participants, it would appear that this may be an option warranting further exploration.

**Histogram.** Participants also discussed the use of a histogram style response format, and described how this method can be used to depict different response options:

> It's like a bar which are filled up to different levels depending on your level of agreement … so it's an empty one, erm, little bit more … somewhere in the middle, up to like a full bar … so you imagine like 'How much d'you agree and how full up is this?'. (Participant 4, Focus Group 1)

Participants highlighted that the CORE-LD30 utilises histogram style visual representations, and that they have found that lower functioning individuals with IDD have been able to complete this. Some participants suggested that the bars could be filled in with different colours to aid differentiation between the weighting of the different response options. One participant suggested that incorporation of graded colour could be beneficial (e.g., using darker colours to emphasise stronger responses) and to help individuals to differentiate between the different response options:

> Maybe it goes from kind of a shade of one colour to a deeper colour and then they can kind of point to whereabouts … how strong it is for them and then that would reflect you know whether it's "a little", "somewhat", "quite a lot". (Interview 3)

Within the study conducted by Chester et al. (2015), the inclusion of graded colour was also mentioned as a way of further demonstrating the differences between the response options. It is clear that, if colour were to be incorporated within the response format, this would be most appropriate within the histogram style visual representations, as it would not seem practical to utilise colour within any of the other visual representations discussed earlier in this section.

**Summary.** Based on the above findings, it was judged most appropriate to use histogram style visual representations to depict the different response options. One of the main reasons for this decision is that histogram style response options do not have any positive or negative connotations associated with them in the same way that smiley faces, traffic lights, or thumbs up/thumbs down do. Thus, it would appear less likely that this type of visual representation would lead to confusion, particularly in relation to negatively worded items or items that include negative concepts. This approach has also been used successfully within the CORE-LD30.

#### *3.6.3.3 Sub-Theme 3: The Number of Response Options Provided*

There were differing opinions regarding the number of response options that should be included, with individual participants having difficulty expressing a clear preference.

Suggestions varied between three, four, or five, with no clear conclusion regarding the most suitable number. Participants expressed that this lack of consensus was likely due to the diversity of the IDD population, meaning that it would be incredibly difficult to advocate a particular number that would be appropriate for all individuals. Some participants suggested that two versions of the response format could be provided; one which is suitable for more able individuals, and one which caters for those with lower ability levels. Clearly, this is a suggestion that also needs to be considered from a statistical viewpoint; as there would be considerable difficulties in merging data gathered using different versions of the response format.

**Three-Point and Four-Point Likert Scales.** Some participants briefly discussed the use of a three-point Likert scale, stating that a reduced number of options would simplify the response format. Previous research provides support for this (e.g., Fang et al., 2011; Sentell & Ratcliff-Baird, 2003). Also, some existing questionnaires, specifically adapted for individuals with IDD, have reduced the number of response options from five to three (e.g., the CORE-LD30). However, participants were quick to point out this could pose difficulties as it would fail to capture more in-depth data, stating, for example "I think a three-point scale would be easier to understand but I do think you'd be losing quite a lot of … information" (Participant 3, Focus Group 1).

A four-point Likert scale was also discussed, with participants expressing that this could be a way of simplification. Some participants suggested that using a four-point scale, thus removing the "mid-point" option, could be beneficial:

> That's a problem I find a lot with, especially when they're not, being a little bit unsure or maybe they don't understand and not that forthcoming about saying so you'll get "somewhat", you'll get the middle answer … because they're not sure and they think it's a, a safe ground. Erm, that's always the danger with having a, a middle option. It's the safety blanket isn't it, it's the middle ground. (Participant 4, Focus Group 1)

However, participants highlighted that there are disadvantages, particularly on occasions where the mid-point option may be an accurate representation of their opinion. One

participant commented "'sometimes' - it's probably quite a valid option here isn't it for some of the things we're asking about? It's just being aware that they're not doing it for all of them" (Participant 1, Focus Group 1).

The current EssenCES utilises a five-point Likert scale. Participants drew attention to the fact that changing this to either a three- or four-point scale would impact on the ability to compare any data gathered through an adapted version of the EssenCES with any historical EssenCES data gathered. They also noted that it would be difficult to compare the social climate of different wards, units, and services if data is gathered using both the original and adapted versions of the EssenCES.

Clearly, it is essential for further consideration to be afforded to the prospect of reducing the number of response options provided. One would need to ensure that an appropriate balance was sought between simplifying the response format through providing fewer response options and between making any changes that could result in the adapted version of the EssenCES failing to capture important data. Also, consideration must be given to the extent to which pre-existing EssenCES data needs to be comparable with future data gathered using an adapted version of the EssenCES.

**Five-point Likert Scale.** Some participants felt that inclusion of five response options would not be appropriate for individuals with IDD. This is due to individuals experiencing difficulties differentiating between the subtle differences in the response options. Participants highlighted difficulties they had faced when utilising other measures incorporating five response options with individuals with IDD:

> Whatever the first one I go for, they then refer it back to that so "Is that more than the last one?" … It's very referential … in the way they fill it out. Coz there's too many options for them to … just for them to work out really. I think, I would say five is too many. (Participant 2, Focus Group 2)

This draws attention to how the provision of too many response options has the potential to lead to the occurrence of recency bias, resulting in the collection of invalid data. Similarly,

participants also expressed concern that the use of a five-point scale involves inclusion of a mid-point. This, again, could introduce bias through individuals frequently selecting the mid-point option. Participants noted that these biases could be further compounded by difficulties that individuals can have in relation to working memory as they could struggle to retain all five response options.

However, some participants felt that the provision of five options was most appropriate:

> Having the five and the middle … just helps some of the people who, who, who might struggle with actually declaring an opinion about the ward if you like … it enables people to have a very middle … fence to sit on. (Participant 3, Focus Group 2)

Research such as that conducted by Hartley and Maclean (2006) has suggested that five response options can be used with IDD populations without resulting in reduction in response rates. However, the authors also acknowledged that this does not mean that five options should be used. Participants noted that if five options were to be provided, there would also need to be consideration of additional resources that would aid individuals to understand the five-point scale, for example, visual representations and staff support. One participant commented that they thought that the number of response options provided could impact upon the choice of visual representations, stating "if you had a five point and you were thinking about kind of presenting it … faces are confusing" (Participant 3, Focus Group 2). Comments such as these underscore the importance of considering all aspects of the response format simultaneously, rather than as distinct points, and of considering appropriate support by staff administering the EssenCES when making decisions regarding the response format.

**"I don't know" Response Option.** Participants also mentioned the possibility of including an "I don't know" response option as this may help to reassure individuals that not knowing the answer to a particular item is acceptable. This suggestion was also proposed by Finlay and Lyons (2001) who reported that within forced choice response formats (yes/no) this can reduce acquiescence. Some participants noted that there was the potential for this response option to become over-used. However, most still felt that there would be clear

benefits in providing this option. One participant expressed that "if you don't have the 'don't know' patients might just be … when they don't know they might just be putting, ticking anywhere … so that might affect the validity of your results possibly" (Interview 2). Similar to the mid-point option discussed earlier, although there may be some disadvantages to the inclusion of an additional response option of "I don't know", there is the potential that it may result in more valid data being collected.

**Summary.** Further exploration is required regarding the number of response options that should be provided. The views of individuals with IDD may aid decision making in this area, particularly given that there is no clear consensus within previous research regarding the most appropriate number of response options to use for IDD populations (Hartley & Maclean, 2006). However, consideration also needs to be given to the impact that any changes made to the number of response options could have from a statistical and comparative viewpoint. Furthermore, any change to the number of response options clearly needs to be made in conjunction with the development of visual representations of the response options, and any guidelines developed regarding method of administration of the EssenCES.

#### *3.6.3.4 Sub-Theme 4: The Use of Comment Boxes*

Participants suggested the potential for inclusion of comment boxes as a way of gathering qualitative feedback:

> Just have an additional question around … "Can you tell me sometime when that happened to you?" in a sort of so, you know, you've got we, I can openly talk to staff about all my problems, "Which member of staff would you…?". Just to broaden it out and … just explore it a little bit further … and get a bit more than a yes or no. (Participant 3, Focus Group 2)

Participants proposed that the inclusion of comment boxes could be useful for individuals who wished to provide additional information and also as a means of clarifying that individuals have understood the nature of the questions:

> Coz it'd give us that help for information about comprehension I suppose … there's a bit of a narrative around it that gives us a "yeah they've got what we're asking them" … because they, they've given you an anecdote about something that's happened on the ward like an incident, they might then start telling, describing an incident that's happened where they've clearly been afraid … and you think yes, they've got that. (Participant 1, Focus Group 2)

Participants also highlighted that there may be some individuals who are unsure which response option to select. Also, that they may have relevant feedback to provide that does not directly correspond to what the item is asking. Here, an opportunity to provide qualitative information through the inclusion of comment boxes would increase the accessibility of the questionnaire. Participants noted that the provision of comment boxes could be utilised as a way of guiding individuals, who are unsure of which response option to select, towards the provision of a quantitative response. This would be through exploration of their comments and the additional processing time required to do this. Furthermore, participants mentioned that this qualitative feedback could be helpful on a service level in terms of explaining the rationale behind individuals' responses and enabling a clearer understanding of the perceptions of individuals with IDD of the social climate. This, in turn, could help elicit beneficial service level changes:

> I suppose what I'm trying to say is "here, we want to know what you think about and what you feel about being here at the moment and any kind of problems" … coz if all we know is people are really afraid very much of the time, we don't get any meaningful information from that. (Participant 1, Focus group 2)

This idea was also discussed by Robinson et al. (2018), who suggested that the gathering of qualitative information could contribute to a more in-depth understanding of perceptions of social climate.

Participants did, however, note that the use of comment boxes may not always be appropriate. There may be individuals who have difficulties in providing additional

information or examples in relation to the items. Here, it may be more appropriate for completion of comment boxes to be optional. Thus, the inclusion of comment boxes that are of an optional nature may be beneficial, enabling further opportunity for individuals to provide feedback, and also as a way of services gathering further feedback which could be used to identify any changes required on an individual service level.

#### *3.6.3.5 Summary*

Adaptations that have been proposed are:

1. The response option headings need to be reworded. Simple, familiar words are needed.
2. In addition to written response option headings, visual representations of these are also needed. A histogram style visual representation was considered the most appropriate way to do this.
3. There is a need for further exploration of the number of response options that should be provided. It would be beneficial to involve individuals with IDD in this process.
4. Optional comment boxes should be included to enable individuals to provide qualitative information relating to the items.
5. Similar to the previously discussed themes, the response format of the EssenCES cannot be considered as a distinct entity as the presentation, linguistic content of the EssenCES items, and the administration of the EssenCES will all impact upon decisions made regarding any necessary amendments to the response format for individuals with IDD.

### 3.6.4 Theme 4: Administration

This theme describes the main issues that participants raised with regards to how they currently administer the EssenCES with individuals with IDD, and the difficulties that could be encountered when administering an adapted version. Potential administration biases were acknowledged, and ways in which these could be reduced were explored. Many

participants emphasised that the way in which the EssenCES was administered was the most important aspect to be considered when seeking to adapt it for individuals with IDD. Suggestions regarding ways in which its administration could be made more consistent were also discussed. Participants noted that the provision of clear administration guidelines would be beneficial.

Data gathered were allocated to six sub-themes: (1) the importance of administration, (2) individual versus group completion, (3) who should administer the EssenCES, (4) practice items, (5) scripted rewording of items, and (6) communication of response choices. These themes are discussed below.

#### *3.6.4.1 Sub-Theme 1: The Importance of Administration*

The majority of participants considered that support would be vital when individuals with IDD are completing the EssenCES. Also, if appropriate support were to be provided, many individuals would be able to complete an adapted version. However, some participants also drew attention to the diverse nature of the IDD population, stating that there would be many different factors that affect whether an individual is able to complete the questionnaire and how much support they would require.

Some participants discussed allowing individuals to complete the EssenCES independently, with one participant reflecting on an occasion when individuals within their service had done so:

> The first time we did the EssenCES with the guys, they all got quite uppity that we were suggesting that we helped them with it and "no, we'll do it on our own" and, and went off and did it on their own, and so then there was obviously no explanation or … anything. Erm, bar possibly one of our more able residents explaining it to other people, which may have been slightly flawed. (Participant 1, Focus Group 5)

One participant suggested that independent completion would be most appropriate, expressing that "we need to have the tool to be as user friendly as possible for … patients to

use themselves" (Interview 1), although this was not the opinion expressed by the majority of participants. Clearly, whilst some individuals may not wish to be supported when completing the EssenCES, this approach would raise concerns with regards to a lack of knowledge as to whether individuals had understood the questionnaire and, therefore, whether the responses they provided were valid.

Participants expressed that they felt the administration was the most important factor in determining whether individuals are not only able to complete the EssenCES, but to do so in a reliable way:

> It doesn't matter how you word it, what structure it's got, each person is an individual and it's the support that they get to answer it that'll make the difference and whether they're able to engage with it in a meaningful way or if it just goes over their head and the survey becomes … inaccurate. (Participant 3, Focus Group 5)

Many participants also underscored the importance of consistent administration, stating that this would reduce subjectivity:

> I can understand the adaptation for a certain group, but I think it's something about how it's actually delivered, because in some ways … actually if that's just given to somebody and then it's kind of just open to whatever interpretation they wanna make of it, just generally, regardless of LD. But then if you sit down with someone and actually go through it … it can be a bit different. (Participant 5, Focus Group 4)

This point was also highlighted by Chester et al. (2015) and is discussed further within the subsequent sub-themes. With regard to administration, participants highlighted the importance of consistency, who it is administered by, and also the potential to include scripted rewording of items. Based on these findings, it will be necessary to provide clear guidelines for administrators regarding how to administer the EssenCES with individuals with IDD.

### *3.6.4.2 Sub-Theme 2: Individual Versus Group Completion*

Participants discussed how the EssenCES was currently administered within their services. Various methods were reported - within a group setting with staff available to offer support if required, and also completion on an individual basis. Many participants highlighted that, when considering the most appropriate method of administration, a consistent method would be necessary and that staff support would be vital:

> It would need consistency with administration then as well I guess. That it would always be done on a … either a one to one or a group basis, where they're all getting that same explanation rather than giving them the questionnaire and the explanation and then letting them do it themselves. (Participant 1, Focus Group 5)

Some participants felt that completion within a group setting could be beneficial on a service level as it would help to ensure completion by as many individuals as possible and would reduce the time taken for administration. However, participants acknowledged that this approach could present difficulties as some individuals may struggle to ask for support or may not perceive that they need support. This could result in difficulties understanding the questionnaire and, therefore, the provision of inaccurate responses. One participant provided an example of an occasion when this had occurred, stating "we'd said to the guy who said he just ticked at random, that you know, if he want, wanted help we'd support him with that, erm … but he just decided he wasn't going to ask [laugh] for help" (Participant 3, Focus Group 4).

Many participants felt that administration on an individual basis would be most beneficial. This would enable provision of consistent and individualised support, and reduce the need for individuals to actively request it:

> I think it depends on, err, the degree of learning disability and I think staff'll [sic] need to sort of assess you know "How much support do I need to give this person? Do I need to explain this, or do I not?". Some people might think it's a bit patronising

> if you're explaining it as well … especially for those who're less disabled than others, so I think it varies. (Interview 2)

Participants noted that administrators would be able to read out the information contained within the questionnaire if this approach were to be used and that this would be consistent with the approach they utilised when administering other questionnaires with individuals with IDD. This approach is consistent with that of other adapted questionnaires (e.g., the CORE-LD30, MWLQ, and GAS-ID) which have been validated in IDD populations. Individual support for individuals with IDD was also provided within Neimeijer et al.'s (2018) study of group climate, and within Robinson and Craig's (2019) and Barker et al.'s (2020) studies of social climate.

#### *3.6.4.3 Sub-Theme 3: Who Should Administer the EssenCES?*

There was much debate over who should administer the EssenCES. The suggested options were familiar staff who work on the ward or unit on a regular basis, unfamiliar staff that are independent of the service, or familiar staff who are independent of the service.

Many participants felt that individuals may be more trusting of familiar staff and may, therefore, find it easier to provide more honest responses and to ask for support. Participants also highlighted that familiar staff would have an understanding of individuals' strengths and difficulties, so would be best placed to provide individualised support. However, one participant felt that there may be an increased likelihood of administration bias occurring if familiar staff who worked on the ward or unit administered the questionnaire due to these staff having reduced objectivity:

> If you are asking a member of staff who is always working with them at all times I think, I think that may, erm, introduce a, a degree of bias I, I suspect and, and I would be very careful about how I would interpret that data. There are some staff who are quite objective I think, but there are some staff who are perhaps less objective. It's not deliberate but it, it's sometimes inevitable … that that bias comes in. (Interview 1)

A number of participants also highlighted that administration by familiar staff could result in a loss of anonymity, and some participants drew attention to how individuals may fear potential repercussions if they were to provide negative feedback:

> "Some people won't like me if I say… officers, will they get to know about it?". Like if they say that the wing's not nice and the support isn't good are the officers gonna get to know about it and will they then be treated differently? (Participant 2, Focus Group 3)

This participant was discussing the concerns that individuals may have regarding whether or not prisoner officers would be privy to their responses. However, this point is clearly relevant with regards to who is best placed to administer the questionnaire, as this difficulty would also have the potential to arise if prison officers, or ward staff, administered it. This could have the potential to increase socially desirable responding and acquiescence (Finlay & Lyons, 2001).

Some participants felt that utilising unfamiliar staff, or staff independent of the service, would allow individuals to provide more honest and valid responses:

> The validity of everything will depend on … the fact that it's being used ideally … by somebody asking questions of somebody and they don't know each other particularly that well but they are independent of the unit … and they're not relying too much on people knowing them … because there's other biases … by being too involved with the person and trying to ask these questions. (Participant 3, Focus Group 2)

However, whilst participants felt that there would be some clear drawbacks to familiar ward- or unit-based staff administering the questionnaire, they also highlighted that difficulties could be encountered using unfamiliar staff. Some participants perceived that individuals may find it difficult to be open and honest with unfamiliar staff regarding their

responses or level of understanding, and may struggle to ask for help due to concerns regarding how they may be perceived:

> You've got someone new with you, you don't have the confidence to say "I don't really understand what that means", "Can you help me with this?", "I, I don't know what to do", whereas if it's with someone they work with regularly then they're going to be more comfortable to be able to do that kind of thing. (Interview 2)

This participant highlighted that utilising a familiar staff member who was independent of the service could help overcome some of these issues. An administrator that was independent of the individuals' treatment was used when validating the GCI for IDD populations (Neimeijer et al., 2018). Here, the authors reported their findings to be reliable, thus suggesting that this did not lead to the presence of additional response biases. However, this approach relies on services having access to independent staff members with whom individuals with IDD are familiar. This is not the case within many services. Many participants highlighted problems with using unfamiliar or independent staff on a service resource level, stating, for example, "ideal world, you would have someone independent coming in … so they're not inclined to answer questions favourably for anyone. Erm, resources wise I think that's probably not really gonna happen" (Participant 1, Focus Group 3). This seems of particular relevance given that Robinson and Craig (2019) reported allowing an hour for each individual with IDD to complete their adapted version of the EssenCES.

Participants within one focus group felt that the compromise for their service may be that Multi-Disciplinary Team members or staff who are external to the individuals' ward or wing are utilised as opposed to staff providing direct day-to-day support (Focus Group 3). However, this is clearly an area in which further feedback from staff and, more importantly, from individuals with IDD, would be beneficial prior to a recommendation being made. This is of particular importance given that there is no existing research exploring who is best placed to administer social climate questionnaires with forensic IDD populations.

It is, however, clear that anonymity of the responses provided must be preserved. This is also referred to within the EssenCES manual (Schalast & Tonkin, 2016). Here, the authors commented that participants must be provided with the opportunity to be honest about their perspectives of the ward or unit and that, should anonymity not be guaranteed, this may invalidate participant responses, making monitoring of social climate purposeless.

#### *3.6.4.4 Sub-Theme 4: Practice Items*

Participants discussed the inclusion of practice items, with advantages and disadvantages to this being apparent. Participants felt that the inclusion of practice items could guide administrators in their decision as to whether or not to continue administering the questionnaire. This would help to ensure that those individuals going on to complete the questionnaire understood the response format and response options and were, therefore, providing more reliable responses. When using Likert scales, it has been demonstrated that the use of practice questions or pre-test screening results in improved reliability and validity of responses in IDD populations (Cummins et al., 1997; Hartley & Maclean, 2006). However, concerns were raised as some participants felt that practice questions could be seen by individuals with IDD as a "test". This could potentially have negative connotations and impact upon motivation to engage through bringing about feelings of failure, judgement, and embarrassment. Some participants made suggestions as to the type of practice items that could be included. They discussed ideas such as phrasing these practice items as "ice-breakers" or as a way of the administrators getting to know the individual, expressing that this may help to remove the focus from the fact that they are practice items.

Participants expressed concerns that the inclusion of practice items could mean that some individuals are deemed as unable to continue to complete the questionnaire. As noted by Emerson et al. (2013), this approach would help to ensure that only reliable and valid insights into social climate are gained. However, participants were keen to argue that some of these individuals may be able to comprehend the questionnaire should there be appropriate support:

> It feels like then we're screening out people who're non-verbal or have less … expressive communication who might have comprehension of the things … so if we're, if we're then doing such screening measures that relies on them being able to tell us narratively … then we're ruling out those who can't necessarily verbalise things but can understand if we explain things in a way that they can comprehend. (Participant 1, Focus Group 2)

Participants highlighted that, for some individuals, it can take a few items before they grasp the nature of the questionnaire:

> Some people it takes them four or five questions to really warm up and understand what the questions they're answering … and for you to get a hand, a handle of … "but actually no, I don't think you understood the first five … so I'm going to go back to it" and if you've done that with screening questions then you might have already screened them in or screened them out inappropriately. (Participant 2, Focus Group 2)

Although this is a valid point, attention needs to be drawn to the fact that the questionnaire design of the EssenCES dictates the order of the items, and that, therefore, the items should be completed in the order they are placed. Amending the order of the items has the potential to impact on the reliability and validity of the responses. It could also introduce bias as the individual may feel they are being asked to re-do certain items because they provided an incorrect response. It would, therefore, be beneficial to ensure that administration guidelines state the importance of completing the items in the order in which they are placed.

Participants also discussed what they thought should happen if it was evident that an individual didn't understand the response format or response options based on their responses to the practice questions. Most staff felt that they would continue on to complete the questionnaire with the individual due to the potential negative impact that curtailing completion could have, along with concerns that this could damage the therapeutic relationship:

> It might not be very nice for them as well if you sit down and do the first two questions … and then say "aah, you don't understand this so you don't get to fill it in". So … it might be nicer just to let them do it … and then, then write it up afterwards. (Participant 4, Focus Group 2)

This approach is consistent with that used within the CORE-LD30 and GAS-ID. However, a small number of participants commented that they would not continue to complete the questionnaire if it was evident that the individual did not understand. This is the approach utilised within the MWLQ:

> I think if you try and give support and try and help them to understand and they still didn't understand or they still didn't get it then I don't think you could use the questionnaire with them. I suppose that's the reason why you have practice questions is to … check for understanding and it's to try and help people understand and if they're not … it might be that you know their, their disability is too much for them to be able to understand it. (Interview 2)

Participants suggested that the most appropriate method to establish whether or not individuals have understood the items and the response format was for administrators to be attuned to pick up on response biases:

> I think that really comes down to the clinician or the person administering it really to get a sense of the level of, the person's level of comprehension whilst you're doing it with them, and, and also perhaps what happens in terms of their responses … in terms of whether … there's kind of a pattern coming out. (Participant 1, Focus Group 2)

Participants perceived that, if an individual had experienced difficulties with understanding the questionnaire, the administrators would need to provide this feedback alongside the questionnaire responses. A feedback box could be added at the end of the questionnaire for this purpose. If comment boxes were included within the response format, it may be that an

individual is still able to provide some valuable feedback. However, for the purpose of calculating subscale scores and including these within those of the ward or unit, it would appear difficult to know whether these responses should be included or not at this stage.

One participant expressed that the inclusion of the "I don't know" response option may eliminate the need for practice questions:

> Whether it would be worth like as, as we were talking about just having a "don't know" box and then if they … if they fill out like three or four "don't knows" in that it's almost the whole questionnaire to some extent. (Participant 2, Focus Group 2)

This could be an alternative means of assessing an individual's understanding of the items and response options as they progress through the questionnaire.

It is obvious that numerous difficulties could be encountered if using practice items with this population. The inclusion of an "I don't know" response option may be a way of enabling individuals who are completing the questionnaire to feel able to state that they are unsure of their response to particular items which could reduce response biases. The cut-off points defined by Schalast and Tonkin (2016) could then be used to determine whether an individual had provided enough responses on each subscale for the subscale responses to be included within the ward or unit feedback.

#### *3.6.4.5 Sub-Theme 5: Scripted Rewording*

Participants emphasised the benefits of providing alternative scripted rewording of items. They stated that this would enable more consistent administration both within and across services and expressed that this would help to ensure validity of the data gathered. Some participants noted that there are other questionnaires that utilise scripted rewording, and that they found this to be helpful:

> Something I did find useful with … is it the PICT? That has an explanation table for all those questions and their questions are way more complicated than these. Erm, and

> has “you could say it like this” so for each … there’s kind of set prompts … for some of the questions. (Participant 1, Focus Group 5)

Participants expressed that this could help reduce administration bias. It would prevent administrators rewording items based on their own interpretation of what the item, or a particular word, meant. This could, therefore, prevent projection of their own interpretation of the item on to individuals with IDD:

> I think it, the, there could be benefits to, in a consistent approach coz sometimes … for example you know say “What d’you mean by staff take a personal interest in the progress of…?”. You know like, for example, “when I asked you this” and then you’re kind of leading them, you know … it can be easy to reinterpret the question in a way that actually leads them to an answer. (Participant 1, Focus Group 4)

Participants also suggested that scripted rewording would be beneficial for individuals with IDD. It would enable administrators to utilise different words and phrases to support individuals to better understand their meaning. Interestingly, some participants also expressed that they felt scripted rewording would be of greater benefit for individuals with IDD than utilising visual representations as a means of providing further explanation of the items. One participant commented “I would be more inclined to put some additional support for each question in terms of what phrases and words you can use to explain it clearly without being biased or leading … rather than trying to create pictures” (Participant 2, Focus Group 5).

Some participants drew attention to the fact that, regardless of the provision of alternative scripted rewording, some individuals may still struggle to understand what the items mean. Therefore, administrators may still be required to elaborate and provide their own interpretations:

> Sometimes the interaction and like a live example actually helps you to understand it … so if it’s something scripted it just feels like another piece of information that I’ve got, you know, a scripted two sentences “this is what liveable means”, and I’m trying

> to understand that [laugh] … and then you can still end up at the end of the day having to, erm, sort of freestyle. (Participant 5, Focus Group 4)

Clearly this is a valid point, as the scripted rewording may not support every individual to understand the items. Attention, therefore, would need to be afforded to how administrators could approach this situation if it arises.

Participants discussed that the scripted rewording should be available for individuals to see in order to provide transparency. This would also have the potential to enable learning, through individuals building on their understanding of particular words. One participant suggested that the scripted rewording could be included on the questionnaire page (Participant 3, Focus Group 2). Other participants suggested that it could be presented on a separate page to avoid this additional information detracting from the items or leading to the inclusion of a large amount of text on the page. One participant proposed that the scripted rewordings could be incorporated with a booklet format (Participant 2, Focus Group 3), which ties in with other participants' suggestions surrounding the development of an administration pack.

Most participants, therefore, felt that scripted rewording of the items would be beneficial for both individuals with IDD and administrators. The use of scripted phrasing of questions and of providing alternatives to enable questions to be explained in a different way have been discussed in the literature (Finlay & Lyons, 2001; Hartley & Maclean, 2006). Robinson and Craig (2019) developed a glossary of alternative words that could be used within their adapted version of the EssenCES, and Neimeijer et al. (2018) utilised alternative scripted rewording of items on the GCI for individuals with IDD. Most participants appeared to feel that the scripted rewording of the items would be best placed on a separate page, which could be provided within an administration pack.

#### *3.6.4.6 Sub-Theme 6: Communication of Response Choices*

Participants discussed the importance of providing individuals with different options regarding how they communicate their response choices. Many expressed that a large-scale

version of the response options would also be beneficial. This was also suggested by participants within the study conducted by Chester et al. (2015) and is used within the CORE-LD30. Participants felt that this approach would provide increased consistency by preventing administrators from developing their own, individual, large-scale versions of the response format which could be different and could, therefore, have the potential to impact upon the questionnaire's validity.

Participants drew attention to the limitations in working memory that individuals with IDD may have and commented that this can lead to individuals struggling to retain the different response options if they do not have a copy in front of them. Participants discussed that, if a large-scale version of the response options was provided, it would help to reduce some of the difficulties that individuals with IDD can encounter in relation to retaining the different response options, along with providing a more visual resource.

One participant drew attention to the benefits of using a large-scale response format when administering this CORE-LD30:

> In addition to the CORE they're given sometimes a laminated, just the three response scale, just on a big … no questions … but just the response scales to, to help orientate them back because there's a lot to process on the page. (Participant 1, Focus Group 2)

Participants suggested that the large-scale version could be provided as a separate sheet or that laminated cards could be provided; however, they also acknowledged that some individuals may not wish to utilise this resource, again highlighting the diverse nature of the IDD population:

> It depends very much on the individual isn't it … you can always say "this is an additional resource to support, erm, should it be needed" … maybe provide a downloadable format that a clinician could take if it's suitable for their patient or client. (Interview 3)

Of note, however, is that using laminated cards to depict each response option could be problematic. This is because administrators could be inclined to remove some of the cards as a way of reducing the number of response options. This may occur if administrators feel that the individual may struggle with the full number of response options provided. Clearly, this would impact upon the reliability of the data gathered and would, therefore, not be appropriate to incorporate.

Participants discussed how individuals may choose to communicate their choice of response option. Suggestions included (i) utilising counters to place on, (ii) pointing at, (iii) holding up a card depicting, or (iv) stating out loud, their chosen response option. However, the key point that many participants highlighted was that the individual should be able to select how they would prefer to communicate their response.

Participants also expressed that, where possible, individuals should be encouraged to take ownership by ticking the box on the questionnaire that corresponds to their chosen response option themselves. This highlights the close link to the transparency and openness that should be provided within these settings.

Based on participants' suggestions, it would appear necessary for a large-scale version of the response format to be provided. Administrators should also provide individuals with a choice as to how they choose to communicate their chosen response options and should encourage or support individuals to tick the corresponding box on the questionnaire themselves.

#### *3.6.4.7 Summary*

Adaptations that have been proposed are:

1. The EssenCES should be administered by a staff member on an individual basis.
2. The EssenCES should be administered either by a familiar staff member or by someone independent of the service, with this decision being clearly stated within the administration guidelines. However, further feedback from staff and feedback

from individuals with IDD is required as there is no existing research that has considered who is best placed to administer social climate questionnaires with forensic IDD populations.

3. Practice items should not be included.
4. Inclusion of an "I don't know" response option may be beneficial.
5. The cut-off points referred to in the EssenCES manual (Schalast & Tonkin, 2016) should be utilised when analysing data gathered through the questionnaire as per their recommendations.
6. A feedback box should be added at the end of the questionnaire for administrators to document their perception of the presence of any response biases.
7. Scripted rewording of the items should be provided on a separate page, which could be provided within the administration pack.
8. A large-scale version of the response format should be provided.
9. Individuals should be provided with a choice as to how they communicate their response choices and should tick the corresponding box on the questionnaire themselves where possible.
10. Administration guidelines need to be developed to aid consistency of administration within and across services. These guidelines should be placed within a pack which would also include the scripted rewording of items and the large-scale version of the response format.

## 3.7 Discussion

It is widely acknowledged that it is of utmost importance to consider the perspectives of individuals with IDD when developing resources for these populations (e.g., Buell, 2017; Department of Health, 2010). However, it was considered necessary to establish an initial overview of the difficulties that staff perceived individuals with IDD would experience in relation to the EssenCES and to consider their suggestions for potential adaptations. Thus, preliminary adaptations could be made before individuals with IDD were asked to provide their input. This approach aimed to avoid the potential for individuals with IDD becoming overwhelmed as a result of involvement in the research at this early stage. Furthermore,

this approach meant that the perspectives of staff could be used to provide a basis on which to guide the discussions with individuals with IDD during the subsequent studies.

Consequently, the two studies included within this chapter set out to:

a. Explore staff perceptions of the difficulties that can be experienced by individuals with IDD when completing the EssenCES; and
b. Develop an understanding of the adaptations that may be required to improve the suitability of the EssenCES for these individuals.

A total of 80 staff members completed the online questionnaire to aid identification of relevant difficulties. Some participants also made suggestions for adaptations they considered would be beneficial for individuals with IDD. Interviews and focus groups with 25 participants were then used to enable an in-depth exploration of the main points raised by questionnaire participants and to facilitate discussions surrounding how the EssenCES could be adapted for individuals with IDD. An obvious strength of this two-step approach was the opportunity to elicit the perspectives of a diverse sample of participants through the questionnaire. This provided a substantial quantity of data. Consequently, a broad understanding of various, at times differing, perspectives of staff working across a range of forensic settings was developed. These differing perspectives were introduced within the interviews and focus groups, encouraging participants to explore a number of different viewpoints and various potential adaptations to the EssenCES. This approach also provided additional benefits. Firstly, it resulted in participants providing justifications for their viewpoints. This enhanced understanding of the rationale behind their perspectives. Secondly, within focus groups, it enabled participants to consider and challenge one another's perspectives in an attempt to reach more unanimous decisions regarding the adaptations they felt were required.

Participant perspectives were sought in different ways across Studies 1 and 2, and also within Study 2. A questionnaire design afforded absolute anonymity to participants; whereas the interviews and focus groups did not. This may have had the potential to impact upon participants' ability to provide honest responses. Furthermore, as the focus groups were conducted with groups of colleagues working within the same department there is the

potential that this could have resulted in some participants feeling unable to share their perspectives, particularly if they directly opposed that of their colleagues. All participants in Study 2 were provided with the option to participate in either an interview or focus group; however, it is possible that, as some of the focus groups occurred within scheduled staff meeting times, some participants may not have felt able to request an individual interview outside of this, should this have been their preferred option.

Inclusion criteria for both studies stipulated that participants needed to be currently working within forensic IDD settings and that they considered that they possessed an understanding of the cognitive difficulties experienced by individuals with IDD; however, it was not a pre-requisite that they had previous experience of using the EssenCES. Indeed, only 16% of questionnaire participants reported having used it with individuals with IDD. It was important to gather feedback from those that have used the EssenCES with individuals with IDD as these participants were able to describe some of the difficulties they have faced and adaptations they had needed to make when administering it with this population. However, the perspectives of participants who had no such experience was considered equally important as they would be able to provide an objective, critique of the EssenCES.

Data from these studies demonstrated that the majority of participants shared similar concerns regarding the difficulties they felt individuals with IDD would experience when completing the EssenCES and, indeed, the items they felt were most problematic. However, their perspectives regarding how the questionnaire should be adapted were, at times, conflicting. Participants made various suggestions regarding:

- How items could be reworded;
- The use of pictorial representations of the items;
- The duration of the time-frame;
- The number of response options;
- The choice of both the wording and visual representations of the response options; and
- The way in which the questionnaire should be administered.

Most participants provided clear justifications for the amendments they proposed. They used their knowledge and experience of communicating with individuals with IDD along with their experiences of completing other questionnaire measures with such individuals as the basis for their suggestions. It is apparent that there is no "right way" to adapt the EssenCES for individuals with IDD, with the differing perspectives of participants perhaps being a reflection of the individuals with IDD with whom they have worked and the type of environments they have worked in along with, potentially, their job role.

The studies included in this chapter included a variety of staff participants from forensic IDD services in the UK, Australia, and New Zealand. However, within Study 1 only 13% of participants worked in prison settings (as opposed to hospital or residential settings). Furthermore, all of the aforementioned participants worked in prison settings in the UK. Arguably, this could have resulted in the data gathered through the online questionnaires not being reflective of all settings. All participants within Study 2 worked in the UK. Thus, interview and focus group findings may have been biased towards the views of UK staff. Furthermore, the decision not to include individuals with IDD within the current studies may have led to certain difficulties or adaptations being overlooked. This is a potential limitation of the current studies' findings; however, it is envisaged that the subsequent studies involving individuals with IDD will likely address any issues that may have resulted from this.

## 3.8 Conclusions

This chapter has underscored the importance of adapting the EssenCES for individuals with IDD and has explored potential adaptations that may be required for this population. Many of the main points made by participants have also been highlighted within the general literature pertaining to IDD and self-reporting, and within more specific studies relating to using social climate measures with IDD populations (e.g., Bell et al., 2018). There were, however, some suggested adaptations which contradicted the literature. For example, a number of participants felt that visual representations of the EssenCES items would not be appropriate. Some participants also highlighted points which do not appear to have been afforded much, if any, attention within the literature. For example, potential consequences

of over-simplifying the questionnaire and the potential to gather qualitative social climate data through the inclusion of comment boxes. Issues surrounding who is best placed to administer social climate questionnaires within forensic IDD settings were also raised, with it being apparent that this is a key area yet to be resolved within the social climate literature. Furthermore, both studies (in particular Study 2) also took tentative steps towards exploring the concept of social climate within forensic IDD settings, with participants starting to engage in discussions surrounding how they perceive social climate to be constructed within these settings. This concept has not been discussed in the literature to date.

The adaptations suggested within this chapter need to be considered within the context of relevant literature and accessible information guidelines before an adapted version is developed. Involving individuals with IDD in the development of the adapted questionnaire is vital to ensure that their perspectives are reflected in the adapted EssenCES. The next chapter will seek to develop an initial pilot version of the adapted EssenCES, before the views of individuals with IDD, staff, and social climate experts are sought with regards to any further amendments that may be required.

# Chapter 4: Development of the Initial Pilot Version of the EssenCES-IDD

## 4.1 Introduction and Aims

The EssenCES is widely used to measure social climate within forensic settings; however, little attention has been afforded to its suitability for individuals with IDD. The limited research in this area (Barker et al., 2020; Bell et al., 2018; Chester et al., 2015; Robinson & Craig, 2019) has drawn attention to a number of difficulties these individuals may experience when completing the EssenCES and made tentative suggestions as to how it could be adapted for them. Robinson and Craig (2019) and Chester et al. (2015) both explored staff perspectives regarding how the EssenCES could be adapted for IDD populations; however, they only involved a small number of participants from a single UK-based forensic hospital service. Barker et al. (2020) developed a modified version of the EssenCES based on input from a Lead Psychologist and Speech and Language Therapists. However, it appears that these staff were based solely in UK forensic hospital settings. The studies detailed within Chapter 3 of this thesis, therefore, represent the first comprehensive attempt to elicit the viewpoints of a broad range of staff, including UK and international participants from both forensic hospital and prison settings.

The findings from the studies included in Chapter 3 evidence that the majority of participants did not perceive that the EssenCES is suitable for individuals with IDD in its current form, and that it would be beneficial for an adapted version to be developed. Participants highlighted a variety of difficulties that they perceived these individuals would experience when completing the EssenCES. They also made suggestions regarding potential adaptations that could improve its suitability for these individuals. Many of these difficulties and suggested adaptations are supported by the wealth of literature surrounding IDD and completion of self-report questionnaires, and by relevant accessible information guidelines. Additionally, many of the suggested amendments have also been utilised within other questionnaires that have been successfully adapted for individuals with IDD. However, some of the suggested adaptations do not concur with previous research or follow relevant accessible information guidelines (e.g., refraining from including pictorial representations of the items).

This chapter considers the findings from Chapter 3 in conjunction with the literature surrounding IDD and self-reporting, recommendations made within relevant accessible information guidelines, and adaptations included within other questionnaires that have been successfully adapted for individuals with IDD in order to develop an initial pilot version of the EssenCES for individuals with IDD (the EssenCES-IDD). Adaptations made and the rationale for such changes is explained and the initial pilot version of the EssenCES-IDD is presented.

## 4.2 Identified Adaptations

This section aims to identify the adaptations to the EssenCES that are required for individuals with IDD. It will utilise the four over-arching themes identified within Chapter 3 to provide a comprehensive and structured framework within which these adaptations will be discussed. Those adaptations that can be considered relatively straightforward, and are strongly supported by relevant literature and accessible information guidelines or have been successfully utilised within other IDD-specific questionnaires, are presented. Areas where different opinions were expressed within Chapter 3 regarding the required amendments or where suggestions contradicted the literature are discussed in detail, along with an explanation of the final decision. Furthermore, amendments suggested within Chapter 3 that were not incorporated are also discussed, along with an explanation of the rationale for this.

### 4.2.1 How Many Versions?

As reported in Chapter 3, some participants queried whether two versions of the EssenCES-IDD may be required. They also discussed how a more simplistic version could include pictorial representations of the EssenCES-IDD items along with fewer response options, enabling different ability levels to be catered for. However, most participants considered that one version would be sufficient. This would eliminate the potential for confusion amongst administrators with regards to which version should be used with different individuals. This would also ensure that data gathered is in a consistent format, thus

simplifying statistical interpretation of EssenCES-IDD data. Whilst it is acknowledged that this approach could still exclude some individuals with IDD, it is important to note that other questionnaires that have been specifically adapted for IDD populations have successfully utilised a single adapted version (e.g., the CORE-LD30 and GAS-ID). Individuals with IDD and staff will, therefore, complete the same version of the EssenCES-IDD (although small differences in the cover sheets will be present – see Section 4.2.3). This will enable direct comparison of resident and staff responses.

### 4.2.2 Layout

The layout of the EssenCES needs to be adapted. Although individuals with IDD will complete the EssenCES-IDD with support from an administrator, its layout remains important. Chapter 3 identified that individuals need to be able to see a copy of the EssenCES-IDD and associated materials during completion. Therefore, the EssenCES-IDD and any additional materials should be developed using an accessible format and should be shared with individuals (see Section 4.2.7).

Chapter 3 highlighted the importance of using a clear style of font (e.g., Century Gothic). Recommended alternatives within accessible information guidelines could also be used, including Arial, Calibri, and Tahoma styles. These do not include any complicated letter shapes and, therefore, facilitate ease of reading (NOMS, 2014). Buell (2017) noted that Arial style was the most commonly used font style within easy read information for individuals with IDD and, as this font style is already used within the EssenCES, it was deemed appropriate for this to remain. Participants also drew attention to the font size, suggesting that this should be enlarged to facilitate ease of reading and to promote inclusion for individuals who are short-sighted or dyslexic. This is supported by accessible information guidelines (e.g., Department of Health, 2010; NOMS, 2014) who recommend a minimum of 14-point font. The font size of all text will, therefore, be increased to at least 14-point. This font size and style will also be used across any additional resources which individuals may be provided with during completion of the EssenCES-IDD.

The spacing of the EssenCES items was also discussed within Chapter 3, with some participants expressing a preference for the questionnaire to remain on a single page whilst others considered that splitting the questionnaire over multiple pages would be more beneficial. Whilst the rationale for presenting the EssenCES-IDD on a single page is acknowledged, and the potential benefits understood, it is important to note that the increase in font size as detailed above is unlikely to allow for use of a single page. Given that accessible information guidelines recommend the inclusion of plenty of white space and the use of extra spacing between lines, and advise against the inclusion of too much information on a single page (Mencap, 2002; NOMS, 2014), it would appear that presenting the EssenCES-IDD on a single page would not promote accessibility. Chapter 3 highlighted that, at times, individuals with IDD and staff may express a lack of motivation to complete questionnaires that appear lengthy and require sustained attention. However, a lack of motivation to complete a questionnaire that appears cluttered and overwhelming was also discussed. Given that motivational difficulties may occur if using either a single or multiple page layout, it would seem most appropriate to utilise the layout which allows the EssenCES-IDD to be presented in the most accessible format. The use of a multiple page layout would enable the inclusion of plenty of white space, a larger font size and extra spacing between items. It would also allow for the inclusion of any symbols or pictorial representations of the items or response options, and for the inclusion of any comment boxes. This additional spacing should enable individuals to distinguish between the different items and the different response options with more ease, and would be in line with the layout of the successfully validated CORE-LD30. The EssenCES-IDD will, therefore be presented across multiple pages with two items included per page.

### 4.2.3 Cover Sheets

Chapter 3 drew attention to the need for cover sheets to be developed for both individuals with IDD and staff. It was agreed that the cover sheets would need to include the following information:

1. The purpose of the EssenCES-IDD. This will ensure individuals and staff are informed about the topic area covered by the questionnaire and why they are being asked about it.
2. Information detailing how the data gathered through the EssenCES-IDD will be used. This will ensure individuals and staff understand why they are being asked to complete the questionnaire (and the importance of doing so) and what will happen with the information they provide. This could also increase motivation to engage.
3. A statement concerning anonymity of responses and the importance of providing honest responses. This will aim to encourage open and honest responding, and to reduce concerns surrounding any fears of negative repercussions should they provide negative feedback.
4. A statement informing individuals with IDD that the EssenCES-IDD is not a test. This will help to ensure that individuals do not feel embarrassed if they experience any difficulties or need to ask for support during completion.
5. A space for the name of the ward or unit. This will ensure individuals and staff are aware of the environment the questionnaire is asking for their opinions about.

Given that the EssenCES-IDD is going to be presented over multiple pages, it will also be necessary to inform individuals and staff about the length of the questionnaire. This could be explained using a simple statement such as “This form has 17 questions”.

#### *4.2.3.1 Initial Statements*

When considering how to explain the purpose of the EssenCES-IDD to individuals with IDD, it is important to think about how this can be accomplished. The questionnaire seeks to explore perceptions of social climate which, in itself, is a difficult concept to comprehend. As discussed within Chapter 3, ensuring that individuals understand the purpose of the questionnaire forms a part of gaining informed consent. Consequently, it is vital that any explanation provided is straightforward and easy to understand. Given the likelihood that these individuals will experience difficulties in understanding the concept of social climate, it

would seem most appropriate for the term social climate to not be included. Instead, this should be replaced with a statement such as “We are getting your opinion about the ward” or “We are getting your opinion about what it is like to live on the ward” as suggested within Chapter 3. Both these statements encompass the concept of social climate; namely that it pertains to how individuals perceive the environment of their ward or unit. A further statement such as “We are doing this because we want to find out if there are any changes we can make” (as suggested within Chapter 3) could then be included. This would be a way of highlighting the benefits of completing the EssenCES-IDD.

The above suggestions were also considered in conjunction with recommendations regarding the language that should be used when communicating with individuals with IDD (see Section 2.3.2). Clarifying that data gathered would be used to consider how *positive* changes or improvements to the ward or unit could be made (as opposed to “changes” - which could be taken in a positive or negative way) was also considered important. This resulted in the statements included in Table 4A being derived.

**Table 4A**

*Initial Cover Sheet Statements*

| **Cover sheet for individuals with IDD** | **Cover sheet for staff** |
|---|---|
| This form has 17 questions. | |
| The questions ask about how things have been on the ward/wing. | |
| Your answers will help staff find out what it is like to be on the ward/wing and if there are any changes they can make to help make your life better on the ward/wing. | We are asking these questions because we want to find out what it is like to be on the ward/wing and if there are any changes we can make that will help to improve the ward/wing for both patients/prisoners and staff. |

The importance of ensuring individuals are aware that the EssenCES-IDD is not a test was also highlighted within Chapter 3. It was evident that individuals would need to be informed of this and would benefit from knowing that they could ask for support if required (see

Section 4.2.7). The following statements were, therefore, derived for inclusion within the cover sheet for individuals with IDD.

- This is not a test.
    - There are no right or wrong answers.
    - It is okay if you do not know the answer to a question.
    - Please say if you do not understand a question.

#### *4.2.3.2 Anonymity*

Chapter 3 highlighted the importance of attempting to elicit honest feedback from individuals completing the EssenCES, identifying the necessity of anonymity of responses as a key contributor to this. Anonymity of responses to social climate questionnaires has also been described as essential within the literature (Moos, 1975). As a result, it was deemed essential for the cover sheet to inform individuals that their responses will be anonymous and to request that they attempt to provide honest responses. Inclusion of the term "anonymous" is likely to be too challenging for individuals with IDD; therefore, a statement highlighting that they will not be required to include their name on the questionnaire would be a suitable alternative. This resulted in the statements included in Table 4B being derived.

**Table 4B**

*Cover Sheet Statements Regarding Anonymity*

| Cover sheet for individuals with IDD | Cover sheet for staff |
|---|---|
| You do not need to put your name on the form. | Your answers are anonymous and you do not need to put your name on the form. |
| Please try to be honest when you answer the questions. | |

#### *4.2.3.3 Name of the Ward or Wing*

The inclusion of a space for individuals and staff to document the name of the ward or wing they reside or work on was considered important. This would provide clarity regarding the environment that the questions pertain to. Interestingly, this does not appear to be a point which has been considered within the social climate literature to date. Although the items included within most social climate questionnaires enquire as to the views of individuals with regards to the ward or unit, they do not confirm the individual's understanding of the definition of these terms. This may be due to the fact that these questionnaires are not designed for individuals with IDD and, therefore, these terms are considered self-explanatory. However, for individuals with IDD it would be beneficial to clarify these terms. Furthermore, inclusion of the ward or wing name would be useful if data gathered are also being used as a part of outcome monitoring. A space for individuals and staff to write the name of their ward or wing will, therefore, be included on the cover sheets.

#### *4.2.3.4 Summary*

For individuals with IDD, the cover sheet will help to ensure that they have been provided with the necessary information regarding the EssenCES-IDD. Furthermore, it will also enable administrators to establish whether individuals have understood the purpose of the questionnaire and how any information they provide will be used. Both of these are important aspects of gaining informed consent. It will, therefore, need to be recommended that administrators go through the cover sheet before establishing consent and before completing the questionnaire with individuals with IDD. This will be highlighted within the administration guidelines. Individuals with IDD should be encouraged to read the cover sheet themselves where possible so as to reduce working memory demands; however, those administering the questionnaire can read this out if necessary (see Section 4.2.7).

Forensic hospital and prison versions of the cover sheets were developed based on the aforementioned points and copies can be found in Appendices 11 and 12 (individuals with IDD) and Appendices 13 and 14 (staff). It is acknowledged that the addition of the cover sheets will increase the time taken to complete the EssenCES-IDD. However, the benefits of

explaining the purpose of the questionnaire will improve understanding, enhance motivation to engage, and increase the likelihood of gathering reliable and valid data.

### 4.2.4 Time-Frames

Chapter 3 identified that there is a need to provide clarity regarding the time-period to which the EssenCES-IDD items relate. There does not appear to be any literature that has specifically explored the most appropriate time-frames to use with individuals with IDD nor any recommendations surrounding this within accessible information guidelines. Consequently, suggestions made within Chapter 3 were considered alongside the time-frames used within other IDD-specific questionnaires.

Differing options for the time-frame were suggested within Chapter 3, and the difficulties individuals with IDD can experience in terms of understanding the concept of time were discussed. However, the overall opinion was that a one-week time-frame would be most appropriate. This would enable the EssenCES-IDD to be used for both longitudinal and cross-sectional monitoring of social climate in the same way as the original version. It would also help enable individuals to identify recent situations and events relevant to the questions. Furthermore, it may also improve accuracy of responses as the short time-frame could help to negate memory difficulties. This time-frame has been utilised within other questionnaires developed for individuals with IDD (e.g., the CORE-LD30 and GAS-ID). However, it is worth noting the dynamic nature of social climate, which may mean that data gathered is more susceptible to the impact of brief fluctuations in the environment as opposed to if a longer time-frame were used.

Chapter 3 also drew attention to the potential to utilise anchor events as an aid to understanding the time-frame and to provide a clear point for the commencement of the time-frame. Identification of an anchor event specifically for each individual with IDD would ensure that they are relevant and comprehensible to each individual. Again, this approach has been used successfully within other questionnaires developed for individuals with IDD (e.g., the GAS-ID) and has also been recommended within relevant literature (e.g., Finlay & Lyons, 2001; Prosser & Bromley, 2012).

When considering how to incorporate the one-week time-frame and anchor event into the EssenCES-IDD, it was important to determine whether the time-frame or anchor event should be referenced within each item or solely at the beginning of the questionnaire. Within the CORE-LD30, the phrase "over the last week" was added as a precursor to all individual items; however, the authors do not discuss whether they utilised a method of checking the understanding of individuals with IDD with regards to this time-frame. The GAS-ID utilised informal discussions with individuals with IDD in order to identify individualised anchor events as a means of establishing the one-week time period that the questions pertained to. The anchor event was then used to frame the questions at the start of the questionnaire, with administrators stating "I am going to ask you some questions about how you have been feeling since [the anchor event] over the past week"; however, it does not appear that this time-frame was referred to within each individual question. Given that both the use of a one-week time-frame and the inclusion of an anchor event were suggested within Chapter 3, it would appear that these suggestions more closely resemble the approach used within the GAS-ID. Therefore, individuals should be supported by administrators to identify an anchor event. The anchor event and time-frame should then be reiterated to individuals prior to commencing the questionnaire. Repeated references to the time-frame within each individual item may serve as important reminders of it; however; this would increase the length of the items which would not be beneficial. Therefore, this will not be incorporated within the EssenCES-IDD.

These adaptations are included within the cover sheets for the EssenCES-IDD (Appendices 11-14). The inclusion of a specific time-frame should provide individuals and staff with clarity regarding the time-period to which the questions on the EssenCES-IDD relate. Additionally, the use of an anchor event should prove beneficial in terms of helping individuals with IDD to comprehend this time-period. However, it would be useful to gain feedback regarding these adaptations from both these individuals and staff in order to ascertain whether or not this time-frame is understood by individuals with IDD, or whether an alternative approach needs to be considered. It is also important to draw attention to the fact that the process of administrators supporting individuals to identify an anchor event will extend the length of time taken to complete the EssenCES-IDD. It is anticipated that this

approach will result in the collection of more reliable and valid data. However, there is the potential that these additional demands on administrators in terms of time could mean that, on a practical level, services are less able to collect EssenCES-IDD data on a regular basis. Further input from staff with regards to the practicalities of this approach will be essential.

### 4.2.5 Linguistic Content

Chapter 3 drew attention to various adaptations that may be required in order to increase the suitability of the language used within the EssenCES items for individuals with IDD. Some of these were general adaptations that would be applicable across all items and others were item-specific. The general changes suggested with regards to the language used across all items were relatively consistent. However, for specific items there was often no clear agreement with regards to the most appropriate way to adapt these.

#### *4.2.5.1 General Adaptations*

General linguistic adaptations that were proposed within Chapter 3, and that will be incorporated within the EssenCES-IDD, are detailed in Table 4C. The rationale for these changes is also provided.

**Table 4C**

*Summary of Adaptations Required to the Linguistic Content of the EssenCES Items*

| Adaptation | Rationale | Reference |
|---|---|---|
| Replace the term "unit" with "wing", and the term "inmates" with "prisoners" within the prison version of the EssenCES-IDD. The terms "ward" and "patients" will remain the same for the hospital version of the EssenCES-IDD. | To ensure the wording that depicts the environment and those residing within it is appropriate, in line with current terminology used within the relevant settings, and is familiar to individuals completing the EssenCES-IDD. | These terms are specific to the EssenCES questionnaire and were proposed within Chapter 3. |
| Phrase items as questions instead of agreement statements. | To aid flow between questions and response options by simplifying the questionnaire format. | Finlay & Lyons (2001) |
| | To reduce short-term memory demands by removing the need for individuals to identify how much they agree with each item. | Kells (2011) |
| | To reduce potential for leading bias. | Finlay & Lyons (2001) |
| Shorten sentences and remove unnecessary qualifying words. | To ensure questions are brief and simple. | Prosser & Bromley (2012) |
| Remove words pertaining to frequency from the questions. | To reduce sentence length by avoiding repetition (frequency is already covered within the response options). | Prosser & Bromley (2012) |

| Adaptation | Rationale | Reference |
|---|---|---|
| **Adaptation** | **Rationale** | **Reference** |
| Adapt questions which are asking two questions to ask one only (covering one single idea or point). | To reduce confusion and provide clarity. | Mencap (2002) |
| Adapt questions which include more than one clause so that they include one only, and remove commas where possible. | To reduce confusion and simplify the questions. | Beail & Jahoda (2012); Finlay & Lyons (2001) |
| Remove apostrophes where possible. | To simplify the questions. | Change (2009) |
| Remove complex or abstract words and phrases where possible, and replace with simple, concrete terminology. | To simplify the questions and improve readability. | Chester et al. (2015); Finlay & Lyons (2001) |
| Provide the option to add the prefix of "do you think" to the beginning of questions that enquire about the views of staff. | Reduce theory of mind difficulties and increase response rate for the questions pertaining to the opinions of staff.<br><br>Provide this as an optional addition so as not to increase sentence length unnecessarily. | Jolliffe & Farrington (2004)<br><br>Hartley & Maclean (2006); Prosser & Bromley (2012) |

#### *4.2.5.2 Visual Representations of the EssenCES-IDD Items*

Many questionnaires developed for individuals with IDD utilise visual representations of the questionnaire items. However, Chapter 3 indicated that this approach would not be appropriate for the EssenCES-IDD, with it being considered difficult to source appropriate visual representations of the EssenCES-IDD items and to ensure that they are interpreted in the same way by all individuals. These findings clearly contradict the suggestions made by Barker et al. (2020), Glennon and Sher (2018), and Robinson and Craig (2019) who proposed that an adapted version of the EssenCES for individuals with IDD should seek to incorporate visual aids, and suggestions included within existing literature (e.g., Hartley and MacLean, 2006) which report that visual aids are known to improve the response rate in IDD populations. However, it is important to consider the nature of the EssenCES and the concept of social climate. Clearly, the items included within the questionnaire, even following simplification for individuals with IDD, are not of a particularly concrete nature. One must also consider that the EssenCES is designed for use in forensic settings, and the boundaries that are associated with such settings. For example, although within non-forensic questionnaires it may be considered appropriate to include visual aids denoting individuals hugging each other to depict the concept of care; this would clearly be unsuitable within forensic settings. This point is further highlighted by Robinson and Craig (2019) who noted that they experienced difficulties identifying appropriate images to represent the EssenCES items within their study. Visual representations of the items will, therefore, not be included within the initial pilot version of the EssenCES-IDD. However, individuals' comprehension of the written items will need to be explored, with the potential for this decision to be revised should individuals experience substantial difficulties.

#### *4.2.5.3 Specific Adaptations Required for Individual EssenCES Items*

Various adaptations were proposed within Chapter 3 for individual EssenCES items. These suggested adaptations and the rationale for them are detailed in Table 4D.

**Table 4D**

*Adaptations Proposed for Individual EssenCES Items*

| Item number | Hospital (a) and prison (b) versions of item | Adaptations required |
|---|---|---|
| 1. | (a) This ward has a homely atmosphere<br>(b) This unit has a liveable atmosphere | Replace the term "homely" with a simpler and more concrete term<br>• Subjective term<br>• Implies home = good<br>• Limited understanding of what a "homely" atmosphere is (upbringing)<br>• Complicated and abstract term<br>Replace the term "liveable" with a simpler and more concrete term<br>• Subjective term<br>• Limited understanding of what a "liveable" atmosphere is (upbringing)<br>• Complicated and abstract term<br>Replace the term "atmosphere" with a simpler and more concrete term<br>• Abstract concept – open to interpretation by staff and patients<br>• Long and complicated word |
| 2. | (a) The patients care for each other<br>(b) The inmates care for each other | Replace the phrase "care for" with "care about"<br>• Should patients "care for" each other (not in line with hospital policy)<br>• "Care" in what capacity/what does "care" mean?<br>• Confusing as staff are paid to care – the item needs to differentiate between patient support and staff care |

| Item number | Hospital (a) and prison (b) versions of item | Adaptations required |
|---|---|---|
| 3. | (a) (b) Really threatening situations can occur here | Remove the words “threatening”, “situations”, and “occur”<br>• Replace with shorter, more concrete, and less complex words<br>• Replace with words that are more familiar to individuals with IDD<br>Remove the word “really”<br>• Unnecessary qualifying word<br>Remove the word “can”<br>• Unnecessary word<br>Rephrase as a question so as to improve neutrality<br>• To reduce the potential for leading bias |
| 4. | (a) On this ward, patients can openly talk to staff about all their problems<br>(b) In this unit, inmates can openly talk to staff about all their problems | Reduce the length of the item<br>• Sentence too long and complex<br>Rephrase the item to enable removal of the comma<br>• Simplify sentence structure<br>Remove the phrase “openly talk”<br>• Confusing and vague concept with no clear meaning |

| Item number | Hospital (a) and prison (b) versions of item | Adaptations required |
|---|---|---|
| 5. | (a) Even the weakest patient finds support from his fellow patients<br>(b) Even the weakest inmate finds support from his/her fellow inmates | Reduce the length of the item<br>• Sentence too long and complex<br>Remove the word “his” from the patient version<br>• Make gender neutral<br>Rephrase the item to reduce the complexity of the concept<br>• Complex concept for individuals with IDD, and staff, to understand<br>• Deficit focused and judgemental, feeds into a hierarchical structure<br>Remove the word “even”<br>• Unnecessary and implies that some individuals should not be supported<br>Replace the term “weakest”<br>• Subjective term (i.e., physical vs emotional weakness)<br>• Implies that there are “weak” individuals on the ward/unit and encourages respondents to try and identify these individuals<br>• Inflammatory word to use within forensic settings<br>Be aware of the need to retain inclusion of the concept of the “weakest” individual<br>• Otherwise becomes very similar to items 8 and 14<br>Replace the word “fellow” with “other”<br>• Uncommon word and difficult to understand<br>Replace “finds support” with “gets support”<br>• Individuals do not always actively seek out support when they are struggling. More likely that support is offered to them |

| Item number | Hospital (a) and prison (b) versions of item | Adaptations required |
|---|---|---|
| 6. | (a) There are some really aggressive patients on this ward<br>(b) There are some really aggressive inmates in this unit | Remove the words “some” and “really”<br>• Unnecessary qualifying words<br>Replace the word “aggressive” with a shorter and simpler word<br>• To reduce complexity of the question |
| 7. | (a) Staff take a personal interest in the progress of patients<br>(b) Staff take a personal interest in the progress of inmates | Remove the term “personal” from the phrase “personal interest”<br>• To ensure appropriate staff/patient boundaries are drawn upon within the question<br>• To ensure the question does not link in with any individual’s history of abuse (personal vs. professional interest)<br>Remove the term “progress”<br>• Replace with a more concrete term that is simpler to understand<br>Add the optional prefix of “do you think” to the start of the item<br>• To reduce the impact of theory of mind difficulties |
| 8. | (a) Patients care about their fellow patients’ problems<br>(b) Inmates care about their fellow inmates’ problems | Replace the word “fellow” with “other”<br>• Uncommon word and difficult to understand |
| 9. | (a) Some patients are afraid of other patients<br>(b) Some inmates are afraid of other inmates | Rephrase as a question to improve neutrality<br>• To reduce the potential for leading bias<br>Remove the word “afraid”<br>• Replace with a simpler, more familiar word or a behavioural example |

| Item number | Hospital (a) and prison (b) versions of item | Adaptations required |
|---|---|---|
| 10. | (a) Staff members take a lot of time to deal with patients<br>(b) Staff members take a lot of time to deal with inmates | Remove the phrase “take a lot of time” and replace with a simpler and clearer phrase<br>• Negative statement that implies that patients/inmates are a burden<br>• Ambiguous item as unclear whether this is meant as a positive or negative (i.e., they take too much time to get around to helping patients vs. they spend a lot of time helping patients)<br>Remove the phrase “deal with” and replace with a simpler and clearer phrase<br>• Ambiguous and vague phrase – unclear as to whether this is meant as a positive or negative (i.e., dealing with challenging patients vs. supporting patients) |
| 11. | (a) When a patient has a genuine concern, he finds support from his fellow patients<br>(b) When inmates have a genuine concern, they find support from their fellow inmates | Reduce sentence length and rephrase sentence<br>• Item is too long and has a convoluted sentence structure<br>• Item contains too many words and clauses, and complicated punctuation<br>Remove the word “he” from the patient version<br>• Make gender neutral<br>Remove the word “genuine”<br>• Difficult, word to understand<br>• Implies some concerns are not genuine<br>Remove the word “concern”<br>• Replace with a simpler, more familiar word<br>Replace the word “fellow” with “other”<br>• Uncommon word and difficult to understand<br>Replace “finds support” with “gets support”<br>• Individuals do not always actively seek out support when they are struggling. More likely that support is offered to them |

| Item number | Hospital (a) and prison (b) versions of item | Adaptations required |
|---|---|---|
| 12. | (a) At times, members of staff are afraid of some of the patients<br>(b) At times, members of staff feel threatened by some of the inmates | Remove the phrase “at times”<br>• Unnecessary qualifier<br>• Results in a convoluted sentence structure<br>Remove the word “afraid”<br>• Replace with a simpler, more familiar word or a behavioural example<br>Add the optional prefix of “do you think” to the start of the item<br>• To reduce the impact of theory of mind difficulties |
| 13. | (a) Often, staff seem not to care if patients succeed or fail in treatment<br>(b) Often, staff seem not to care if inmates succeed or fail in the daily routine/program | Reduce sentence length and rephrase sentence<br>• Item is too long and has a convoluted sentence structure<br>• Item contains several elements which could result in confusion<br>• Item is of an abstract nature<br>Remove the word “often”<br>• Unnecessary qualifier<br>Rephrase the phrase “seem not to care”<br>• Negative, uncommon and confusing wording<br>Rephrase the item to remove the dual element of “succeed or fail”<br>• To ensure the item is asking one question only<br>• To simplify the item<br>Remove the phrase “succeed or fail”<br>• Unclear as to what does success or failure in treatment mean<br>• Replace with a more concrete concept<br>Remove the phrase “daily routine/program” from the prison version<br>• Unclear as to exactly what this phrase refers to<br>Add the optional prefix of “do you think” to the start of the item<br>• To reduce the impact of theory of mind difficulties |

| Item number | Hospital (a) and prison (b) versions of item | Adaptations required |
|---|---|---|
| 14. | (a) There is good peer support among patients<br>(b) There is good peer support among inmates | Remove the word “peer”<br>• Uncommon word that is difficult to understand |
| 15. | (a) Some patients are so excitable that one deals very cautiously with them<br>(b) Some inmates are so excitable that one deals very cautiously with them | Reduce sentence length and rephrase sentence<br>• Long and complex sentence<br>Rephrase the item to reduce the complexity of the concept<br>• Complex concept for individuals with IDD, and staff, to understand<br>• Unclear what the item means/is “getting at”<br>• Current phrasing assumes that excitability evokes caution – individuals with IDD would likely struggle to understand this<br>Remove the word “excitable” and replace with a more concrete word<br>• Unclear what is meant by this word within the context of this item (i.e., happy vs. aggressive vs. unpredictable vs. too much energy)<br>Remove the word “one” and replace with a word pertaining to patients/prisoners/staff<br>• Uncommon and third person terminology<br>• Unclear who “one” pertains to (i.e., patients/prisoners/staff/all)<br>Remove the word “cautiously” and replace with a simpler, more familiar word or a behavioural example<br>• Difficult and abstract word |

| Item number | Hospital (a) and prison (b) versions of item | Adaptations required |
|---|---|---|
| 16. | (a) Staff know patients and their personal histories very well<br>(b) Staff know inmates and their personal histories very well | Remove the phrase "personal history" and replace with a more concrete phrase<br>• Confusing and vague phrase<br>• Individuals with IDD may relate this to their sexual history<br>Add the optional prefix of "do you think" to the start of the item<br>• To reduce the impact of theory of mind difficulties |
| 17. | (a) Both patients and staff are comfortable on this ward<br>(b) Both inmates and staff are comfortable in this unit | Consider amending this item and separating into two items<br>• Dual nature of the item ("both patients/inmates and staff")<br>• Or omit the word "both" as a way of simplifying the item<br>Amend the word "comfortable" to a simpler and more concrete word if possible<br>• Difficult word to understand and is open to interpretation (i.e., physical vs. emotional comfort) |

It is evident that adapting the EssenCES items for individuals with IDD will not be as straightforward as simply changing some of the words within the items. Many of the items will need to be completely rephrased to incorporate the suggestions above and to ensure that they are in line with relevant accessible information guidelines. Numerous suggestions were made by participants within Chapter 3 in relation to incorporating the adaptations detailed in Table 4D. Many participants proposed alternative ways of wording the items. However, rewording the items has the potential to be incredibly problematic. Firstly, it will be necessary to ensure that there is a clear and shared understanding of the intended meaning of each individual item. Secondly, consideration will need to be afforded as to how each item can be simplified. It is essential to bear in mind the need to avoid over-simplification as it has been identified within Chapter 3 that this could result in items on each of the EssenCES subscales becoming very similar in nature, with the potential that this could impact on inter-item correlations. It will be necessary to ensure that the revised items are understood by individuals with IDD. It will also be essential to enquire as to how individuals with IDD and staff interpret the meaning of the items to confirm that their original meanings have been retained. The views of specialists working in the area of social climate will also be required to confirm this.

Within the studies reported in Chapter 3, participants discussed their understanding of the meaning of the majority of the EssenCES items. It was evident that there was a shared understanding of the meaning across most items. There were, however, some notable exceptions. For example, Item 15 states “Some patients are so excitable that one deals very cautiously with them”. Participants were unclear as to the meaning of the terms “excitable” and “cautiously” within the context of this item, and were also unsure to whom the term “one” was intended to relate. Similarly, Item 10 states “Staff members take a lot of time to deal with patients”. Here, participants appeared somewhat unclear as to whether the phrase “a lot of time” was intended to be interpreted as a positive or negative attribute. The intended meaning of these items was, therefore, discussed with one of the project supervisors who was involved in validating the EssenCES (M. Tonkin, personal communication, November 19, 2020). This enabled confirmation of the meaning of these items and ensured that any adaptations to these items did not alter their meaning.

Following this, a document was developed which detailed all rewordings suggested by participants within Chapter 3 for each item, with a variety of individual words and terms relating to each item also being included (Appendix 15). This document was considered in conjunction with the rationale that participants in Chapter 3 provided for the adaptations that they proposed, along with the literature surrounding IDD and self-reporting, and recommendations made within accessible information guidelines.

Table 4E summarises the original EssenCES items and the revised items to be included in the EssenCES-IDD.

**Table 4E**

*Summary of Original EssenCES Items and the Revised Items to be Included in the EssenCES-IDD*

| Item number | Original item | | EssenCES-IDD item |
|---|---|---|---|
| | Hospital version | Prison version | |
| 1. | This ward has a homely atmosphere | This unit has a liveable atmosphere | Is this ward/wing a nice place to be? |
| 2. | The patients care for each other | The inmates care for each other | Do patients/prisoners care about each other? |
| 3. | Really threatening situations can occur here | Really threatening situations can occur here | Do scary things happen on the ward/wing? |
| 4. | On this ward, patients can openly talk to staff about all their problems | In this unit, inmates can openly talk to staff about all their problems | Can patients/prisoners talk to staff about all their problems? |
| 5. | Even the weakest patient finds support from his fellow patients | Even the weakest inmate finds support from his/her fellow inmates | Do patients/prisoners that are having a bad day get support from other patients/prisoners? |
| 6. | There are some really aggressive patients on this ward | There are some really aggressive inmates in this unit | Are there angry patients/prisoners on this ward/wing? |
| 7. | Staff take a personal interest in the progress of patients | Staff take a personal interest in the progress of inmates | Do staff care whether patients/prisoners are doing well? |
| 8. | Patients care about their fellow patients' problems | Inmates care about their fellow inmates' problems | Do patients/prisoners care about the problems of other patients/prisoners? |

| Item number | Original item | | EssenCES-IDD item |
|---|---|---|---|
| | Hospital version | Prison version | |
| 9. | Some patients are afraid of other patients | Some inmates are afraid of other inmates | Are some patients/prisoners scared of other patients/prisoners? |
| 10. | Staff members take a lot of time to deal with patients | Staff members take a lot of time to deal with inmates | Do staff spend a lot of time helping patients/prisoners? |
| 11. | When a patient has a genuine concern, he finds support from his fellow patients | When inmates have a genuine concern, they find support from their fellow inmates | Do patients/prisoners get support from other patients/prisoners when they are worried? |
| 12. | At times, members of staff are afraid of some of the patients | At times, members of staff feel threatened by some of the inmates | Are staff scared of some of the patients/prisoners? |
| 13. | Often, staff seem not to care if patients succeed or fail in treatment | Often, staff seem not to care if inmates succeed or fail in the daily routine / program | Do staff care about patients/prisoners getting better? |
| 14. | There is good peer support among patients | There is good peer support among inmates | Is there good support between patients/prisoners? |
| 15. | Some patients are so excitable that one deals very cautiously with them | Some inmates are so excitable that one deals very cautiously with them | Are some patients/prisoners so scary that you have to stay away from them? |
| 16. | Staff know patients and their personal histories very well | Staff know inmates and their personal histories very well | Do staff know patients/prisoners well? |
| 17. | Both patients and staff are comfortable on this ward | Both inmates and staff are comfortable in this unit | Are patients/prisoners and staff comfortable on this ward/wing? |

#### *4.2.5.4 Readability Statistics*

Various readability statistics exist. These all aim to assess linguistic complexity and to approximate the reading age of text. The Flesch reading ease score rates text on a 100-point scale, with a score of 100 indicating that the document is extremely simple, while a score of 0 indicates a document is much more complex. The Flesch-Kincaid grade level score rates text based on an American school grade level with, for example, a score of three indicating that a third-grade student could read the text, whilst a score of eight indicates that an eighth-grade student could read it.[4] Therefore, the lower the score, the easier it is to read the document. Both of these readability statistics are widely used to assess the readability of text within IDD and non-IDD settings (Buell, 2017).

The Flesch reading ease score and the Flesch-Kincaid grade level score were calculated for the items on the original versions of the EssenCES and the initial pilot versions of the EssenCES-IDD, with the results shown in Table 4F.

**Table 4F**

*Reading Ease Scores for the EssenCES and the Initial Pilot Versions of the EssenCES-IDD*

| Version | Original EssenCES | | EssenCES-IDD initial pilot version | |
|---|---|---|---|---|
| | Flesch reading ease score | Flesch-Kincaid grade level | Flesch reading ease score | Flesch-Kincaid grade level |
| Hospital version | 72.6 | 5.4 | 85.0 | 3.4 |
| Prison version | 69.1 | 6.0 | 73.6 | 5.0 |

*Note.* Higher Flesch reading ease scores and lower Flesch-Kincaid grade level scores indicate greater readability.

[4] American grade school levels: grade 1 = age 6-7, grade 2 = age 7-8, grade 3 = age 8-9, grade 4 = age 9-10, grade 5 = age 10-11, grade 6 = age 11-12, grade 7 = age 12-13, grade 8 = age 13-14, grade 9 = age 14-15, grade 10 = age 15-16, grade 12 = age 16-17, grade 12 = age 17-18.

The scores calculated for the initial pilot versions of the EssenCES-IDD are clearly higher for the Flesch reading ease and lower for the Flesch-Kincaid grade level than those for the original versions of the EssenCES. This indicates that initial pilot versions of the EssenCES-IDD are simpler to read that the original versions.

There is a small difference in the scores calculated for the hospital and prison versions of the EssenCES-IDD. This is the result of slight alterations in wording between the prison and hospital versions. The hospital version uses the terms patient and ward whereas the prison version uses the terms prisoner and wing. As highlighted by Buell (2017), readability scores are based solely on surface level linguistic features, using calculations of the relative number of words per sentence and the number of syllables in words. As such, the differences in readability scores are due to the inclusion of the term prisoner (three syllables) vs. patient (two syllables). However, given that this word will clearly be familiar to individuals with IDD within prison settings, it is unlikely that this would result in increased difficulty within this context.

#### *4.2.5.5 Scripted Rewording of EssenCES-IDD Items*

The use of scripted rewording of questionnaire items has been discussed in the literature (Finlay & Lyons, 2001; Hartley & Maclean, 2006). It has also been used in various formats by other authors when attempting to adapt social climate questionnaires for IDD populations (Neimeijer et al., 2018; Robinson & Craig, 2019). Chapter 3 highlighted the necessity of developing scripted rewordings for the EssenCES-IDD items. Participants acknowledged that this would enable administrators to utilise different words and phrases to support individuals to understand the meaning of the items. This would enable more consistent administration both within and across services and help to ensure validity of EssenCES-IDD data. Chapter 3 identified that the scripted rewordings should be developed in an accessible format which could be shared with individuals with IDD if required. Also, that they should be provided on a separate page incorporated within the administration pack (see Section 4.2.7). The scripted rewordings were developed based on the feedback gathered within Chapter 3 using a combination of participants' suggestions along with recommendations

made within the literature and within accessible information guidelines. Table 4G summarises the EssenCES-IDD items and the scripted rewordings.

**Table 4G**

*EssenCES-IDD Items and Scripted Rewording of Items*

| Item number | EssenCES-IDD item | Scripted rewording of EssenCES-IDD item |
|---|---|---|
| 1. | Is this ward/wing a nice place to be? | Do patients/prisoners like being on the ward/wing? |
| 2. | Do patients/prisoners care about each other? | Do patients/prisoners look out for each other? |
| 3. | Do scary things happen on the ward/wing? | Do patients/prisoners feel unsafe on the ward/wing? |
| 4. | Can patients/prisoners talk to staff about all their problems? | Do staff listen to patients/prisoners who have problems? |
| 5. | Do patients/prisoners that are having a bad day get support from other patients/prisoners? | If a patient/prisoner is having a bad day do other patients/prisoners help them? |
| 6. | Are there angry patients/prisoners on this ward/wing? | Do patients/prisoners get angry? |
| 7. | Do staff care whether patients/prisoners are doing well? | **Do you think** staff care whether patients/prisoners are doing well?<br>Do staff care if patients/prisoners are doing ok (in their treatment)?<br>**Do you think** staff care if patients/prisoners are doing ok (in their treatment)? |

| Item number | EssenCES-IDD item | Scripted rewording of EssenCES-IDD item |
|---|---|---|
| **Item number** | **EssenCES-IDD item** | **Item number** |
| 8. | Do patients/prisoners care about the problems of other patients/prisoners? | Do patients/prisoners talk to each other about their problems? |
| 9. | Are some patients/prisoners scared of other patients/prisoners? | Are some patients/prisoners scary? |
| 10. | Do staff spend a lot of time helping patients/prisoners? | Do staff spend a lot of time talking to patients/prisoners or doing activities with them? |
| 11. | Do patients/prisoners get support from other patients/prisoners when they are worried? | How helpful are other patients/prisoners when a patient/prisoner is upset? |
| 12. | Are staff scared of some of the patients/prisoners? | **Do you think** staff are scared of some of the patients/prisoners?<br>Do some of the patients/prisoners scare the staff?<br>**Do you think** some of the patients/prisoners scare the staff? |
| 13. | Do staff care about patients/prisoners getting better? | **Do you think** staff care about patients/prisoners getting better?<br>Are staff interested in patients/prisoners getting well?<br>**Do you think** staff are interested in patients/prisoners getting well? |

| Item number | EssenCES-IDD item | Scripted rewording of EssenCES-IDD item |
|---|---|---|
| 14. | Is there good support between patients/prisoners? | Do patients/prisoners help each other? |

| Item number | EssenCES-IDD item | Item number |
|---|---|---|
| 15. | Are some patients/prisoners so scary that you have to stay away from them? | Do patients/prisoners keep clear of scary/angry patients/prisoners? |
| 16. | Do staff know patients/prisoners well? | **Do you think** staff know patients/prisoners well?<br>Do staff know about patients/prisoners and their past?<br>**Do you think** staff know about patients/prisoners and their past? |
| 17. | Are patients/prisoners and staff comfortable on this ward/wing? | Are patients/prisoners and staff happy on this ward/wing?<br>Is everyone comfortable/happy on this ward/wing? |

### 4.2.6 Response Format

Chapter 3 highlighted that the response format of the EssenCES requires adapting for individuals with IDD. Suggestions made included simplifying the response option headings, amending the number of response options provided, and incorporating visual representations of the response options. Addition of an "I don't know" response option was also proposed, along with inclusion of comment boxes to enable provision of qualitative feedback, and feedback boxes for administrators to document the presence of any response biases.

#### *4.2.6.1 Number of Response Options*

The findings discussed within Chapter 3 highlighted that there was not a clear consensus regarding the most appropriate number of response options to provide within the EssenCES-IDD. There were both pros and cons for three, four, and five options. Accessible information guidelines do not appear to include recommendations regarding how many response options should be included within questionnaires for individuals with IDD. Recommendations cited within the literature also varied. Fang et al. (2011) and Sentell and Ratcliff-Baird (2003) provide support for the inclusion of fewer response options. However, Hartley and Maclean (2006) suggest that five response options can be used with IDD populations without causing a reduction in response rates. Many questionnaires specifically developed to measure different constructs for individuals with IDD utilise a three-point response scale (e.g., the CORE-LD30 and GAS-ID) or a four-point scale (e.g., the QVES). However, this does not necessarily mean that this would be appropriate for a social climate questionnaire. Barker et al. (2020) did not comment on the number of response options they included when validating their modified version of the EssenCES for a low secure IDD population. Neimeijer et al. (2018) included five response options in their adapted GCI for individuals with IDD. However, the authors do not explain their rationale for retention of the original five-point scale within their adapted questionnaire. It may be that they acknowledged that making any changes to the number of response options could result in the adapted questionnaire failing to capture important data, or for data to be incomparable with data gathered using the original questionnaire.

Despite EssenCES data no longer being a requirement within the CQUIN standards in the UK, many services do continue to use the EssenCES as a form of outcome monitoring. Comparability of data gathered using the EssenCES-IDD and the original EssenCES, therefore, would be useful. Furthermore, retention of the five-point scale would ensure that the questionnaire maintains the ability to capture in-depth data (which is more difficult to achieve using a three-point scale). Also, as the same version of the EssenCES-IDD will be used by individuals with IDD and staff, reduction in the number of response options provided would also preclude collection of this in-depth data from staff. As highlighted within Chapter 3, the appropriate number of response options provided within the EssenCES-IDD would also be dependent on the other adaptations made within the response format. Adaptations are going to be made to the response option headings and visual representations of these options are going to be provided. Consequently, it may be that these adaptations result in the response format being more accessible without there being a need to alter the number of response options. It is, therefore, proposed that the initial pilot version of the EssenCES-IDD should retain the five-point response scale. However, feedback from individuals with IDD will need to be sought as to their interpretation of the different response options. Their ability to discriminate between these different options will also require exploration.

#### *4.2.6.2 Wording of the Response Option Headings*

Chapter 3 drew attention to the wording of the response option headings, suggesting that simplification was required and that more familiar words should be used. This is supported by relevant literature and accessible information guidelines (Buell, 2017; Department of Health, 2010; Mencap, 2002). Simplifying the wording of these headings would aid comprehension and reduce the need for administrators to reword them in their own words. This would help to reduce potential administration bias. Chapter 3 identified that the EssenCES-IDD items should be phrased as questions as opposed to agreement statements, meaning it is important to ensure that the adapted response option headings fit this format. Other questionnaires developed for individuals with IDD use various response option headings. The terms “not at all”, “sometimes”, and “always/a lot” are used within the CORE-

LD30. Similarly, the terms “never”, “sometimes”, and “always” are used within the GAS-ID. The terms “not much of the time”, “some of the time”, and “a lot of the time” are used within the SIS. Those that have used five-point scales have incorporated response options such as varying from “not applicable” to “entirely applicable” (GCI adapted for IDD).

Suggestions as to how the response option headings for the EssenCES-IDD could be reworded included using “a bit” instead of “little”, “sometimes” instead of “somewhat”, and “a lot” instead of “quite a lot”. These were considered to be more familiar terms. The phrase “all the time” instead of “very much” was also suggested in order to aid differentiation between the final two response options. Of note, however, is that using the phrase “all the time” would substantially alter the meaning of this response option, and would likely impact upon the frequency of it being selected given its concrete nature. The phrase “nearly all the time” would be more appropriate as it would also enable improved differentiation between these two response options along with providing a slightly more open option. No alternatives were suggested for “not at all” which implies that this phrase is suitable. The response option headings that will be used within the initial pilot version of the EssenCES-IDD will, therefore, be “not at all”, “a bit”, “sometimes”, “a lot”, and “nearly all the time”.

#### *4.2.6.3 Inclusion of an “I Don’t Know” Response Option*

Chapter 3 highlighted the potential to include an additional response option of “I don’t know”. It was proposed that inclusion of this response option would enable individuals to indicate when they are unsure of their response to a question and would ensure they are aware it is permissible to be unsure of their response. Although the addition of this option would increase the number of response options to six; it was suggested that this addition would be beneficial as it would reduce the potential for individuals to select an option at random when they are unsure of their response. This would, therefore, result in increased validity of EssenCES-IDD data. Furthermore, this additional option has been used within the adapted version of the QVES for IDD and has also been suggested in the literature as a means of reducing acquiescence (Finlay & Lyons, 2001). The additional response option of “I don’t know” will, therefore, be included within the initial pilot version of the EssenCES-IDD.

There is, however, a risk that this option could be over-used; resulting in large amounts of missing data and an inability to calculate subscale scores. Further exploration of the inclusion of this option will be necessary to assess how often it is selected and to gain an understanding of reasons for selecting it.

#### *4.2.6.4 Visual Representations of the Response Options*

Chapter 3 indicated that visual representations of the response options should be provided using histogram style images. Inclusion of such images would be in line with accessible information guidelines and relevant research (e.g., Mencap, 2002; Sigelman & Budd, 1986). Many other successfully validated questionnaires for individuals with IDD have incorporated visual representations of the response options (e.g., the CORE-LD30 and GAS-ID), indicating that they can, indeed, be beneficial. Chapter 3 drew attention to some of the potential benefits of this being incorporated within the EssenCES-IDD. These benefits included supporting individuals to comprehend the written response option headings and providing an additional means of differentiating between these options. The histogram style visual representations have been incorporated within other questionnaires developed for individuals with IDD (e.g., the CORE-LD30). They were also used within Robinson's (2017) adapted version of the EssenCES for individuals with IDD, with the author suggesting that these images would be familiar to them.

Chapter 3 also indicated that incorporation of graded colour within the visual representations of response options would be beneficial; using a lighter shade of colour and gradually moving towards a stronger shade to depict the strength of response. It was considered that this would provide an additional visual means for individuals to differentiate between the response options. However, given that various adaptations to the response format are already being made, it was decided that the inclusion of colour will not be necessary at this stage. Feedback regarding the adapted response format should be gathered from individuals with IDD first and the option of adding colour should be discussed with them.

#### *4.2.6.5 Inclusion of Comment Boxes*

Chapter 3 indicated that the provision of comment boxes within the response format could be beneficial for individuals with IDD and staff. It was suggested that this would enable provision of qualitative feedback to evidence the reasons for their choice of responses. It would provide individuals with IDD who feel unable to select a response with an opportunity to offer relevant feedback, and it could provide increased processing time (i.e., whilst thinking about what to write in the open comments this might help the respondent to make a decision on how to respond via the Likert scale). On a service level, this qualitative feedback could enable a clearer understanding of the perceptions of individuals and staff. This, in turn, could help elicit beneficial service level changes. It was proposed that comment boxes should be optional as some individuals may struggle to complete them. Furthermore, the optional nature of the comment boxes would also be important for staff given the additional time it may take to complete them.

The majority of social climate questionnaires have solely gathered quantitative data (with the exception of the MQPL which contains a qualitative component). Furthermore, most self-report questionnaires developed for individuals with IDD do not provide opportunities for qualitative feedback. It is, therefore, not possible to establish whether this suggestion would be beneficial for individuals with IDD or whether it would enhance data gathered. However, Chapter 3 identified many potential benefits to the inclusion of comment boxes. Therefore, it would seem appropriate to trial their use within the initial pilot version of the EssenCES-IDD. This would enable exploration of whether and how the comment boxes are used by individuals and staff, and whether their optional nature is understood by individuals with IDD. It would also allow for discussions to take place surrounding the perceived benefits and repercussions of their inclusion. This is of particular importance given that inclusion of comment boxes will substantially increase the length of the questionnaire. This could impact on motivation to complete the EssenCES-IDD and could lead to reduced completion rates. Furthermore, there is the potential that, for individuals with IDD, any discussions surrounding their comments could result in the introduction of administration bias. This could reduce consistency of administration. Therefore, gaining feedback from individuals and staff surrounding the practicalities of including comment boxes is essential.

No suggestions were made within Chapter 3 as to how the comment boxes should be introduced within the EssenCES-IDD. It was, therefore, decided that a comment box should be provided for each item and that a brief question such as “Is there anything you would like to say about this?” would be sufficient to open up the opportunity for comments to be provided. The optional nature of the comment boxes will need to be made clear within the cover sheets.

Participants in Chapter 3 highlighted that there was the potential for individuals with IDD to provide biased responses. They enquired as to what mechanism would be used to prevent this, and whether responses that administrators considered to be inaccurate could be discarded. Clearly, it would not be appropriate to discard responses. However, including a feedback box where administrators can comment on their observations in terms of the accuracy of responses could be of benefit. Therefore, a feedback box for this will be included at the end of the version of the questionnaire for individuals with IDD.

The response format that will be used within the initial pilot version of the EssenCES-IDD can be found in Appendices 11-14.

### 4.2.7 Administration

Chapter 3 drew attention to the importance of considering how the EssenCES-IDD should be administered. Potential administration biases were also highlighted, with suggestions being made as to how the questionnaire could be administered to reduce such biases.

#### *4.2.7.1 Openness and Transparency*

Chapter 3 highlighted the necessity for individuals to be able to see a copy of the EssenCES-IDD and associated materials. This would promote transparency and openness, provide potential opportunities for learning, and reduce suspicion surrounding information that is not provided in a written format. However, despite the inclusive practice that this approach promotes, many questionnaires developed for individuals with IDD document that the

questions and/or response options are read out to individuals (in an interview-style format) but do not report that a copy was provided to them. It would, however, appear that provision of information in a written format is an essential component of ensuring accessibility of self-report questionnaires for individuals with IDD through reducing short-term memory demands (Kabzems, 1985). Whilst it is appreciated that many individuals may experience difficulties reading, the collaborative nature of providing support throughout completion of the EssenCES-IDD and providing copies of all information would promote equality and openness. This may, as suggested within Chapter 3, increase motivation to engage and encourage more honest responding. Therefore, copies of the EssenCES-IDD questionnaire, cover sheet, scripted rewordings of items, and large-scale response format will be developed in an accessible manner so that they can be shared with individuals. However, the views of individuals with IDD will need to be sought, as there is the potential that presentation of what could be considered a large amount of written information could appear overwhelming.

#### *4.2.7.2 Who Should Administer the EssenCES-IDD?*

Chapter 3 indicated that the EssenCES-IDD should be administered on an individual basis as this would enable provision of consistent, individualised, support throughout completion and reduce the need for individuals to actively request support. This approach has also been suggested by the author of the original EssenCES as a means of providing explanation, and assisting with rating, of the EssenCES items (Schalast, 2010). Use of an administrator would also enable assessment of individuals' understanding of the cover sheet, EssenCES-IDD questions, and response format. There was, however, considerable discussion surrounding identification of who would be best placed to administer the EssenCES-IDD. Some participants considered that it should be administered by a staff member from the ward or wing who knew the individual well and could ensure that tailored support was provided. This approach was utilised by Glennon and Sher (2018) who commented that use of a familiar staff member ensured that different levels of support could be provided based on individual needs. However, others commented on the necessity of enabling anonymity of responses and providing the opportunity for individuals to provide honest feedback so as to minimise socially desirable responding. This would mean that using a staff member who

worked on the ward or wing would likely not be appropriate. This point was also highlighted by Glennon and Sher (2018) who identified that their use of familiar staff may have influenced responses, particularly if individuals had a propensity to responding in a socially desirable manner. The EssenCES manual (Schalast & Tonkin, 2016) states that those completing the EssenCES must be provided with the opportunity to be honest about their perspectives of the ward or wing and that, if anonymity cannot be guaranteed, responses may not be valid. This clearly supports the viewpoint above.

There is no existing research that has considered who is best placed to administer social climate questionnaires within forensic IDD populations. Other self-report questionnaires developed for individuals with IDD have utilised a variety of different administrators (varying from familiar staff members to researchers) during validation. However, they have not commented on who should administer the questionnaire in practice. This is evidently an area warranting further attention. One must also consider the nature of social climate questionnaires and how they differ from self-report questionnaires exploring the perspectives of individuals with IDD surrounding constructs such as, for example, anxiety and general mood. Given that social climate questionnaires explore perspectives of the ward or wing, and often include items pertaining to perceptions of staff, the identification of who is best placed to administer such questionnaires is not straightforward. On a practical level, some IDD services may have access to external advocates with capacity to administer the questionnaire, whereas others may not. Individuals will likely have differing relationships with different members of staff. They may feel more able to discuss their perspectives openly with those with whom they feel they have a better relationship. Time implications also need to be considered given that Robinson and Craig (2019) reported allowing up to one hour for each individual to complete their adapted EssenCES. Weighing up the approach that would be feasible on a practical level alongside the need to provide appropriate support and the need for anonymity will evidently differ across services, and may even be different amongst individuals within a single ward or wing.

Neimeijer et al. (2018) used a student or an assistant researcher to administer the adapted GCI within their validation study. Similarly, Robinson and Craig (2019) used a researcher to collect their adapted EssenCES data. Barker et al. (2020) and Glennon and Sher (2018) took

a slightly different approach, using Assistant Psychologists to collect the data for their studies. One reason for this difference may be that Neimeijer et al. (2018) and Robinson and Craig (2019) were conducting research studies designed to assess the suitability of the adapted measures for IDD populations, whereas Glennon and Sher (2018) were conducting a service review and Barker et al. (2020) administered the questionnaires as a part of the service's clinical routine. Many studies that have examined the validity of self-report questionnaires for individuals with IDD have used researchers to administer the questionnaires. This could be somewhat problematic in terms of whether or not the researchers are able to provide an appropriate level of individualised support and also in terms of honest responding. Most of these questionnaires do not stipulate who should administer it if it is to be used for practical, as opposed to research, purposes. Again, this is an area that does not appear to have been afforded consideration within the IDD research. This is somewhat surprising given that a multitude of research has considered IDD and self-reporting. Much of this research highlights the various biases that can be increasingly prevalent in IDD populations, including administration biases.

The sparsity of the research in this area means, at present, it is impossible to identify who would be best placed to administer the EssenCES-IDD. The best that one can currently advise is that it should be administered on an individual basis. It must not be administered within a group setting nor should it be given to individuals with IDD to complete independently. The decision as to who should administer the questionnaire must rest with individual services and will likely depend on their available resources. However, one must strongly advise that services remain consistent with their choice of administrator. For example, they should not use a staff member that is known well by individuals to administer some of the questionnaires and an external, unfamiliar, staff member to administer others. This could result in a lack of consistency, introduce different administration biases, and affect the accuracy of the data gathered. It is likely that different services will, therefore, use individuals within differing job roles to administer the questionnaire. Whilst this may make comparison between services difficult, it should not impact upon comparisons across wards or wings within individual services nor on either longitudinal or cross-sectional monitoring (provided the method of administration remains consistent).

#### *4.2.7.3 Practice Items*

Chapter 3 indicated that practice items should not be included within the EssenCES-IDD. Participants stated that their inclusion would make the questionnaire appear too much like a test and may exclude individuals who take time to gain an understanding of the format of the questions and response format. Additionally, concerns were raised surrounding how administrators would inform individuals that, should they struggle with the practice items, they were unable to complete the questionnaire. Many other questionnaires developed for individuals with IDD do, however, use some form of practice items or pre-test screening (e.g., the CORE-LD30, GAS-ID, & MWLQ). This means that a decision not to include practice items would not be in line with the approach used within many IDD-specific questionnaires. The rationale for including practice items or pre-test screening appears, generally, to be as a means of supporting individuals' understanding of the response format and of reducing the potential for response biases to occur. However, one must also consider the administration of the EssenCES-IDD as a whole. As individual support will be present throughout completion, it is anticipated that administrators will be attuned to pick up on response biases and to establish whether individuals have understood the response format. It is considered that a compromise would be for a comment box to be provided for administrators to fill out following completion of the questionnaire. This would enable feedback on any observations of biased responding and their perception of the individuals' comprehension of the EssenCES-IDD items. However, this feedback must not result in any individuals' responses being excluded from the dataset and should only be used to aid understanding of individuals' responses (i.e., to explain discrepancies between an individual's quantitative and qualitative responses or to highlight possible reasons for outliers within ward or wing level quantitative data).

The original EssenCES utilises cut-off points to determine whether an individual has provided enough responses for each subscale. A minimum of four out of five responses is required for the subscale responses to be included within the ward or wing feedback (Schalast & Tonkin, 2016). In order to ensure consistency, this approach should also be utilised when examining data gathered using the EssenCES-IDD. This may mean that subscale scores cannot be calculated for some of the subscales for some individuals.

However, it is anticipated that the addition of comment boxes within the response format will still enable these individuals to express their views. It should be noted that this approach does not appear to have been utilised previously. Therefore, feedback from individuals with IDD and staff will need to be sought (and, potentially, subsequent follow up or validation studies will need to be used) to assess its suitability.

#### *4.2.7.4 Provision of Responses*

Chapter 3 indicated that a large-scale version of the response format should be provided within the administration pack. It was felt that this would prevent administrators from developing their own, individual, large-scale versions of the response format. These could differ and potentially impact upon the questionnaire's validity. It was considered that having a larger copy of the response format would help to increase retention of the response options and reduce demands on short-term memory. Also, the larger text and images would benefit those who are short sighted or dyslexic. This approach has been used within other IDD-specific questionnaires (e.g., the CORE-LD30). It was also suggested by Chester et al. (2015) as a potential adaptation that could be incorporated within the EssenCES for individuals with IDD.

Some questionnaires for individuals with IDD also incorporate cards depicting each individual response option (e.g., the MWLQ). However, this was not considered to be appropriate. If used, this approach would enable administrators to remove some of the cards as a way of simplifying the response format. This would impact upon the validity of responses. Consequently, cards will not be provided nor advocated.

Individuals with IDD should be provided with a choice as to how they communicate their chosen response options and should be encouraged to tick the corresponding box on the questionnaire themselves where possible. This encourages individuals to take ownership of their completion of the EssenCES-IDD, as described within Chapter 3.

#### *4.2.7.5 Administration Guidelines*

There is a variety of information which needs to be clearly provided to those administering the EssenCES-IDD. This is essential to ensure consistent administration both within and across services. Findings from Chapter 3 drew attention to the potential to develop written administration guidelines for the EssenCES-IDD in order to ensure that information is provided in a comprehensive and accessible manner. It was suggested that these guidelines should be placed within a pack which would also include the scripted rewording of items and the large-scale version of the response format (see Appendix 16).

Most questionnaires developed for individuals with IDD and, indeed, most questionnaires in general, provide limited guidance regarding administration. Often questionnaires are straightforward and the process of completion can be considered self-explanatory. However, for individuals with IDD, and for questionnaires that are being administered as opposed to completed independently, it appears that the provision of guidelines for completion is a necessity. The initial pilot version of the administration guidelines for the EssenCES-IDD can be found in Appendix 16. These guidelines will need to be discussed with staff working within IDD settings to ascertain whether they perceive that all necessary information is included.

### 4.2.8 Summary

Table 4H summarises the adaptations that will be made to the EssenCES in order to develop the initial pilot version of the EssenCES-IDD. These initial pilot questionnaires (hospital and prison versions for individuals with IDD and staff) can be found in Appendices 11-14.

**Table 4H**

*Summary of Adaptations – Development of the EssenCES-IDD*

<table>
<tr><td>Layout<br>Arial size 14+ font must be used.<br>Split the questionnaire across multiple pages.</td><td rowspan="3">Linguistic Content<br>Use the terms “patient” and “ward” for the patient version, and “prisoner” and “wing” for the prison version.<br>Rephrase items as questions.<br>Shorten sentences.<br>Use simple punctuation.<br>Remove complex words.<br>Simplify complex concepts where possible.<br>Remove qualifying words.<br>Ensure only one question is asked per item.<br>Remove negative wording of items but retain negative concepts.<br>Retain wording of items in the third person, but enable addition of the prefix “do you think” for items enquiring as to the perceptions of staff.<br>Do not add pictorial aids.</td></tr>
<tr><td>Cover Sheets<br>Provide cover sheets for staff and for individuals with IDD.</td></tr>
<tr><td>Time-Frame<br>Provide a one-week time-frame.<br>Include anchor events.</td></tr>
<tr><td>Response Format<br>Retain the five-point response scale.<br>Include an additional response option of “I don’t know”.<br>Simplify response option headings.<br>Provide visual representations of the response options using histogram style images.<br>Provide optional comment boxes within the response format.<br>Add a feedback box for administrators to document the presence of any response biases.</td><td>Administration<br>Individuals with IDD must be able to see the questionnaire and associated information.<br>The questionnaire should be administered on an individual basis.<br>There is not enough evidence to make suggestions as to who is best placed to administer the questionnaire.<br>Practice items should not be included.<br>Use Schalast’s cut-off points to determine whether sub-scale scores can be calculated.<br>Provide scripted rewording of the items on a separate page.<br>Provide an administration pack.</td></tr>
</table>

## 4.3 Conclusions

This chapter discussed the adaptations that are currently proposed to improve the accessibility of the EssenCES for individuals with IDD. Findings of Chapter 3 were discussed, and relevant literature and accessible information guidelines were considered, to ensure that there was a clear rationale for the adaptations proposed. It was also of importance to ensure that the constructs underlying the three EssenCES subscales were retained, and that the adaptations made did not result in individual EssenCES items diverting from their intended meaning as this would result in loss of construct validity and alter the data gathered by the EssenCES-IDD. Within Chapter 3, many participants demonstrated an awareness of the EssenCES subscales, and the constructs which underpin these subscales, and as such were keen to make suggestions for adaptations that they perceived were in keeping with the meanings of the original items. Within the current chapter, the researcher carefully considered the adaptations suggested by participants within Chapter 3 for each individual item to ensure that they were confident that the adapted items retained the meanings of the original items.

The majority of adaptations that were made are supported by a clear evidence base. However, research within certain areas was found to be considerably lacking. This resulted in a small number of adaptations being solely based on the findings of Chapter 3 and, on rare occasions, the inability to propose anything suitable (e.g., by whom the EssenCES-IDD should be administered). These issues resulted in a degree of difficulty in ascertaining the most appropriate way of adapting some aspects of the questionnaire. Furthermore, it is overwhelmingly evident that there is no “right way” to adapt the EssenCES for individuals with IDD. The initial pilot version can, therefore, only be viewed as the most appropriate version of the EssenCES-IDD given the information gathered so far.

It is important to note that the views of individuals with IDD have not yet been sought. It is possible that their views could differ from those expressed by staff within Chapter 3. Consequently, some of the proposed adaptations may need to be amended based on their feedback. It is possible that the decision not to include the views of individuals with IDD at this stage may have led to certain difficulties or adaptations being overlooked. It will,

therefore, be necessary to gain feedback on the initial pilot version of the EssenCES-IDD from both individuals with IDD and staff. This will establish whether any further changes are required. Involvement of Speech and Language Therapy would be of benefit with regards to providing further, specialist feedback regarding the linguistic content. Input from professionals in the field of social climate, who are well-versed with the EssenCES, will also be essential in order to confirm whether the meaning of the original items has been retained within the revised items on the EssenCES-IDD. Chapter 5 describes research that sought the views of these important stakeholders.

# Chapter 5: Gathering Feedback on the Initial Pilot Version of the EssenCES-IDD: Perspectives of Individuals with IDD and Professionals

## 5.1 Introduction

Individuals with IDD can encounter difficulties when completing self-report questionnaires (see Section 2.3 for a summary of difficulties that may be experienced when completing the EssenCES). Chapter 3 explored these difficulties in depth and also considered suggestions made by staff working across international forensic IDD settings regarding how the EssenCES could be adapted to improve its suitability for the IDD population. Chapter 4 considered these proposed adaptations in conjunction with relevant literature and accessible information guidelines. Following this, an initial pilot version of the EssenCES for individuals with IDD (the EssenCES-IDD) was developed.

This chapter explores the perspectives of both individuals with IDD residing in forensic settings and staff working in these settings regarding the initial pilot version of the EssenCES-IDD. An opportunity to complete the initial pilot version of the EssenCES-IDD was provided. Following this, interviews and focus groups sought to gather data surrounding any further adaptations that may be required. Input from Speech and Language Therapy was sought to provide specific feedback regarding the linguistic content. Input from social climate experts was also obtained to ensure that the EssenCES-IDD items retained their original meanings.

Previous studies that have explored the suitability of the EssenCES for IDD populations (Barker et al., 2020; Chester et al., 2015; Robinson & Craig, 2019) have only sought feedback from staff members or professionals. Thus, the views of individuals with IDD have not been obtained within any research conducted in this area to date. Furthermore, these studies did not include input from social climate experts. Therefore, the study reported here provided the opportunity to compile data from a broader range of individuals. It was envisaged that this would ensure that the updated pilot version of the EssenCES-IDD is suitable for the IDD population, conforms with accessible information guidelines, and retains the meaning of the items included in the original EssenCES.

## 5.2 Aims of the Current Chapter

This chapter reports on one study which aimed to explore the suitability of the initial pilot version of the EssenCES-IDD and to establish whether any further amendments were required. The study sought feedback from individuals with IDD and from staff working in forensic IDD settings. It also drew upon the expertise of a Speech and Language Therapist and experts in the area of social climate. The different constructs that are covered within the EssenCES (experienced safety, therapeutic hold/hold and support, and patient/inmate cohesion) were also explored with individuals with IDD, allowing for initial consideration of how individuals with IDD interpret these constructs.

## 5.3 Methodology

### 5.3.1 Participants

#### *5.3.1.1 Sample 1*

A short, initial briefing was undertaken with individuals with IDD in a group setting on one UK prison wing for male individuals with IDD. This enabled the researcher to explain the study to potential participants and provided an opportunity for them to ask questions. Following this, potential participants were provided with an accessible version of the information sheet (Appendix 17) and given a period of two weeks to decide whether to volunteer to participate. Wing staff were asked to confirm that all individuals with IDD who had volunteered fulfilled the inclusion criteria. This included: 1) capacity to consent to participation and 2) diagnosis of IDD, borderline IDD (IQ < 80), and/or autism. Furthermore, at the time of participation, wing staff were also asked to confirm that participants were not presenting with a high level of risk. This resulted in a sample of six individuals with IDD who participated in the study.

#### *5.3.1.2 Sample 2*

A copy of the participant information sheet (Appendix 18) was shared, by the wing Psychologist, with staff on one UK prison wing for individuals with IDD. Potential

participants were given a period of two weeks to decide whether to volunteer to participate. This resulted in a sample of seven staff members who participated in the study. All participants had direct clinical contact with forensic IDD residents. Thus, it was expected that participants had an understanding of the cognitive difficulties experienced by such individuals. Some familiarity with the EssenCES was considered advantageous, but not a necessity. Staff who did not have regular clinical contact with forensic IDD individuals, or who did not feel able to comment on the cognitive difficulties experienced by them, were not included.

#### *5.3.1.3 Sample 3*

The researcher approached one Speech and Language Therapist who had recently conducted PhD research exploring the development of accessible information for individuals with IDD and who, therefore, was considered to possess expertise in the development of accessible information for individuals with IDD. The researcher also approached two social climate experts, both of whom had published a number of journal articles exploring forensic social climate and examining the EssenCES questionnaire. These experts, therefore, possessed considerable insight into the concept of social climate and understood the purpose and nature of the EssenCES questionnaire, including the constructs underpinning the EssenCES and the meaning of the individual EssenCES items. A summary of the study was shared with potential participants and they were asked to confirm whether they would like to participate in the study. All agreed to participate.

### 5.3.2 Materials and Measures

#### *5.3.2.1 Sample 1*

Patient/prisoner interview schedule: This utilised a semi-structured approach and was developed in an accessible manner specifically for individuals with IDD. It introduced key topic areas relating to individuals' experience of completing the EssenCES-IDD. This included discussion surrounding their understanding of the items contained in the EssenCES-IDD and the response format, and their opinions regarding the presentation of the EssenCES-IDD and

how it was administered. Preliminary exploration of their understanding of the constructs underpinning social climate was also undertaken. A copy of the interview schedule can be found in Appendix 19.

The initial pilot version of the EssenCES-IDD (prison version - prisoners): As described in Chapter 4 (see Appendix 12).

#### *5.3.2.2 Sample 2*

Focus group schedule: This utilised a semi-structured approach and introduced broad topic areas for discussion. These included experience of completing the EssenCES-IDD, opinions of the appropriateness of the EssenCES-IDD for individuals with IDD and for staff, and identification of further amendments that may be necessary. A copy of the focus group schedule can be found in Appendix 20.

The initial pilot version of the EssenCES-IDD (individuals with IDD and staff – prison version) and administration pack: As described in Chapter 4 (see Appendices 12, 14, and 16).

#### *5.3.2.3 Sample 3*

The initial pilot version of the EssenCES-IDD and administration pack: As described in Chapter 4 (see Appendices 11-14 and 16).

### 5.3.3 Procedure

#### *5.3.3.1 Sample 1*

Participants were provided with the accessible version of the information sheet (Appendix 17) and consent form (Appendix 21). The researcher explained the information sheet to them and consent forms were completed with support from the researcher. This ensured that understanding, and therefore consent, was voluntary and fully informed.

The EssenCES-IDD was administered by the researcher on an individual basis, with administration guidelines followed throughout. Follow-up interviews were conducted immediately following completion. This process lasted approximately 45 minutes per participant.

#### *5.3.3.2 Sample 2*

A focus group was used to provide an opportunity to gather more detailed perspectives regarding the suitability of the EssenCES-IDD and further amendments that may be required. The group nature of this approach also enabled participants to challenge one another's suggestions and to work towards developing a shared opinion regarding further amendments. This approach was also utilised successfully within one of the studies included in Chapter 3.

Information sheets (Appendix 18) were provided to participants in advance of the focus group. Consent forms (Appendix 22) were provided and completed immediately prior to the focus group. Participants completed the initial pilot version of the EssenCES-IDD for staff. Following completion, participants were provided with a copy of the EssenCES-IDD for individuals with IDD (due to small differences between the staff and patient/prisoner cover sheets) along with a copy of the administration pack. The semi-structured focus group schedule was then used to guide discussions surrounding the initial pilot version of the EssenCES-IDD.

The focus group lasted approximately one hour and was held at the relevant establishment to facilitate ease of access. The room used was on the prison wing to enable more staff members to attend. However, the door was closed and disruptions were minimised. The focus group was recorded using a Dictaphone.

#### *5.3.3.3 Sample 3*

Participants were sent copies of the initial pilot versions of the EssenCES-IDD and administration pack via email. The researcher explained the purpose of the study and all participants provided written consent. Social climate experts were asked to provide free-text feedback via email regarding the EssenCES-IDD items and whether they considered the items retained the meaning of those on the original EssenCES. The Speech and Language Therapy expert was asked to provide free-text feedback via email regarding the accessibility of the EssenCES-IDD for the IDD population. All participants were also encouraged to provide any additional, relevant, feedback regarding the questionnaire, scripted rewordings, cover sheet, and administration guidelines.

## 5.4 Analysis

The audio-recordings of the focus group and interviews were downloaded onto the researcher's computer and transcribed verbatim into Word documents with pseudonyms used to ensure confidentiality. Thematic analysis was used to describe and interpret data gathered, following the six-phase analysis process described by Braun and Clarke (2006).

It is important to note that analysis of the completed EssenCES-IDD questionnaires was not undertaken. Completion of the EssenCES-IDD was solely for the purpose of providing staff and individuals with IDD with an opportunity to trial the questionnaire prior to engaging in the focus group or interviews.

## 5.5 Ethical Considerations

Ethical approval was granted by Birmingham City University's Business, Law and Social Sciences Ethics Committee prior to the study being conducted (Appendix 23). Additional approval was granted by The National Offender Management Service. It was agreed that a summary report detailing the main findings of the study would be sent to the organisation involved for dissemination to staff participants. A separate, easy-read summary would be provided for participating individuals with IDD.

Individuals with IDD have been described as a marginalised and vulnerable group in relation to research activity (Emerson et al., 2013). It was, therefore, necessary to ensure that the procedural elements of this study reflected this. The staff focus group was used to ensure that the abilities and difficulties of individuals with IDD were explored, through knowledgeable staff participants, in an ethically sound and meaningful way. Completion of the EssenCES-IDD by individuals with IDD was conducted in line with the administration guidelines described in Chapter 4. Individual support was provided throughout completion; however, a staff member was also present to conform with the organisational safety policies. The flexible nature of the interview schedule enabled the researcher to rephrase questions where required and allowed various aspects of the EssenCES-IDD to be explored as they came up within the discussion.

Informed consent from all participants was recorded in writing. The interviews and focus group did not include any topics of a sensitive nature and all participants were reminded beforehand that they were not to refer to any residents by name. Data remained anonymous and was kept in a secure manner to ensure no individuals other than the researcher and their supervisors had access. No identifiable participant information has been included in the dissemination of research findings.

## 5.6 Results

A summary of the amendments suggested by participants is provided in Table 5A. Suggestions were grouped by the over-arching theme to which they relate. Six over-arching themes were identified. This includes the four themes identified within Chapter 3. The time-frame and cover sheet were added as separate themes as it was evident that these areas required further, individual, consideration.

**Table 5A**

*Summary of Suggested Amendments to the EssenCES-IDD*

| **Layout** | **Time-Frame** |
|---|---|
| Update the administration guidelines to include the suggestion that coloured overlays are provided if required for individuals with dyslexia.<br><br>Inform administrators that they can provide large, single, sheets that include only the wording for each individual question in a larger font. | The one-week time-frame is not appropriate. Further consideration regarding the inclusion of a time-frame, and its duration, is needed. |
| **Cover Sheets** | **Linguistic Content** |
| Include a statement on the cover sheet to ensure that that it is clear that the cover sheet is intended to be read by the individual with IDD where possible.<br><br>A statement requesting all questions are answered needs to be added for both staff and individuals with IDD.<br><br>A statement that informs individuals with IDD that there is no time limit for completion needs to be added to the cover sheet for individuals with IDD.<br><br>Remove the statement "We are asking these questions because we want to find out what it is like to be on the wing and if there are any changes we can make that will help to improve the wing for both prisoners and staff" and replace this with "We are asking these questions to help us think about how the ward/wing can be improved".<br><br>Include a brief statement at the end of the questionnaire which directs individuals with IDD to speak to staff if they have any concerns after completion. | Include the prefix of "do you think" within all questions pertaining to individuals' perception of the views of staff.<br><br>Consider removing Questions 1 and 17 (the unscored questions).<br><br>Consider whether to remove the scripted rewordings.<br><br>Reword Question 2 to state "Do patients/prisoners *show* care for each other?"<br><br>Replace the word "scary" with "threatening" in Question 3.<br><br>Reword Question 4 to state "Are patients/prisoners able to talk to staff about their problems?"<br><br>Replace the word "angry" with "aggressive" in Question 6.<br><br>Swap Questions 7 and 13.<br><br>Further consideration is required regarding the terminology used in Questions 13 and 15.<br><br>Further consideration is required regarding the cohesion of the questions and response format. |

| Response Format | Administration |
| --- | --- |
| Add answer boxes.<br>Include graded colour within the visual representations of the response options.<br>Reword the statement pertaining to the optional nature of the comment boxes on the staff cover sheet to state “We would welcome your feedback but you may choose to leave the comment boxes blank”.<br>Make it clear on the cover sheet for individuals with IDD that the comment boxes are optional. Also state that administrators can write comments down on behalf of patients/prisoners if needed. | Make minor modifications to the administration guidelines (simplify some of the language, shorten sentences and change the word order in some places). |

### 5.6.1 Theme 1: Layout

Feedback from individuals with IDD and staff indicated that the amendments made to the layout of the EssenCES were beneficial, and that the EssenCES-IDD was presented in a much more accessible format. Both individuals with IDD and staff found the layout appropriate and did not consider that splitting the questionnaire over multiple pages made it appear overly long. Staff commented on the potential to present the questionnaire as double sided. They considered this would be appropriate, providing administrators pointed this out to individuals in order to ensure that questions on the back pages were not missed. Individuals with IDD commented on the inclusion of two questions per page. For example, one individual stated “it might look a bit overwhelming but it’s not when you open it and see there’s only two questions to a page” (Interview 3). This demonstrates that they considered this was a suitable way of presenting the questionnaire.

Individuals with IDD also commented on the way in which the pages were presented. They commented that the layout of the individual questions was appropriate and that the comment boxes were of an appropriate size. One individual also noted that the use of a solid line to differentiate between the two questions on each page was beneficial, stating

“you got different questions … you got the box you know. No that, that’s perfect … you got the line going across to say that’s Question 1, Question 2” (Interview 1).

Chapters 3 and 4 drew attention to the font size used on the EssenCES and how a larger font size would improve accessibility. The font size was, therefore, increased to a minimum of size 14. Individuals with IDD voiced feeling content with this. Through observation by the researcher conducting the interviews, it was evident that they were able to read the information on the cover sheet, the questions, and the response format headings without excessive difficulty. The exception to this was one individual with dyslexia who struggled to read any of the information provided. This highlights the need for administrators to clearly communicate the information to individuals who are unable to read it themselves and for this to be included within the administration guidelines.

One individual with IDD suggested that it could be beneficial to also allow use of single pages which include only the wording for each individual question in a larger font. They thought this could help individuals who struggle to read or who require an even larger font size to be able to read (Interview 2).

### 5.6.2 Theme 2: Time-Frame

Chapters 3 and 4 highlighted the necessity of providing a concrete time-frame to which the EssenCES items pertain. Staff and individuals with IDD were informed by the cover sheet that the EssenCES-IDD questions pertained to the previous week. Individuals with IDD were supported by the researcher to identify an anchor event and were asked to answer the questions in relation to the one-week time-period since this event.

All individuals with IDD were eventually able to identify an anchor event with support from the researcher. However, difficulties arose because some individuals struggled to recall what happened one week earlier and some identified a negative event as their anchor (e.g., a situation where they had become angry). This would have the potential to provide a negative framework for the time-frame. Staff also drew attention to the use of an anchor event. They commented that the event identified as the anchor could also be considered to

be an “example” in relation to answering the questions which could bias individuals’ responses.

Both staff and individuals with IDD commented that they had difficulties remaining within the one-week time-frame when answering the questions. One staff member noted that they had forgotten about the time-frame when answering some of the questions (Focus Group Participant 3), whilst another staff member commented that some of the questions (e.g., “Is this wing a nice place to be?” [Question 1]) do not draw respondents towards focusing solely on the last week (Focus Group Participant 7). Some individuals with IDD also commented that they had answered the questions more generally as opposed to utilising the one-week time-frame. Clearly this would impact upon their responses and render the data less accurate.

Both staff and individuals with IDD also commented on the choice of time-frame. Nearly all participants considered the one-week time-frame too short. The majority of individuals with IDD stated that they thought this time-frame was restrictive in nature, and that this would not enable the provision of an accurate reflection of the environment of the wing:

> You can’t restrict them to a week, erm, you know because everything can be fine and dandy for a week, it can be fine and dandy for a month. I’ve been here four years - I’ve seen everything come and go you know what I mean … so you gotta take the rough with the smooth and that’s where you’re gonna get your experiences. (Interview 2)

Staff were keen to stress that their service only utilises the EssenCES twice a year. Thus, restricting the time-frame to the last week would mean that the data gathered was not necessarily reflective of the environment of the wing in general. One staff member commented that this could become more apparent if the one-week time-period prior to completion of the EssenCES-IDD had been “difficult” (Focus Group Participant 7). Staff expressed how quickly the environment of a ward or wing can change, again highlighting how the use of a one-week time-frame would likely fail to capture these differences:

> You could have a week where none of the prisoners seem to be supporting each other, where staff are at, you know, are at each other's throats, and then you could have another week where there's incredibly pro-social, pro-therapeutic things going on and you, you, you, you know, you're sort of in tears at how concerned prisoners are for each other and staff are getting along really well and … so in terms of if you're just representing a week, where d'you go with that week? (Focus Group Participant 5)

This staff member queried the purpose of the EssenCES-IDD, questioning how the data would be used by services to assess the social climate of the ward or unit in light of the dynamic nature of social climate. Clearly this is an important point; if data pertained solely to the previous one-week time-period, it would be necessary to consider what conclusions could be drawn about the social climate of the ward or wing over a longer time-period. Thus, it may provide a less reliable estimate of social climate. However, it should be noted that the EssenCES was developed with the intention of providing a snapshot view of the social climate of a ward or wing, not with the intention of a single administration being used to measure social climate in a long-term manner.

Staff also commented that the one-week time-frame could have the potential to lead to suspicion amongst individuals with IDD. For example, one staff member considered that individuals with IDD may express opinions such as "oh so they want to ignore all the bad stuff that happened two weeks ago" (Focus Group Participant 4). Staff felt that this could have a negative impact upon their motivation to complete the questionnaire. This could also apply to staff completion.

Individuals with IDD discussed finding the one-week time-frame too short to allow them to think of examples of situations to which the questions pertained. One individual explained why they had used a longer time-frame when answering the questions, stating "it's been quite, erm, relaxed over the last week you know … so I, I was going back further you know what I mean … because if things don't happen in that week then there's nothing to discuss" (Interview 1). It is evident that this individual utilised a longer time-frame in order to provide examples of situations that had occurred which related to the questions. This individual also

suggested that the “I don’t know” response option would not be relevant if the duration of the time-frame was increased. They stated “if they go back that far they’ll think of an incident like I did you know” (Interview 1). Another individual with IDD considered that the “not at all” response option would not be necessary if the time-frame was increased (Interview 2).

It is apparent that individuals with IDD were keen to think of examples of situations that had occurred when answering the questions. However, the purpose of the questionnaire is not to encourage individuals to think of situations that enable them to answer “yes” to every question, but for them to provide a response based on what has or has not occurred in the given time-frame. Individuals appeared keen for situations that occurred more than one week earlier to be included within their responses. This highlights the importance of these situations and the necessity of ensuring they can be reflected within their responses.

Staff briefly discussed alternative options for the time-frame and stated that using the phrase “at the moment” may be more appropriate. It is unclear exactly what time period they intended this phrase to relate to, although they did comment that a longer time-frame would be less restrictive. Individuals with IDD clearly expressed that a longer time-frame would be beneficial and provided a variety of justifications for this, most of which centred around enabling a more reflective portrayal of social climate. For example, one individual commented that a longer time period would enable “a better sense of what the community’s about rather than just the last week” (Interview 3). All individuals with IDD reported a preference for a time-frame of between one and three months. They considered they would be able to recall situations that had occurred over this time-frame.

It is evident that staff and individuals with IDD did not perceive the one-week time-frame to be appropriate. Thus, further consideration will be required.

### 5.6.3 Theme 3: Cover Sheets

Individuals with IDD and staff provided generally positive feedback on the initial pilot versions of the cover sheets, noting that they contained the necessary information.

Individuals with IDD commented that their cover sheet was presented appropriately; using short sentences, familiar words, and straightforward concepts. They made some suggestions for minor amendments, such as specifying that there is not a time limit for completing the questionnaire to ensure that individuals do not feel rushed. One social climate expert commented that it is unclear whether the cover sheet is intended to be read by the individual with IDD or read out to them by the administrator. They suggested including a statement on the cover sheet to ensure that this is clear (Social Climate Expert 1).

Staff highlighted that the initial pilot versions of both cover sheets do not explicitly state that individuals should complete all questions. They suggested including the phrase "please answer all the questions" on both cover sheets to ensure that this point is made clear. Staff also drew attention to the statement on the cover sheet which describes how the EssenCES-IDD data will be used. They highlighted that change can be an unsettling experience for individuals with IDD and advised removal of this word. They suggested using the phrase "we are asking these questions to help us think about how the ward/wing can be improved". This does not imply that changes will be made, although does acknowledge that there is the potential for feedback to lead to improvements on the ward or wing.

Staff acknowledged that, whilst the EssenCES-IDD does not contain any contentious questions, some draw upon concepts such as anger and fear. This may mean that there is the potential that completion of the questionnaire could bring up concerns or memories of difficult events for individuals with IDD. The questions on the EssenCES-IDD cover identical concepts to those included on the original EssenCES (which has been deemed appropriate for use in forensic settings). However, there is the potential that individuals with IDD could be more vulnerable in this respect than non-IDD individuals. The inclusion of a brief statement at the end of the questionnaire which directs individuals to speak to staff if they have any concerns after completing the questionnaire could be a way of acknowledging this, whilst also ensuring individuals feel fully supported both during and after completion.

### 5.6.4 Theme 4: Linguistic Content

#### *5.6.4.1 Sub-Theme 1: Theory of Mind*

Individuals with IDD were asked specifically about their experience of understanding and responding to questions which required them to comment on the views of others, in particular the views of staff. All stated that they found this type of question difficult. This issue was also raised within the study conducted by Chester et al. (2015) and by Barker et al. (2020).

When administering the questionnaire with individuals with IDD, the researcher noted that individuals initially struggled to answer the questions pertaining to the views of staff, often stating "I don't know" as their response. The scripted rewordings for these questions (adding the prefix "do you think") were required by all individuals on some occasions. All individuals were able to provide a response to these questions once this prefix was added. This suggests that the addition of this prefix is beneficial.

To further explore the reasons why individuals with IDD find this type of question difficult, the researcher asked how they arrived at their answers. All individuals were able to provide clear explanations regarding the processes they had gone through. This tended to involve observation of physical or behavioural signs that may indicate how someone else is feeling, or the use of logical reasoning to ascertain information which they perceived staff would know. For example, when discussing Question 16 ("Do staff know prisoners well?"), one individual demonstrated how they had thought through their response:

> The only solution I come up with is they are probably done their, erm … background check on us and, err, know about their things, their crimes, their things like that, you know, so … yeah. Coz that's how they … get to know about it, you know. (Interview 1)

Another individual commented on how the presence of physical signs can give an indication of how someone else may be feeling. They stated "I think you can tell with like the body language innit, if someone's scared of someone" (Interview 3). When asked whether prisoners would know whether staff were scared, one individual commented on the presence of behavioural markers. They stated "I think probably, maybe cuz they would

probably avoid 'em in a way" (Interview 5). Other individuals provided examples of how they had been able to consider how they may have felt in a particular situation, and how they were able to utilise this to gauge how staff may feel in a similar situation.

When asked directly what the difference was when the prefix of "do you think" was added to these questions, one individual provided a clear explanation as to how this addition changed the meaning of the questions for them. They stated "If it was 'Do you think…?' then that's directed at you, so you're asking me a question then to answer, right? So that's directed at me … where 'Are staff scared?'. Well, I can't answer for them" (Interview 6). This provides clear evidence to support the rationale for the inclusion of this prefix as detailed in Chapters 3 and 4. However, consideration needs to be afforded to whether the prefix of "do you think" should remain within the scripted rewordings, or whether it should be added into the questionnaire 'as standard'.

Chapter 3 identified that individuals with IDD may also struggle to respond to questions that enquire about the views of the patient or prisoner group as a whole. Whether individuals would include themselves within the collective group of patients or prisoners, or whether they would only answer on behalf of themselves as opposed to on behalf of the group as a collective, was also raised. When asked directly about questions pertaining to the views of prisoners, one individual expressed that they would be able to comment on the views of the prisoner group, despite feeling unable to comment on the views of staff. They explained their rationale for this in terms of prisoners spending more time together and, therefore, having a better knowledge of other prisoners than of staff (Interview 5). Another individual stated that they interpreted the term prisoners as meaning "the majority of everyone" (the majority of the group of prisoners; Interview 4). They stated that they had been able to think about the views of the group when providing their responses. However, they also acknowledged some difficulties that they had experienced when doing this:

> I've got support … I've experienced support and I think others do experience support, but you can't say "yes all the time" because you don't know what's going on for others on the wing. You don't know whether them others are getting support, so it's not fair for you to answer for … others on the wing [laugh]. It wouldn't be fair for me

> to answer “all the time” when I don’t see it all the time. It wouldn’t be right. (Interview 4)

This individual was able to justify their response choices. However, they drew attention to how they felt unable to select a stronger response choice due to their lack of knowledge regarding the support provided to other prisoners. In addition to demonstrating that some individuals with IDD are able to comment on the views of other prisoners within this capacity, this also highlights the potential for the strength of an individual’s response to be reduced when merged within their view of the perspective of the group as a whole.

In summary, individuals did encounter some difficulties with questions that required them to comment on the views of staff and other prisoners. However, they were all able to provide answers to this type of question (sometimes using the scripted rewordings when questions referred to staff views). They were all able to justify how they had selected their responses which shows their responses are likely to be valid. Thus, it appears appropriate to continue to include questions which relate to the views of the patient or prisoner group as a whole and the views of staff. However, as mentioned earlier, adding the prefix of “do you think” to questions pertaining to the views of staff may help to clarify that these questions pertain to *their perspective* of the views of staff. One must consider, however, that the individuals who participated in this study may not be reflective of the forensic IDD population as a whole. It is possible that those with more profound difficulties may experience more difficulty with this type of question. This would need to be examined within any future validation studies.

#### *5.6.4.2 Sub-Theme 2: The Unscored Questions*

There are two unscored questions included within the EssenCES-IDD (“Is this wing a nice place to be?” [Question 1] and “Are prisoners and staff comfortable on this wing?” [Question 17]). These questions intend to set the questionnaire’s “tone” and to guide individuals towards thinking about the social climate. Staff noted that Question 1 can be difficult in light of the fact that it is being asked within a prison environment. This issue was also raised within Chapter 3.

One individual with IDD drew attention to Question 17. They considered it would be more appropriate to ask this as two separate questions as they would wish to provide different responses regarding whether they considered it was prisoners or the staff who are comfortable on the wing (Interview 6). Again, this point was also made in Chapter 3.

This feedback leads to the question of whether further amendments need to be made to these items or whether, given they are both unscored items, there is any need for them. One of the social climate experts suggested that it may be better to omit them as, in their opinion, they are "wasteful of everyone's time" (Social Climate Expert 1). Question 1 intends to set the tone for the rest of the questionnaire. However, this may not be recognised by individuals with IDD. Question 17 may be unnecessary given that all scored items will have been completed by the time individuals reach it. Their omission would also reduce the length of the questionnaire.

#### *5.6.4.3 Sub-Theme 3: Scripted Rewordings*

Staff and the Speech and Language Therapy expert drew attention to the scripted rewordings of the EssenCES-IDD questions. They stated that the rewordings often failed to capture the meaning of the initial questions. When commenting on the Question 1 ("Is this ward a nice place to be?"), the Speech and Language Therapy expert expressed that the rewording of "Do patients like being on the ward?" was not equivalent. They queried "Does liking being on a ward mean that the person thinks in general it is a nice place to spend time?". Similarly, with regards to Question 3 ("Do scary things happen on the ward?") and the reworded question ("Do patients/prisoners feel unsafe on the ward?"), the Speech and Language Therapy expert commented that they were "unsure that feeling unsafe equates to scary things happening. I can watch something scary (a road accident from the pavement) but I don't necessarily feel unsafe". They also drew attention to the inclusion of some abstract concepts within the scripted rewordings (e.g., "look out" and "keep clear"), and stated that individuals with IDD would likely find these concepts difficult to understand.

The rewordings were developed as a way of helping to ensure consistency across those administering the EssenCES-IDD, thus reducing the potential for administration bias. However, any disparities in meaning between the initial and reworded questions would result in slightly different questions being asked if the rewordings were used. This would also have the potential to impact upon validity, although perhaps to a lesser degree.

The rewordings were rarely used within the current study. The only questions that required their use were those pertaining to the views of staff. This leads to the question of whether the rewordings are required. The questionnaire was administered by the researcher. However, Chapter 3 highlighted that individuals may find it more difficult to admit they have not understood a question if the questionnaire is administered by someone who is not familiar to them. Therefore, although individuals rarely utilised the rewordings, this does not mean that there may have been occasions where they could have benefitted from them. Individuals were, however, asked to explain their interpretations of various questions and all demonstrated an understanding of what the questions were asking. Similarly, the information individuals shared in the comment boxes also indicated they had understood the meaning of the questions. However, as mentioned earlier, whether or not these individuals are reflective of the broader population of individuals with IDD within forensic settings warrants consideration. These findings may not be generalisable to, for example, those with profound IDD. Further research is required to allow more definite conclusions to be drawn regarding the use of scripted rewordings.

#### *5.6.4.4 Sub-Theme 4: The EssenCES-IDD Questions*

Individuals with IDD generally provided positive feedback regarding the language included within the EssenCES-IDD questions. They commented that the questions were clear and there was no overly-complex or unfamiliar terminology used. For example, one individual stated “it’s not something that you wouldn’t have read before or not seen before” (Interview 3). Individuals considered that they had a good understanding of what the questions were asking, making comments such as “I understood every word what was on there and what it meant and what it was trying to ask me” (Interview 5). When asked whether they thought that the questions could be perceived as overly-simplistic, one

individual responded “when you’re doing a questionnaire no, no question’s easy” (Interview 1). This highlights that, although they appeared to understand the language and the questions, it remains important to ensure that the questions are phrased as simply as possible.

Individuals were asked to explain their choice of response option for particular questions in order to check their understanding of the questions and to ascertain their understanding of the constructs underpinning the questions. These discussions also proved useful in terms of understanding what these constructs mean to individuals with IDD and establishing whether individuals are interpreting the constructs and questions as intended.

**Anger.** Question 6 refers to anger (“Are there angry prisoners on this wing?”). Individuals discussed the concept of anger, with general agreement in their interpretations of this. Individuals considered that anger would include instances of verbal aggression or threatening behaviour and were able to provide examples such as “shouting and screaming” and “[someone being] face to face, this close to me” (Interview 2). Interestingly, most individuals considered that instances of physical aggression would not come under the definition of anger. One individual stated “it’s [anger is] not a physical … I don’t think … it’s not really a physical aggression, I think it’s more verbal” (Interview 4). Similarly, another individual stated “I think angry is different to violent” and defined violence as meaning “that’s where you attack someone innit” (Interview 3). However, one individual reported that they were unsure as to what was being referred to by anger within the context of Question 6:

> You got different ways of being angry, you know … because you’ve had a bad day or you know you feel a bit angry, or you’re angry all the time … you know what I mean? And that’s why I said “what d’you mean by ‘angry?’”. Interview 1

Clarification of the intended meaning of the term “angry” within this question is evidently required. Alternatively, replacing this word with an alternative term may be needed to ensure that its intended meaning is retained.

This question also requires individuals to identify when other prisoners are angry. Some individuals described how they would know if others were angry, with responses being based primarily around behavioural markers of anger. For example, “by the way they were slamming doors, which ‘as been happening … err, there’s been slamming doors, there’s been shouting, there’s been arguments” (Interview 5).

Individuals also discussed the prevalence of anger, making statements such as “everyone gets angry at times” (Interview 3). They drew attention to the fact that anger is not always negative. One individual also commented on what they considered to be the difference between anger and aggression or violence. They stated “obviously you’re angry if you’re attacking somebody but using violence innit … I think anger’s more of an emotion innit rather than physical” (Interview 3).

The original EssenCES used the term “aggressive” in this question, with this being changed to “angry” within the EssenCES-IDD. The above feedback, however, leads to the question of whether this amendment is appropriate, given that individuals are able to differentiate between these terms and that they define them differently. A social climate expert also commented on this. They highlighted a potential risk that, in using the term “angry” as opposed to “aggressive”, the question would not be measuring the same construct as the original question (Social Climate Expert 1). Thus, responses could be overly negative as a result of individuals interpreting anger as a common emotion as opposed to the question asking about aggression (which is clearly negative). Consequently, lower scores on the experienced safety subscale may be reported. This could impact upon the validity of the data gathered and could also render the data incomparable to any data gathered through the original EssenCES.

The term “aggressive” was, therefore, discussed with individuals with IDD. They considered that this term was familiar to them. It appears that, having trialled replacing the term “aggressive” with “angry”, it would be more appropriate to retain the term “aggressive” within the context of this question.

Staff also discussed the use of the term “angry” within prison settings. They expressed that this can be a difficult term for prisoners to associate themselves with:

> They’ll say in a very angry way “I wasn’t at all angry, I was upset”. Or “I was frustrated” or “I was…” something else. “Angry” has been such a negative thing I think in their past, you know, that it’s been such a bad thing to be that, erm, it, it’s a word that … doesn’t get used. (Focus Group Participant 5)

This contradicts feedback discussed in Chapter 3 whereby staff reported that individuals in forensic settings would feel able to express that they felt angry. This contradiction is highlighted in the example below, where an individual discussed that they had “lost my [their] rag a little bit” (Interview 4). They were asked whether others may have perceived them as being angry, but appeared to have difficulty acknowledging this:

> I was pissed off. I wasn’t, I wasn’t angry, I was more pissed off. But like I was angry … I was disappointed and pissed off to be honest. I was more pissed off and disappointed … because it was like the cheek … I wasn’t angry. When I get angry it’s different. (Interview 4)

This supports reverting to use of the term “aggressive” as opposed to “angry”. Furthermore, this also provides a justification for continuing to phrase the questions as enquiring about the perceptions of the group of prisoners as a whole, as opposed to asking for individual perceptions. This enables individuals to essentially hide their perspectives within that of the group, meaning they may find it easier to provide more honest responses.

**Fear.** Four questions on the EssenCES-IDD refer to the concept of fear (Questions 3, 9, 12, and 15). Staff drew attention to the use of the term “scary” within Question 3. They noted that individuals can interpret different things as being scary and made suggestions as to how the meaning of the term “scary” could be made clearer, including adding the word “event” or “situation” afterwards. One participant was unsure whether use of the term “scary” would appear childish (Focus Group Participant 6). One social climate expert expressed that it would be important to retain use of the word “threatening” within this question (as used

on the original EssenCES). They stated that "'scary' could mean a lot of things but it's not necessarily capturing the sense of malign behaviour that the original item is seeking out, and might result in over-reporting" (Social Climate Expert 1). This is an important point to consider given the need to ensure that the EssenCES-IDD questions accurately reflect the meanings of the original EssenCES items. This social climate expert also drew attention to Question 15. They highlighted that the amended question on the EssenCES-IDD did not capture the underlying sense of the original item. This occurred as a result of changing the term "excitable" to "scary". This social climate expert commented that "it's not necessarily that some patients are scary/threatening but that they can behave in an unboundaried or disinhibited way that increases risk" (Social Climate Expert 1). They suggested reverting to use of the term "excitable" or "excited". However, as discussed in Chapters 3 and 4, multiple concerns were raised with regards to use of the term "excitable" given that it can be interpreted in very different ways (see Section 3.6.2.5). Evidently, the language used in Question 15 requires further consideration.

Individuals with IDD were asked about their understanding of the terms "scared" and "scary" as a means of assessing whether they were interpreting these terms in the way in which they were intended and to establish whether they found these terms appropriate. No individuals mentioned finding the term "scary" to be too simplistic. Individuals provided fairly consistent explanations regarding what they would perceive as being scary or what may cause them, or someone else, to feel scared. They also expressed that both verbal and physical aggression could cause someone to feel scared, as could unpredictable behaviour:

> I think some, some prisoners do get scared of each other at times cuz err, of what they're gonna say or you don't know if they're gonna do it so you could be like always lookin' over your shoulder like in a way. (Interview 5)

Individuals recognised that that this fear could result in generalised caution around other prisoners. One individual commented "I'm always cautious anyway, all the time" (Interview 5). Other individuals acknowledged they were careful around, and often avoided, other prisoners who they perceived as being scary and that they would move away from situations where they felt scared. They made comments such as "I think some people don't

want to go and approach them because they're afraid of the outcome" and "you're trying to move yourself away from that equation" (Interview 4). These comments highlight the way in which individuals had identified particular behavioural markers (e.g., caution or avoidance) as a consequence of feeling scared. This ties in with Chapter 3, whereby participants discussed the potential of including behavioural examples within the EssenCES-IDD as a means of aiding understanding of some of the concepts included within the questions. The Speech and Language Therapy expert did, however, draw attention to the behavioural markers used within Question 15. They highlighted that the phrase "stay away from" (EssenCES-IDD question) is more concrete than the phrase "keep clear" (EssenCES-IDD scripted rewording) and suggested a need to focus on including more concrete phrases.

**Care and Support.** Four questions on the initial pilot version of the EssenCES-IDD ask about the concept of "care" (Questions 2, 7, 8, and 13) and three questions ask about whether prisoners are supportive towards one another (Questions 5, 11, and 14). Staff participants drew attention to two questions that consider care and support and made suggestions for minor amendments.

*Question 2 – "Do prisoners care about each other?"*

Staff participants discussed the difference between prisoners caring about each other and prisoners showing care for each other, expressing that there may be some prisoners who do not care for one another, but that are able to *show* care for one another within the prison setting. One staff participant commented "one's I guess a deep-down feeling whilst the second one's more important … whether they actually show care for each other" (Focus Group Participant 6). On the original EssenCES this item was worded as "The inmates care for each other". The amended wording appears to maintain the concept of the original item. However, given that individuals with IDD may find it easier to identify when others are *showing* care towards other prisoners as opposed to knowing whether or not others *feel* that they care about other prisoners, this question may require further amendments.

*Question 4 – "Can prisoners talk to staff about all their problems?"*

Staff participants highlighted the inclusion of the word "all" within this question. They stated that prisoners may talk to different staff dependent on the type of problem that they are experiencing. They were also unclear whether this question was enquiring about whether prisoners are provided with opportunities to talk to staff about their problems, or whether they feel able to. Within the original EssenCES, this item was worded as "In this unit, inmates can openly talk to staff about all their problems". This appears to draw upon whether prisoners feel able to talk to staff as opposed to whether they are actually provided with opportunities to do so. This would suggest that this question would benefit from being reworded to ask "Are prisoners able to talk to staff about their problems?".

*Individuals with IDD*

In order to establish how individuals with IDD interpret the terms "care" and "support", and to gain an understanding of what they would observe that would lead them to perceive that others were showing care or providing support, they were asked what these terms mean to them in relation to the group of prisoners within the prison setting. They were able to provide explanations such as "it means that, err, you know you're trying to help each other" (Interview 5). Individuals understood that these terms related to prisoners helping each other and supporting one another's wellbeing, although acknowledged that this could be limited given that they were currently residing within a prison setting. They appreciated that support could be required for different reasons and, although most discussions were based around the provision of emotional support, one individual drew attention to the different types of support that prisoners provided to one another, commenting "you're trying to help 'em with either emotional stuff or physically or mentally" (Interview 5).

Individuals discussed undertaking activities together such as cooking and playing games. They expressed that this indicated a supportive environment. They were also able to describe behaviours that they perceived would indicate that other prisoners were being caring or supportive towards one another. These behaviours centred around talking to one another and expressing their feelings, providing reassurance and positive feedback, checking on one another and offering verbal support, and behavioural reminders if they observed another prisoner engaging in negative behaviours. It was clear through the

examples provided that individuals perceived support between prisoners as being important. However, one individual commented on the need for prisoners to ensure that they were caring for and supporting themselves as a priority over providing support to other prisoners:

> I like to listen to other people's issues or I listen to … or I'll sit there and I'll just like worry about others but … I'll see everything else around me just like sink. Sink, sink, sink … and before you know it, I'm sinking myself. I have to learn to stop doing that … because I'm here for me and not everyone else [laugh]. (Interview 4)

This individual also had an awareness that there were times where providing care and support to other prisoners was not appropriate:

> It would all depend on the situation as well … because it might be a situation where we can offer support … but it, it might be where they have to go and speak to the staff … they need more … or they need more support than us. (Interview 4)

This leads into the second aspect of care and support included in the EssenCES-IDD. This aspect focuses on whether individuals with IDD perceive that staff care about prisoners. Individuals were able to describe instances that they perceived would indicate that staff were showing care for prisoners such as the occurrence of events where staff and prisoners get together. However, there was much less discussion surrounding care and support from staff in comparison to other prisoners. This may be a result of individuals experiencing difficulties with some of the questions on the EssenCES-IDD that enquired about the care and support that they perceived staff provided (see Section 5.6.4.1).

It is evident that Chapter 3 raised questions around whether care and support amongst individuals with IDD was important to the IDD population. The current study highlights that the individuals with IDD that participated in the current study understood the concepts of care and support and what constitutes appropriate care and support within the prison setting. Thus, it is appropriate for the EssenCES-IDD to continue to measure these concepts.

**Doing Well and Getting Better.** One question on the EssenCES-IDD refers to whether individuals with IDD perceive staff care about whether prisoners are "doing well" (Question 7) and another refers to whether they perceive staff care about prisoners "getting better" (Question 13). Staff participants drew attention to Question 13. They commented that they perceived it would be inappropriate to ask this question within a prison setting. They expressed that this question insinuates that prisoners are unwell and, although they acknowledged this would be suitable within a hospital setting, they considered that for prison settings it would be more appropriate to reword this question (e.g., "Do staff care about prisoners progressing?"). However, inclusion of the concept of "progress" makes this question very similar to the original wording of Question 7. This draws attention to the similarities between Questions 7 and 13 on the EssenCES-IDD, which have likely occurred as a result of simplification.

Individuals with IDD were asked what the phrase "getting better" meant to them. They stated that it meant that prisoners were behaving more appropriately and that they were adapting to life on the wing and becoming more accepting of the support offered. Similarly, they considered that "doing well" referred to making progress towards their goals and behaving more appropriately. One individual explained the difference they perceived there to be between Questions 7 and 13:

> Well it's like … if you're doing something, like if you're doing like a topic now … and you understand it so, so you're doing well at it … and then if you done it over a period of time and you get used to it, certain environments or whatever it could be … then you're, then obviously you're, err, being better at doing it cuz you understand it. (Interview 5)

This individual perceived "doing well" to reflect someone's achievements in the "here and now", whereas they perceived "getting better" to mean achievements that were sustained over a longer time-period.

Both staff and individuals with IDD perceived the phrase "getting better" as relating to progress. Individuals with IDD perceived the phrase "doing well" as pertaining to more

immediate achievements. Within the original EssenCES, Question 7 pertained to progress and Question 13 pertained to individuals' success in "treatment" (hospital version) and their success in the "program" or "daily routine" (prison version). Thus, it may be that Questions 7 and 13 need to be swapped on the EssenCES-IDD so that Question 7 still pertains to general progress, and Question 13 to "doing well" either on a daily basis or across their treatment or programme. If these questions were swapped, it would appear that no further amendments would need to be made to Question 7. However, Question 13 would benefit from improved clarity and removing the implication that prisoners are unwell.

#### *5.6.4.5 Sub-Theme 5: Cohesion of the EssenCES-IDD Questions and Response Format*

Chapter 3 indicated that it would be beneficial to phrase the EssenCES items as questions rather than agreement statements in order to improve the flow between the items or questions and the response format. However, staff participants in the current study expressed that there was a mismatch between some of the re-worded questions and the response options.

Staff interpreted the EssenCES-IDD questions in different ways. They discussed how some could be interpreted as quantity-orientated, thus enquiring *how much* the respondent agrees with the question (e.g., "Do prisoners care about each other?"). However, most could be interpreted as frequency-orientated, thus enquiring *how often* the situation referred to in the question occurs (e.g., how often prisoners or patients get angry). Additionally, most could be interpreted as enquiring *how prevalent* the construct referred to in the question is present on the ward or wing (e.g., how much support prisoners or patients get from others). The original EssenCES asked respondents how much they agreed with the items. However, there was no guidance stipulating how this ought to be interpreted. Most items could be interpreted in any of the ways described above, with it being likely that respondents would consider a combination of frequency and quantity when selecting their responses.

Staff queried whether the response options needed to remain the same for all questions. They perceived that some of the questions required response options which were

frequency-orientated ("how often"), and others required response options that were quantity-orientated ("how much"). For example, they considered that the question "Do prisoners care about each other" requires a response that denotes *how much* prisoners care about each other, whereas the question "Are there angry prisoners on this wing?" requires a response which depicts *how often* there are angry prisoners on the wing. However, individuals with IDD highlighted the benefit of using the same response format throughout the questionnaire. They described how this enabled them to become more familiar with the response options as they progressed with completion of the questionnaire. For example, one individual stated "it's all the same, they don't change … once you've got, gone through it a few times you know what they are don't you" (Interview 3).

Some useful feedback was also gathered from the Speech and Language Therapy expert. Their comments were similar to those of staff. They remarked that "some of these descriptors are quantifiers ('a bit' and 'a lot') and others are time orientated ('not at all', 'sometimes', and 'nearly all the time'). It would be better if they were all quantifiers or all time orientated". Both the Speech and Language Therapy expert and staff suggested changing the quantity-orientated response options to frequency-orientated alternatives. The Speech and Language Therapy expert suggested changing "a bit" to "a bit of the time" and changing "a lot" to "a lot of the time". Staff also made similar suggestions such as using "never", "occasionally", "sometimes", "often", and "nearly all the time".

Staff also expressed that the response options did not fit some of the questions, and made suggestions as to amendments that could be made to resolve this:

> Number 10, for example, so: "Do staff spend a lot of time helping prisoners?". "Not at all", "a bit", "sometimes", "a lot", "nearly all the time". I don't know, it, it felt like perhaps a better way to frame the question would be "How much time do staff spend helping prisoners?". (Focus Group Participant 1)

It is evident that changing the EssenCES items to questions has led to a mismatch between the questions and response options on some occasions. Furthermore, a lack of continuity among the response options has also been highlighted, with some being quantity- and

others frequency-orientated. Resolution of these issues will be required. However, making a decision regarding the most appropriate terminology for the response option headings will not be straightforward. As mentioned earlier, the original EssenCES enquired how much respondents agreed with the items. It would, therefore, appear that attempting to simplify the response option headings has, inadvertently, led to a change in what they are measuring. This poses a number of issues, including whether the EssenCES-IDD is actually gathering the same data as the original EssenCES. If different data are gathered then any attempts to compare data gathered using the EssenCES-IDD with data gathered using the original EssenCES will be futile. This is a point which deserves further consideration.

### 5.6.5 Theme 5: Response Format

#### *5.6.5.1 Sub-Theme 1: Number of Response Options*

Staff participants were supportive of the EssenCES-IDD retaining the five-point Likert response scale used in the original EssenCES. However, their support of this appeared to be contingent upon the response option headings being amended so as they were all either quantity- or frequency-orientated and amendments being made to some of the questions to ensure the questions and response options were cohesive (see Section 5.6.4.5).

Staff discussed the inclusion of the mid-point option of "sometimes" and commented on the potential for this option to be over-used. For example, one staff participant stated "'sometimes' almost increases the attractiveness of the middle option, doesn't it?" (Focus Group Participant 6). Another queried "don't people always tend to gravitate towards the, the third of the five scale?" (Focus Group Participant 5). However, there appeared to be a general consensus that this option was needed with one staff participant commenting that removal of this option would mean "it's a big jump then from whatever you want to call the 'a bit' one and 'a lot'" (Focus Group Participant 3). Some individuals with IDD also commented on this. One individual discussed how they had used the response option of "sometimes" quite frequently and explained their reason for this: "It's a wing and it goes up and down … one day it could be perfect, next day it could be shit" (Interview 4). This

demonstrates the importance of the mid-point option and shows how it can be a valid response, particularly given the dynamic nature of the environment of forensic settings.

Individuals with IDD also discussed the addition of the "I don't know" response option. One individual stated that, although they had not needed to use the "I don't know" response option, they were able to consider occasions when this may be required by others:

> Some people might not see some things other people don't and do innit … you know what I mean, so I might see someone getting angry and they might not see them being angry so they don't know. (Interview 3)

However, another individual considered that extending the time-frame for the EssenCES-IDD questions would render this additional response option unnecessary:

> I don't think it's, it's helpful at all … coz if you gonna change it to, add it like from last week to say two months or three months, I don't think it's relevant. Well people, erm, if they go back that far they'll think of an incident like I did you know. (Interview 1)

Another individual considered that inclusion of the "not at all" response option may be unnecessary, with their rationale being similar to that described above. However, this individual was able to acknowledge that other individuals may require this:

> If you didn't restrict the week I think you could lose the "not at all" because, erm, like for instance I've been here four years so I've seen, I've seen a lot … but some people here have only been here a few months or, or … I mean some of the people that I've seen they've scared me, erm, and threatened me. These guys haven't seen that. (Interview 2)

It would not be possible, nor appropriate, to remove the "not at all" response option. However, it is interesting to know that this individual perceived that if prisoners had been on the wing for a lengthy period, they would have experienced all of the situations, both

positive and negative, that are referred to in the questions. The "I don't know" response option could be removed. However, Chapters 3 and 4 clearly indicated this option would be beneficial.

#### *5.6.5.2 Sub-Theme 2: Selecting a Response*

Staff participants commented on their own ability to differentiate between the five response options and to select an appropriate response. One staff participant described having experienced some difficulty in doing this. They stated "I also was looking for something that, less than 'a bit' … an occasional incident … somehow I didn't feel the words necessarily reflected the response that I'd have comfortably gone for" (Focus Group Participant 3). Another staff participant commented on an occasion where they had struggled to select a response option that reflected the answer they wished to provide:

> On Question 12: "Are staff scared of some of the prisoners?" … I struggled with the scale on that one … so for me that question's asking as a whole … "Is the staff scared… team scared… of some of the prisoners?", and it was really hard to, to answer coz I, I suppose I was thinking about one or two staff for one or two occasions and I didn't know which one to choose, you know? (Focus Group Participant 1)

Individuals with IDD also commented on the process of selecting their responses. One individual highlighted that the questionnaire does not include any answer boxes in which to tick corresponding responses (Interview 3). This was also mentioned by one of the social climate experts (Social Climate Expert 1). Therefore, answer boxes need to be added. Most individuals reported that generally they had found the process of selecting their responses to be straightforward. One individual commented that there had been occasions where they had found it more difficult:

> Sometimes it was straightforward, some were, erm, in between you know what I mean like I said sometimes when there's … if you're thinking of support from certain … prison officers, yeah you do get it … but, erm, but not all of them. (Interview 2)

Individuals with IDD demonstrated that they were able to differentiate between the five response options through using the response option headings in conjunction with the visual representations. One individual was asked why they had selected "a lot" as their response to one of the questions regarding staff support, and was clearly able to articulate their rationale for this:

> Coz they help as much as they can so … it's not "nearly all the time". That'd mean practically every time you ask you gonna get something … but "a lot" is, is when they can pretty much you know what I mean. (Interview 2)

Similarly, another individual was asked why they had selected "a lot"; they stated "just sometimes people have disagreements with other people then … you know what I mean, sometimes it's not as supportive as it could be" (Interview 3). They were also able to describe why they considered that the response they selected needed to be greater than "sometimes". They explained "coz even though there's disagreements you're still like, everything's … everyone's alright you know … you don't like blank them or … you know what I mean just call them names or whatever" (Interview 3).

These comments show that these individuals were able to consider the meaning of the different response options in terms of the amount of support provided and that they were able to select their response accordingly. They were also able to consider what would need to have occurred for them to have selected a different response. This demonstrates an understanding of the response scale and the different response options. However, this does not mean that all individuals with IDD would possess the ability to do this given the diversity of the IDD population.

#### *5.6.5.3 Sub-Theme 3: Visual Representations of the Response Options*

One social climate expert remarked that "the 'glass half full' approach to gathering responses is very innovative and helpful for this particular client group" (Social Climate Expert 1). Staff and individuals with IDD also provided positive feedback regarding the visual representations of the response options. It was apparent that staff perceived the visual

representations that had been selected were of an appropriate nature. One staff participant commented “I like the visuals. They’re not patronising kind of … visuals” (Focus Group Participant 1). One individual with IDD also commented on this. They stated “we have learning disabilities; I don’t think it’s putting us down by having graphs” (Interview 4).

Staff considered that the visual representations would aid individuals with IDD in selecting their response options. Also, they would be particularly helpful for individuals who were unable to differentiate between the meaning of the different written response option headings:

> [They] won’t be able to say what “a bit” is, “sometime” is, “a lot”, “nearly all the time”. They … can’t differentiate. The pictures actually show … how much of it is in there so it gives a visual of what that means. (Focus Group Participant 2)

One staff participant suggested that the top of the “cups” within the visual representations could be closed off and the cups made into “boxes”. They expressed that this may help to better proportion the amount in which the cups were filled (Focus Group Participant 1).

It was also important to ascertain whether individuals with IDD perceived that the addition of visual representations was of benefit. Their feedback was positive and highlighted that this was a useful addition. All but one of the individuals with IDD stated that they had used the visual representations when selecting their response options. Three individuals reported that they had used a combination of the written headings and the visual representations. One individual only used the visual representations when selecting their response options.

To ensure the visual representations were correctly interpreted by individuals with IDD, most individuals were asked to explain their interpretation of them. They provided fairly consistent feedback and were able to explain how the visual representations depicted the words used within the response option headings:

> Well just the level of support or level of what you see of it … a lot of the support or whatever … there's a little bit … some little bits, occasional, there's, there's quite a bit of it and practically all the time. (Interview 2)

Individuals were able to draw on similarities between the visual representations and other scales, evidencing an understanding of the incremental increases depicted by the images. For example, one individual commented "it's like a one to ten scale innit, where that's nought coz there's none in it and ten coz it's full" (Interview 3).

One individual misinterpreted the response options. Their diagnosis of dyslexia likely contributed to this and meant that they were unable to read any of the text on the questionnaire. This draws attention to the fact that those who struggle to read may not be able to utilise the response options headings in conjunction with the images to gain an understanding of their meaning. This individual initially explained their understanding of the visual representations in relation to anger and discussed how, as the level of anger increased, the cup would become increasingly full:

> This one where it's empty, right? That means everything's fine. Everything's going on right, then this one, there's erm, something's not right but it needs to be looked at … and then it's building from that going up. (Interview 6)

In the context of a negative concept (i.e., anger), the above interpretation of the images is correct. However, when asked about questions depicting positive concepts (i.e., whether staff care about prisoners), this individual's interpretation of the response options was inaccurate. The researcher pointed to the full cup and asked what it would mean if the individual selected this response. The individual responded that "there'd be no communication, communication would stop. There'd be … there'd be nothing. There wouldn't be anything there". When the researcher pointed to the empty cup, the individual stated "that means they did care … they did care and they made you feel like they cared". This shows that this individual had interpreted the visual representations as depicting how problematic they perceived the concepts included in the questions to be, with the full cup depicting that they perceived the concept to be very problematic, and the empty cup

meaning they perceived there to be no problems with that concept on the wing. The researcher also asked this individual about their response to the question “Can prisoners talk to staff about all their problems?”. The individual had selected “nearly all the time” as their response. However, justified their reason for selecting this option by stating “I think there’s times that … I think staff aren’t bothered. I don’t think you really get that interaction”. Evidently, this individual had not interpreted the visual representations in the way in which they were intended. This draws attention to the potential for difficulties to arise should individuals use only the visual representations when interpreting the meaning of the response options. Further consideration will be required to address this issue.

Finally, the use of colour was highlighted by one individual, who reflected that incorporating some colour within the questionnaire could be beneficial:

> Bit of colour in the glasses, you know what I mean, or … just make it a bit more colourful instead of like “test-ish” you know what I mean. Just even that little bit just makes it a lot more … a lot more cheerful. (Interview 3)

Chapter 3 also indicated that the inclusion of colour would help the questionnaire to appear less like a test and that colour could be beneficial if used in a graded way within the visual representations of the response format. This could help individuals to differentiate between the weighting of the different response options. This adaptation was not made within the initial pilot questionnaire. However, in light of this point being raised again, it may be beneficial to introduce graded colour.

#### *5.6.5.4 Sub-Theme 4: Comment Boxes*

Individuals with IDD and staff all utilised the comment boxes on some occasions. The majority of comments were examples of situations or experiences that supported their choice of response option, thus providing context to their responses. This qualitative information could clearly be useful on both clinical and research levels.

Staff discussed that the staff cover sheet states that the comment boxes are optional. They considered that this has the potential to lead to staff opting not to provide any qualitative feedback. They suggested that the comment boxes should be presented as a distinct "opt-out" as opposed to an "opt-in". They considered that this may increase staff engagement in the provision of qualitative feedback.

Staff expressed that encouraging provision of qualitative feedback was important as it would help to explain why respondents had selected particular response options:

> Coz even if you took things like "Is this wing a nice place to be?" or a question like that that's a bit ambiguous you might get some of them if, if they're then saying something like "the toilets are shit" or "people don't clean up after each other" or … you know … you'll get more of an idea of why they've given that. (Focus Group Participant 1)

The administration guidelines informed questionnaire administrators to highlight the optional nature of the comment boxes to individuals with IDD. However, their cover sheet did not include a statement pertaining to this. Staff considered that allowing the comment boxes to be optional for individuals with IDD would mean that a proportion would choose not to provide any comments. Staff suggested that provision of comments could depend on reading and writing abilities and that those who struggle more may be less likely to provide comments.

Individuals with IDD also discussed the comment boxes. One individual suggested that it would be helpful to include a statement on the cover sheet that explains that administrators can write the comments on their behalf if needed. They expressed that this would make it easier to provide comments (Interview 2). Although this is stated in the administration guidelines, it is apparent that both this, and the optional nature of the comment boxes, also need to be included on the cover sheet.

Individuals with IDD stated that the comment boxes were of an appropriate size for them to include a short sentence. One individual also mentioned finding the comment boxes helpful

as they helped to direct them towards thinking about examples of situations relating to the questions and, therefore, to decide which response option to select (Interview 1).

### 5.6.6 Theme 6: Administration

Chapters 3 and 4 identified that the EssenCES-IDD should be administered on an individual basis. Scripted rewording of the EssenCES-IDD questions was also proposed, along with the development of administration guidelines to enable consistent administration.

All individuals with IDD received individual support from the researcher when completing the initial pilot version of the EssenCES-IDD. Four individuals required the researcher to read out the questions and response options. Two individuals read the questions and response options out themselves. Five individuals ticked their responses independently. Only one individual required the researcher to tick their response options for them. This was due to this individual having dyslexia and, therefore, being unable to read the text themselves.

The Speech and Language Therapy expert provided some general feedback on the administration guidelines. They suggested improvements centring around simplifying some of the language, shortening sentences, and changing the word order in some places to improve clarity.

Staff drew attention to the feedback box included at the end of the version of the questionnaire for individuals with IDD. This was added to provide a way for administrators to provide feedback regarding their perceptions of an individuals' understanding of the response format and any identified patterns of responding that may be indicative of the presence of response bias. Staff considered that the opportunity to provide this feedback would be beneficial.

One individual with IDD discussed the need to provide accurate responses to the EssenCES-IDD questions. They stated that they would not have any difficulties answering the questions, including those relating to fear, even if other prisoners were around and were privy to their responses (Interview 4). The researcher did, however, observe that this

individual had experienced some difficulties in providing honest responses when participating in the current study. They did not provide an answer to the question "Are some prisoners scared of other prisoners?". When asked why they had found it difficult to answer this question, this individual waited for the staff member who was escorting the researcher to leave the room before explaining their difficulties to the researcher. They stated that "I didn't want to really disclose too much … I felt a bit, I'll be honest with you, [staff name] was sat here and I didn't really want to express it too much" (Interview 4). They also explained why they were unable to disclose their perceptions in the presence of a staff member:

> I don't wanna slag the place off because it's a really good place for people … I think it will help me a lot and help others, but when that question came up, I didn't know how to respond to you … because I didn't wanna … backbite and say something and slander as well if that makes sense? Even though it's a brilliant place, but then there's that other slandering it because of the, the, the protocol it's got behind it of how they remove someone from … you know and, and maybe put others in, in the same situation where it can affect their ability to change and their therapy … and I didn't, you know, think that was fair. That's what I was getting at. (Interview 4)

This highlights how some individuals may find it difficult to provide honest responses in the presence of staff members with whom they are familiar. Clearly this has the potential to cause difficulties if services opt to use familiar staff to administer the questionnaire. However, similarly (as discussed in Chapters 3 and 4) difficulties could also arise if the questionnaire was administered by unfamiliar staff or those external to the ward or wing.

## 5.7 Discussion

This chapter aimed to explore the perceptions of individuals with IDD, staff and experts regarding the suitability of the initial pilot version of the EssenCES-IDD and to establish whether any further amendments are required. Initial exploration of how individuals with IDD perceive the constructs of experienced safety, hold and support, and inmate cohesion was also undertaken. Six individuals with IDD and seven staff members from one UK prison

service provided feedback within a focus group and individual interviews. Two social climate experts and one Speech and Language Therapy expert also provided feedback via email. A clear strength of this approach is that it allowed perceptions of individuals with IDD, staff, and experts to be considered simultaneously, thus preventing the need to develop multiple pilot versions of the questionnaire following each set of feedback. It also enabled equal weighting to be given to the perceptions of individuals with IDD and professionals. This ensured that the views of individuals with IDD were not overshadowed by those of professionals. Based on the author's review of previous social climate research, this is the first time that the perspectives of individuals with IDD have been considered when adapting measures of social climate for the IDD population.

Involvement of individuals with IDD within this stage of the research was paramount given that the EssenCES-IDD is being developed specifically for this population. The design of the research meant that the researcher could observe and support individuals with IDD to complete the questionnaire. This proved beneficial as the researcher was able to draw upon their observations (such as any questions individuals appeared to find more difficult or any difficulties selecting response options) during the subsequent interviews. The researcher was also able to use the completed questionnaires within the interviews to understand why individuals had selected certain responses, to ascertain their understanding of what it would have meant had they selected a different response option, and to explore the comments they provided. This approach, therefore, provided the opportunity to develop a more in-depth understanding of the perceptions of individuals with IDD. Similarly, this approach also appeared beneficial for staff. They were able to draw upon their personal experience of completing the questionnaire and identify difficulties which they had experienced. They were also able to consider how individuals with IDD could interpret different questions and the response format.

This approach does, however, have some limitations. Only a small number of social climate and Speech and Language Therapy experts participated in the study, and the individuals with IDD and staff were from one UK prison service. This may mean that the findings are not reflective of the entirety of the population of individuals with IDD or professionals across forensic IDD services in the UK or, indeed, internationally. Additionally, the participating

service was a prison, which means the findings may not apply to staff and individuals with IDD in forensic hospital settings.

Furthermore, it is necessary to reflect upon the fact that individuals with IDD volunteered to participate in the study. There is the potential that some individuals who were less confident or who did not believe that they had a good understanding of the nature of the research did not volunteer. This could have been more prevalent in those with more moderate IDD as these individuals would be expected to experience more difficulties in understanding the nature of the research and comprehending what their participation would involve. This could mean that individuals who would be more likely to experience difficulties in completing the questionnaire chose not to participate. If this were to have occurred, then the findings gathered from the individuals with IDD within this study may not be reflective of the IDD population of the wing. Additionally, although staff confirmed that all participants had an IQ < 80 or a diagnosis of autism, IQ scores were not collected. Therefore, it is impossible to establish whether the participants' ability levels were reflective of the IDD population within prison and forensic hospital settings as a whole. This could mean that aspects of the questionnaire which individuals with IDD found suitable within this study may be too challenging for some individuals whose ability levels are somewhat lower.

One must also take into account the potential biases that could have been introduced as a result of the questionnaire being administered, and the interviews conducted, by the researcher (who was not familiar to the individuals with IDD). Individuals demonstrated throughout the interviews that they generally possessed a good understanding of the meaning of the questions and response format. They were able to justify their responses and appeared comfortable providing some responses expressing their dissatisfaction with aspects of the wing. Furthermore, the researcher did not observe any patterns of responding that would demonstrate socially desirable responding. Despite the presence of a staff escort within the interviews, individuals generally seemed able to openly discuss the reasons for their responses including aspects of the wing which they perceived as being more negative. One individual did express feeling unable to share some of their views of the wing in the presence of the staff member. However, as the purpose of the study was to explore their perceptions of the EssenCES-IDD and understanding of the questions and

response format, it is not considered that this issue would have impacted on the study's findings. It is important to note that the researcher had experience of working in forensic IDD settings and was, therefore, able to draw upon their own experience of communicating with individuals with IDD when administering the questionnaire and throughout the interviews, and would have been likely to be able to identify occasions when individuals had not understood questions or where patterns of responding were present.

## 5.8 Conclusions

Findings from the study reported on within this chapter indicate that the EssenCES-IDD requires a small number of amendments. Attention was also drawn to areas requiring further exploration (e.g., the time-frame and scripted rewordings). It was evident that participants had differing views regarding some aspects of the EssenCES-IDD. This, again, highlights that developing a questionnaire that is appropriate for all individuals with IDD and for staff is a difficult task.

This chapter has also evidenced the importance of involving individuals with IDD in the development of the EssenCES-IDD. It has shown that they were able to contribute to the research process through engaging in interviews. They were also able to discuss their perceptions of the questionnaire and their understanding of the meaning of the questions and response format, and to make suggestions for improvements. To the author's knowledge, there is no evidence that individuals with IDD have previously been involved in the development of any IDD-specific social climate questionnaires.

The next chapter aims to update the pilot version of the EssenCES-IDD based on the adaptations suggested in this chapter.

# Chapter 6: Finalising the Pilot Version of the EssenCES-IDD

## 6.1 Introduction and Aims

The previous chapter explored the perceptions of individuals with IDD, staff, and experts regarding the suitability of the initial pilot version of the EssenCES-IDD. Further amendments were suggested. These amendments related to six themes: layout, time-frame, cover sheets, linguistic content, response format, and administration.

This chapter explores the findings of Chapter 5 alongside relevant literature and accessible information guidelines. This ensures that there is a clear theoretical basis to support any further adaptations. These adaptations, and the rationale for them, is explained and the updated pilot version of the EssenCES-IDD is presented.

## 6.2 Identified Adaptations

This section aims to identify the amendments that are required to develop the updated pilot version of the EssenCES-IDD. The six over-arching themes identified within Chapter 5 will be used to provide a comprehensive and structured framework within which the amendments suggested within Chapter 5 will be discussed. Many of these amendments can be considered straightforward, but some require further exploration as a result of participants expressing conflicting views. In other cases, difficulties were identified, but suggestions of specific amendments required to overcome these difficulties were not provided. Existing literature and accessible information guidelines will, therefore, be used to inform these decisions.

### 6.2.1 Layout

Chapter 5 highlighted that the layout of the initial pilot version of the EssenCES-IDD was much more accessible than that of the original EssenCES. A small number of suggestions for improvements were made.

Participants suggested that the EssenCES-IDD could be printed double sided, providing that administrators highlighted this to individuals with IDD prior to completion. This will be added to the administration guidelines.

The use of large, single pages including the wording for each question in a larger font was suggested as a way of supporting those who have difficulties reading or who struggle to read standard sized text. This approach has been used within other IDD specific questionnaires such as the CORE-LD30. Therefore, administrators will be informed within the administration pack that they can print the EssenCES-IDD questions on single pages if required.

Finally, the addition of colour was suggested as a way of making the questionnaire appear less like a test, thus reducing the negative connotations individuals may associate with tests. It was suggested that colour could be included in a graded way within the visual representations of the response format. Participants highlighted that this would also bring about benefits in terms of aiding individuals to differentiate between the weighting of the different response options. It does not appear that colour has been included in this manner within other IDD specific questionnaires. However, given that this point was also raised within Chapter 3 it seems appropriate to incorporate this suggestion. Avoidance of colours relating to traffic lights appears essential (see Section 3.6.3.2), with the colours red and green also reported as being problematic for individuals who are dyslexic (British Dyslexia Association, 2018). Therefore, the colour blue will be used as this does not have any positive or negative connotations and is not documented to cause difficulties for individuals who are dyslexic. Administrators would need to be made aware of the need to print the questionnaires in colour, although greyscale printing would still enable utilisation of the graded colour, albeit in varying shades of grey. Of note is that those with additional diagnoses, such as dyslexia, may struggle with visual discrimination and experience difficulties differentiating between the subtle differences in colour, including shades of grey. However, given that they may also struggle to read the questions and response option headings, they may be more reliant on administrators to present the questions and response options verbally. This has the potential to impact upon their understanding and subsequently the validity of their responses. Attention may need to be afforded to this

within future research. A note regarding colour printing will be added to the administration guidelines along with a brief sentence highlighting the potential importance of presenting information verbally to individuals with dyslexia or similar conditions.

### 6.2.2 Time-Frame

The original EssenCES does not stipulate a time-frame to which the items on the questionnaire relate. Chapter 3 highlighted the need to provide a concrete time-frame, with participants suggesting either "over the last one week" or in the "here and now". The initial pilot version of the EssenCES-IDD incorporated a one-week time-frame; however, Chapter 5 drew attention to the potential difficulties of this (see Section 5.6.2). It is evident that identification of an appropriate time-frame is going to be problematic. There are difficulties with using a one-week time-frame as discussed earlier; however, using either a shorter or longer time-frame could also result in difficulties. If a "here and now" time-frame was used this could be interpreted in a concrete manner by individuals with IDD. Thus, any questions enquiring about aggressive patients or prisoners would be asking whether this is occurring right now, and would obviously lead to a large underrepresentation of the presence of aggression on the ward or wing. Consequently, it would fail to provide an overall gauge of the social climate of the ward or wing. Equally, using a longer time-frame of, for example, one to two months, could also result in a variety of difficulties. Individuals with IDD can present with differing long-term memory abilities (Kells, 2011), thus, some may not be able to recall information across this duration of time. This could also result in some individuals experiencing difficulties in identifying an anchor event. Some individuals may not have been on the ward or wing for this length of time, meaning that a decision would have to be made as to whether or not they are able to complete the questionnaire. Feedback from individuals with IDD in Chapter 5 indicated that these individuals considered that they would be able to recall events from over the last three months. However, this does not mean that all individuals with IDD would possess this ability, particularly given that it is unclear how representative these participants were of the broader forensic IDD population.

A variety of other questionnaires developed for the IDD population use a one-week time-frame (e.g., the CORE-LD30 and GAS-ID). However, these measure very different concepts to

that of social climate and require individuals to consider internal thoughts and feelings as opposed to external or environmental factors. These concepts are also likely to be less dynamic in nature than social climate. Chester et al. (2015) reviewed difficulties experienced by individuals with IDD when completing the EssenCES. However, the time-frame was not mentioned. Barker et al. (2020) and Robinson and Craig (2019) developed adapted versions of the EssenCES for individuals with IDD. Again, they did not make reference to the time-frame. Furthermore, Neimeijer et al. (2018) did not discuss inclusion of a time-frame within their adapted version of the GCI for individuals with IDD. This would suggest that either it was not considered an important factor within these questionnaires or that this area was not afforded any attention. Thus, further consideration is warranted.

When considering the most appropriate time-frame to use, it is important to consider the purpose of the EssenCES-IDD, in particular what services would hope to achieve through gathering and analysing the data. The original EssenCES was intended to be used for either longitudinal or cross-sectional monitoring, enabling exploration of changes in social climate over time. It is envisioned the same would apply for the EssenCES-IDD. The original EssenCES does not include a time-frame. However, the wording of the items implies a "here and now" approach. This ties in with the author's comments that the original questionnaire is intended to provide a "snapshot" view of the social climate of the ward or wing (Schalast & Tonkin, 2016). Therefore, one can question whether attempts to identify an appropriate time-frame are actually overcomplicating the process of developing the EssenCES-IDD. In particular, given that the addition of a time-frame could render EssenCES-IDD data incomparable with data gathered using the original EssenCES, it must be questioned whether a time-frame should be provided at all.

The EssenCES-IDD items do not necessarily lend themselves towards a fixed time-frame. Thus, leaving the time-frame open would be the most appropriate choice at this stage. Identification of a time-frame that would be appropriate for all individuals with IDD, and that would also be suitable for the variety of purposes for which services may seek to gather EssenCES-IDD data, seems difficult to establish based on the data gathered through this research. Leaving the time-frame open would mean that individual services can make their own decisions regarding their chosen time-frame in line with their reasons for using the

questionnaire. This would ensure that services can maximise the benefits from the data gathered and would also be in line with purpose of the original EssenCES. This decision might appear to disregard the feedback of participants within Chapter 3 (who suggested that a concrete time-frame would be necessary). However, there is no strong justification for the inclusion of any particular time-frame at this point. Also, there is no literature to date which has explored the suitability of different time-frames within social climate questionnaires for individuals with IDD. Thus, further research will be required in order to establish whether a time-frame is necessary and, if so, its duration.

### 6.2.3 Cover Sheets

Further adaptations that were proposed within Chapter 5, and that will be incorporated within the updated pilot version of the EssenCES-IDD, are detailed in Table 6A. The rationale for these changes is also provided. Updated cover sheets for individuals with IDD and staff can be found in Appendices 24-27.

**Table 6A**

*Summary of Adaptations Required to the Cover Sheets of the EssenCES-IDD*

| Population | Amendment Required | Rationale |
|---|---|---|
| Individuals with IDD and staff | Add the statement "Please answer all the questions". | Subscale scores for the EssenCES cannot be calculated if there is more than one missing response for the subscale. Missing responses may be more common in IDD. |
| | Replace the statement "We are asking these questions because we want to find out what it is like to be on the wing/ward and if there are any changes we can make that will help to improve the wing for both prisoners and staff" with "We are asking these questions to help us think about how the wing/ward can be improved". | Inclusion of the word "change" within the original statement could be problematic given that change can be a worrying prospect for individuals with IDD.<br><br>The original statement could be seen to be promising change on the ward or wing. This may not be appropriate given that it is up to individual services to determine how they utilise EssenCES-IDD data.<br><br>If services wish to provide further information for individuals with IDD or staff regarding their reasons for administering the EssenCES-IDD then they must take responsibility for doing so. This point will be noted within the administration guidelines |
| | Remove any references to the time-frame and anchor events.<br>Ensure that all sentences are ended with a full stop. | This is no longer required as the time-frame for the EssenCES-IDD items has been removed.<br>To improve clarity of punctuation within the cover sheets and to ensure that punctuation is in line with recommendations made within accessible information guidelines. |

| Population | Amendment Required | Rationale |
|---|---|---|
| Staff | Replace the statement “Please note that the comment boxes are optional; however, we would welcome any additional feedback that you wish to provide” with “We would welcome any additional feedback within the comment boxes. However, you may choose to leave the comment boxes blank if you prefer”. | To ensure the comment boxes are presented as “opt-out” as opposed to “opt-in”. This may increase staff engagement in the provision of qualitative feedback. |
| Individuals with IDD | Add the following statement to the top of the cover sheet “This sheet should be read by patients/prisoners. Staff can read the sheet to patients/prisoners if they need to”. | This will provide clarity regarding who should read the cover sheet. |
| | Add the statement “There is not a time limit”. | To ensure that individuals with IDD do not feel rushed when completing the questionnaire. |
| | Add the statement “The comment boxes are optional. Please ask staff if you need any help with writing your comments”. | To ensure individuals are made aware that the comment boxes are optional. Some individuals with IDD may experience difficulties in writing their own comments. Therefore, it should be made clear to that administrators can write their comments down for them if required. |
| | Add the statement “Please speak to staff if you have any worries or concerns after finishing the questionnaire”. | The questionnaire does not include any contentious items. However, it does encourage respondents to think about the environment of the ward or wing, including perceptions of safety. There is the potential that a small number of respondents could find this difficult and may need to speak with staff following completion. |

### 6.2.4 Linguistic Content

Chapter 5 highlighted that the linguistic content of the EssenCES-IDD was generally more accessible than that of the original version. Minor amendments were suggested for some of the EssenCES-IDD questions to further improve clarity and to ensure that the questions and response options are cohesive. Attention was also afforded to the scripted rewordings of the EssenCES-IDD questions.

This section aims to identify any further amendments required to the EssenCES-IDD items and to explore whether the scripted rewordings are necessary. The accessibility of the EssenCES-IDD questions will then be examined using readability statistics.

#### *6.2.4.1 EssenCES-IDD Questions*

A small number of amendments were proposed within Chapter 5. Table 6B details the amendments that will be incorporated within the updated pilot version of the EssenCES-IDD. The rationale for these changes is also provided.

**Table 6B**

*Adaptations Proposed for Individual EssenCES-IDD Items*

| Item number | EssenCES-IDD item | Adaptations required and rationale |
|---|---|---|
| 1. | Is this ward/wing a nice place to be? | Remove this item<br>• It is an unscored item and therefore considered unnecessary |
| 2. | Do prisoners care about each other? | Replace with "Do patients/prisoners show care for each other?"<br>• Places emphasis on the behavioural aspect of "showing" care which may be easier for individuals with IDD to recognise. |
| 3. | Do scary things happen on the wing? | Replace with "Do threatening events happen on the ward/wing?"<br>• Revert back to use of the word "threatening". Although this is a more complex word, the word "scary" may not capture the same sense of harmful behaviour that the original item is enquiring about and may, therefore, result in over-reporting.<br>• Include the word "events" to make it clear that the question pertains solely to events that respondents have found threatening. |
| 4. | Can prisoners talk to staff about all their problems? | Replace with "Are patients/prisoners able to talk to staff about their problems?"<br>• The word "all" is unnecessary.<br>• Makes it clear that the question is asking whether individuals are *able* to talk to staff as opposed to whether they do talk to staff. |

| Item number | EssenCES-IDD item | Adaptations required and rationale |
|---|---|---|
| **Item number** | **EssenCES-IDD item** | **Adaptations required and rationale** |
| 5. | Do prisoners that are having a bad day get support from other prisoners? | No amendments required. |
| 6. | Are there angry prisoners on this wing? | Replace with "Are there aggressive patients/prisoners on this ward/wing?"<br>• Revert back to the word "aggressive". Although this is a more complex word, the word "angry" may not capture the behavioural aspect that the original item is enquiring about (anger is an emotion whereas aggression is a behaviour) and may, therefore, result in over-reporting. |
| 7. | Do staff care whether prisoners are doing well? | *Swap this question with Question 13, as this question should be based more around long-term progress, and Question 13 around short-term achievements. Therefore, this question becomes: Do staff care about patients/prisoners getting better?<br>Replace with "Do you think staff care whether patients/prisoners are making progress?"<br>• Add the prefix of "do you think" to ensure it is clear that the question is asking about the opinion of patients/prisoners as opposed to expecting patients/prisoners to know whether staff care.<br>• Replace "getting better" with "making progress" to ensure the question is asking about patients/prisoners moving forward over a longer time-period. Although the concept of progress is somewhat abstract, there does not appear to be a more concrete alternative. "Getting better" also implies that individuals are unwell which is inappropriate within prison settings. |

| Item number | EssenCES-IDD item | Adaptations required and rationale |
|---|---|---|
| 8. | Do prisoners care about the problems of other prisoners? | No amendments required. |

| Item number | EssenCES-IDD item | Adaptations required and rationale |
|---|---|---|
| 9. | Are some prisoners scared of other prisoners? | No amendments required. |
| 10. | Do staff spend a lot of time helping prisoners? | Replace with “Do staff help patients/prisoners?”<br>• Remove “spend a lot of time” as the time aspect is covered within the response format. |
| 11. | Do prisoners get support from other prisoners when they are worried? | No amendments required. |
| 12. | Are staff scared of some of the prisoners? | Replace with “Do you think staff are scared of some of the patients/prisoners?”<br>• Add the prefix of “do you think” to ensure it is clear that the question is asking about the opinion of patients/prisoners as opposed to expecting patients/prisoners to know what staff feel. |
| 13. | Do staff care about prisoners getting better? | *Swap this question with Question 7, as this question should be based more around short-term achievements, and Question 13 around long-term progress. Therefore, this question becomes: Do staff care whether patients/prisoners are doing well?<br>Replace with “Do you think staff care whether patients/prisoners are doing well?” |

| Item number | EssenCES-IDD item | Adaptations required and rationale |
|---|---|---|
| | | • Add the prefix of “do you think” to ensure it is clear that the question is asking about the opinion of patients/prisoners as opposed to expecting patients/prisoners to know whether staff care. |
| 14. | Is there good support between prisoners? | No amendments required. |

| Item number | EssenCES-IDD item | Adaptations required and rationale |
|---|---|---|
| 15. | Are some prisoners so scary that you have to stay away from them? | Replace with “Do patients/prisoners stay away from unpredictable patients/prisoners?”<br>• Replace “scary” with “unpredictable” to ensure that the underlying concept of the question is retained. Although this is a complex word, there does not appear to be any alternative, simple, words which would fully capture this concept of un-boundaried or unpredictable behaviour.<br>• Amend the sentence structure to make it simpler to follow. |
| 16. | Do staff know prisoners well? | Replace with “Do you think staff know patients/prisoners well?”<br>• Add the prefix of “do you think” to ensure it is clear that the question is asking about the opinion of patients/prisoners as opposed to expecting patients/prisoners to know what knowledge staff have. |
| 17. | Are prisoners and staff comfortable on this wing? | Remove this question<br>• It is an unscored item and therefore considered unnecessary. |

#### *6.2.4.2 Scripted Rewordings*

Chapter 3 highlighted that scripted rewordings of the EssenCES-IDD questions would be beneficial and these scripted rewordings were developed in Chapter 4. However, Chapter 5 identified some difficulties with these, as it is difficult to find alternative phrases that do not substantively change the meaning of individual items.

There are various ways that this issue could be addressed:

1. Amend the scripted rewordings

Feedback from Chapter 5 could be used to make changes to the scripted rewordings. This approach may be preferable to the introduction of more uncontrollable biases which could occur should administrators reword the questions in their own way. However, based on the feedback gathered through Chapter 5, this would be a very difficult, if not impossible, task.

Neimeijer et al. (2018) did not include scripted rewordings in their revised version of the GCI for individuals with IDD and Barker et al. (2020) did not include this within their adapted EssenCES for individuals with IDD. Robinson and Craig (2019) attempted to develop a glossary of alternative words for their adapted EssenCES but commented that it was difficult to find appropriate alternatives. Given that the EssenCES-IDD questions are simplified versions of the items on the original EssenCES, further simplification of the questions to develop these rewordings will be difficult to achieve. Furthermore, the risk of oversimplification and subsequently the risk that questions on each subscale essentially become identical would present further difficulties (see Section 3.6.2.3).

2. Include behavioural descriptors that depict the concepts included within the questions as opposed to using scripted rewordings

This was discussed in Chapter 3. Participants suggested that this approach would support individuals to elicit meaning from the questions. They also perceived that this approach would make the items more concrete as behavioural descriptors would provide a more

observable construct for individuals to relate to. These behavioural descriptors could utilise data gathered from individuals with IDD in Chapter 5, incorporating their understanding of the different concepts included within the EssenCES-IDD to identify key words or phrases relating to observable behaviours. This technique has been used within questionnaires developed for individuals with IDD (e.g., the CORE-LD30). However, some of the EssenCES-IDD questions already include behavioural descriptors (e.g., showing care, threatening events, staff helping patients/prisoners, and staying away from unpredictable patients/prisoners) and, for many of the remaining questions, it would be very difficult to identify appropriate behavioural descriptors (i.e., how would one describe behaviours that would demonstrate making progress, knowing patients or prisoners well, or feeling scared?). These issues are similar to those that would likely be experienced if attempts were made to include pictorial representations of the EssenCES-IDD questions.

In Chapter 5, individuals with IDD were able to identify behavioural descriptors themselves and included them as examples within their qualitative feedback on the questionnaire. They also discussed these descriptors with the researcher. However, this does not mean all individuals with IDD would possess this ability. Furthermore, it is likely that individuals with IDD will likely be able to relate to different behavioural descriptors. This would mean that a variety of behavioural descriptors may be required for each question, thus increasing the potential for this to alter the meaning of the questions and, consequently, reducing the validity of data gathered.

3. Remove scripted rewordings

The scripted rewordings could be removed completely on the premise that, having trialled the questionnaire with individuals with IDD, the scripted rewordings generally were not used and, therefore, are not required. It may be that the amendments made when simplifying the questions for the EssenCES-IDD (e.g., using short simple sentences and removing complex and abstract words) have been sufficient to enable understanding of the questions.

In summary, given that it has proven difficult to reword the EssenCES-IDD questions in such a way that both retains their original meanings and does not result in oversimplification, inclusion of scripted rewordings would appear, at this stage, to be of no benefit. The inclusion of behavioural descriptors also appears inappropriate due to the multitude of issues that this could lead to. It is important to ensure that the EssenCES-IDD resembles the original EssenCES as closely as possible given that the original questionnaire has been validated across a variety of countries and settings. This means that the more changes made, the less likely the adapted version is to be comparable to the original. The scripted rewordings will, therefore, be removed. The administration guidelines will also be updated to reflect this decision. It is, however, important that this issue be given attention in future research.

#### *6.2.4.3 Readability Statistics*

To examine the readability of the updated pilot of the EssenCES-IDD, Flesch and Flesch-Kincaid reading ease scores were calculated and compared to the initial pilot version and the original EssenCES (see Table 6C).[5]

[5] Of note is that the author of this thesis would have liked to include readability statistics for the adapted EssenCES developed by Barker et al. (2020) and the revised GCI developed by Neimeijer et al. (2018), but these questionnaires are not available in published literature and it was not possible to obtain copies from the authors.

**Table 6C**

*Reading Ease Scores for the Original Versions of the EssenCES, and the Initial and Updated Pilot Versions of the EssenCES-IDD*

| Version | Original EssenCES | | EssenCES-IDD initial pilot version | | EssenCES-IDD updated pilot version | |
|---|---|---|---|---|---|---|
| | Flesch reading ease score | Flesch-Kincaid grade level | Flesch reading ease score | Flesch-Kincaid grade level | Flesch reading ease score | Flesch-Kincaid grade level |
| Hospital version | 72.6 | 5.4 | 85.0 | 3.4 | 80.1 | 4.1 |
| Prison version using original terms of "inmates" and "unit" | 69.1 | 6.0 | 82.6 | 3.7 | 78.7 | 4.3 |
| Prison version using amended terms of "prisoners" and "wing" | 69.1 | 6.0 | 73.6 | 5.0 | 67.3 | 5.9 |

*Note.* Higher Flesch reading ease scores and lower Flesch-Kincaid grade level scores indicate greater readability.

The readability scores for the updated pilot versions of the EssenCES-IDD show that the Flesch reading ease scores are lower, and the Flesch-Kincaid grade levels are higher, than those for the initial pilot versions. This indicates that the updated pilot versions are somewhat more complex to read. It is likely that the reintroduction of longer, multi-syllable words such as “aggressive”, “unpredictable” and “progress” have contributed to this. Inclusion of the prefix “do you think” for questions pertaining to perceptions of the views of staff has also increased the length of some sentences. These amendments were all made based on feedback from staff, individuals with IDD, the Speech and Language Therapist, and social climate experts. Thus, there are clear justifications for their necessity.

Concerningly, the Flesch reading ease score for the prison version of the updated pilot questionnaire is slightly lower than that of the original EssenCES, seemingly indicating that this IDD-specific version is more complex to read than the original EssenCES. Given that the only differences between the hospital and prison versions of the EssenCES-IDD are that the hospital version uses the terms “patient” and “ward” whereas the prison version uses the terms “prisoner” and “wing”, it is evident that it is these terms that are being highlighted as problematic within the readability statistics. Table 6C shows that, if these terms were to be replaced with the terms “inmate” and “unit” (as used within the original prison version of the EssenCES) then the readability statistics improve considerably and are not dissimilar to those obtained for the updated hospital pilot version. Readability statistics use formulas based on surface level language features such as the number of words in a sentence and the number of syllables in each word (Buell, 2017). It is apparent that the increase in syllables that has occurred as a result of changing the word “inmates” to “prisoners” has been highlighted as being more complex. However, given that both staff and individuals with IDD that participated in this research stated that the term “prisoner” was commonly used, and understood, within UK prison settings, using this term within the EssenCES-IDD is appropriate and unlikely to lead to challenges in understanding the EssenCES-IDD. Furthermore, accessible information guidelines frequently state the need to use high frequency (common) words within resources for individuals with IDD, thus providing additional support for the inclusion of the term “prisoner”. It is also necessary to note that, as discussed in Section 3.6.2.3, individual services can amend

these terms as required to incorporate the terms which best suit their service and which individuals are familiar with.

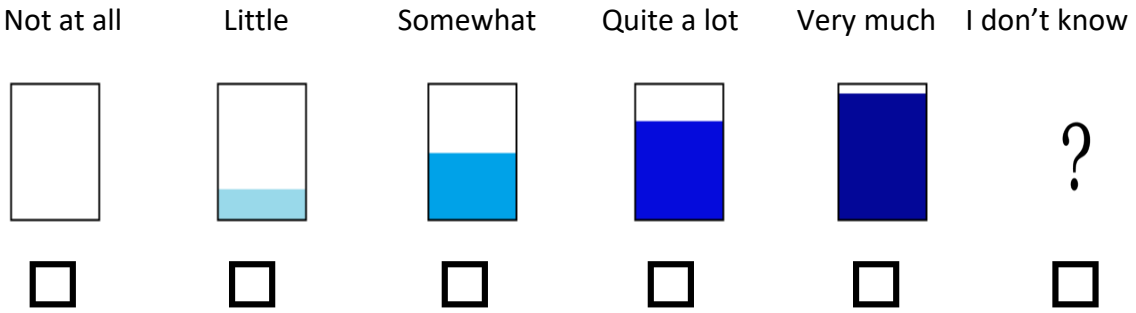
### 6.2.5 Response Format

Chapter 5 highlighted that the response format of the initial pilot version of the EssenCES-IDD was more suitable for individuals with IDD than that of the original EssenCES. Participants did, however, draw attention to a small number of further amendments that may be required.

The need to include tick boxes so respondents can mark their response choices on the questionnaire was highlighted. Participants also suggested adding a solid line to the top of the "cups" used within the visual representations of the response options. Other IDD specific questionnaires that have used similar visual representations (e.g., the CORE-LD30) have not added this line. However, as there does not appear to be any reason why this addition would be problematic, and as there may be the potential for this to benefit some individuals, this amendment will be included.

Attention was also drawn within Chapter 5 to the wording of the response option headings. Participants noted that some response option headings on the EssenCES-IDD were quantity-orientated whilst others were frequency-orientated. The original EssenCES measured level of agreement with each item, as opposed to either quantity or frequency. Participants suggested further amendments to the response option headings so that they were either all quantity-orientated or all frequency-orientated. However, discussion surrounding this led to the identification of problems that could occur as a result of making changes to the response format. Given that the original EssenCES measures level of agreement with the items, if the EssenCES-IDD were to use quantity or frequency-based response option headings, this would result in the EssenCES-IDD gathering different data to that gathered by the EssenCES. On this basis, it seems necessary to retain use of the response option headings that are used within the original EssenCES. However, given that the items have been rephrased as questions, inclusion of the prefix of "I agree" (as included on the original EssenCES) was not deemed to be required.

The response format for the updated pilot version of the EssenCES-IDD will, therefore, be presented as follows:




| |
|---|
| Is there anything you would like to say about this? |

Finally, it was observed that one individual with IDD within Chapter 5 did not understand the visual representations of the response options. This individual was unable to read the response option headings, thus utilised only the visual representations to select their responses. All other individuals with IDD appeared to have no issues understanding the response format; however, this has highlighted the need for administrators to check individuals' understanding of the response format prior to completion of the questionnaire. As discussed within Chapters 3 and 4, practice questions were not felt to be appropriate and, indeed, practice questions may not have identified this individual's lack of understanding of the response format. An alternative way of addressing this issue would be that individuals with IDD are asked to complete a short sequencing task prior to completion of the questionnaire. This task could involve individuals being presented with cards depicting the visual representations of the response options along with the response option headings and being asked to put these cards in order from the empty box to the full box. This task was utilised within development of the CORE-LD30 and appears to have been used as

a learning experience whereby, if an individual experienced difficulty completing the task correctly, administrators demonstrated the correct sequence. All individuals were able to continue to complete the CORE-LD30 regardless of their initial understanding of the sequencing task.

Section 3.6.4.4 highlighted that participants in the current research recognised the importance of allowing individuals to continue on to complete the EssenCES-IDD regardless of their response to any pre-test screening that may be added. It would therefore appear necessary to include additional support for individuals that experience difficulties with the sequencing task. This could include both demonstrating and explaining the correct sequence. Despite this, some individuals may still struggle to understand and, in these cases, administrators could be asked to remind individuals of the correct sequence after the individual (or administrator) has read out each individual question. They could also be asked to note this in the feedback box at the end of the questionnaire. The addition of the sequencing task is not likely to result in all individuals gaining an accurate understanding of the response option headings and visual representations, but it is anticipated that it will enable provision of extra support to understand the response options along with drawing administrators' attention to individuals who may require additional support to select their responses.

### 6.2.6 Administration

Chapter 5 identified minor amendments to the administration guidelines, including the simplification of language, shortening sentences, splitting longer sentences, and changing the word order within some sentences. All of the recommended changes have been made, as they enhance clarity of the updated pilot version of the EssencES-IDD. References to scripted rewording and anchor events will be removed and points relating to administration that have been discussed within earlier sections of this chapter will be added.

Staff participants in Chapter 5 expressed that they considered the feedback boxes at the end of the questionnaire were a useful addition and could be used to document

their observations of the presence of any response biases. Difficulties with the sequencing task could also be documented within these boxes (see Section 6.2.5). However, it will need to be made clear within the administration guidelines that difficulties understanding the sequencing task, or the presence of response biases, must not result in any individuals' responses being excluded from the dataset. This feedback should only be used to aid understanding of individuals' responses (i.e., to explain discrepancies between an individual's quantitative and qualitative responses or to highlight possible reasons for outliers within ward or wing level quantitative data).

Finally, Chapter 5 again highlighted that the decision regarding who is best placed to administer the EssenCES-IDD is not straightforward. At the present time there is no research evidence that identifies who is best placed to administer social climate questionnaires with individuals with IDD in forensic settings. This decision must be made by the individual services, who it is expected would take into consideration the pros and cons of administration by both familiar and unfamiliar administrators. Until further research is conducted in this area, this is the only advice that can be offered.

### 6.2.7 Summary

Following the various amendments discussed within this chapter, Table 6D documents the amendments that will be made to the initial pilot version of the EssenCES-IDD. The updated pilot versions of the questionnaire (hospital and prison versions for individuals with IDD and staff) can be found in Appendices 24-27 and the updated version of the administration guidelines can be found in the administration pack (Appendix 28).

**Table 6D**

*Summary of Adaptations – Development of the Updated Pilot Version of the EssenCES-IDD*

| **Layout** | **Time-Frame** |
|---|---|
| Include the option for double sided printing within the administration guidelines.<br><br>Inform administrators that they can provide large, single, sheets that include only the wording for each individual question in a larger font.<br><br>Include graded colour within the visual representations of the response options.<br><br>Add a note regarding colour printing to the administration guidelines along with a brief sentence highlighting the potential importance of presenting information verbally to individuals with dyslexia or similar conditions. | Remove the time-frame along with any references to identifying an anchor event. |
| **Cover Sheets** | **Linguistic Content** |
| Include amendments as highlighted in Table 6A. | Include amendments as highlighted in Table 6B.<br><br>Remove scripted rewordings. |
| **Response Format** | **Administration** |
| Add answer boxes.<br><br>Amend response option headings (not at all, little, somewhat, quite a lot, very much).<br><br>Add sequencing task and include information surrounding this within the administration guidelines. | Make minor modifications to the administration guidelines (simplify some of the language, shorten sentences and change the word order in some places). |

## 6.3 Conclusions

This chapter sought to describe the amendments made to the initial pilot version of the EssenCES-IDD. Feedback from individuals with IDD, staff working within IDD settings, social climate experts and a Speech and Language Therapist was explored. This resulted in a small number of amendments being made. The updated pilot version of the questionnaire was then presented.

When developing the updated pilot version of the EssenCES-IDD it was important to ensure that the revised items retained their original meanings. Input from social climate experts, Speech and Language Therapy, and professionals was paramount with regards to gathering feedback regarding whether the meanings of the original items were retained and whether the scripted rewordings also retained the original items' meanings. A small number of instances were identified by the Speech and Language Therapist and by the social climate experts whereby the meanings of the revised items were considered to differ from the original meanings (e.g., as a result of changing the word 'angry' to 'aggressive' and the word 'threatening' to 'scary') or where there was a discrepancy between the revised item and the scripted rewording (e.g., "Is this ward a nice place to be?" versus "Do patients like being on the ward?"). This resulted in some further amendments being made, including reinstating some words which had been removed from the items and replaced with simpler words. Despite some of these words being considered as more complex for individuals with IDD, their reintroduction was necessary to enable retention of the items' meanings, thus ensuring construct validity was maintained.

# Chapter 7: Conclusions, Implications, and Future Considerations

## 7.1 Introduction

The aims of this thesis were to:

1. Ascertain whether the current version of the EssenCES is suitable for use with individuals with IDD;
2. Identify what adaptations need to be made to improve the suitability of the EssenCES for individuals with IDD;
3. Develop a pilot version of an adapted EssenCES for individuals with IDD (the EssenCES-IDD); and
4. Conduct a preliminary exploration of how individuals with IDD interpret the concepts that underpin forensic social climate.

This chapter reviews the unique contributions the literature review and empirical studies included with this thesis make to theory, policy, and practice, discusses the limitations of this research, and makes suggestions as to how future research could build upon its findings.

## 7.2 Contribution of the Thesis to Theory

The theoretical implications of this thesis encompass three key areas:

1. Enhancing understanding of the suitability of existing social climate questionnaires for forensic IDD populations;
2. Developing social climate questionnaires for forensic IDD populations; and
3. Developing an initial understanding of how individuals with IDD interpret the concepts that underpin forensic social climate.

### 7.2.1 Enhancing Understanding of the Suitability of Existing Social Climate Questionnaires for Forensic IDD Populations

The measurement of the social climate of forensic IDD settings has received little attention within the literature to date. Concerningly, the small number of studies that have explored the social climate of such settings have generally done so using social climate questionnaires that have not been validated for the IDD population (e.g., Glennon & Sher, 2018; Langdon et al., 2012; McGee & Woods, 1978; Quinn et al., 2012; Willets et al., 2014). Recent research has highlighted difficulties relating to the use of existing social climate questionnaires in IDD populations (e.g., Bell et al., 2018; Chester et al., 2015; Robinson & Craig, 2019). However, as discussed in Chapter 2, the lack of an appropriate measurement tool that encompasses the entirety of forensic IDD services remains – thus precluding broad exploration of the social climate of forensic IDD settings.

The current research has made a significant contribution to understanding the suitability of existing social climate questionnaires for the IDD population. This has been achieved through conducting a comprehensive review of the literature surrounding IDD social climate. This review expanded on the work of Bell et al. (2018) and incorporated (i) literature pertaining to IDD social climate, (ii) literature surrounding general difficulties experienced by individuals with IDD when completing self-report questionnaires, (iii) literature and existing IDD-specific questionnaires that have sought to explore ways in which self-report questionnaires can be adapted for the IDD population, and (iv) accessible information guidelines pertaining to the development of IDD-specific resources. As far as the author is aware, this is the most comprehensive review of the topic conducted to date. This review concurred with the findings of Bell et al. (2018), identifying that existing social climate questionnaires are not suitable for use with forensic IDD populations in their current forms. Moreover, the studies included in this research have also provided empirical evidence that supports the aforementioned point, specifically in relation to the original EssenCES. These studies identified a multitude of difficulties that individuals with IDD could experience when completing the original EssenCES, all of which would likely impact upon the reliability and validity of data gathered. This research, therefore,

underscores the importance of developing IDD-specific social climate questionnaires and provides solid theoretical justifications for doing so.

This research has also drawn attention to difficulties that staff can experience when completing the original EssenCES, with data clearly demonstrating that even the staff that participated in the studies included within this research struggled to understand some of the original EssenCES items. One of the reasons for this may be that the EssenCES was originally written in German and later translated to English. This could have resulted in the items contained on the English version of the EssenCES being worded in a way that is uncharacteristic of the conventional structure of the English language. Evidently, this has the potential to impact not only on staff completion, but also on the ability of non-IDD individuals in forensic settings to complete the original EssenCES. This is obviously a cause for concern, particularly given that English will not be the first language for everyone who will complete this questionnaire. Fundamentally, however, the key issue is that the questionnaire must be understood by as many patients, prisoners, and staff as possible regardless of IQ or native tongue. Based on the author's review of relevant literature, these issues do not appear to have been identified or explored in the literature to date. This does, however, raise the question of whether it would be appropriate for the EssenCES-IDD to replace the original EssenCES across all forensic settings, as opposed to just forensic IDD settings.

### 7.2.2 Developing Social Climate Questionnaires for Forensic IDD Populations

This research represents the first wide-scale attempt to develop an IDD-specific version of a social climate measure for the IDD population, incorporating the views of staff members working in IDD settings, Speech and Language Therapists, social climate experts and, most importantly, the views of individuals with IDD. Other climate questionnaires have been developed for individuals with IDD. For example, Neimeijer et al. (2018) developed an IDD version of the GCI which demonstrated adequate reliability and retention of the four-factor structure of the original version of the GCI. However, this questionnaire pertains to group climate which is a slightly different concept to social climate (see Section 2.2 for further information). Furthermore, some studies have attempted to adapt the EssenCES for IDD populations. For example,

Robinson and Craig (2019) examined the relationship between social climate and aggression in IDD settings and developed an IDD version of the EssenCES to use within their study. However, the authors acknowledged difficulties with the adaptation process and reflected that further research was required in this area. Barker et al. (2020) also developed a modified version of the EssenCES for use in low secure settings. However, both studies only sought feedback on the adaptations required to the EssenCES from a small number of staff or professional participants within UK forensic hospital settings. Furthermore, neither sought the views of social climate experts or individuals with IDD (which are of particular importance with regards to ensuring that the meaning of the items has been retained, and ensuring that both the items and pictures are interpreted by individuals with IDD in the way in which they are intended). Thus, the large-scale, international, nature of the current research has made a distinct contribution to existing literature.

The comprehensive literature review and the studies included within this research have furthered existing knowledge regarding the difficulties individuals with IDD may experience when completing social climate questionnaires, and how such questionnaires can be adapted. Although this research focused solely on development of an IDD version of the EssenCES, it is likely that both the difficulties experienced when completing this questionnaire, and the adaptations made, would be applicable not only to other social climate questionnaires, but to questionnaires for individuals with IDD in general. There is a significant lack of research exploring the adaptation of questionnaires for the IDD population and, concerningly, many questionnaires that have been adapted for individuals with IDD do not provide rationale for the adaptations made. Thus, this research provides both researchers and clinicians with valuable insights into the types of adaptations that could be applied to improve the accessibility of a multitude of questionnaires for individuals with IDD, along with clear theoretical justifications for such adaptations. Furthermore, this research has drawn attention to key points requiring further consideration when adapting social climate questionnaires for the IDD population. This includes questions surrounding, for example, (i) who is best placed to administer such questionnaires, (ii) whether appropriate pictorial aids can be identified and successfully used to depict the constructs that make up social climate, and (iii) whether there is a way of

incorporating scripted rewordings to further simplify easy read questions without this impacting upon question meaning. Again, some of these points are also applicable on a broader scale to other questionnaires for individuals with IDD, but have received very little, if any, attention in the literature to date.

This research incorporated broad methods of collecting social climate data through the inclusion of comment boxes within the EssenCES-IDD. This provided a means of gathering additional qualitative social climate data. It is evident that the social climate literature to date has rarely utilised qualitative data (the exception being the MQPL). Consequently, there is limited existing qualitative social climate data relating to prison environments and none relating to forensic hospital settings. The introduction of this unique qualitative element within the EssenCES-IDD will likely further understanding of IDD social climate. It could also be incorporated without extensive effort within other existing social climate questionnaires, both for IDD and non-IDD populations. This has the potential to further current understanding of social climate through enabling more in-depth exploration of the subjective experiences of the ward or wing environment from both forensic residents and staff. This meets the call from researchers to include more qualitative data collection in social climate research (Robinson et al., 2018).

Finally, this research has highlighted the difficulties in developing questionnaires that are accessible to the entirety of the IDD population. It has evidenced the need to consider the heterogeneity of the IDD population and to acknowledge that, regardless of the adaptations that are made or of the way in which questionnaires are specifically developed for individuals with IDD, the majority are going to exclude some individuals with IDD. However, as pointed out by Emerson et al. (2013), this is the most inclusive approach that currently exists, and is evidently preferable to not adapting these questionnaires at all.

### 7.2.3 Developing an Initial Understanding of how Individuals with IDD Interpret the Concepts that Underpin Forensic Social Climate

The qualitative data gathered through the interviews conducted with individuals with IDD in this research has made a unique contribution to the social climate literature. Part of these interviews focused on exploring how individuals with IDD interpreted the concepts that underpin the three EssenCES-IDD subscales which, according to its authors, are the key components of forensic social climate (Schalast & Tonkin, 2016). Although Neimeijer et al. (2021) explored the concepts underpinning group climate with individuals with IDD, it is evident that exploration of this important area in relation to the EssenCES or, indeed any other measures of social climate, has not been addressed within the social climate literature to date, either with IDD or non-IDD populations.

Undertaking such exploration proved beneficial in terms of ensuring that key concepts included within the EssenCES-IDD questions were being interpreted by individuals with IDD in the way in which they were intended. However, an additional advantage of this process is that, similarly to Neimeijer et al. (2021) in their study exploring group climate, this data has helped to form an initial understanding of what the different components of forensic social climate mean to individuals with IDD. The concepts that underpin the experienced safety subscale were explored through discussions surrounding anger, aggression and fear. Similarly, discussions surrounding care and support enabled exploration of the concepts that form the basis of the inmate cohesion, and hold and support, subscales. Importantly, data gathered through these discussions evidenced that care and support were perceived as valuable components of the wing environment by individuals with IDD. Perceptions of threat and fear also clearly contributed to how individuals viewed the wing as a whole. This provides some preliminary evidence of the relevance of the three EssenCES subscales for the IDD population.

## 7.3 Contribution of the Thesis to Policy

The literature review included within this thesis has drawn together a wealth of evidence regarding social climate questionnaires for IDD populations. The findings of this review do not provide support for the use of generic social climate questionnaires within forensic IDD settings. This is also demonstrated through the data gathered in the studies undertaken within this research. No existing questionnaire measures of social climate have been validated for use across the full range of forensic IDD settings. One social climate questionnaire has been validated for use in low secure IDD settings (the modified EssenCES; Barker et al., 2020). However, this thesis has raised concerns regarding its development and, subsequently, the credibility of the authors' findings (see Section 2.2). The current research, therefore, points towards discouraging IDD services from using social climate questionnaires at present, regardless of purpose.

Previous recommendations under the Commissioning for Quality and Innovation (CQUIN) framework required many forensic IDD settings in the UK to monitor social climate, often using the EssenCES. This requirement no longer remains. However, many forensic IDD services continue to monitor social climate as a part of their outcome monitoring processes. Furthermore, research conducted by Morrissey et al. (2017) identified monitoring of social climate using the EssenCES as one of the key outcome domains that forensic IDD hospital services should seek to assess on a regular basis. They recommended that at least 50% of staff should complete the EssenCES and that at least 50% of patients should complete an adapted version of the EssenCES for individuals with IDD within each 12-month period. Evidently, this would not be possible to achieve given that, at present, there is not an IDD-specific version of the EssenCES that has been validated across the full range of forensic hospital settings.

The current research strongly suggests that IDD services should refrain from using questionnaire measures of social climate to gather data from individuals with IDD until an adapted, validated, social climate questionnaire that addresses the difficulties raised within this thesis is available. Services may wish to update their policies or outcome measures databases to reflect this. Any data gathered to date using non-IDD specific social climate questionnaires with forensic IDD populations should not be used to inform policies or practice. Caution should be used when interpreting findings from

research that has used such questionnaires with forensic IDD populations, and these findings should not be used to inform service policies. It is acknowledged that this may result in inconvenience for service policymakers and may interfere with monitoring of Key Performance Indicators. Moreover, failure to include individuals with IDD in the monitoring of social climate could be seen as further marginalisation of this vulnerable group. Thus, it is important for services to consider alternative ways of gathering social climate information from individuals with IDD in the interim (e.g., through collection of qualitative feedback) to ensure that such individuals' perceptions regarding social climate are captured. However, until a specific social climate questionnaire for forensic IDD settings, such as the EssenCES-IDD, has been validated across the full range of IDD settings, it seems prudent to discontinue monitoring of forensic IDD social climate as opposed to continuing to collect, analyse, and act upon data that may well be meaningless. Whilst this thesis has suggested that staff can also experience some difficulties when completing the EssenCES, this area was not explored in any detail. Thus, collection of staff EssenCES data in forensic IDD settings or, indeed, non-IDD settings, should not be altered.

This research has drawn attention to a number of factors relating to the purpose of collecting social climate data that would need to be considered by individual services once a suitably validated measurement tool is available. It is impossible to provide any concrete information regarding how individual services should utilise EssenCES-IDD data as this would depend on the time and resources that services have at their disposal, and on the services' reasons for utilising the EssenCES. The manual for the original EssenCES (Schalast & Tonkin, 2016) describes how it can be used to evaluate the impact of an intervention on the social climate of a ward or wing, or as a means of monitoring the social climate of a ward or wing over time as a way of drawing attention to areas in which service level changes may need to be made. However, the manual does not stipulate any particular changes that should be made as a result of the data gathered. Clearly this will depend on the nature of the issues that are raised and how the individual services choose to respond. It would, therefore, be important for any service policies pertaining to collection of EssenCES-IDD data and, indeed, social climate data in general, to be clear as to the purpose of data collection. Ensuring

that this information is also shared appropriately with staff and patients or prisoners would also be wise.

### 7.4 Contribution of the Thesis to Clinical Practice

The EssenCES-IDD has been developed based on the views of individuals with IDD and of staff working within forensic IDD settings. The perspectives of a specialist Speech and Language Therapist and social climate experts were also sought. To the author's knowledge, input from such a broad range of individuals has not previously been elicited within the development of any social climate questionnaire developed specifically for individuals with IDD. The resulting questionnaire is, therefore, expected to provide a more accurate gauge of IDD social climate, which would bring about many benefits for forensic IDD services. The EssenCES-IDD is likely to afford IDD services the opportunity for both longitudinal and cross-sectional monitoring of social climate, thus maintaining the ability of the original EssenCES to be used for diverse purposes within clinical practice. Administration of the questionnaire on an individual basis with individuals with IDD is likely to offer additional benefits such as opening a channel of communication for individuals with IDD to begin to engage in discussions surrounding their perspectives of the environment within which they reside. EssenCES-IDD data from the ward or wing could be presented to individuals with IDD and staff, thus providing feedback regarding positive aspects of the services' social climate and also highlighting suggestions for service-level changes that could be considered as a result of such discussions.

The ability to collect qualitative data surrounding social climate in IDD settings opens up further opportunities for services. These include gaining an understanding of why individuals with IDD and staff have provided particular responses to the EssenCES-IDD questions and, on a broader level, gathering more in-depth information regarding the reasoning behind ward- or wing-level subscale scores. With the exception of the MQPL, this is an area of evaluation that is not available within any other social climate questionnaires. Although data gathered using the original EssenCES could be used by services as a springboard to open up discussions surrounding social climate within ward or wing meetings, this does not afford individuals with IDD or staff the

opportunity to provide written, individual, feedback in a confidential manner. The combination of statistical and qualitative data gathered using the EssenCES-IDD will, therefore, help services to use EssenCES-IDD data for more than merely outcome monitoring purposes. Services will have the opportunity to use EssenCES-IDD data in a more meaningful way through developing an understanding of respondents' rationale for their quantitative feedback. Thus, if a ward or wing (or service) achieves a low score on a particular subscale, they will be able to comprehend the reasons for this through evaluating the qualitative feedback. Subsequently, this qualitative feedback can be used as the basis for services to identify particular changes that may be required on a ward or wing, or across a service as a whole. It is anticipated that both individuals with IDD and staff will be more likely to engage in completing the questionnaire if they are able to see that their views are being acknowledged and acted upon to drive positive service-level change.

Furthermore, this research has emphasised the need for services to afford increased consideration as to who administers self-report questionnaires with individuals with IDD, particularly with regards to ensuring a degree of consistency, and especially when administering repeated measures. The need to avoid over-simplification of information has also been reiterated through this research. This draws attention to the need for services to ensure that they strike a balance when developing accessible information for individuals with IDD, as information that could be perceived as overly-simplistic has the potential to appear patronising to some individuals and may result in disengagement. To the author's knowledge, this issue has not been highlighted within previous literature.

### 7.5 Contribution of the Thesis to Individuals with IDD in Forensic Settings

Government strategies (e.g., Department of Health, 2001, 2009) have highlighted the importance of providing individuals with IDD with opportunities to express their views and opinions, and to have these views taken into consideration. Development of the pilot version of the EssenCES-IDD is a significant, initial, step towards enabling individuals with IDD to express their opinions regarding the social climate of the ward or wing on which they reside, using a specifically developed, accessible, questionnaire.

It is envisaged that, once validated, the accessible nature of the EssenCES-IDD and the support provided by an administrator throughout completion will encourage more individuals with IDD to provide feedback on their ward or wing. This will enhance inclusion and offer opportunities to contribute to service development, with the aim of improving the environment of the ward or wing on which they reside. The opportunity to provide qualitative feedback through the EssenCES-IDD will enable individuals with IDD to provide relevant, free-text, comments and suggestions, which in turn will aid service-level understanding of the context of individuals' responses to the EssenCES-IDD questions and may open up further opportunities for discussions surrounding the social climate between residents and staff. Ultimately, this may enhance the quality of services delivered to the IDD population and improve resident perceptions of these services, leading to better long-term rehabilitation outcomes (e.g., reduced reoffending).

Individuals with IDD were involved in the development of the EssenCES-IDD. To the author's knowledge, this is the first time that individuals with IDD have contributed to development of an IDD-specific social climate questionnaire. This is concerning given that co-production of accessible information is recommended within various accessible information guidelines (e.g., Department of Health, 2010; Mencap, 2002). Involvement in this research enabled individuals with IDD to express their opinions on the initial pilot questionnaire, and to make suggestions for further amendments which they felt would be beneficial. As demonstrated through Chapters 5 and 6 of this thesis, many of their suggestions have been incorporated within the updated pilot version of the EssenCES-IDD. This has demonstrated that individuals with IDD are able to make useful and valid contributions to development of IDD-specific questionnaires. It is likely that the individuals with IDD who were involved in this research derived benefits from their participation. For example, feeling that their views and opinions were important and, subsequently feeling valued and empowered. Should the EssenCES-IDD be successfully validated, individuals with IDD will have access to a more suitable measure of social climate. Thus, there will be an increased likelihood that data collected will accurately reflect their perceptions of the social climate, resulting in enhanced feelings of inclusion and confirmation that their opinions regarding social climate are important and can drive positive changes within the ward, wing, or service.

## 7.6 Limitations of the Research and Future Directions

Despite the significant contributions of this thesis, a small number of limitations have been identified. It is also evident that a considerable amount of future research remains outstanding. This section will discuss the limitations of this thesis and outline the most important directions for future research.

### 7.6.1 Limitations of This Thesis

The specific limitations regarding the studies included in this thesis have been discussed within the relevant chapters (see Sections 3.7 and 5.7). This section aims to reflect on some of these points and discuss how they may have impacted on the findings of this thesis.

The main limitation of the studies reported in Chapters 3 and 5 is that they all included relatively small participant numbers. Furthermore, broad samples were not obtained within some studies. For example, the interviews and focus groups reported in Chapter 3 were only conducted with UK participants, and the study reported in Chapter 5 only sought the views of individuals with IDD and staff from one UK prison wing. Thus, one could argue that the findings of this thesis may not reflect the views of staff, and individuals with IDD, across the entirety of English speaking forensic IDD settings. However, it was clear within Chapters 3 and 4 that the majority of staff that participated in the studies shared similar perspectives regarding the difficulties individuals with IDD may experience when completing the original EssenCES and the amendments that would be required to develop the initial pilot version of the EssenCES-IDD. Furthermore, it was also evident within Chapters 5 and 6 that the individuals with IDD, staff, and experts that participated in the study generally provided consistent feedback regarding the final amendments that were required to the EssenCES-IDD. There was a clear pattern of themes that evolved within Chapters 3 and 4, and which continued within Chapters 4 and 5, indicating that these themes were important to most participants across most studies. These themes were also supported by relevant literature and accessible information guidelines. This

demonstrates that it is likely that the suggested amendments and, subsequently, the updated pilot version of the EssenCES-IDD, will be relevant across a variety of IDD forensic hospital and prison settings within the UK and internationally.

It is, however, worth drawing attention to the small sample of individuals with IDD that participated in the study reported in Chapter 5. The IQ scores of these individuals were not collected and it could be postulated that the individuals that volunteered to participate in the study were those who were more cognitively able. Nevertheless, it is impossible to ascertain whether this sample was reflective of the entirety of the forensic IDD population. Arguably, this could mean that the updated pilot version of the EssenCES-IDD is not pitched at a level which is accessible to all individuals with IDD. However, as mentioned previously, one must also recognise the heterogeneity of the IDD population and acknowledge that even questionnaires that are specifically developed for individuals with IDD are not going to be suitable for the entirety of this population.

Finally, it is necessary to acknowledge the time constraints imposed on this thesis as a result of it being a student PhD research project and the practical constraints imposed as a consequence of services being unable to allow access to participants due to the Coronavirus pandemic. Should more time have been available, and should services have remained open to research activity, it would have been beneficial to include larger, and broader, participant samples, particularly within the study reported in Chapter 5.

### 7.6.2 Future Directions

#### *7.6.2.1 The EssenCES-IDD: Validation and Exploration of Psychometric Properties*

It will be imperative to examine the validity and psychometric properties of the EssenCES-IDD (e.g., factor structure and internal consistency). This should involve a broad sample of individuals with IDD and staff within English-speaking prison and forensic hospital IDD settings in the UK and internationally. The factor structure of the EssenCES-IDD should be examined using confirmatory factor analysis (CFA) as this

method accounts for the fact that statistical independence cannot be assumed - participants' responses may not be completely independent from the responses of other participants given that participants on each ward or wing are residing/working in the same environment (Kinnear & Gray, 2009; Tonkin et al., 2012). Factor structure could be examined across resident and staff groups, and across prison and hospital settings. This would enable confirmation regarding whether the original three-factor structure of the EssenCES has been retained within the EssenCES-IDD. The internal consistency of the three EssenCES-IDD subscales could be assessed using Cronbach's alpha (α) and Corrected Item-Total Correlation (CITC) coefficients. Construct validity could be examined through exploring the relationships between the scores on the EssenCES-IDD subscales and any of the variety of clinical and organisational outcomes with which there is evidence to support their relationship with social climate. This could include resident and staff satisfaction, institutional violence, staff morale and stress, and treatment engagement and outcomes (e.g., reoffending). Statistically significant correlations would provide support that the EssenCES-IDD subscales measure the constructs they intend to measure. Validation research of this nature is essential before use of the EssenCES-IDD in practice can be recommended.

A further area worth consideration would be to conduct a qualitative analysis of the data gathered through the comment boxes incorporated within the EssenCES-IDD. This could assist researchers with gaining an understanding of the aspects of social climate that are important to individuals with IDD and staff, along with enabling consideration of how services may be able to use the qualitative data practically to aid service development.

At present the question of whether it may be appropriate for the EssenCES-IDD to replace the original EssenCES across all forensic settings (including non-IDD settings) cannot be answered. Before this can be determined, a large-scale validation study, including both staff and non-IDD residents across UK and international prison and forensic hospital settings, would be required. This would need to address the internal consistency and factor structure of the EssenCES-IDD in comparison to the original EssenCES. However, given the lower-than-average intellectual abilities of the forensic population, this is clearly an area worth investigating.

#### *7.6.2.2 The EssenCES-IDD: Self-Reporting*

Consideration of who is best placed to administer self-report social climate questionnaires with individuals with IDD is a necessity. This question remained unanswered throughout the current research. Furthermore, it does not appear to have been addressed within previous research that has utilised the EssenCES, or other social climate questionnaires, with individuals with IDD. This issue may be less important within self-report questionnaires for individuals with IDD that explore other areas (e.g., mental health symptomology, attitudes towards offending, etc.) as they are not generally making enquiries regarding opinions of service provision. However, it is evident that most self-report questionnaires that have been developed for individuals with IDD have not afforded attention to who should administer them. This highlights the necessity of considering this on a broader level. However, with reference specifically to the EssenCES-IDD, future research may consider utilising different types of administrator (e.g., familiar staff, unfamiliar staff, external advocates), thus enabling examination of the reliability and validity of the questionnaire across different types of administrator. This may help to identify any differences across different types of administrators and to guide a decision regarding who is best placed to administer the questionnaire. However, as discussed in the current research, it may be that future research also experiences difficulties in identifying a single "correct" way forward in this regard.

The current research identified that it would be very difficult to source appropriate pictorial representations for the individual EssenCES-IDD items. Future research may, therefore, wish to consider whether there is a way of depicting the items in a pictorial form whilst ensuring that these pictorial representations are interpreted in the same way by all individuals and that their inclusion does not result in a loss of the items' meanings. Whether this is possible to achieve remains uncertain at this stage. The addition of a time-frame to which the EssenCES-IDD items pertain was also discussed in the current research. However, the necessity of this, and the most appropriate duration, were unclear. This area would also benefit from further exploration. Future research may also wish to trial differing numbers of response options along with

affording further attention to determining the most appropriate terminology to denote the response option headings. Use of the "I don't know" response option could also be explored to determine whether the inclusion of this additional option results in the loss of significant amounts of data.

Finally, a single version of the EssenCES-IDD has been developed through the current research. Future research directions may include establishing the proportion of individuals with IDD for whom this questionnaire remains inaccessible. Although it is considered likely that this will be a small minority of the IDD population, the potential to develop a further, more simplistic version may require investigation.

#### *7.6.2.3 IDD Social Climate*

The development of a validated questionnaire to measure social climate across the full range of forensic IDD settings would open up a vast number of opportunities for both researchers and clinicians to explore the social climate of such settings. Primarily, it would provide a means for services to begin to engage in conversations surrounding social climate with individuals with IDD through discussions regarding data gathered both on quantitative and qualitative levels. This would allow services to consider improvements that could be made to facilitate a more positive social climate, benefitting both individuals with IDD and staff members, along with forensic IDD services as a whole.

Further research may also wish to explore what this quantitative and qualitative data can tell us about the social climate of IDD wards or wings in a broader manner. For example:

1. Establishing the aspects of social climate that are most important to individuals with IDD;
2. Exploring whether services are able to bring about effective change as a result of data gathered using the EssenCES-IDD;

3. Exploring whether development of the EssenCES-IDD helps individuals with IDD to feel more involved in their ward or wing and to feel that their opinions matter; and
4. Exploring whether individual administration of the questionnaire facilitates open discussions between individuals with IDD and staff regarding their views of the ward or wing, thus facilitating more cohesive working.

One may also wish to explore how social climate changes over time within IDD settings and to utilise the EssenCES-IDD to examine social climate pre and post interventions in a similar way to existing research that has been conducted using the original EssenCES. Investigation of the links between social climate and key clinical and organisational outcomes could also be conducted. For example, by examining the relationship between social climate and aggression in forensic IDD settings and exploring whether improving the social climate can reduce incidents of challenging behaviour (as suggested by Robinson and Craig, 2019). Studies such as this could be used as a means of directing increased focus towards the environment of wards and wings, and to enable consideration of how changes to the environment can enhance resident and staff wellbeing and promote rehabilitation.

Researchers could also explore how data gathered regarding social climate through the EssenCES-IDD compares to non-IDD populations. This could include whether the same aspects of social climate are important to both populations, and whether the same relationships are found between clinical and organisation outcomes, and the same discrepancies between staff and resident perceptions. Assessment of the potential to use the EssenCES-IDD within both adolescent IDD services and neurorehabilitation services may also be an area worthy of future consideration, as this would provide a means to begin exploring the social climate of these settings (which are significantly under-explored at present). Given such services also lack a valid measure of social climate there would obviously be many benefits associated with this. As discussed in Section 7.6.2.1, assessment of the potential to use the EssenCES-IDD within non-IDD populations would prove useful. This also links in with the potential for researchers to consider whether the original and IDD versions of the EssenCES could be used interchangeably, for example, in situations whereby

individuals with IDD are residing on a non-IDD ward or wing. One would need to ascertain the impact that combining such data would have on the validity of the findings and also how one would establish a cut-off point to determine whether an individual should complete the IDD or non-IDD version. Translation of the English version of the EssenCES-IDD into other languages could also be undertaken; ensuring translations are accurate and that adaptations take into account cultural differences. This may be an important consideration, given that many people living in the UK (and other predominantly English-speaking countries) do not have English as their first language.

Finally, it is also necessary to note that attention has not yet been afforded to whether the concepts that are perceived to underpin the social climate of forensic IDD settings (as reflected in the EssenCES-IDD subscales) encompass all relevant components within such settings. The current research began to explore the meaning and importance of these concepts to individuals with IDD (see Section 5.6.4.4). However, there is no universal definition of forensic social climate, meaning that different social climate questionnaires incorporate various concepts. Furthermore, all of these questionnaires have initially been developed for non-IDD populations and settings. It is, therefore, possible that there may be different, or additional, components that contribute to the social climate of IDD settings. Given that when adapting the CORE-OM for IDD populations, the authors identified the need to include an additional subscale (the "missed domain") due to the differing profiles of non-IDD and IDD individuals (Brooks & Davies, 2008), it is not implausible that a similar approach may be required with regards to the EssenCES. However, until a broad-scale validation study has been conducted, it will not be possible to ascertain whether or not amendments to the EssenCES-IDD subscales will be required.

## 7.7 Concluding Statement

The current research has made a valuable contribution to both the IDD social climate literature, and to social climate literature more generally. An IDD-specific version of the EssenCES has been developed based on extensive feedback from various professionals, individuals with IDD, and social climate experts, with there also being

clear theoretical justifications for the adaptations that were made. This questionnaire has the potential to measure social climate of IDD settings in a more accurate and reliable way than the original EssenCES, and to further develop understanding of IDD social climate and its relationship with other clinical and organisational outcomes, benefitting researchers, IDD services, staff, and individuals with IDD. A variety of new ideas within the field of social climate have been identified within the current research, including gathering qualitative feedback within social climate questionnaires and suggestions regarding how social climate data can be utilised in a more clinically meaningful way. Development of the EssenCES-IDD has also drawn attention to a number of difficulties that can be experienced by individuals with IDD when completing self-report questionnaires, and has identified a multitude of suggestions as how these challenges can be addressed. Importantly, the research has corroborated the findings of previous research which has questioned the suitability of the original EssenCES for IDD populations; suggesting that the original EssenCES is not suitable for use with such populations. Furthermore, the research has also begun to explore how individuals with IDD interpret the concepts underpinning forensic social climate. Very little attention has been afforded to IDD social climate to date. This is likely due to the lack of a suitable measurement tool. It is hoped that the current research will be the first step towards significant developments in terms of the IDD social climate research, and that this will result in services developing ways in which to promote a more positive social climate; ultimately enhancing both the treatment environment and outcomes for offenders with IDD.

## References


Alderman, N., & Groucott, L. (2012). Measurement of social climate within neurobehavioural rehabilitation services using the EssenCES. *Neuropsychological Rehabilitation*, *22*(5), 768-793. https://doi.org/10.1080/09602011.2012.689683

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

Annesley, P., Hamilton, Z., Galway, R., Akiens, S., Hicks, R., & Clarke, M. (2020). Evaluating neuropsychologically informed rehabilitation training for staff within a high secure intellectual disability service. *Journal of Intellectual Disabilities and Offending Behaviour*, *11*(2), 61-73. https://doi.org/10.1108/JIDOB-08-2019-0016

Auty, K. M., & Liebling, A. (2020). Exploring the relationship between prison social climate and reoffending. *Justice Quarterly*, *37*(2), 358-381. https://doi.org/10.1080/07418825.2018.1538421

Bakken, T. L., Røssberg, J. I., & Friis, S. (2012). The Ward Atmosphere Scale for psychiatric inpatients with intellectual disability: A pilot study. *Advances in Mental Health and Intellectual Disabilities*, *6*(5), 265-272. https://doi.org/10.1108/20441281211261159

Barker, L., McKeown, A., Small, M., & Meggs, J. (2020). Validating the Essen Climate Evaluation Schema modified for people with learning disabilities in a low-risk secure forensic setting. *Criminal Behaviour and Mental Health*, *31*(2), 143–150. https://doi.org/10.1002/cbm.2175

Barrowcliff, A. L., Oathamshaw, S. C., & Evans C. (2018). Psychometric properties of the Clinical Outcome Routine Evaluation-Learning Disabilities 30-Item (CORE-

LD30). *Journal of Intellectual Disability Research*, *62*(11), 962-973. https://doi.org/10.1111/jir.12551

Beail, N., & Jahoda, A. (2012). Working with people: Direct interventions. In E. Emerson, C. Hatton, K. Dickson, R. Gone, A. Caine and J. Bromley (Eds.), *Clinical Psychology and People with Intellectual Disabilities* (2nd ed., pp. 121-139). Wiley. https://doi.org/10.1002/9781118404898

Beech, A. R., & Hamilton-Giachritsis, C. (2005). Relationship between therapeutic climate and treatment outcome in group-based sexual offender treatment programs. *Sexual Abuse: A Journal of Research and Treatment*, *17*(2), 127-140. https://doi.org/10.1177/107906320501700204

Bell, N., Tonkin, M., Chester, V., & Craig, L. (2018). Adapting measures of social climate for use with individuals with intellectual developmental disability in forensic settings. *Psychology, Crime & Law*, *24*(4), 362–378. https://doi.org/10.1080/1068316x.2017.1298761

Blagden, N., Winder, B., & Hames, C. (2016). "They treat us like human beings"- Experiencing a therapeutic sex offenders prison: Impact on prisoners and staff and implications for treatment. *International Journal of Offender Therapy and Comparative Criminology*, *60*(4), 371–396. https://doi.org/10.1177/0306624X14553227

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Bressington, D., Stewart, B., Beer, D., & MacInnes, D. (2011). Levels of service user satisfaction in secure settings - A survey of the association between perceived social climate, perceived therapeutic relationship and satisfaction with forensic services. *International Journal of Nursing Studies*, *48*(11), 1349–1356. https://doi.org/10.1016/j.ijnurstu.2011.05.011

British Dyslexia Association. (2018). *Dyslexia style guide 2018: Creating dyslexia friendly content.* Retrieved August 7, 2021, from https://d23aipgwensgtz.cloudfront.net/images/News/Legacy/Dyslexia_Style_Guide_2018-final.pdf

Brooks, M., & Davies, S. (2008). Pathways to participatory research in developing a tool to measure feelings. *British Journal of Learning Disabilities*, *36*(2), 128–133. https://doi.org/10.1111/j.1468-3156.2007.00476.x

Buell, S. (2017). *Health-based information for people with intellectual disabilities: An investigation into the linguistic properties of 'easy read' literature and its contribution to the construction of meaning. The Easy Read Project* [Doctoral dissertation, University of East Anglia]. University of East Anglia Digital Repository. Retrieved June 16, 2021, from https://ueaeprints.uea.ac.uk/id/eprint/65618/1/Susan_E_Buell_Thesis_2017

Centre for Mental Health (2011). *Pathways to unlocking secure mental health care*. Retrieved August 7, 2021, from https://www.centreformentalhealth.org.uk/sites/default/files/2018-09/Pathways_to_unlocking_secure_mental_health_care.pdf

Change. (2009). *How to make information accessible: A guide to producing easy read documents.* Retrieved February 11, 2021, from https://www.scie-socialcareonline.org.uk/how-to-make-information-accessible-a-guide-to-producing-easy-read-documents/r/a11G00000017thKIAQ

Chester, V., McCathie, J., Quinn, M., Ryan, L., Popple, J., Loveridge, C., & Spall, J. (2015). Clinician experiences of administering the Essen Climate Evaluation Schema (EssenCES) in a forensic intellectual disability service. *Advances in Mental Health and Intellectual Disabilities*, *9*(2), 70–78. https://doi.org/10.1108/AMHID-06-2014-0024

Clare, I. C., & Gudjonsson, G. H. (1993). Interrogative suggestibility, confabulation, and acquiescence in people with mild learning disabilities (mental handicap): Implications for reliability during police interrogations. *The British Journal of Clinical Psychology*, *32(*3), 295–301. https://doi.org/10.1111/j.2044-8260.1993.tb01059.x

Cummins, R. A., McCabe, M. P., Romeo, Y., Reid, S., & Waters, L. (1997). An initial evaluation of the Comprehensive Quality of Life Scale-Intellectual Disability. *International Journal of Disability, Development and Education*, *44*(1), 7-19. https://doi.org/10.1080/0156655970440102

Day, A., Casey, S., Vess, J., & Huisy, G. (2012). Assessing the therapeutic climate of prisons. *Criminal Justice and Behavior*, *39*(2), 156–168. https://doi.org/10.1177/0093854811430476

de Vries, M. G., Brazil, I. A., van der Helm, P. G., Verkes, R.-J., & Bulten, B. H. (2018). Ward climate in a high-secure forensic psychiatric setting: Comparing two instruments. *International Journal of Forensic Mental Health*, *17*(3), 247–255. https://doi.org/10.1080/14999013.2018.1478915

Department of Health. (2001). *Valuing people: A new strategy for learning disability for the 21st century*. Retrieved April 11, 2020, from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf

Department of Health. (2009). *Valuing people now: A new three-year strategy for people with learning disabilities.* Retrieved April 11, 2020, from https://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093375.pdf

Department of Health. (2010). *Department of Health guidelines: Making written information easier to understand for people with learning disabilities* (Revised

edition). Retrieved April 11, 2020, from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215923/dh_121927.pdf

Department of Health. (2012). *Transforming care: A national response to Winterbourne View Hospital.* Retrieved April 11, 2020, from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf

Doyle, P., Quayle, E., & Newman, E. (2017). Social climate in forensic mental health settings: A systematic review of qualitative studies. *Aggression and Violent Behavior*, *36,* 118–136. https://doi.org/10.1016/j.avb.2017.06.008

Emerson, E., Felce, D., & Stancliffe, R. J. (2013). Issues concerning self-report data and population-based datasets involving people with intellectual disabilities. *Intellectual and Developmental Disabilities*, *51*(5), 333–348. https://doi.org/10.1352/1934-9556-51.5.333

Esan, F., Chester, V., Gunaratna, I. J., Hoare, S., & Alexander, R. T. (2015). An analysis of the clinical, forensic, and treatment outcome factors of those with autistic spectrum disorders treated in forensic intellectual disability settings. *Journal of Applied Research in Intellectual Disabilities*, *28*(3), 193–200. https://doi.org/10.1111/jar.12121

Fang, J., Fleck, M. P., Green, A., McVilly, K., Hao, Y., Tan, W., Fu, R., & Power, M. (2011). The response scale for the intellectual disability module of the WHOQOL: 5-point or 3-point*? Journal of Intellectual Disability Research*, *55*(6), 537–549. https://doi.org/10.1111/j.1365-2788.2011.01401.x

Finlay, W. M. L., & Lyons, E. (2001). Methodological challenges in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment*, *13*(3), 319–335. https://doi.org/10.1037/1040-3590.13.3.319

Finlay, W. M. L., & Lyons, E. (2002). Acquiescence in interviews with people who have mental retardation. *Mental Retardation*, *40*(1), 14-29. https://dx.doi.org/10.1352/0047-6765(2002)040%3C0014:AIIWPW%3E2.0.CO;2

Fish, R., & Culshaw, E. (2005). The last resort?: Staff and client perspectives on physical intervention. *Journal of Intellectual Disabilities*, *9*(2), 93–107. https://doi.org/10.1177/1744629505049726

Friis, S., & Helldin, L. (1994). The contribution made by the clinical setting to violence among psychiatric patients. *Criminal Behaviour and Mental Health*, *4*(4), 341–352. https://doi.org/10.1002/cbm.1994.4.4.341

Gaab, S., Brazil, I. A., de Vries, M. G., & Bulten, B. H. (2020). The relationship between treatment alliance, social climate, and treatment readiness in long-term forensic psychiatric care: An explorative study. *International Journal of Offender Therapy and Comparative Criminology*, *64*(9), 1013–1026. https://doi.org/10.1177/0306624x19899609

Gentile, J. P., & Gillig, M. P. (2012). Interviewing techniques. In J. P. Gentile & P. M. Gillig (Eds.), *Psychiatry of Intellectual Disability: A practical manual* (pp. 90-124). Wiley. https://doi.org/10.1002/9781119945925.ch6

Glennon, C., & Sher, M. A. (2017). Evaluation of the EssenCES in a neurodevelopmental inpatient service for adolescents. *Journal of Intellectual Disabilities, 22*(3), 233–245. https://doi.org/10.1177/1744629517691654

Haigh, R. (2013). The quintessence of a therapeutic environment. *Therapeutic Communities: The International Journal of Therapeutic Communities*, *34*(1), 6–15. https://doi.org/10.1108/09641861311330464

Harding, R. (2014). Rehabilitation and prison social climate: Do 'What Works' rehabilitation programs work better in prisons that have a positive social climate? *Australian & New Zealand Journal of Criminology*, *47*(2), 163–175. https://doi.org/10.1177/0004865813518543

Hartley, S. L., & Maclean, W. E. (2006). A review of the reliability and validity of Likert-type scales for people with intellectual disability. *Journal of Intellectual Disability Research*, *50*(11), 813–827. https://doi.org/10.1111/j.1365-2788.2006.00844.x

Heal, L. W., & Sigelman, C. K. (1995). Response biases in interviews of individuals with limited mental ability. *Journal of Intellectual Disability Research*, *39*(4), 331–340. https://doi.org/10.1111/j.1365-2788.1995.tb00525.x

Healthcare Improvement Scotland. (2013). *Brain injury rehabilitation in adults* (Sign 130). Retrieved June 11, 2021, from https://www.sign.ac.uk/media/1068/sign130.pdf

House of Commons. (2017). *Mental health in prisons*. Retrieved August 9, 2021, from https://publications.parliament.uk/pa/cm201719/cmselect/cmpubacc/400/400.pdf

Howells, K., Tonkin, M., Milburn, C., Lewis, J., Draycot, S., Cordwell, J., Price, M., Davies, S., & Schalast, N. (2009). The EssenCES measure of social climate: A preliminary validation and normative data in UK high secure hospital settings. *Criminal Behaviour and Mental Health*, *19*(5), 308–320. https://doi.org/10.1002/cbm.745

Hurtado, B., Jones, L., & Burniston, F. (2014). Is easy read information really easier to read? *Journal of Intellectual Disability Research*, *58*(9), 822–829. https://doi.org/10.1111/jir.12097

Johansson, H., & Eklund, M. (2004). Helping alliance and ward atmosphere in psychiatric in-patient care. *Psychology and Psychotherapy: Theory, Research and Practice*, *77*(4), 511–523. https://doi.org/10.1348/1476083042555415

Joint Commissioning Panel for Mental Health. (2013). *Guidance for commissioners of forensic mental health services*. Retrieved September 1, 2019, from https://mentalhealthpartnerships.com/resource/guidance-for-commissioners-of-forensic-mental-health-services/

Jolliffe, D., & Farrington, D. P. (2004). Empathy and offending: A systematic review and meta-analysis. *Aggression and Violent Behavior*, *9*(5), 441–476. https://doi.org/10.1016/j.avb.2003.03.001

Kabzems, V. (1985). The use of self-report measures with mentally retarded individuals. *Mental Retardation and Learning Disability Bulletin*, *13*(2), 106-114. https://psycnet.apa.org/psycinfo/1986-20543-001

Keeling, J. A., Rose, J. L., & Beech, A. R. (2007). A preliminary evaluation of the adaptation of four assessments for offenders with special needs. *Journal of Intellectual & Developmental Disability*, *32*(2), 62–73. https://doi.org/10.1080/13668250701378538

Kells, M. (2011). *The psychometric assessment of offenders with an intellectual disability* [Doctoral dissertation, University of Birmingham]. University of Birmingham eTheses Repository. Retrieved October 8, 2019, from https://etheses.bham.ac.uk//id/eprint/3014/1/Kells11PhD.pdf

Kennedy, H. G. (2002). Therapeutic uses of security: Mapping forensic mental health services by stratifying risk. *Advances in Psychiatric Treatment*, *8*(6), 433–443. https://doi.org/10.1192/apt.8.6.433

Kinnear, P. R., & Gray, C. D. (2009). *SPSS 16 made simple.* Psychology Press.

Kinnear, D., Morrison, J., Allan, L., Henderson, A., Smiley, E., & Cooper, S. A. (2018). Prevalence of physical conditions and multimorbidity in a cohort of adults with intellectual disabilities with and without Down syndrome: Cross-sectional study. *British Medical Journal Open*, *8*(2), 1-9. https://doi.org/10.1136/bmjopen-2017-018292

Langdon, P. E., Swift, A., & Budd, R. (2006). Social climate within secure inpatient services for people with intellectual disabilities. *Journal of Intellectual Disability Research*, *50*(11), 828–836. https://doi.org/10.1111/j.1365-2788.2006.00847.x

Liebling, A., Hulley, S., & Crewe, B. (2011). Conceptualising and measuring the quality of prison life. In D. Gadd, S. Karstedt & S. Messner (Eds.), *The SAGE handbook of criminological research methods* (pp. 358-372). SAGE Publishing. https://dx.doi.org/10.4135/9781446268285.n24

Livingston, J. D., Nijdam-Jones, A., & Brink, J. (2012). A tale of two cultures: Examining patient-centered care in a forensic mental health hospital. *Journal of Forensic Psychiatry & Psychology*, *23*(3), 345–360. https://doi.org/10.1080/14789949.2012.668214

Long, C. G., Anagnostakis, K., Fox, E., Silaule, P., Somers, J., West, R., & Webster, A. (2011). Social climate along the pathway of care in women's secure mental health service: Variation with level of security, patient motivation, therapeutic alliance and level of disturbance. *Criminal Behaviour and Mental Health*, *21*(3), 202–214. https://doi.org/10.1002/cbm.791

Long, C. G., Langford, V., Clay, R., Craig, L., & Hollin, C. R. (2011). Architectural change and the effects on the perceptions of the ward environment in a medium secure unit for women. *The British Journal of Forensic Practice*, *13*(3), 205–212. https://doi.org/10.1108/14636641111157850

Lowe, K., & Paiva, S. D. (1988). Canvassing the views of people with a mental handicap. *The Irish Journal of Psychology*, *9*(2), 220–234. https://doi.org/10.1080/03033910.1988.10557718

Macinnes, D., Beer, D., Keeble, P., Rees, D., & Reid, L. (2010). The development of a tool to measure service user satisfaction with in-patient forensic services: The Forensic Satisfaction Scale. *Journal of Mental Health*, *19*(3), 272–281. https://doi.org/10.3109/09638231003728133

Mann, B., Matias, E., & Allen, J. (2014). Recovery in forensic services: Facing the challenge. *Advances in Psychiatric Treatment*, *20*(2), 125–131. https://doi.org/10.1192/ap§§§§§§§§§§§§§t.bp.113.011403

Marshall, P. (1997). *A reconviction study of HMP Grendon therapeutic community* (Research Findings No. 53). London: Home Office Research and Statistics. Retrieved October 8, 2020, from https://www.ojp.gov/ncjrs/virtual-library/abstracts/reconviction-study-hmp-grendon-therapeutic-community

Marshall, K., & Willoughby-Booth, S. (2007). Modifying the Clinical Outcomes in Routine Evaluation measure for use with people who have a learning disability. *British Journal of Learning Disabilities*, *35*(2), 107–112. https://doi.org/10.1111/j.1468-3156.2006.00422.x

Marshall, L. A., & Adams, E. A. (2018). Building from the ground up: Exploring forensic mental health staff's relationships with patients. *The Journal of Forensic Psychiatry & Psychology*, *29*(5), 744–761. https://doi.org/10.1080/14789949.2018.1508486

McGee, M. G., & Woods, D. J. (1978). Use of Moos' Ward Atmosphere Scale in a residential setting for mentally retarded adolescents. *Psychological Reports*, *43*(2), 580–582. https://doi.org/10.2466/pr0.1978.43.2.580

Mencap. (2002). *Am I making myself clear? Mencap's guidelines for accessible writing.* Retrieved May 21, 2019, from https://accessibleinfo.co.uk/pdfs/Making-Myself-Clear.pdf

Milsom, S. A., Freestone, M., Duller, R., Bouman, M., & Taylor, C. (2014). Factor structure of the Essen Climate Evaluation Schema measure of social climate in a UK medium-security setting. *Criminal Behaviour and Mental Health*, *24*(2), 86–99. https://doi.org/10.1002/cbm.1878

Mindham, J., & Espie, C. A. (2003). Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID): Development and psychometric properties of a new measure for use with people with mild intellectual disability. *Journal of Intellectual Disability Research*, *47*(1), 22–30. https://doi.org/10.1046/j.1365-2788.2003.00457.x

Moos, R.H. (1968). The assessment of the social climates of correctional institutions. *Journal of Research in Crime and Delinquency*, *5*(2), 174–188. https://doi.org/10.1177/002242786800500207

Moos, R. H. (1974). *Ward Atmosphere Scale manual.* Consulting Psychologists Press.

Moos, R. H. (1975). *Evaluating correctional and community settings*. Wiley.

Moos, R. H. (1987). *Correctional Institutions Environment Scale* (2nd ed.). Consulting Psychologists Press.

Moos, R. H. (1989). *Ward Atmosphere Scale manual* (2nd ed.). Consulting Psychologists Press.

Moos, R. H., & Houts, P. S. (1968). Assessment of the social atmospheres of psychiatric wards. *Journal of Abnormal Psychology*, *73*(6), 595–604. https://doi.org/10.1037/h0026600

Moos, R. H., & Schaefer, J. A. (1987). Evaluating health care work settings: A holistic conceptual framework. *Psychology & Health*, *1*(2), 97–122. https://doi.org/10.1080/08870448708400318

Moos, R., Shelton, R., & Petty, C. (1973). Perceived ward climate and treatment outcome. *Journal of Abnormal Psychology*, *82*(2), 291–298. https://doi.org/10.1037/h0035184

Mottram, P. G. (2007). *HMP Liverpool, Styal and Hindley Study Report.* University of Liverpool. Retrieved August 9, 2021, from https://www.choiceforum.org/docs/hmpliverpool.pdf

Morrissey, C., Langdon, P. E., Geach, N., Chester, V., Ferriter, M., Lindsay, W. R., McCarthy, J., Devapriam, J., Walker, D. M., Duggan, C., & Alexander, R. (2017). A systematic review and synthesis of outcome domains for use within forensic services for people with intellectual disabilities. *British Journal of Psychiatry Open*, *3*(1), 41–56. https://doi.org/10.1192/bjpo.bp.116.003616

Murray, H.A. (1938). *Explorations in personality*. Oxford University Press.

National Health Service England. (2017). *Accessible information standard specification.* Retrieved August 9, 2021, from https://www.england.nhs.uk/wp-content/uploads/2017/08/accessilbe-info-specification-v1-1.pdf

National Offender Management Service (NOMS). (2014). *Developing Easy Read information for prisoners with learning disabilities.* Retrieved August 10, 2021, from https://slidelegend.com/download/developing-easy-read-information-for-prisoners-with-ldd-navigator_59ea85941723dd20194f710a.html

Neimeijer, E., Kuipers, J., Peters-Scheffer, N., Van der Helm, P., & Didden, R. (2021). “Back off means stay with me”. Perceptions of individuals with mild intellectual disability or borderline intellectual functioning about the group climate in a

secure forensic setting. *Journal of Intellectual Disabilities and Offending Behaviour*, *12*(1), 47–60. https://doi.org/10.1108/jidob-09-2020-0015

Neimeijer, E. G., Roest, J. J., van der Helm, G. H. P., & Didden, R. (2018). Psychometric properties of the Group Climate Instrument (GCI) in individuals with mild intellectual disability or borderline intellectual functioning. *Journal of Intellectual Disability Research*, *63*(3), 215–224. https://doi.org/10.1111/jir.12567

Owen, A. L., & Wilson, R. R. (2006). Unlocking the riddle of time in learning disability. *Journal of Intellectual Disabilities*, *10*(1), 9–17. https://doi.org/10.1177/1744629506062269

Petty, M., Rolfe, J., & Chester, V. (2013). *Moving from feelings of terror to 'I like learning maths': An evaluation of a teaching activity in a forensic intellectual disability setting* (Low Secure Newsletter Number 3). Quality Network for Forensic Mental Health. Retrieved August 10, 2021, from https://www.researchgate.net/publication/323457265_Moving_from_feelings_of_terror_to_%27I_like_learning_maths%27_An_evaluation_of_a_teaching_activity_in_a_forensic_intellectual_disability_setting

Prosser, H., & Bromley, J. (2012). Interviewing people with intellectual disabilities. In E. Emerson, C. Hatton, K. Dickson, R. Gone, A. Caine and J. Bromley (Eds.), *Clinical Psychology and People with Intellectual Disabilities* (2nd ed., pp. 121-139). Wiley. https://doi.org/10.1002/9781118404898.ch6

Quinn, M., Thomas, C., & Chester, V. (2012). The Essen Climate Evaluation Schema measure of social climate in a secure service for people with intellectual disabilities. *Advances in Mental Health and Intellectual Disabilities*, *6*(4), 171–178. https://doi.org/10.1108/20441281211236562

Reading, L., & Ross, G. E. (2020). Comparing social climate across therapeutically distinct prison wings. *The Journal of Forensic Practice*, *22*(3), 185–197. https://doi.org/10.1108/jfp-04-2020-0017

Robinson, J. (2017). *Perceptions of social climate and their influence on aggression in forensic intellectual developmental disability (IDD) services* [Doctoral dissertation, University of Birmingham]. University of Birmingham eTheses Repository. Retrieved August 14, 2021, from https://etheses.bham.ac.uk/id/eprint/8576/1/Robinson18ForenPsyD.pdf

Robinson, J., Craig, L. A., & Tonkin, M. (2018). Perceptions of social climate and aggressive behavior in forensic services: A systematic review. *Trauma, Violence, & Abuse*, *19*(4), 391–405. https://doi.org/10.1177/1524838016663936

Robinson, J. E., & Craig, L. (2019). Social climate and aggression in IDD services. *Journal of Intellectual Disabilities and Offending Behaviour*, *10*(1), 8–18. https://doi.org/10.1108/jidob-11-2018-0013

Ros, N., Van der Helm, P., Wissink, I., Stams, G. J., & Schaftenaar, P. (2013). Institutional climate and aggression in a secure psychiatric setting. *Journal of Forensic Psychiatry & Psychology*, *24*(6), 713–727. https://doi.org/10.1080/14789949.2013.848460

Rose, J. (1993). Stress and staff in residential settings: The move from hospital to the community. *Mental Handicap Research, 6*(4), 312–332. https://doi.org/10.1111/j.1468-3148.1993.tb00062.x

Rose, J., Mills, S., Silva, D., & Thompson, L. (2013). Client characteristics, organizational variables and burnout in care staff: The mediating role of fear of assault. *Research in Developmental Disabilities*, *34*(3), 940–947. https://doi.org/10.1016/j.ridd.2012.11.014

Røssberg, J. I., & Friis, S. (2004). Patients' and staff's perceptions of the psychiatric ward environment. *Psychiatric Services*, *55*(7), 798–803. https://doi.org/10.1176/appi.ps.55.7.798

Royal College of Physicians and British Society of Rehabilitation Medicine. (2003). *Rehabilitation following acquired brain injury: National clinical guidelines*. Retrieved September 12, 2020, from https://www.headway.org.uk/media/3320/bsrm-rehabilitation-following-acquired-brain-injury.pdf

Royal College of Psychiatrists. (2013). *People with learning disability and mental health, behavioural or forensic problems: The role of in-patient services*. Retrieved September 12, 2021, from https://www.rcpsych.ac.uk/docs/default-source/members/faculties/intellectual-disability/id-fr-id-03.pdf?sfvrsn=cbbf8b72_2

Royal College of Psychiatrists. (2014). *Forensic care pathways for adults with intellectual disability involved with the criminal justice system.* Retrieved August 10, 2021, from https://www.rcpsych.ac.uk/docs/default-source/members/faculties/forensic-psychiatry/forensic-fr-id-04.pdf?sfvrsn=2fdf0def_2

Schalast, N. (2010). *EssenCES: Essen Climate Evaluation Schema: Occasionally asked questions*. Retrieved May 12, 2020, from www.unidue.de/imperia/md/content/rkeforensik/projekte/occ_asked_questions_2010.pdf

Schalast, N., & Groenewald, I. (2009). Ein Kurzfragebogen zur Einschätzung des sozialen Klimas im Strafvollzug. Erste Befunde auf Abteilungen des Regelvollzugs und derSozialtherapie [A short questionnaire to assess the social climate in prisons. Initial results from regular wards and social therapy units]. In R. Haller, & J. M. Jehle (Eds.), Drogen – Sucht – Kriminalität (pp. 329-352).

Schalast, N., Redies, M., Collins, M., Stacey, J., & Howells, K. (2008). EssenCES, a short questionnaire for assessing the social climate of forensic psychiatric wards. *Criminal Behaviour and Mental Health*, *18*(1), 49–58. https://doi.org/10.1002/cbm.677

Schalast, N., & Tonkin, M. (Eds.). (2016). *The Essen Climate Evaluation Schema - EssenCES: A manual and more.* Hogrefe. https://doi.org/10.1027/00481-000

Sentell T. L., & Ratcliff-Baird B. (2003). Literacy and comprehension of Beck Depression Inventory response alternatives. *Community Mental Health Journal*, *39*(4), 323–331. https://doi.org/10.1023/a:1024072108467

Sharp, K., Murray, G.C., McKenzie, K., Matheson, E., Quigley, A., & Patrick, S. (2001). A matter of time. *Learning Disability Practice, 3*(6), 10-13. https://doi.org/10.7748/ldp2001.03.3.6.10.c1444

Siess, J., & Schalast, N. (2017). Psychometric properties of the Essen Climate Evaluation Schema (EssenCES) in a sample of general psychiatric wards. *Archives of Psychiatric Nursing*, *31*(6), 582–587. https://doi.org/10.1016/j.apnu.2017.08.001

Sigelman, C. K., & Budd, E. C. (1986). Pictures as an aid in questioning mentally retarded persons. *Rehabilitation Counseling Bulletin*, *29*(3), 173–181.

Sigelman, C. K., Budd, E. C., Winer, J. L., Schoenrock, C. J., & Martin, P. W. (1982). Evaluating alternative techniques of questioning mentally retarded persons. *American Journal of Mental Deficiency, 86*(5), 511-518.

Stancliffe, R. J., Wilson, N. J., Bigby, C., Balandin, S., & Craig, D. (2014). Responsiveness to self-report questions about loneliness: A comparison of mainstream and intellectual disability-specific instruments. *Journal of Intellectual Disability Research*, *58*(5), 399–405. https://doi.org/10.1111/jir.12024

Taylor, R. (2000). *A seven year reconviction study of HMP Grendon therapeutic community*. Home Office Research, Development and Statistics Directorate. Retrieved on August 13, 2021, from https://webarchive.nationalarchives.gov.uk/20070906193335/https://www.homeoffice.gov.uk/rds/pdfs/r115.pdf

Thompson, L., & Rose, J. (2011). Does organizational climate impact upon burnout in staff who work with people with intellectual disabilities? A systematic review of the literature. *Journal of Intellectual Disabilities*, *15*(3), 177–193. https://doi.org/10.1177/1744629511419616

Toch, H. (1977). *Living in prison: The ecology of survival.* Free Press.

Tomporowski, P. D. & Hager, L. D. (1992). Sustained attention in mentally retarded individuals. In N.W. Bray (Ed.), *International review of research in mental retardation* (Vol. 18, pp. 111-136). San Diego. https://doi.org/10.1016/S0074-7750(08)60117-2

Tonkin, M. (2016). A review of questionnaire measures for assessing the social climate in prisons and forensic psychiatric hospitals. *International Journal of Offender Therapy and Comparative Criminology*, *60*(12), 1376–1405. https://doi.org/10.1177/0306624X15578834

Tonkin, M., & Howells, K. (2011). Evaluating regimes and environments. In K. Sheldon, J. Davies, & K. Howells (Eds.), *Research in practice for forensic professionals* (1st ed., pp. 249-270). Routledge. https://doi.org/10.4324/9780203805329

Tonkin, M., Howells, K., Ferguson, E., Clark, A., Newberry, M., & Schalast, N. (2012). Lost in translation? Psychometric properties and construct validity of the English Essen Climate Evaluation Schema (EssenCES) social climate questionnaire. *Psychological Assessment*, *24*(3), 573–580. https://doi.org/10.1037/a0026267

Turley, C., Payne, C., & Webster, S. (2013). Enabling Features of Psychologically Informed Planned Environments. National Offender Management Service. Retrieved on January 18, 2022, from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/211730/enabling-pipe-research-report.pdf.

van der Helm, P., Stams, G. J., & van der Laan, P. (2011). Measuring group climate in prison. *The Prison Journal*, *91*(2), 158–176. https://doi.org/10.1177/0032885511403595

van der Molen, M. J., van Luit, J. E. H., Jongmans, M. J., & van der Molen, M. W. (2007). Verbal working memory in children with mild intellectual disabilities. *Journal of Intellectual Disability Research*, *51*(2), 162–169. https://doi.org/10.1111/j.1365-2788.2006.00863.x

Willets, L., Mooney, P., & Blagden, N. (2014). Social climate in learning disability services. *Journal of Intellectual Disabilities and Offending Behaviour*, *5*(1), 24–37. https://doi.org/10.1108/jidob-10-2013-0025

Wood, H., Thorpe, L., Read, S., Eastwood, A., & Lindley, M. (2008). Service user satisfaction in a low secure forensic learning disability unit? *Mental Health and Learning Disabilities Research and Practice*, *5*(2), 176–191. https://doi.org/10.5920/mhldrp.2008.52176

Wright, K. N. (1985). Developing the Prison Environment Inventory. *Journal of Research in Crime and Delinquency*, *22*(3), 257–277. https://doi.org/10.1177/0022427885022003005

Zetlin, A. G., Heriot, M. J., & Turner, J. L. (1985). Self-concept measurement in mentally retarded adults: A micro-analysis of response styles. *Applied Research in Mental Retardation*, *6*(2), 113–125. https://doi.org/10.1016/s0270-3092(85)80065-5

## Appendices

### Appendix 1: The EssenCES Questionnaire – Hospital Version

**Essen CES©**

Essen Climate Evaluation Schema (rev. 2010)

| | I agree | not at all | little | somewhat | quite a lot | very much |
|---|---|---|---|---|---|---|
| 1 | This ward has a homely atmosphere | ☐ | ☐ | ☐ | ☐ | ☐ |
| 2 | The patients care for each other | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3 | Really threatening situations can occur here | ☐ | ☐ | ☐ | ☐ | ☐ |
| 4 | On this ward, patients can openly talk to staff about all their problems | ☐ | ☐ | ☐ | ☐ | ☐ |
| 5 | Even the weakest patient finds support from his fellow patients | ☐ | ☐ | ☐ | ☐ | ☐ |
| 6 | There are some really aggressive patients on this ward | ☐ | ☐ | ☐ | ☐ | ☐ |
| 7 | Staff take a personal interest in the progress of patients | ☐ | ☐ | ☐ | ☐ | ☐ |
| 8 | Patients care about their fellow patients' problems | ☐ | ☐ | ☐ | ☐ | ☐ |
| 9 | Some patients are afraid of other patients | ☐ | ☐ | ☐ | ☐ | ☐ |
| 10 | Staff members take a lot of time to deal with patients | ☐ | ☐ | ☐ | ☐ | ☐ |
| 11 | When a patient has a genuine concern, he finds support from his fellow patients | ☐ | ☐ | ☐ | ☐ | ☐ |
| 12 | At times, members of staff are afraid of some of the patients | ☐ | ☐ | ☐ | ☐ | ☐ |
| 13 | Often, staff seem not to care if patients succeed or fail in treatment | ☐ | ☐ | ☐ | ☐ | ☐ |
| 14 | There is good peer support among patients | ☐ | ☐ | ☐ | ☐ | ☐ |
| 15 | Some patients are so excitable that one deals very cautiously with them | ☐ | ☐ | ☐ | ☐ | ☐ |
| 16 | Staff know patients and their personal histories very well | ☐ | ☐ | ☐ | ☐ | ☐ |
| 17 | Both patients and staff are comfortable on this ward | ☐ | ☐ | ☐ | ☐ | ☐ |

**Correspondence:** Norbert Schalast | Institute of Forensic Psychiatry
University Duisburg-Essen | P.O. Box 10 30 43 | 45030 Essen | Germany

## Appendix 2: The EssenCES Questionnaire – Prison Version

UNIVERSITÄT DUISBURG ESSEN

# Essen CES ©

Essen Climate Evaluation Schema (rev. 2010)

**Version for Prisons and Correctional Settings**

LVR Qualität für Menschen

| | | I agree | | | | |
|---|---|---|---|---|---|---|
| | | not at all | little | somewhat | quite a lot | very much |
| 1 | This unit has a liveable atmosphere | ☐ | ☐ | ☐ | ☐ | ☐ |
| 2 | The inmates care for each other | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3 | Really threatening situations can occur here | ☐ | ☐ | ☐ | ☐ | ☐ |
| 4 | In this unit, inmates can openly talk to staff about all their problems | ☐ | ☐ | ☐ | ☐ | ☐ |
| 5 | Even the weakest inmate finds support from his/her fellow inmates | ☐ | ☐ | ☐ | ☐ | ☐ |
| 6 | There are some really aggressive inmates in this unit | ☐ | ☐ | ☐ | ☐ | ☐ |
| 7 | Staff take a personal interest in the progress of inmates | ☐ | ☐ | ☐ | ☐ | ☐ |
| 8 | Inmates care about their fellow inmates' problems | ☐ | ☐ | ☐ | ☐ | ☐ |
| 9 | Some inmates are afraid of other inmates | ☐ | ☐ | ☐ | ☐ | ☐ |
| 10 | Staff members take a lot of time to deal with inmates | ☐ | ☐ | ☐ | ☐ | ☐ |
| 11 | When inmates have a genuine concern, they find support from their fellow inmates | ☐ | ☐ | ☐ | ☐ | ☐ |
| 12 | At times, members of staff feel threatened by some of the inmates | ☐ | ☐ | ☐ | ☐ | ☐ |
| 13 | Often, staff seem not to care if inmates succeed or fail in the daily routine / program | ☐ | ☐ | ☐ | ☐ | ☐ |
| 14 | There is good peer support among inmates | ☐ | ☐ | ☐ | ☐ | ☐ |
| 15 | Some inmates are so excitable that one deals very cautiously with them | ☐ | ☐ | ☐ | ☐ | ☐ |
| 16 | Staff know inmates and their personal histories very well | ☐ | ☐ | ☐ | ☐ | ☐ |
| 17 | Both inmates and staff are comfortable in this unit | ☐ | ☐ | ☐ | ☐ | ☐ |

**Correspondence:** Norbert Schalast | Institute of Forensic Psychiatry
University Duisburg-Essen | P.O. Box 10 30 43 | 45030 Essen | Germany

## Appendix 3: Background to the EssenCES Questionnaire

EssenCES Subscales

The EssenCES consists of three subscales: therapeutic hold/hold and support, patient/inmate cohesion, and experienced safety.

*Therapeutic Hold/Hold and Support*

This refers to how supportive the unit is perceived to be in relation to therapeutic gains and how positive and supportive therapeutic relationships on the unit are perceived to be. It is considered that therapeutic hold is an essential component of all therapeutic settings.

*Patient/Inmate Cohesion*

This refers to whether the characteristics of a therapeutic community are perceived as being present on the unit.

*Experienced Safety*

Safety can be considered to be a basic human need. A unit with low perceived levels of aggressive tension and threat of violence is considered to be more conducive to rehabilitation.

Scoring the EssenCES

Each item on the EssenCES is scored between 0 and 4, with subscale scores being calculated by adding the scores together for the five items within each subscale (disregarding items one and 17 which are unscored items). The minimum score for each subscale is 0 and the highest is 20, with higher scores being indicative of a positive perception of social climate and lower scores suggesting a negative perception. Missing data is accounted for by averaging the other four items on the subscale and adding that value to that of the other four items for instances whereby only one response is missing on a subscale. For instances whereby more than one response is missing on a subscale, the authors recommend that a subscale score is not calculated for that subscale (Schalast & Tonkin, 2016). It is important to

note that the authors do not suggest the combining of the three subscale scores to form a total EssenCES score as the intention of the EssenCES is not to provide an overall measure of social climate, but to assess a small number of dimensions relevant to social climate that are applicable across a wide range of settings (Schalast & Tonkin, 2016).

Interpretation of EssenCES Data

The authors highlight that EssenCES scores should not be used for the purpose of assessing staff or unit/service performance or to ascertain which wards or units are 'better' than others; the questionnaire only intends to provide an overview of how residents and staff feel about the environment and/or how changes to the environment have affected resident and staff perceptions of it (Schalast & Tonkin, 2016).

**Appendix 4: Participant Information Sheet (Study 1)**

# PARTICIPANT INFORMATION SHEET

**Title of Project**: Measuring Social Climate in Forensic Learning Disability Services: Staff Experiences and Perspectives

**Name of Researcher:** Natalie Bell

**Research Supervisors:** Dr Matthew Tonkin, Professor Leam Craig and Professor John Clibbens

**Institution:** Birmingham City University

*You are being invited to participate in a research study. Before you make your decision it is important for you to understand the purpose of the research and what participation will involve. Please read the following information carefully, and contact us if you would like more information before deciding whether or not to take part.*

**Background**

- Social climate refers to the 'personality' of a setting or environment and encompasses how safe residents and staff feel, how supportive the unit is perceived to be of therapeutic gain and the physical/psychological needs of residents.
- The Essen Climate Evaluation Schema (EssenCES; Schalast et al., 2008) is a questionnaire-based measure of social climate that is widely used in UK forensic settings. Although there is strong evidence that the EssenCES is a useful measure of social climate in non-LD forensic settings, there have been questions raised regarding its use in LD settings.

**Purpose of Study**

- This study is the first part of a larger scale research project that seeks to adapt the EssenCES for use in forensic LD settings.
- The purpose of this study is to identify staff views and experiences of the EssenCES in forensic LD settings, specifically highlighting issues that impact on the questionnaire's ability to measure social climate in this population.

**What will my participation involve?**

- Participation will consist of completing a web-based questionnaire which will take approximately 20 minutes.
- The questionnaire considers a variety of aspects of the EssenCES including the nature and wording of the items, the response scale, the format and presentation of the EssenCES and the guidelines for completion.
- There is a 12-week timeframe within which you can choose to complete the questionnaire.

If you choose to complete the questionnaire, you will also be offered the opportunity to volunteer to attend a focus group or interview in order to provide more in-depth feedback on the suitability of the EssenCES for forensic LD populations. However, you are not required to attend a focus group or interview and can simply fill out the questionnaire if you wish.

**Can I take part?**
In order to participate, we ask that you check that you meet the following criteria:

- You are currently working (or have recently worked) in forensic LD settings
- Your role provides (or provided) direct support to residents of forensic LD settings
- Your role involves (or involved) working in locked rehabilitation, low secure, medium secure, high secure or prison units.
- You have an understanding of the cognitive difficulties experienced by residents with LD.

**Why will my participation be helpful?**
Information gathered through this study will be used to develop an LD-specific version of the EssenCES which will:

- Help to improve understanding of the social climate of forensic LD settings and of the aspects of social climate important to those with LD.
- Help to facilitate examination of the relationships between social climate and other important outcomes in forensic LD settings (such as institutional aggression, resident and staff satisfaction and treatment outcomes).

**Additional Information**
If you choose to participate in the study, any information you share will remain strictly confidential as at no point will your name, or any information that could be linked back to you, be used. Your responses to the questionnaire will be anonymous and will only be used for the purpose of this study and subsequent dissemination of research findings.

The information gathered during this study will contribute to an academic journal article summarising staff experiences and perspectives of the EssenCES in forensic LD settings, and may also be used for the purpose of additional reports and conference presentations.

**If you would like to discuss the study in more detail or would like further information about the study, please contact Natalie Bell: natalie.bell@mail.bcu.ac.uk.**

## Appendix 5: Online Questionnaire (Study 1)

**Measuring the Social Climate in Forensic Learning Disability Settings: Staff Experiences and Perspectives**

**Demographic Questions**

1. What is your gender?

   Male  Female

2. What is your job title?

   _____

3. What service do you currently work in?

   Locked rehabilitation  Low secure  Medium secure

   High secure  Prison

   Other _____

4. Approximately how long have you worked in forensic Learning Disability (LD) services? _____

5. Have you used the EssenCES in clinical practice?

   Yes  No

6. Have you used the EssenCES with people with LD?

   Yes  No  N/A

7. Does your service use the EssenCES?

   Yes  No  Don't know

   a. If yes, how often?

      _____

8. Have you used any other measures of social climate with LD populations?

   Yes No

   a. If yes, please list the measures

      _____

**The Essen Climate Evaluation Schema (EssenCES)**

*The 17 items of the EssenCES are presented below. Please indicate whether you think each item is suitable for individuals with LD and explain your response using the space below.*

1. This ward/unit has a homely/liveable atmosphere

   Yes No

   _____
   _____
   _____

2. The patients/inmates care for each other

   Yes No

   _____
   _____
   _____

3. Really threatening situations can occur here

   Yes No

   _____
   _____
   _____

4. On this ward/unit, patients/inmates can openly talk to staff about all their problems

   Yes No

   _____
   _____
   _____

5. Even the weakest patient/inmate finds support from his fellow patients/inmates

   Yes No

   _____
   _____
   _____

6. There are some really aggressive patients/inmates on this ward/unit

   Yes No

   _____
   _____
   _____

7. Staff take a personal interest in the progress of patients/inmates

   Yes No

   _____
   _____
   _____

8. Patients/inmates care about their fellow patients'/inmates' problems

   Yes No

   _____
   _____
   _____

9. Some patients/inmates are afraid of other patients/inmates

   Yes No

   _____
   _____
   _____

10. Staff members take a lot of time to deal with patients/inmates

    Yes No

    _____
    _____
    _____

11. When a patient/inmate has a genuine concern, he finds support from his fellow patients/inmates

    Yes No

    _____
    _____
    _____

12. At times, members of staff are afraid of some of the patients/inmates

    Yes No

    _____
    _____
    _____

13. Often, staff seem not to care if patients/inmates succeed or fail in treatment/their daily routine/program

    Yes No

    _____
    _____
    _____

14. There is good peer support among patients/inmates

    Yes No

    _____
    _____
    _____

15. Some patients/inmates are so excitable that one deals very cautiously with them

    Yes No

    _____
    _____
    _____

16. Staff know patients/inmates and their personal histories very well

    Yes No

    _____
    _____
    _____

17. Both patients/inmates and staff are comfortable on this ward/unit

    Yes No

    _____
    _____
    _____

*Please refer to the attached copy of the EssenCES questionnaire when completing the following sections.*

**Presentation**

1. The way that the questionnaire is set out on the page is appropriate for individuals with LD

   Not at all Little Somewhat Quite a lot Very much

2. The type and size of font is appropriate for individuals with LD

   Not at all Little Somewhat Quite a lot Very much

3. The length of questionnaire is appropriate for individuals with LD

   Not at all Little Somewhat Quite a lot Very much

4. Are there any other comments you would like to make regarding the presentation of the questionnaire?

   _____
   _____
   _____

**Response Format**

1. The five-point response format of the EssenCES is suitable for use with individuals who have LD

   Not at all Little Somewhat Quite a lot Very much

2. Individuals with LD understand the difference between different response headings (for example, between 'little' and 'somewhat' and between 'quite a lot' and 'very much')

   Not at all  Little  Somewhat  Quite a lot  Very much

3. Have you ever had to / do you think you would need to explain the response format in an alternative way to individuals with LD?

   Yes  No  N/A

   a. If yes, how have you done this?

      _____

      _____

      _____

4. Have you ever had to / do you think you would need to use pictorial aids to help individuals with LD to understand the response format?

   Yes  No  N/A

   a. If yes, how have you done this?

      _____

      _____

      _____

5. Which of the response formats below do you think is most suitable for individuals with LD?

   a  b  c  d  e  f

   Other_____

   a. Current response format (Likert 5-point scale)

| Not at all | Little | Somewhat | Quite a lot | Very much |
|---|---|---|---|---|

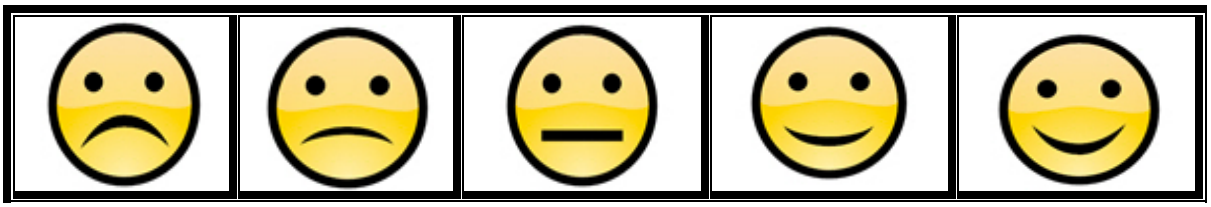
   b. Likert 3-point scale

| Not at all | Somewhat | Very much |
|---|---|---|

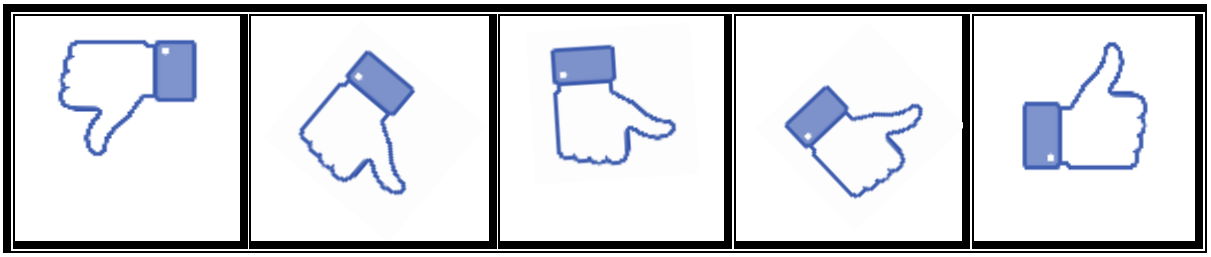
c. Rating scale 1-5

| 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|

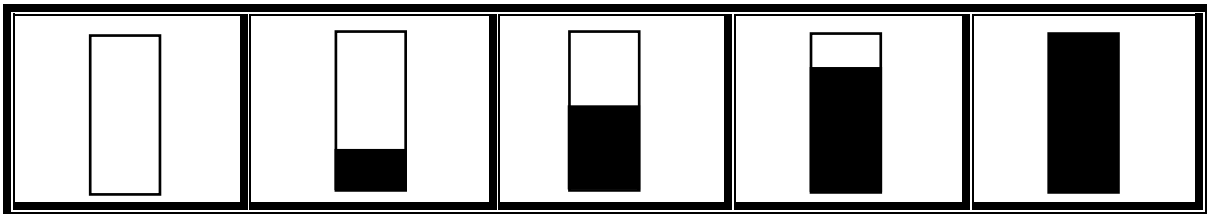
d. Smiley faces scale



e. Thumbs scale



f. Bar chart



6. Are there any other comments you would like to make regarding the response format of the questionnaire?

_____

_____

_____

**Administration**

1. Individuals with LD are motivated to complete the questionnaire

   Yes No N/A

2. It is helpful to read out the questionnaire statements to individuals with LD

   Yes No N/A

3. Individuals with LD are able to complete the questionnaire unsupported

   Yes No N/A

4. Have you ever completed the questionnaire on behalf of an individual with LD due to their difficulties understanding the questionnaire?

   Yes No N/A

5. Are all individuals with LD able to complete the questionnaire?

   Yes No N/A

   a. If not, why? (e.g. cognitive / behavioural / psychiatric difficulties)

_____

_____

_____

6. Are there any other comments you would like to make regarding administration of the questionnaire?

_____

_____

_____

**Social Climate of LD Units**

1. What do you think are the most important aspects of social climate on LD units?

_____

_____

_____

2. Do you think there are any aspects of social climate that are relevant to individuals with LD that are not covered in the EssenCES questionnaire?

   _____

   _____

   _____

3. Do you think social climate differs between LD and non-LD units?

   Yes No

   a. If yes, why?

      _____

      _____

      _____

**Adapting the EssenCES for LD**

1. Have you ever been provided with a simplified version of the EssenCES questionnaire to use with individuals with LD?

   Yes No

   a. If yes, how was the simplified version different?

      _____

      _____

      _____

   b. Did the simplified version help and why?

      _____

      _____

      _____

2. Would an LD-specific version of the EssenCES questionnaire be beneficial for the service?

   Yes No

   a. If yes, why?

      _____

_____

_____

3. Are there any other aspects of the EssenCES that you think might need changing in order to make the questionnaire suitable for use with forensic LD populations? If so, how might these issues be addressed?

   _____

   _____

   _____

**Study 2**

The second part of this research will seek to gather more in-depth information with regards to the suitability of the EssenCES for forensic LD populations. The second study will consist of participating in either an interview or focus group lasting up to one hour. If you are interested in taking part in the second study, please indicate this below. You will then be taken to a separate page where you can leave your name and email address so that we can get in touch with you. Please note that this does not mean that you are committing to take part in the second study at this stage.

**Appendix 6: Participant Information Sheet (Study 2)**

## PARTICIPANT INFORMATION SHEET

**Title of Project**: Measuring Social Climate in Forensic Learning Disability Services: Staff Experiences and Perspectives

**Name of Researcher:** Natalie Bell

**Research Supervisors:** Dr Matthew Tonkin, Professor Leam Craig and Professor John Clibbens

**Institution:** Birmingham City University

*You are being invited to participate in a research study. Before you make your decision it is important for you to understand the purpose of the research and what participation will involve. Please read the following information carefully, and contact us if you would like more information before deciding whether or not to take part.*

**Background**

- Social climate refers to the 'personality' of a setting or environment and encompasses how safe residents and staff feel, how supportive the unit is perceived to be of therapeutic gain and the physical/psychological needs of residents.
- The Essen Climate Evaluation Schema (EssenCES; Schalast et al., 2008) is a questionnaire-based measure of social climate that is widely used in UK forensic settings. Although there is strong evidence that the EssenCES is a useful measure of social climate in non-LD forensic settings, there have been questions raised regarding its use in LD settings.

**Purpose of Study**

- This study is the second part of a larger scale research project that seeks to adapt the EssenCES for use in forensic LD settings.
- The purpose of this study is to identify staff views and experiences of the EssenCES in forensic LD settings, specifically highlighting issues that impact on the questionnaire's ability to measure social climate in this population.

**What will my participation involve?**

- You can choose whether you would prefer to attend **either** a focus group or interview.
- The focus groups and interviews will last up to one hour and will take place at your workplace.
- Interviews can also be offered via telephone or skype if you prefer.
- The focus groups and interviews will consider a variety of aspects of the EssenCES including the nature and wording of the items, the response scale, the format and presentation of the EssenCES and the guidelines for completion.

The aim is that the information gathered will provide more in-depth information with regards to the suitability of the EssenCES for forensic LD populations.

**Can I take part?**
In order to participate, we ask that you check that you meet the following criteria:

- You are currently working (or have recently worked) in forensic LD settings
- Your role provides (or provided) direct support to residents of forensic LD settings
- Your role involves (or involved) working in locked rehabilitation, low secure, medium secure, high secure or prison units.
- You have an understanding of the cognitive difficulties experienced by residents with LD.

**Why will my participation be helpful?**
Information gathered through this study will be used to develop an LD-specific version of the EssenCES which will:

- Help to improve understanding of the social climate of forensic LD settings and of the aspects of social climate important to those with LD.
- Help to facilitate examination of the relationships between social climate and other important outcomes in forensic LD settings (such as institutional aggression, resident and staff satisfaction and treatment outcomes).

**Additional Information**
If you choose to participate in the study, any information you share will remain strictly confidential as at no point will your name, or any information that could be linked back to you, be used. Your responses to the questionnaire will be anonymous and will only be used for the purpose of this study and subsequent dissemination of research findings.

The information gathered during this study will contribute to an academic journal article summarising staff experiences and perspectives of the EssenCES in forensic LD settings, and may also be used for the purpose of additional reports and conference presentations.

**If you would like to discuss the study in more detail or would like further information about the study, please contact Natalie Bell: natalie.bell@mail.bcu.ac.uk.**

## Appendix 7: Interview and Focus Group Schedule (Study 2)

| General Staff Questionnaire Feedback |
|---|
| The majority of staff indicated that a LD specific version of the EssenCES would be beneficial for their service. |
| Timeframes aren't clear. Are the questions asking about 'right now' or since an individual arrived on the unit? |
| Ward' and 'unit' may not be appropriate ways of referring to a setting. |
| Should we refer to individuals in prison as 'inmates' or 'prisoners'? Should we refer to individuals in hospitals as 'patients' or 'residents', or would another term be more suitable? |
| The degree to which questionnaire amendments may need to be made could be dependent on the level of LD that individuals' present with. |

1. Do you think that there is a way that we could clarify the timeframes to which the EssenCES statements are referring?
2. Do you think that there are alternative words that we could use instead of 'ward' and 'unit' that would me more suitable?
3. Do you think that there are alternative words that we could use instead of 'patients' and 'inmates' that would be more suitable?
4. Do you think that there is a way in which we can amend the questionnaire so that it is suitable for individuals with different levels of LD?

1. 'This ward has a homely atmosphere' / 'This unit has a liveable atmosphere'

| Staff Questionnaire Feedback |
|---|
| Individuals with LD may struggle to understand the words 'homely', 'liveable' and 'atmosphere'. |
| Individuals with LD may not understand (or be able to relate to) what a 'homely/liveable' atmosphere should entail due to no previous experience of homely environments. |
| Perhaps we shouldn't expect hospital wards and prison units to be homely, particularly those with higher levels of security. |

- Is there any additional feedback you would like to add?

- How do you think we could change this statement to make it more suitable for individuals with LD?

2. ‘The patients care for each other’ / ‘The inmates care for each other’

| Staff Questionnaire Feedback |
|---|
| Individuals with LD may not understand what ‘care’ or ‘care for’ mean. Does it mean do they like each other, do they look out for each other or do they provide care for each other? |
| Does the term ‘patient’ imply that someone is physically unwell? |
| Individuals understanding of the term ‘caring’ may be that professionals are being paid to care for them. |
| It may not be appropriate to expect patients/inmates to care for each other.<br>o Patients/inmates have not chosen to live together so should they be expected to care for each other?<br>o Many wards/units ask patients/inmates to seek support from staff, not from each other. |
| How would this statement fit in with patients/inmates needing to have an individual focus on their own rehabilitation? |
| This statement may be too generalised. Would patients/inmates think that this statement means that ALL patients/inmates care for each other? |
| Individuals with LD (and potentially Autism) may not understand that the statement is asking them to comment on their own views and those of other patients/inmates. They may struggle to comment on the views of other patients/inmates. |

- Is there any additional feedback you would like to add?
- How do you think we could change this statement to make it more suitable for individuals with LD?

3. ‘Really threatening situations can occur here’

| Staff Questionnaire Feedback |
|---|
| Individuals with LD may not understand the phrases ‘can occur’ and ‘threatening situation’. |
| Perceptions of what constitutes a threatening situation or a really threatening situation. |
| Are threatening situations to be expected due to the nature of the institutions? |

| |
|---|
| Is the statement too general? Does the statement refer to the individual unit/ward, or to the whole establishment? |
| This could be considered a leading question<br>○ Placing fear into the heads of others<br>○ Placing blame on particular patients/inmates even though, at times, they cannot control their emotions or behaviour. |

- Is there any additional feedback you would like to add?
- How do you think we could change this statement to make it more suitable for individuals with LD?

4. 'On this ward, patients can openly talk to staff about all their problems' / 'In this unit, inmates can openly talk to staff about all their problems'

| |
|---|
| Staff Questionnaire Feedback |
| Asking patients/inmates to answer on the behalf of others. |
| 'All their problems' is quite a general statement.<br>○ Would individuals with LD take this literally?<br>○ Some problems may not be relevant to discuss with all staff |
| Individuals with LD may not understand what 'openly' means |

- Is there any additional feedback you would like to add?
- How do you think we could change this statement to make it more suitable for individuals with LD?

5. 'Even the weakest patient finds support from his fellow patients' / 'Even the weakest inmate finds support from his/her fellow inmates'

| |
|---|
| Staff Questionnaire Feedback |
| Individuals with LD may not understand the terms 'weakest' and 'fellow patients/inmates'. |
| What constitutes 'support'? |
| Would individuals with ID have the skills to provide appropriate support to each other? |

| |
|---|
| Generalised statement. Does this mean that ALL patients/inmates find support from other patients/inmates? |
| Forced to live together, should they be expected to support each other? |
| Some patients/inmates prefer to receive support from staff rather than from other patients/inmates. |

- Is there any additional feedback you would like to add?
- How do you think we could change this statement to make it more suitable for individuals with LD?

6. ‘There are some really aggressive patients on this ward’ / ‘There are some really aggressive inmates in this unit’

| Staff Questionnaire Feedback |
|---|
| This could be considered a leading question. |
| What does ‘aggressive’ mean, and what does ‘really aggressive’ mean? Would pictures help aid understanding? |
| If individuals with LD are expected to read the questionnaire themselves, they may not be able to read the word ‘aggressive’. |

- Is there any additional feedback you would like to add?
- How do you think we could change this statement to make it more suitable for individuals with LD?

7. ‘Staff take a personal interest in the progress of patients’ / ’Staff take a personal interest in the progress of inmates’

| Staff Questionnaire Feedback |
|---|
| Individuals with LD may not understand the term ‘progress’ |
| Individuals with LD may not understand the phrase ‘personal interest’. |
| If staff have a personal interest, this is unprofessional and crosses professional boundaries. |
| Staff have specific roles with regards to patients/inmates. |

- Is there any additional feedback you would like to add?
- How do you think we could change this statement to make it more suitable for individuals with LD?

8. ‘Patients care about their fellow patients’ problems’ / ‘Inmates care about their fellow inmates’ problems’

| Staff Questionnaire Feedback |
|---|
| What does ‘care’ mean? |
| Generalised statement. Does the statement imply that ALL patients/inmates should care about ALL their fellow patients’/inmates’ problems? |
| Should patients/inmates be sharing their problems with other patients/inmates? Should they be focusing on their individual recovery? |
| Should we expect patients/inmates to care about each other’s problems? They haven’t chosen to live together. |
| Individuals with LD may struggle to understand the complexity of other patients’ problems. |
| Would individuals with LD understand that the statement is asking them to comment on their own views and those of other patients/inmates? Would they be able to comment on the views of other patients/inmates? |

- Is there any additional feedback you would like to add?
- How do you think we could change this statement to make it more suitable for individuals with LD?

9. ‘Some patients are afraid of other patients’ / ‘Some inmates are afraid of other inmates’

| Staff Questionnaire Feedback |
|---|
| Asking individuals to answer on behalf of others, which they may struggle to do. Some individuals with LD have relatively low awareness and may therefore struggle to answer this question. |
| Individuals with LD may not understand what the term ‘afraid’ means. |
| This statement is more applicable to individuals with LD as they can be seen as vulnerable and as targets for bullying. |

- Is there any additional feedback you would like to add?
- How do you think we could change this statement to make it more suitable for individuals with LD?

10. ‘Staff members take a lot of time to deal with patients’ / ‘Staff members take a lot of time to deal with inmates’

| Staff Questionnaire Feedback |
|---|
| Individuals with LD may not understand the phrase ‘deal with’. |
| Ambiguous wording. Staff take a long time to do things for patients/inmates vs staff take time to help patients/inmates. |
| Implication that patients /inmates are a burden to staff? |
| This could be considered to be a leading question. |

- Is there any additional feedback you would like to add?
- How do you think we could change this statement to make it more suitable for individuals with LD?

11. ‘When a patient has a genuine concern, he finds support from his fellow patients’ / ‘When inmates have a genuine concern, they find support from their fellow inmates’

| Staff Questionnaire Feedback |
|---|
| Gender references: ‘he’ and ‘his’. |
| Individuals with LD may not understand the terms ‘genuine’ and ‘concern’. |
| Individuals with LD may not know the difference between a concern and a genuine concern. |
| Does a ‘genuine concern’ imply the need for support? |
| Individuals with LD may not understand the term ‘fellow patients/inmates’. |
| Individuals with LD may not understand what would constitute support from other patients/inmates in this situation.<br>Should we be encouraging patients to support one another? Patients have not chosen to live together so should we expect them to support each other? |
| Inmates with LD look more to staff for support than fellow inmates. |

- Is there any additional feedback you would like to add?
- How do you think we could change this statement to make it more suitable for individuals with LD?

12. ‘At times, members of staff are afraid of some of the patients’ / ‘At times, members of staff feel threatened by some of the inmates’

| Staff Questionnaire Feedback |
|---|
| Individuals with LD may not understand what ‘threatened’ means. |
| Responding on behalf of staff. Would patients/inmates know how staff feel? Would staff keep their feelings hidden? |
| Leading question? |

- Is there any additional feedback you would like to add?
- How do you think we could change this statement to make it more suitable for individuals with LD?

13. ‘Often, staff seem not to care if patients succeed or fail in treatment’ / ‘Often, staff seem not to care if inmates succeed or fail in the daily routine/program’

| Staff Questionnaire Feedback |
|---|
| Negative phrasing. |
| The terms ‘succeed’ and ‘fail’ aren’t defined. |
| ‘Succeed or fail’ – two elements to the statement, individuals with LD may not understand what is actually being asked. |
| Would patients/inmates know whether staff care or not? |
| What constitutes a failure or a success in treatment? |
| Does this imply success/failure on a general basis or in relation to specific goals? |

- Is there any additional feedback you would like to add?
- How do you think we could change this statement to make it more suitable for individuals with LD?

14. ‘There is good peer support among patients’ / ‘There is good peer support among inmates’

| Staff Questionnaire Feedback |
| --- |
| Individuals with LD may not understand what ‘peer support’ means. |
| Should patients rely on staff for support rather than each other? |

- Is there any additional feedback you would like to add?
- How do you think we could change this statement to make it more suitable for individuals with LD?

15. ‘Some patients are so excitable that one deals very cautiously with them’ / ‘Some inmates are so excitable that one deals very cautiously with them’

| Staff Questionnaire Feedback |
| --- |
| Individuals with LD may not understand the terms ‘excitable’, ‘one’ and ‘cautiously’. |
| What does ‘deals’ mean in this context? |
| Excitable vs happy. |

- Is there any additional feedback you would like to add?
- How do you think we could change this statement to make it more suitable for individuals with LD?

16. ‘Staff know patients and their personal histories very well’ / ‘Staff know inmates and their personal histories very well’

| Staff Questionnaire Feedback |
| --- |
| What does ‘personal history’ mean? Personal history vs life history. |

- Is there any additional feedback you would like to add?
- How do you think we could change this statement to make it more suitable for individuals with LD?

17. ‘Both patients and staff are comfortable on this ward’ / ‘Both inmates and staff are comfortable in this unit’

| Staff Questionnaire Feedback |
| --- |

| |
|---|
| Answering on behalf of others. |
| Individuals with LD may not understand what the term ‘comfortable’ means. |
| Physical vs emotional environment (thinking only of the furniture, not of feelings). |

- Is there any additional feedback you would like to add?
- How do you think we could change this statement to make it more suitable for individuals with LD?

Questionnaire presentation

| *Staff Questionnaire Feedback* |
|---|
| Use of the questionnaire isn’t mentioned. |
| Dependent on the degree of LD. |
| Presentation not particularly relevant as tend to read questions out to patients. |
| Text is too small. |
| The letter ‘a’ needs to be written as ‘a’. |
| Some individuals have limited reading abilities. |
| Bigger spaces needed between questions. |
| Answers under questions or next to them? |
| Pictures or symbols would help to explain each question. |

1. Is there any additional feedback you would like to add?
2. Is it necessary to include a summary statement of the purpose of the questionnaire? If so, what type of information do you think should be included in this summary statement?
3. The majority of staff have reported that they would read the questions out to patients/inmates. Do you think the presentation of the questionnaire is, therefore, still important?
4. Which font type would be most suitable to use?
5. Would it be beneficial to place the answer options under each question?

6. Would pictures or symbols be helpful to explain the questions? What sort of pictures or symbols would be most helpful?

Response format

| Staff Questionnaire Feedback |
|---|
| The majority of staff felt that individuals with LD would struggle to understand the response options. |
| The majority of staff stated that they would need to explain the response format differently in order to help individuals with LD understand the response options. |
| The majority of staff indicated that pictorial representations would be helpful to explain the response options. |
| The majority of staff felt the smiley faces scale would be most appropriate. However, some staff reported that a traffic light response system could also be helpful. |
| Individuals with Autism may not understand the smiley faces scale. |
| Five-point scale vs three-point scale. |
| Larger pictures on cards may be helpful for explaining the response options. |
| Pictorial representations may be too simplistic for some individuals with LD. |
| Visual cues such as thumbs up and thumbs down can also be helpful. |

1. Is there any additional feedback you would like to add?
2. Why do you think the smiley faces scale is the most appropriate response format?
3. What do you think about a traffic light response format?
4. Would individuals with Autism be able to use the smiley faces scale, or would an alternative be better for them? If so, which alternative?
5. Would individuals with LD who are higher functioning find the pictorial version too simplistic? Would an alternative response format be better for them? If so, which alternative?
6. Do you see there being significant problems if a five-point scale was retained for use in the adapted EssenCES questionnaire?
7. Would it be helpful to have laminated cards with the response options on?
8. Would it help to include a pre-test as a way of checking and supporting an individual's understanding of the response format with some practice items before completing the questionnaire? If so, how many questions do you think would need

to be included in the pre-test? What type of questions do you think would need to be included in the pre-test?

Administration

| Staff Questionnaire Feedback |
| --- |
| The majority of staff indicated that they would need to read out the current version of the questionnaire to individuals with LD. |
| The majority of staff stated that individuals with LD would not be able to complete the current version of the questionnaire unsupported. |
| Staff have had to explain the questions differently to help individuals with LD understand what they are being asked. |
| The questionnaire needs to be more fun. |
| A computer version of the questionnaire could be helpful to reduce data collection and inputting. |
| Not all individuals with LD are motivated to complete the questionnaire. |

1. Is there any additional feedback you would like to add?
2. If the questionnaire was going to be read out to all individuals with LD (in an interview format), what would be the best way of doing this?
    a. Would individuals with LD see the questionnaire?
    b. Would they be presented with a paper based version of the response options?
    c. Would staff need to be provided with alternative wording of questions in case individuals with LD don't understand the questions?
    d. Would some individuals with LD struggle more with an interview format?
3. How could we make the questionnaire more fun?
4. What would help motivate individuals with LD to complete the questionnaire?
5. Would a computerised version of the questionnaire be helpful? For staff? For patients/inmates?

The social climate of LD units

| Staff Questionnaire Feedback |
| --- |
| The majority of staff indicated that they felt that social climate differed between LD and non LD units. |

| |
|---|
| Higher rate of incidents. |
| Patients have less tolerance for distress. |
| Patients have a different interaction style. |
| Interpersonal relationships between patients differ. |
| Staff communicate information to patients differently. |
| Patients are more vulnerable. |
| Staff need to be more supportive. |
| Patient expectations of the type and level of support and prompting they expect from staff are different. |
| LD services need more consistency, patience, understanding and clear rules/boundaries. |
| More vulnerable to changes in staff / resident balance. |
| Broader mix of levels of ability. |
| Less predictable environment for staff. |
| Often more structured service than non-LD units, so can become process driven rather than relationship focussed. |
| Individuals with ID are less assertive or less able to voice their opinion or express their rights. |
| ID patients require much more time, guidance, explanation, monitoring. |
| It shouldn't be different at all that's what we should be aiming for. |

1. Is there any additional feedback you would like to add?
2. Do you think that the EssenCES questionnaire covers all these aspects of LD social climate?

**Appendix 8: Consent Form (Study 1)**

## CONSENT FORM: STUDY 1

**Title of Project**: Measuring Social Climate in Forensic Learning Disability Services: Staff Experiences and Perspectives

**Name of Researcher:** Natalie Bell

**Research Supervisors:** Dr Matthew Tonkin, Professor Leam Craig and Professor John Clibbens

**Institution:** Birmingham City University

Please initial box

1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw within five days of data collection, but at no point after these five days. If I choose to withdraw, any of my data gathered until the time of withdrawal will be removed from the data collection and destroyed. ☐
3. I agree to take part in the above study. ☐
4. I understand that if I provide my name and professional email address with regards to taking part in study two, these details will be stored in a database on a laptop computer. ☐

| | | |
|---|---|---|
| Name of Participant | Date | Signature |
| Name of Person Taking Consent | Date | Signature |

**Appendix 9: Consent Form (Study 2)**

## CONSENT FORM: STUDY 2

**Title of Project**: Measuring Social Climate in Forensic Learning Disability Services: Staff Experiences and Perspectives

**Name of Researcher:** Natalie Bell

**Research Supervisors:** Dr Matthew Tonkin, Professor Leam Craig and Professor John Clibbens

**Institution:** Birmingham City University

Please initial box

1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw within five days of data collection, but at no point after these five days. If I choose to withdraw, any of my data gathered until the time of withdrawal will be removed from the data collection and destroyed. ☐
3. I agree to the interview/focus group being recorded. ☐
4. I agree to take part in the above study. ☐

| | | |
|---|---|---|
| Name of Participant | Date | Signature |
| Name of Person Taking Consent | Date | Signature |

## Appendix 10: Birmingham City University Ethical Approval (Studies 1 & 2)

21st March 2016

Natalie Bell
Application no. 040/16

Research Title: Measuring the Social Climate in Forensic Learning Disability Services: Staff Experiences and Perspectives

Dear Natalie,

Thank you for submitting an application for Ethical Approval to the BLSS Faculty Research Ethics Committee. This letter is to confirm that your application has been approved as a Category B research proposal

Yours sincerely,

Professor John Clibbens
Chair of the Faculty Research Ethics
Committee

Cc: Matthew Tonkin

# The EssenCES-IDD

## *Hospital version - Patients*

This form has 17 questions.

The questions ask about how things have been on the ward **over the last week**.

Your answers will help staff find out what it is like to be on the ward and if there are any changes they can make to help make your life better on the ward.

You do not need to put your name on the form.

Please try to be honest when you answer the questions.

This is not a test

- There are no right or wrong answers
- It is okay if you do not know the answer to a question
- Please say if you do not understand a question

My ward is: (write name of ward)

| |
|---|
| |

The questions ask about how things have been on my ward since: (write anchor event from one week earlier as identified with administrator)

| |
|---|
| |

Do you have any questions before we start?

1. Is this ward a nice place to be?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

2. Do patients care about each other?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

3. Do scary things happen on the ward?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

4. Can patients talk to staff about all their problems?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

5. Do patients that are having a bad day get support from other patients?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

6. Are there angry patients on this ward?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

7. Do staff care whether patients are doing well?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

8. Do patients care about the problems of other patients?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

9. Are some patients scared of other patients?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

10. Do staff spend a lot of time helping patients?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

11. Do patients get support from other patients when they are worried?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

12. Are staff scared of some of the patients?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

13. Do staff care about patients getting better?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

14. Is there good support between patients?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

15. Are some patients so scary that you have to stay away from them?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

16. Do staff know patients well?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

17. Are patients and staff comfortable on this ward?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

Thank you for doing this questionnaire.

*For use by staff only*

*Feedback:*

# The EssenCES-IDD

## *Prison version – Prisoners*

This form has 17 questions.

The questions ask about how things have been on the wing **over the last week**.

Your answers will help staff find out what it is like to be on the wing and if there are any changes they can make to help make your life better on the wing.

You do not need to put your name on the form.

Please try to be honest when you answer the questions.

This is not a test

- There are no right or wrong answers
- It is okay if you do not know the answer to a question
- Please say if you do not understand a question

My wing is: (write name of wing)

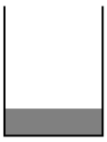
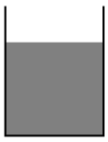
| |
|---|
| |

The questions ask about how things have been on my wing since: (write anchor event from one week earlier as identified with administrator)

| |
|---|
| |

Do you have any questions before we start?

1. Is this wing a nice place to be?

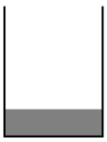
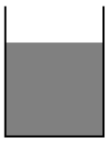
| Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |

Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

2. Do prisoners care about each other?

| Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |

Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

3. Do scary things happen on the wing?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know

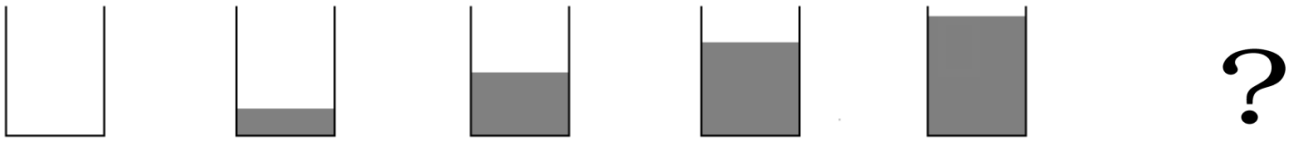

Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

4. Can prisoners talk to staff about all their problems?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know




Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

5. Do prisoners that are having a bad day get support from other prisoners?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know

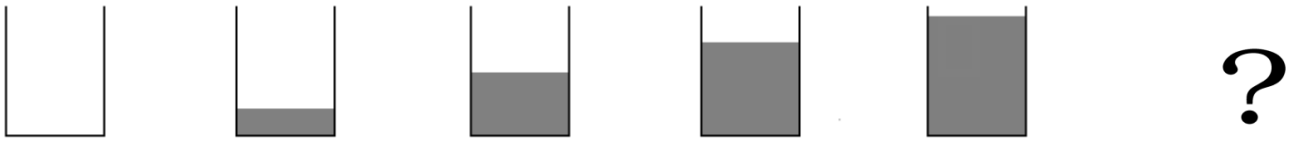

Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

6. Are there angry prisoners on this wing?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know




Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

7. Do staff care whether prisoners are doing well?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know

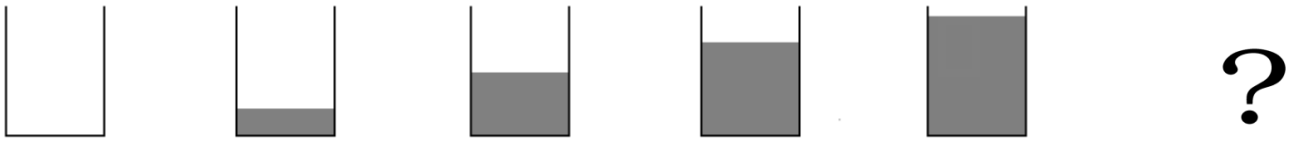

Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

8. Do prisoners care about the problems of other prisoners?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know

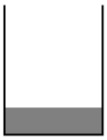
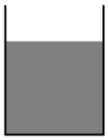



Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

9. Are some prisoners scared of other prisoners?

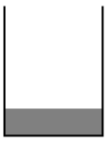
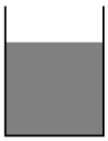
| Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |

Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

10. Do staff spend a lot of time helping prisoners?

| Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |

Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

11. Do prisoners get support from other prisoners when they are worried?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know

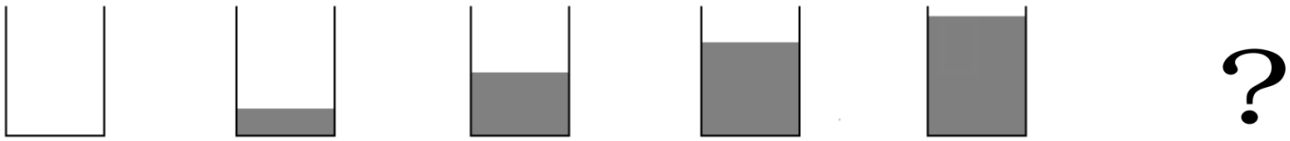

Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

12. Are staff scared of some of the prisoners?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know




Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

13. Do staff care about prisoners getting better?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know

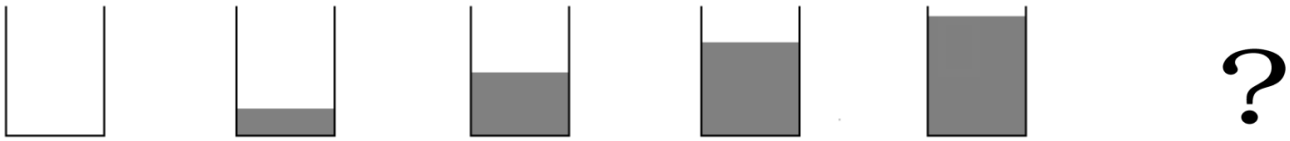

Is there anything you would like to say about this?

*Scripted rewording used* ☐

---

14. Is there good support between prisoners?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know




Is there anything you would like to say about this?

*Scripted rewording used* ☐

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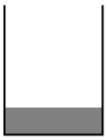
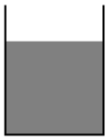
15. Are some prisoners so scary that you have to stay away from them?

| Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |

Is there anything you would like to say about this?

*Scripted rewording used* ☐

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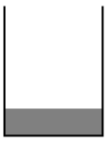
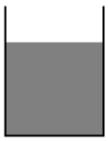
16. Do staff know prisoners well?

| Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |

Is there anything you would like to say about this?

*Scripted rewording used* ☐

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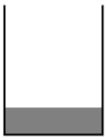
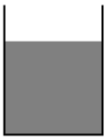
17. Are prisoners and staff comfortable on this wing?

| Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  | ? |

Is there anything you would like to say about this?

*Scripted rewording used* ☐

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Thank you for doing this questionnaire.

*For use by staff only*

*Feedback:*

# The EssenCES-IDD

## *Hospital version – Staff*

This form has 17 questions.

The questions ask about how things have been on the ward **over the last week**.

We are asking these questions because we want to find out what it is like to be on the wing and if there are any changes we can make that will help to improve the ward for both patients and staff.

Your answers are anonymous and you do not need to put your name on the form.

Please try to answer the questions honestly.

Please note that the comment boxes are optional; however, we would welcome any additional feedback that you wish to provide.

**Please write the name of the ward you work on:**

……..

If you have any questions please ask the staff member who provided you with this form.

1. Is this ward a nice place to be?

Not at all A bit Sometimes A lot Nearly all the time I don't know


| Is there anything you would like to say about this? |
|---|

---

2. Do patients care about each other?

Not at all A bit Sometimes A lot Nearly all the time I don't know


| Is there anything you would like to say about this? |
|---|

---

3. Do scary things happen on the ward?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

---

4. Can patients talk to staff about all their problems?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

---

5. Do patients that are having a bad day get support from other patients?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

---

6. Are there angry patients on this ward?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

---

7. Do staff care whether patients are doing well?

Not at all A bit Sometimes A lot Nearly all the time I don't know


| Is there anything you would like to say about this? |
|---|

---

8. Do patients care about the problems of other patients?

Not at all A bit Sometimes A lot Nearly all the time I don't know


| Is there anything you would like to say about this? |
|---|

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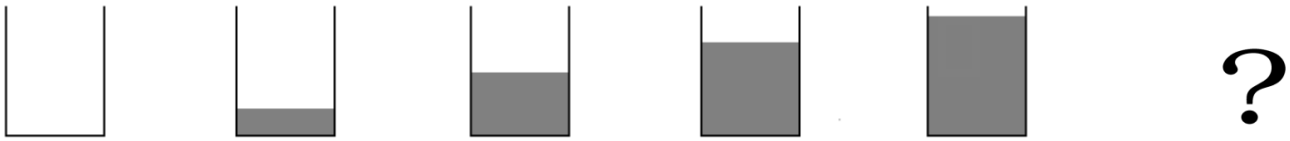
9. Are some patients scared of other patients?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know




Is there anything you would like to say about this?

---

10. Do staff spend a lot of time helping patients?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

---

11. Do patients get support from other patients when they are worried?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


| Is there anything you would like to say about this? |
|---|

---

12. Are staff scared of some of the patients?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


| Is there anything you would like to say about this? |
|---|

---

13. Do staff care about patients getting better?

Not at all A bit Sometimes A lot Nearly all the time I don't know


Is there anything you would like to say about this?

---

14. Is there good support between patients?

Not at all A bit Sometimes A lot Nearly all the time I don't know


Is there anything you would like to say about this?

---

15. Are some patients so scary that you have to stay away from them?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

---

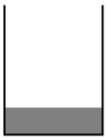
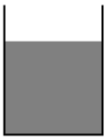
16. Do staff know patients well?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

---

17. Are patients and staff comfortable on this ward?

| Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |

Is there anything you would like to say about this?

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Thank you for doing this questionnaire.

# The EssenCES-IDD

## *Prison version - Staff*

This form has 17 questions.

The questions ask about how things have been on the wing **over the last week**.

We are asking these questions because we want to find out what it is like to be on the wing and if there are any changes we can make that will help to improve the wing for both prisoners and staff.

Your answers are anonymous and you do not need to put your name on the form.

Please try to answer the questions honestly.

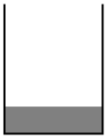
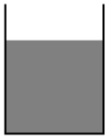
Please note that the comment boxes are optional; however, we would welcome any additional feedback that you wish to provide.

**Please write the name of the wing you work on:**

……..

If you have any questions please ask the staff member who provided you with this form.

1. Is this wing a nice place to be?

| Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |

Is there anything you would like to say about this?

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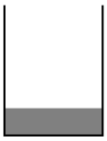
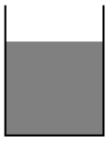
2. Do prisoners care about each other?

| Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |

Is there anything you would like to say about this?

---

3. Do scary things happen on the wing?

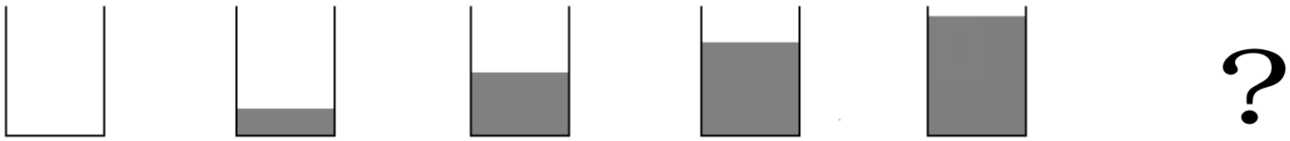
Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

---

4. Can prisoners talk to staff about all their problems?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know




Is there anything you would like to say about this?

---

5. Do prisoners that are having a bad day get support from other prisoners?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


| Is there anything you would like to say about this? |
|---|

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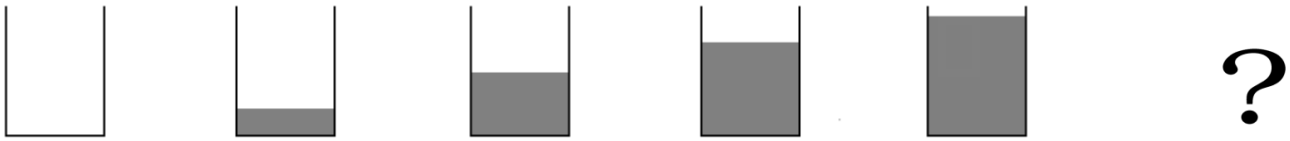
6. Are there angry prisoners on this wing?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know




| Is there anything you would like to say about this? |
|---|

---

7. Do staff care whether prisoners are doing well?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

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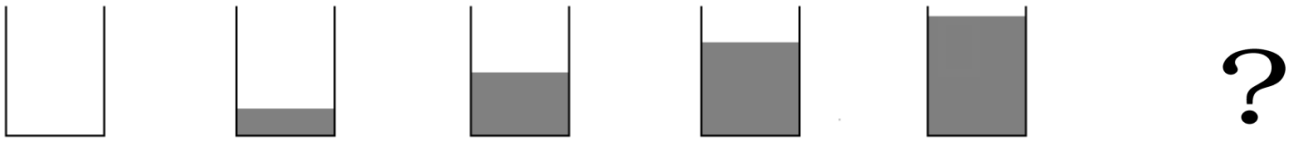
8. Do prisoners care about the problems of other prisoners?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know




Is there anything you would like to say about this?

---

9. Are some prisoners scared of other prisoners?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

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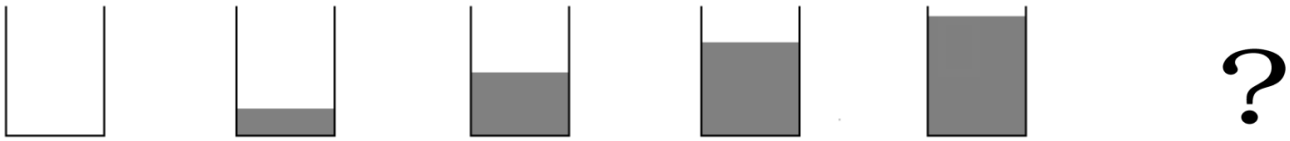
10. Do staff spend a lot of time helping prisoners?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know




Is there anything you would like to say about this?

---

11. Do prisoners get support from other prisoners when they are worried?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

---

12. Are staff scared of some of the prisoners?

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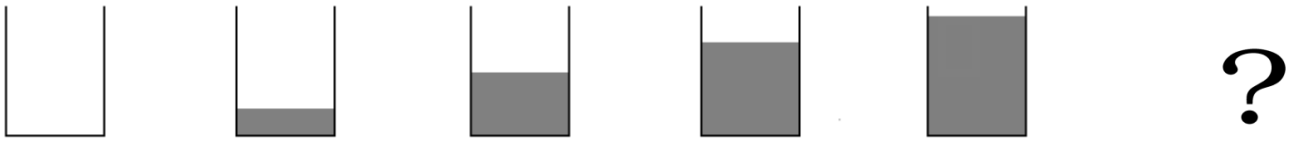


Is there anything you would like to say about this?

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13. Do staff care about prisoners getting better?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

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14. Is there good support between prisoners?

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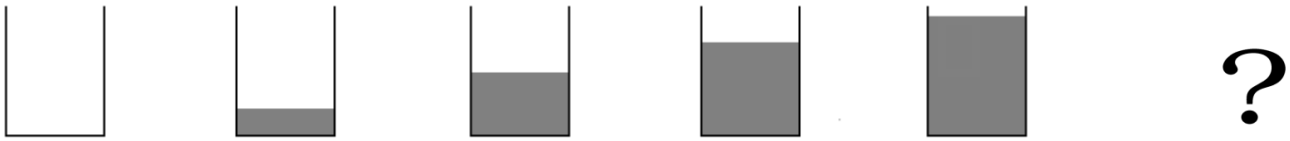



Is there anything you would like to say about this?

---

15. Are some prisoners so scary that you have to stay away from them?

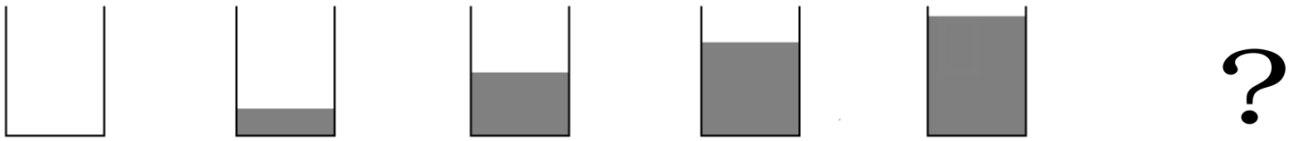
Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know


Is there anything you would like to say about this?

---

16. Do staff know prisoners well?

Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know




Is there anything you would like to say about this?

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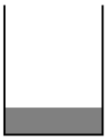
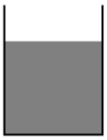
17. Are prisoners and staff comfortable on this wing?

| Not at all | A bit | Sometimes | A lot | Nearly all the time | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  | ? |

Is there anything you would like to say about this?

Thank you for doing this questionnaire.

## Appendix 15: Development of the EssenCES-IDD Items: Suggested Rewordings, Terms, and Phrases

### 1. This ward has a homely atmosphere / This unit has a liveable atmosphere

…feels homely

…comfortable space

…safe place

…feeling

…friendly…

Does the ward feel like a home?

The unit is calm and friendly

Do you feel at home here?

Is it comfortable and safe living here?

This feels like home

It feels comfortable

I feel comfortable…

It feels safe being here

It feels like a safe place

It feels like a comfortable place

I feel comfortable on the wing

Comfortable place to receive treatment

Comfortable place to receive… care

I feel happy and safe

How happy do you feel living on the wing?

It's good living here

Do you like to live there?

Do you like living there?

Is it nice living there?

It's a nice place to be in?

Is it a nice place to live in?

This ward is a nice place to be

This ward is a nice place to live

It's nice to live there

2. **The patients/inmates care for each other**

…care about…

…help…

…support…

I…

Do residents take a positive interest in each other?

3. **Really threatening situations can occur here**

…scary…

Things can get scary

Sometimes things can be scary here

Really threatening situations happen here

Really threatening situations occur here

Behaviours of concern can possible occur here

Do things happen here that make me feel unsafe

Occasionally someone may get upset

Critical incidents occur here

Frightening incidents happen here

I feel unsafe on the ward

I don't feel safe on this ward

4. **On this ward/unit, patients/inmates can openly talk to staff about all their problems**

At (name of ward) residents can openly talk to staff about all their problems

In this unit, residents can openly talk to staff around all their support needs

I can talk to staff about anything

patients/inmates can openly talk to staff about all their problems

In this unit, residents can openly or privately talk to staff at any time about anything

I think prisoners can openly talk to staff about all their problems

I think prisoners can talk to staff about their problems

I think prisoners can talk openly to staff on the wing about their problems

5. **Even the weakest patient/inmate finds support from their fellow patients/inmates**

Do all patients receive support?

Does everybody find support…

Does every prisoner find support…

Do all patients find support from…

Do people find support from…?

Is everyone able to access support?

Do you receive support?

Do you think all patients find support from other patients?

Do you think every prisoner gets support from others?

How supportive are other prisoners?

We all support each other on this ward

All patients get equal support?

Even the least sociable inmate finds support from their peers

All individuals are supported on the wing no matter what their personality

All those that need support find support from their fellow inmates

Inmates find support from their fellow inmates

All inmates can get support from their fellow inmates

Do some people on the ward not get support?

Even if you're not friends with someone you still support them

All residents may seek support from there Co-residents

Even residents that are having a difficult day can find support from fellow residents

Could be rephrased to ask whether or not they feel that all their co-residents are receiving the same support as them

We protect our most vulnerable

Even the weakest inmate can get support from other inmates

Patients help those less able than them

When somebody else may have a problem or an issue have other people helped you, other patients helped you?

I help other people with their problems but other people help me

I can/I have helped other people when they've had problems

I help other people if they have problems

I help other people if they're not feeling ok

6. **There are some really aggressive patients/inmates on this ward/unit**

There are some angry people in this unit

There are aggressive patients on this ward

We have some residents who have challenging behaviours

There are some residents that need to be redirected to use their strategies at times

There are residents who needs to be reminded to utilise there behaviour management stratergies from time to time

I am scared that other patients might hurt me

There is a lot of fighting here

Are you scared that ... might happen?

7. **Staff take a personal interest in the progress of patients/inmates**

Do you think staff care if you are doing well in your treatment?

Staff take an interest in the progress of patients/inmates

Staff take an interest in patients

…take a real interest in progress of inmates

Staff actively support the progress of the residents

Staff and residents work together to achieve the residents' personal goals

…care about me getting better

Staff sit down and talk to clients about their progress

Staff spend time with me and complete activities

Staff try to engage the residents to make steps to archive their progress goals

Staff have specific roles when dealing with residents

Staff are keen for people to make changes

Staff are interested in how inmates get on/deal with things better/get better

Staff get job satisfaction from seeing prisoners' progress

**8. Patients/inmates care about their fellow patients'/inmates' problems**

Inmates care about other inmates' problems

Patients care about other patients' problems

Patients care about the problems other patients are having

Patients care about 'other' patients/residents

Residents are supportive about their fellow residents' problems

We share our problems

Residents are reminded that each resident needs to focus on their own progress, however it is noted that the consideration for a co-resident is supportive

…I…

Residents acknowledge how other residents are traveling

**9. Some patients/inmates are afraid of other patients/inmates**

Some residents have differences with other residents

Some residents may feel concerned around some behaviours co-residents may present

Some patients/inmates are scared of other patients/inmates

Some residents need to be given space once redirected to use their strategies

Bullying can occur at times

…scared…

Other patients make you worry

Other patients make you feel fearful

I feel afraid of some other patients

I am scared of other patients

Some patients are scary

I feel scared by other patients being unsettled

I feel scared by situations

I feel scared when other people are stressed

I stay away from people

I feel threatened by a person

I avoid situations/I avoid things/I withdraw

**10. Staff members take a lot of time to deal with patients/inmates**

Staff members take a lot of time to deal with residents

Staff members try to support the residents as much as they can

Staff members take a lot of time to help patients

…work with…

…help…

Staff are patient and make time for all residents

…assist…

Staff are accessible to residents

Staff spend a lot of time with their patients/helping their patients

Staff members give inmates a lot of time

Staff members take a lot of time to help patients

Staff members take a lot of time to care for patients

…shown me extra care

Staff give me their time when I ask for it/when I need it

Staff do talk to me when I want them to

Staff members take a lot of time to work with patients/complete tasks with patients

**11. When a patient/inmate has a genuine concern, he finds support from his fellow patients/inmates**

When a patient/inmate has a concern, he finds support from his fellow patients/inmates

When a resident has a genuine concern, he finds support from his fellow residents

When a resident has a genuine concern, they can seek support from staff

Other patients help me [with my problems] when I need help

If I/client is worried about something, I/client can get support from my/our co-residents

…I…

When a patient/inmate has a concern/problem, he finds support from his fellow patients/inmates

… fellow patients and staff

Residents can seek support from others

…have worries…

patients are interested in each other's worries

When inmates are upset or worried they can get support from their fellow inmates

if a patient is upset or worried he finds support from his fellow patients

…has a concern/worry he gets support…

How helpful are other prisoners when you have worries?

When you have worries, do other prisoners support you?

When inmates have a problem or a worry they find support from their peers

**12. At times, members of staff are afraid of some of the patients/inmates**

At times, members of staff are needed to reminded residents to use theIr behaviour management strategies, when presenting with behaviours of concern

Members of staff are sometimes afraid of patients

Sometimes, patients scare the staff/staff are scared of patients

Sometimes staff get scared by the clients

At times, members of staff need to give a resident space after being reminded to use their strategies

Staff need to be vigilant at all times

Some staff are scared of some patients

Members of staff are afraid of some of the patients

Do you think members of staff are afraid of patients

**13. Often, staff seem not to care if patients/inmates succeed or fail in treatment/their daily routine/program**

Staff do their best to provide support to residents, to achieve their individual goals

Staff want the very best outcome for all residents

Do all staff care about resident's success and failure in treatment?

Do staff care if patients are doing well in treatment

…do well/don't do so well

Staff don't care if I finish the program

Staff don’t care if inmates do well or fail

Staff don’t seem to care whether we’re doing well

Staff don’t care if prisoners succeed or fail…

Staff don’t care if you follow the rules or not

Staff don’t care if inmates do their sessions/daily sessions/daily things

Often staff don't seem to care ...

Staff seem not to care in inmates succeed or fail

Some staff do not care how patients get on

How well do you feel staff care?

Do they care about you?

… if patients were doing well

Staff seem to care if we are doing ok

The staff care whether we’re doing well or not

Staff care if I follow the rules AND staff care if I do well on programme/I don’t do well on programmes

**14. There is good peer support among patients/inmates**

There is good peer support among residents

The residents are advised to work together to achieve their individual goals

There is good communication…

…help each other out…

We encourage all residents to encourage each other to make steps to achieve their personal goals

All clients feel supported by co-residents

… support each other well

There is good support between inmates

There is good support among patients

…good support between prisoners

Patients help each other

Prisoners support each other

I feel supported by prisoners

**15. Some patients/inmates are so excitable that one deals very cautiously with them**

All residents have different needs and both staff and residents need to be flexible

Some patients have high risks which means staff are worried about working with them

All staff need to know each resident's behaviour support plan

Residents can become very excitable and need to have space

Inmates are so excitable staff are careful/worried about dealing with them

Some inmates get really upset quickly that I am very careful dealing with them

Some inmates mood changes so often/are unpredictable that we are cautious around them/we deal with them cautiously

Are there prisoners that are so unpredictable they make where you live feel unsafe?

Some patients are so aggressive you have to keep clear of them

You have to be careful around some patients that get too excited

Some patients have to be handled gently

… people deal cautiously with them

…very gently…

Do you feel safe round that person?

…unpredictable…

… so excited that you have to be careful around them

Some patients get excited and that can be scary

Some patients get too excited…

Some patients get so excited so that I avoid them

… I stay away from them

I steer clear of scary prisoners

Have prisoners scared you?

I worry about being near…

I worry about being around angry prisoners

I stay away from prisoners that are scary/angry

I'm careful how I talk to angry prisoners

Some inmates struggle to be themselves around hostile/angry/aggressive people

**16. Staff know patients/inmates and their personal histories very well**

Staff are provided with a comprehensive profile of each resident

Staff know residents and their personal histories relevant to their treatment

Staff are responsible for knowing all relevant information about a resident

Staff know patients well

I feel staff understand me/know me well and about my past

do staff know my personal history well?

Do staff know about your life and your experiences?

…know about me and my past

… know you and your past well

… life history…

…your past…

Staff know patients well

Staff know me well

Staff know me and my story

Staff know about me and all of my life

Staff know about my life

**17. Both patients/inmates and staff are comfortable on this ward/unit**

Both residents and staff work together and are comfortable in (name of ward)

Both staff and residents work best together in a harmonious environment

…happy…

…relaxed…

…getting along well…

…safety…

The unit is a relaxed unit

Patients/inmates and staff are comfortable on this ward/unit

Two separate questions, one about staff, and one about patients/residents

Staff are comfortable on this ward AND patients are comfortable on this ward

**Appendix 16: EssenCES-IDD Initial Pilot Administration Pack**

# EssenCES-IDD Administration Guidelines

*It is important to ensure that the guidelines below are followed when administering the EssenCES-IDD. This will help to provide a more consistent method of administration which will lead to more accurate results and information.*

Who should administer the EssenCES-IDD?

**The EssenCES-IDD must be administered with individuals with IDD on a 1-1 basis by a staff member.** It must not be administered within a group setting nor should it be given to individuals with IDD to complete on their own.

At present, there is not enough research evidence to suggest who is best placed to administer the EssenCES-IDD; therefore, this decision must be made by individual services. However, we would strongly advise that services remain consistent with their choice of administrator and do not, for example, use a staff member that is known well by individuals with IDD to administer some of the questionnaires and an external, unfamiliar, staff member to administer some of the questionnaires as this could result in a lack of consistency and affect the accuracy of the results.

How to administer the EssenCES-IDD

*Cover sheet*

- Ensure the patient/prisoner can see a copy of the cover sheet.
- Support the individual with IDD to read the information on the cover sheet out loud themselves if able. Alternatively, read out the information on the cover sheet to the individual with IDD.
- Fill in the name of the ward/unit.
- Support the individual with IDD to identify an anchor event. This is an event that happened **one week prior** to the administration of the questionnaire. Ensure the individual with IDD understands that the questions on the EssenCES-IDD are asking about how things have been on their ward/unit **since this event occurred**.
- Ask the individual with IDD if they have any questions.

*Questionnaire Items*

- Ensure the individual with IDD can see a copy of the questionnaire.
- Remind the individual with IDD that the questions refer to how things have been on their ward/unit over the last one week since the anchor event occurred.
- Reiterate to the individual with IDD that the EssenCES-IDD is not a test; that they can tell you if they don't understand a question, that there are no right or wrong answers, and that it is okay if they don't know the answer to a question.

- Ensure the questions are asked and answered in the order in which they are presented. Do not return to a question later.
- **Do not deviate from the wording of the questions.** Only use the scripted rewordings that have been provided. This ensures that all individuals with IDD are receiving the same explanation of the questions.
- Do not provide any examples of events that may help demonstrate the meaning of a question, as this can increase bias and lead to inaccurate results.

**Please follow the steps below for each question:**

1. Support the individual with IDD to read the question out loud themselves if able. Alternatively, read out the question to the individual with IDD.
2. If the individual with IDD does not understand the question, then read out the scripted rewording. If the individual with IDD is having difficulties considering the perspective of staff (questions 7, 12, 13, and 16), please add the phrase 'do you think' to the start of the question as shown in the scripted rewordings.
3. If the individual with IDD is able to answer the question using the scripted rewording please record their response and also tick the corresponding box on the questionnaire to indicate the scripted rewording has been used for that question.
4. If the individual with IDD still does not understand, then support them to tick the 'I don't know' box.

If it is clear that the individual with IDD is not understanding the questions, please use your clinical judgement to decide whether or not to continue. For some individuals with IDD, distress may be caused by continuing; however, for others, ceasing completion may have a negative impact. If it is deemed more appropriate to continue, then please use the feedback box at the end of the questionnaire to indicate that the data are unreliable.

*Responding to the EssenCES-IDD Questions*

- Ensure the individual with IDD can see the response format. Use the large-scale response format if required.
- Read through the response options with the individual with IDD.
- Response choices can be communicated in any way (i.e., ticking their chosen option on the questionnaire, saying out loud the word, pointing, or holding up the card depicting their chosen option).
- If the individual with IDD does not know the answer to a question then support them to select the 'I don't know' response option.
- Encourage the individual with IDD to take ownership of their response choices by ticking their chosen option or providing support for them to do this when required.
- If the individual with IDD wishes to provide additional information within the comment boxes please allow them to write this themselves if able. If they are not able to write this themselves, then please write down exactly what they have said in their own words.

- Comment boxes can still be utilised even if the individual with IDD answers ‘I don’t know’ to the question.

*Additional information*

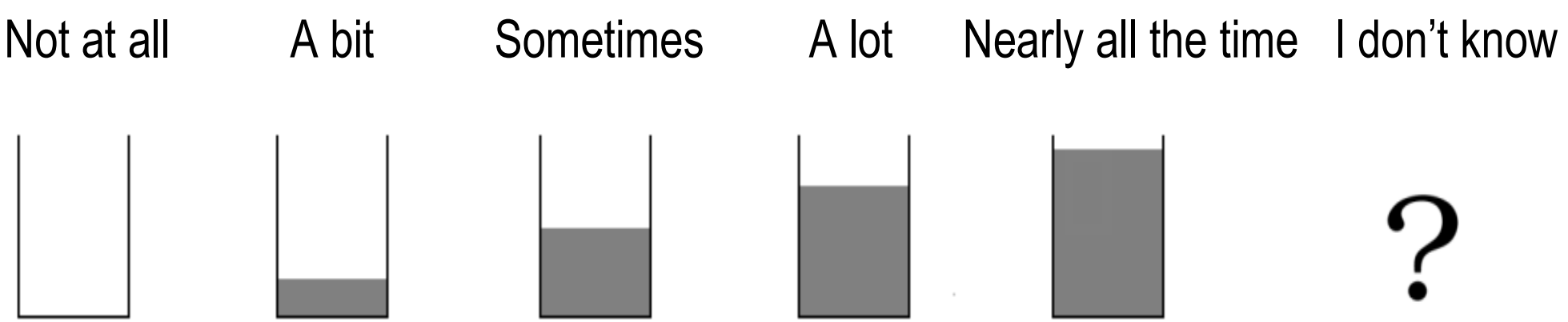
- If you feel that the individual with IDD has not understood the questions, or if you observe a pattern of responses indicative of response bias (i.e., selecting the last option provided for each question, selecting the same option for each question) then please note this in the feedback box at the end of the questionnaire.

**Scripted Rewording of EssenCES-IDD Items**

| Item number | EssenCES-IDD item | Scripted rewording of EssenCES-IDD item |
|---|---|---|
| 1. | Is this ward/wing a nice place to be? | Do patients/prisoners like being on the ward/wing? |
| 2. | Do patients/prisoners care about each other? | Do patients/prisoners look out for each other? |
| 3. | Do scary things happen on the ward/wing? | Do patients/prisoners feel unsafe on the ward/wing? |
| 4. | Can patients/prisoners talk to staff about all their problems? | Do staff listen to patients/prisoners who have problems? |
| 5. | Do patients/prisoners that are having a bad day get support from other patients/prisoners? | If a patient/prisoner is having a bad day do other patients/prisoners help them? |
| 6. | Are there angry patients/prisoners on this ward/wing? | Do patients/prisoners get angry? |
| 7. | Do staff care whether patients/prisoners are doing well? | **Do you think** staff care whether patients/prisoners are doing well?<br>Do staff care if patients/prisoners are doing ok (in their treatment)?<br>**Do you think** staff care if patients/prisoners are doing ok (in their treatment)? |
| 8. | Do patients/prisoners care about the problems of other patients/prisoners? | Do patients/prisoners talk to each other about their problems? |
| 9. | Are some patients/prisoners scared of other patients/prisoners? | Are some patients/prisoners scary? |
| 10. | Do staff spend a lot of time helping patients/prisoners? | Do staff spend a lot of time talking to patients/prisoners or doing activities with them? |
| 11. | Do patients/prisoners get support from other patients/prisoners when they are worried? | How helpful are other patients/prisoners when a patient/prisoner is upset? |

| Item number | EssenCES-IDD item | Scripted rewording of EssenCES-IDD item |
|---|---|---|
| 12. | Are staff scared of some of the patients/prisoners? | **Do you think** staff are scared of some of the patients/prisoners?<br>Do some of the patients/prisoners scare the staff?<br>**Do you think** some of the patients/prisoners scare the staff? |
| 13. | Do staff care about patients/prisoners getting better? | **Do you think** staff care about patients/prisoners getting better?<br>Are staff interested in patients/prisoners getting well?<br>**Do you think** staff are interested in patients/prisoners getting well? |
| 14. | Is there good support between patients/prisoners? | Do patients/prisoners help each other? |
| 15. | Are some patients/prisoners so scary that you have to stay away from them? | Do patients/prisoners keep clear of scary/angry patients/prisoners? |
| 16. | Do staff know patients/prisoners well? | **Do you think** staff know patients/prisoners well?<br>Do staff know about patients/prisoners and their past?<br>**Do you think** staff know about patients/prisoners and their past? |
| 17. | Are patients/prisoners and staff comfortable on this ward/wing? | Are patients/prisoners and staff happy on this ward/wing?<br>Is everyone comfortable/happy on this ward/wing? |

**Large-Scale Response Format**



# Information Sheet

You are being invited to take part in some research.

The research is about making a questionnaire for people with Learning Disabilities.

The questionnaire asks what it is like to be on the ward or unit.

**Who are the researchers?**

The researchers are Natalie Bell and Dr Matthew Tonkin.

The researchers are from Birmingham City University.

**What will you be asked to do?**

The researchers would like you to fill in a questionnaire.

**Can you take part?**

You can take part if you are a patient on a Learning Disability ward or a prisoner on a Learning Disability unit.

**Do you have to take part?**

You can choose if you would like to take part or not.

If you do take part:

- You do not have to answer any questions you do not like.
- If you change your mind you can stop at any time.

**Will taking part be helpful?**

Your answers will help the researchers to find out what it is like to be on the ward or unit and if there are any changes staff can make to help make your life better here.

**Who will the information be shared with?**

Your answers will be shared with other people but they will not be told your name or the name of your hospital or prison.

If you tell me that you may hurt yourself or someone else or if you share something that makes me worry about you then I will have to tell staff on your ward.

I will tell the staff on your ward or unit that you are taking part.

**What else do you need to know?**

You can change your mind about taking part but you need to tell the staff within the next 5 days.

If you change your mind about taking part then the researchers will delete your answers to the questionnaire.

The researchers will keep the information about you for up to 1 year.

The researchers will keep your answers to the questionnaire for up to 5 years.

**If you would like to contact the researchers about the research please tell the staff on your ward.**

## Appendix 18: Staff Participant Information Sheet

### PARTICIPANT INFORMATION SHEET

**Title of Project**: Measuring Social Climate in Forensic Intellectual Developmental Disorder (IDD) Services: Piloting the EssenCES-IDD

**Name of Researcher:** Natalie Bell

**Research Supervisors:** Dr Matthew Tonkin, Professor Leam Craig and Professor Michael Brookes

**Institution:** Birmingham City University

*You are being invited to participate in a research study. Before you make your decision it is important for you to understand the purpose of the research and what participation will involve. Please read the following information carefully, and contact us if you would like more information before deciding whether or not to take part.*

**Background**

- Social climate refers to the 'personality' of a setting or environment and encompasses how safe residents and staff feel, how supportive the unit is perceived to be of therapeutic gain and the physical/psychological needs of residents.
- The Essen Climate Evaluation Schema (EssenCES; Schalast et al., 2008) is a questionnaire-based measure of social climate that is widely used in UK forensic settings and is completed by both residents and staff. Although there is strong evidence that the EssenCES is a useful measure of social climate in non-IDD forensic settings, there have been questions raised regarding its use in IDD settings.

**Purpose of Study**

- This study is the second part of a larger scale research project that seeks to adapt the EssenCES for use in forensic IDD settings.
- The purpose of this study is to gather feedback from staff regarding the suitability of the pilot version of the adapted EssenCES (the EssenCES-IDD) for both individuals with IDD and staff working in forensic IDD settings.

**What will my participation involve?**

- Participation is voluntary and that there will be neither advantage nor disadvantage as a result of your decision to participate or not participate in the research.
- Participation will consist of attendance at a one-hour focus group (4-5 staff members). During the focus group you will be asked to:

    - Complete the EssenCES-IDD.
    - Discuss your feedback regarding the suitability of the pilot version of the EssenCES-IDD for individuals with IDD and staff working in forensic IDD settings. This discussion will consider a variety of aspects of the EssenCES-IDD including the presentation of the EssenCES, the nature and wording of the items, the response format, and the guidelines for completion.
- The focus groups will be recorded.
- Please note that, should you be unable to attend the focus group, an individual interview can be offered as an alternative.

The aim is that the information gathered will help to identify any final amendments that need to be made prior to development of the final version of the EssenCES-IDD.

**Can I take part?**

In order to participate, we ask that you check that you meet the following criteria:

- You are currently working in forensic IDD settings.
- Your role involves working in locked rehabilitation, low secure, medium secure, high secure or prison units.
- Your role involves provision of direct support to residents of forensic IDD settings (i.e. Nurse, HCA/Support Worker, Prison Officer, MDT member, Group Facilitator). If your role only involves non-direct contact with residents of forensic IDD settings (i.e. administration) then, unfortunately, you will be unable to participate.
- You have an understanding of the cognitive difficulties experienced by residents with IDD.

**Why will my participation be helpful?**

Information gathered through this study will be used to develop the final version of the EssenCES-IDD which will help to improve understanding of the social climate of forensic IDD settings and of the aspects of social climate important to those with IDD.

**Additional Information**

Participation is voluntary and that there will be neither advantage nor disadvantage as a result of your decision to participate or not participate in the study. If you choose to participate in the study, any information you share will remain strictly confidential as at no point will your name, or any information that could be linked back to you, be used.

Your responses to the EssenCES-IDD will be anonymous and will not be analysed. We are only asking that you complete the EssenCES-IDD so that you are able to provide feedback during the focus group regarding its suitability for measuring social climate in forensic IDD settings.

There are no foreseeable risks for participants, as the focus groups and interviews will not include any topics of a sensitive nature. All participants will be reminded prior to the focus

groups and interviews that they are not to refer to any residents by name. The information gathered through the focus groups and interviews will be anonymised immediately following transcription, with digital recordings being destroyed at this point. Data will be stored in a secure manner in line with the Data Protection Act (1998). You are able to refuse to answer individual questions and you are free to withdraw from the study within five days of data collection without being compromised in any way. If you choose to withdraw, any of your data gathered until the time of withdrawal will be removed from the data collection and destroyed. If you are unhappy about any aspect of the study, please contact Natalie Bell (natalie.bell@mail.bcu.ac.uk). If you remain unhappy, or would like to make a formal complaint, please contact BLSSEthics@bcu.ac.uk.

The information gathered during this study will contribute to an academic journal article summarising development of the EssenCES-IDD, and may also be used for the purpose of additional reports and conference presentations. Personal data gathered from this study may be kept for up to 12 months following completion of the study, and research data may be kept for up to five years. You will not be individually identifiable in any publications or presentations arising from this work.

**If you would like to discuss the study in more detail or would like further information about the study, please contact Natalie Bell: natalie.bell@mail.bcu.ac.uk.**

## Appendix 19: Individuals with IDD Interview Schedule

### Patient/Prisoner Interview Schedule

*Ensure participants have their completed copy of the EssenCES-IDD in front of them for reference.*

- What did you think about the questionnaire?
    - Was any of it too easy?
    - Was any of it too hard?

Follow up questions

1. What do you think about how the questionnaire looks?
    a. Does it look too long or is it okay?
    b. Is the writing the right size?
    c. Does it look squashed up or is there enough space?
    d. Are the (comment) boxes big enough?
    *e.* How could I change that to make it better? *(If there were things they felt were difficult)*

2. What do you think about the front page? *(make sure participants can see a copy of the front page)*
    a. Are there any words that are too hard/too long?
    b. Was it easy or hard to think of something that happened one week ago *(anchor event)*?
    c. Do you think the front page told you the right information about the questionnaire?
    d. Do you think there is anything else that would be important to put on the front page?

3. What do you think about the questions *(on the questionnaire)*?
    a. Were any questions too easy? *(If participants find this difficult, ask them about specific questions instead)*
    b. Were any questions too hard? *(If participants find this difficult, ask them about specific questions instead)*
    c. Why were they easy/hard? *(i.e., words, phrasing, sentence length, concepts)*
    *d.* How do you think I could make that better? *(If there were things they felt were difficult)*
    e. Can you tell me what this question means to you? *For questions participants seemed to find more difficult during completion, ask participants specifically about these questions.*

*4.* What do you think about the response choices? *(help show participants where they are if needed)*

a. Can you tell me what the pictures mean to you?
b. Can you tell me what the written response headings mean to you?
c. What was it like when you had to choose which answer to pick? *(easy/hard)*
d. What was easy/hard about it?
e. How do you think I could make that better? *(If there were things they felt were difficult)*

5. Is there anything else you would like to say about the questionnaire?

## Appendix 20: Staff Focus Group Schedule

### Staff Focus Group Schedule

Two key areas for consideration:

1. Any amendments required in relation to staff completion of the EssenCES-IDD
2. Any amendments required in relation to individuals with IDD's completion of the EssenCES-IDD

Staff Completion

When thinking about staff completion of the EssenCES-IDD, what was your experience of completing the EssenCES-IDD as a staff member?

Follow up questions

1. How did you feel/do you think staff may feel about completing the same version as individuals with IDD?
    a. Do you think there are benefits to staff completing the same version as individuals with IDD?
2. Do you think any changes may be required for the staff cover sheet?
3. Do you think the reworded items would be required for staff?
4. How do you feel/do you think staff may feel with regards to the response options?
5. What are your thoughts regarding the layout of the EssenCES-IDD for staff completion?
6. What are your thoughts regarding the inclusion of comment boxes in relation to staff completion?

Individuals with IDD completion

*Give the administration guidelines and scripted rewordings out for participants to look at. Also provide participants with a copy of the original version of the EssenCES.*

When thinking about individuals with IDD completing the EssenCES-IDD, is there any feedback you would like to provide or are there any further amendments that you feel may need to be made?

Follow up questions

1. Is there anything that you feel isn't clear or that may need to be changed in the administration guidelines for the benefit of staff administering the EssenCES-IDD?
2. Are there any changes within the administration guidelines that you feel may need to be made in order to help ensure standardisation of administration?
3. Do you think any changes may be required for the cover sheet?
    a. Language
    b. Layout

    c. Information included
4. In relation to the EssenCES-IDD questions, do you think any further amendments may be required?
    a. Any items as a whole that are not clear
    b. Any particular words or phrases that are not clear
5. In relation to the scripted rewordings, are there any specific words that you think we may need to provide alternative words for?
6. Are there any scripted rewordings that you feel are not clear or that don't reflect the meaning of the original question?
7. Do you think the layout of the EssenCES-IDD is appropriate for individuals with IDD?
    a. Length of the questionnaire
    b. Font size
    c. Number of pages
    d. How it is presented on the page
8. Do you think the response format and response options are suitable for individuals with IDD?
    a. Number of response options provided
    b. The 'I don't know' response option
    c. The wording for the response option headings
    d. The visual representations of the response options
    e. The large-scale version of the response options
9. Is there any other feedback that you would like to provide?

# Consent Form

I have made a questionnaire for people with Learning Disabilities.

The questionnaire asks what it is like to be on the ward or unit.

I would like to ask you to do this questionnaire with me.

I would then like to talk to you about what you think about the questionnaire.

It is important for me to find out what people with Learning Disabilities think about the questionnaire and if there are things I can change to make the questionnaire better for people with Learning Disabilities.

- You do not have to answer any questions you do not like.
- You can stop talking to me at any time.

Would you like to do the questionnaire and talk to me about it afterwards?


Can I record us talking about the questionnaire?



Can I tell other people what you think about the questionnaire? I will not tell them your name.



Please write your name in the box below.

| | | |
|---|---|---|
| Name of Person Taking Consent | Date | Signature |

**Appendix 22: Staff Consent Form**

**CONSENT FORM: PILOT STUDY**

**Title of Project**: Measuring Social Climate in Forensic Intellectual Developmental Disorder (IDD) Services: Piloting the EssenCES-IDD

**Name of Researcher:** Natalie Bell

**Research Supervisors:** Dr Matthew Tonkin, Professor Leam Craig and Professor Michael Brookes

**Institution:** Birmingham City University

Please initial box

1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that there will be neither advantage nor disadvantage as a result of my decision to participate or not participate in the research. ☐

3. I understand that I can refuse to answer individual questions and that I am free to withdraw within five days of data collection, and that this will not compromise me in any way. If I choose to withdraw, any of my data gathered until the time of withdrawal will be removed from the data collection and destroyed. ☐

4. I understand that the information gathered during this study will contribute to an academic journal article summarising the development of the EssenCES-IDD, and may also be used for the purpose of additional reports and conference presentations. ☐

5. I understand that personal data may be kept for up to 12 months following completion of the study, and that research data may be kept for up to five years. ☐

6. I agree to the interview/focus group being recorded. ☐

7. I agree to take part in the above study. ☐

| | | |
|---|---|---|
| Name of Participant | Date | Signature |
| Name of Person Taking Consent | Date | Signature |

# Appendix 23: Birmingham City University Ethical Approval

Faculty of Business, Law & Social Sciences Research Office
Curzon Building, 4 Cardigan Street
Birmingham
B4 7BD

BLSSethics@bcu.ac.uk;

10/Jul/2019

Miss Natalie Bell

natalie.bell@Mail.bcu.ac.uk

Dear Natalie ,

**Re:** Bell /3259 /R(C) /2019 /Jul /BLSS FAEC - Measuring the Social Climate in Forensic Intellectual Developmental Disability Services

Thank you for your application and documentation regarding the above study. I am pleased to confirm that Birmingham City University has agreed to take on the role of Sponsor.

Birmingham City University can confirm that our insurance indemnity cover includes the actions of researchers working in suitable premises and under appropriate supervision. Our policy cover will not apply to liability that is more specifically insured under any policy covering medical negligence, malpractice or indemnity, professional errors, omissions or negligence.

A copy of BCU's insurance details is available at: https://icity.bcu.ac.uk/Legal-Services-and-Compliance/Insurance/Index

If you wish to make any changes to your proposed study (by request or otherwise), then you must submit an Amendment application to us. Examples of changes include (but are not limited to) adding a new study site, a new method of participant recruitment, adding a new method of data collection and/or change of Project Lead.

Please also note that the Committee should be notified of any serious adverse effects arising as a result of this activity.

**Keep a copy of this letter along with the corresponding application for your records as evidence of**

**approval.** If you have any queries, please contact BLSSethics@bcu.ac.uk;

I wish you every success with your study.

Yours Sincerely,

Professor Maxine Lintern

On behalf of the Business, Law and Social Sciences Faculty Academic Ethics Committee

# The EssenCES-IDD

## *Hospital version – Patients*

**This sheet should be read by patients.**

**Staff can read the sheet to patients if they need to.**

- This form has 15 questions.
- We are asking these questions to help us think about how the ward can be improved.

- You do not need to put your name on the form.
- Please answer all the questions.
- Please try to be honest when you answer the questions.
- The comment boxes are optional.
- Staff can help you to write down any comments.

This is not a test.

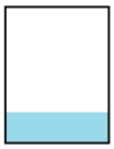
- There is not a time limit.
- There are no right or wrong answers.
- It is okay if you do not know the answer to a question.
- Please say if you do not understand a question.

The name of my ward is:

| |
|---|
| |

Do you have any questions before we start?

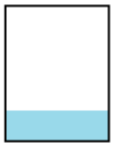
1. Do patients show care for each other?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

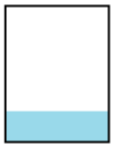
2. Do threatening events happen on the ward?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

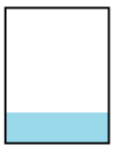
3. Are patients able to talk to staff about their problems?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

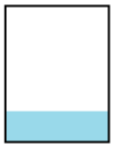
4. Do patients that are having a bad day get support from other patients?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

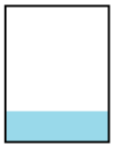
5. Are there aggressive patients on this ward?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

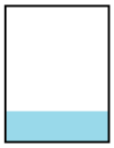
6. Do you think staff care whether patients are making progress?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

7. Do patients care about the problems of other patients?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

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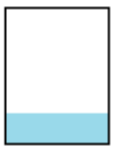
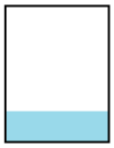
8. Are some patients scared of other patients?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

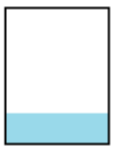
9. Do staff help patients?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

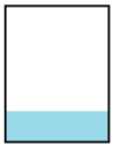
10. Do patients get support from other patients when they are worried?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

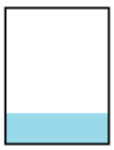
11. Do you think staff are scared of some of the patients?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

12. Do you think staff care whether patients are doing well?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

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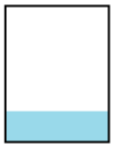
13. Is there good support between patients?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

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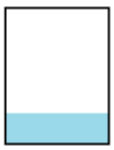
14. Do patients stay away from unpredictable patients?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

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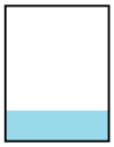
15. Do you think staff know patients well?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

Thank you for doing this questionnaire.

Please speak to staff if you have any worries or concerns after finishing the questionnaire.

*For use by staff only*

*Feedback:*

# The EssenCES-IDD

## *Prison version – Prisoners*

**This sheet should be read by prisoners.**

**Staff can read the sheet to prisoners if they need to.**

- This form has 15 questions.
- We are asking these questions to help us think about how the wing can be improved.

- You do not need to put your name on the form.
- Please answer all the questions.
- Please try to be honest when you answer the questions.
- The comment boxes are optional.
- Staff can help you to write down any comments.

This is not a test.

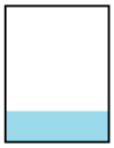
- There is not a time limit.
- There are no right or wrong answers.
- It is okay if you do not know the answer to a question.
- Please say if you do not understand a question.

The name of my wing is:

| |
|---|
| |

Do you have any questions before we start?

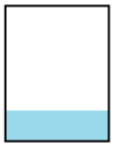
1. Do prisoners show care for each other?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

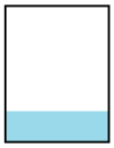
2. Do threatening events happen on the wing?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

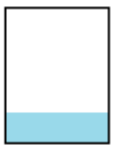
3. Are prisoners able to talk to staff about their problems?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

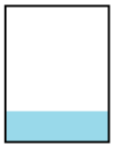
4. Do prisoners that are having a bad day get support from other prisoners?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

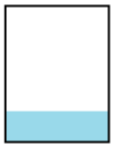
5. Are there aggressive prisoners on this wing?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

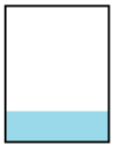
6. Do you think staff care whether prisoners are making progress?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

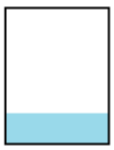
7. Do prisoners care about the problems of other prisoners?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

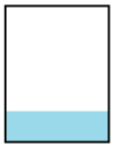
8. Are some prisoners scared of other prisoners?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

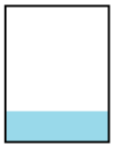
9. Do staff help prisoners?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

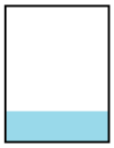
10. Do prisoners get support from other prisoners when they are worried?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

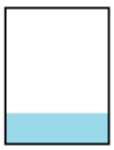
11. Do you think staff are scared of some of the prisoners?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

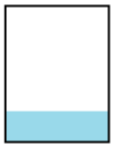
12. Do you think staff care whether prisoners are doing well?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

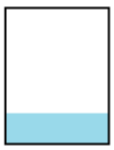
13. Is there good support between prisoners?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

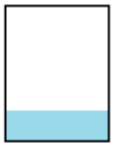
14. Do prisoners stay away from unpredictable prisoners?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

15. Do you think staff know prisoners well?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

Thank you for doing this questionnaire.

Please speak to staff if you have any worries or concerns after finishing the questionnaire.

*For use by staff only*

*Feedback:*

# The EssenCES-IDD

## *Hospital version – Staff*

- This form has 15 questions.
- We are asking these questions to help us think about how the ward can be improved.

- Your answers are anonymous and you do not need to put your name on the form.

- Please answer all the questions.
- Please try to answer the questions honestly.

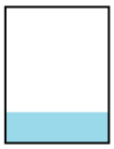
- We would welcome any additional feedback within the comment boxes. However, you may choose to leave the comment boxes blank if you prefer.

**Please write the name of the ward you work on:**

……..

If you have any questions please ask the staff member who provided you with this form.

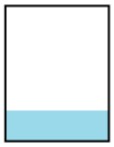
1. Do patients show care for each other?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

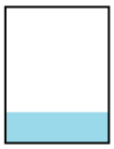
2. Do threatening events happen on the ward?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

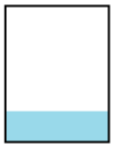
3. Are patients able to talk to staff about their problems?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

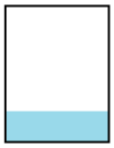
4. Do patients that are having a bad day get support from other patients?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

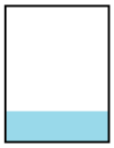
5. Are there aggressive patients on this ward?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

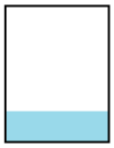
6. Do you think staff care whether patients are making progress?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

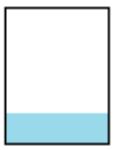
7. Do patients care about the problems of other patients?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

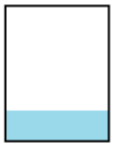
8. Are some patients scared of other patients?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

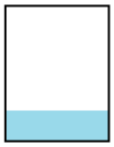
9. Do staff help patients?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

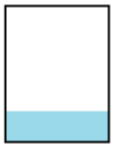
10. Do patients get support from other patients when they are worried?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

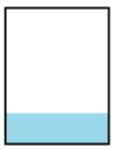
11. Do you think staff are scared of some of the patients?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

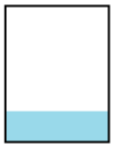
12. Do you think staff care whether patients are doing well?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

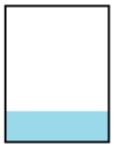
13. Is there good support between patients?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

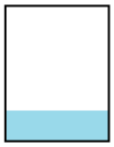
14. Do patients stay away from unpredictable patients?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

15. Do you think staff know patients well?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

Thank you for doing this questionnaire.

**Appendix 27: EssenCES-IDD Updated Pilot Questionnaire (Staff – Prison Version)**

# The EssenCES-IDD

## *Prison version – Staff*

- This form has 15 questions.
- We are asking these questions to help us think about how the wing can be improved.

- Your answers are anonymous and you do not need to put your name on the form.

- Please answer all the questions.
- Please try to answer the questions honestly.

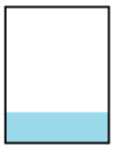
- We would welcome any additional feedback within the comment boxes. However, you may choose to leave the comment boxes blank if you prefer.

**Please write the name of the wing you work on:**

……..

If you have any questions please ask the staff member who provided you with this form.

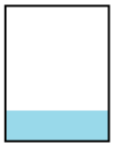
1. Do prisoners show care for each other?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

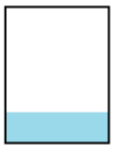
2. Do threatening events happen on the wing?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

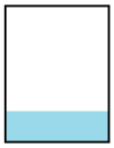
3. Are prisoners able to talk to staff about their problems?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

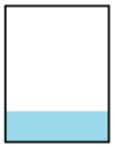
4. Do prisoners that are having a bad day get support from other prisoners?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

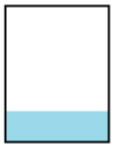
5. Are there aggressive prisoners on this wing?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

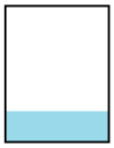
6. Do you think staff care whether prisoners are making progress?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

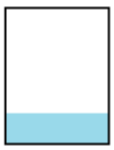
7. Do prisoners care about the problems of other prisoners?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

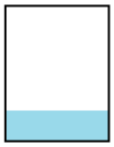
8. Are some prisoners scared of other prisoners?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

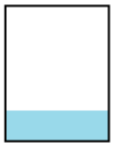
9. Do staff help prisoners?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

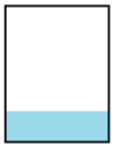
10. Do prisoners get support from other prisoners when they are worried?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

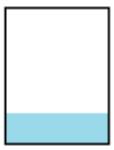
11. Do you think staff are scared of some of the prisoners?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

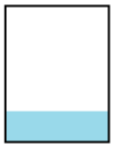
12. Do you think staff care whether prisoners are doing well?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

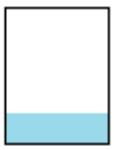
13. Is there good support between prisoners?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

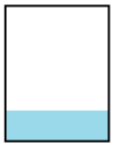
14. Do prisoners stay away from unpredictable prisoners?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

15. Do you think staff know prisoners well?

| Not at all | Little | Somewhat | Quite a lot | Very much | I don't know |
|---|---|---|---|---|---|
|  |  |  |  |  |  |
| ☐ | ☐ | ☐ | ☐ | ☐ | ☐ |

Is there anything you would like to say about this?

---

Thank you for doing this questionnaire.

**Appendix 28: EssenCES-IDD Updated Pilot Administration Pack**

# EssenCES-IDD Administration Guidelines

*It is important to ensure that the guidelines below are followed when administering the EssenCES-IDD. This will help to provide a more consistent method of administration which will lead to more accurate results and information.*

Purpose of the EssenCES-IDD

The EssenCES-IDD is intended to provide a snapshot view of the social climate of the ward or wing. The data gathered can be used for various purposes. The cover sheets provide a brief summary of this and state 'we are asking these questions to help us think about how the ward can be improved'.

If your service wishes to provide further information for individuals with IDD or staff regarding your reasons for administering the EssenCES-IDD then you can do so.

Who should administer the EssenCES-IDD?

**The EssenCES-IDD must be administered with individuals with IDD on a 1-1 basis by a staff member.** It must not be administered within a group setting nor should it be given to individuals with IDD to complete on their own.

**At present, there is not enough research evidence to suggest who is best placed to administer the EssenCES-IDD; therefore, this decision must be made by individual services.** However, we would strongly advise that services remain consistent with their choice of administrator. For example, do not use a staff member that is known well by individuals with IDD to administer some of the questionnaires and an external, unfamiliar, staff member to administer some of the questionnaires. This is because doing so could result in a lack of consistency and affect the accuracy of the results. If services wish to compare EssenCES-IDD data in a longitudinal manner, we would also advise that services remain consistent with their choice of administrator across different time-points where possible. This will enable a more reliable comparison of EssenCES-IDD data over time.

How to administer the EssenCES-IDD

The EssenCES-IDD can be printed single or double sided. If printed double sided, please make sure the individual with IDD is informed of this.

It is advised that the EssenCES-IDD should be printed in colour. If this is not possible then please print it in greyscale.

You may print copies of the EssenCES-IDD questions on large, single, sheets if individuals require the questions in large print.

Please ensure that you are aware of any individuals with IDD who also have dyslexia, and that appropriate coloured overlays are utilised. These individuals may struggle with visual discrimination and experience difficulties differentiating reading the items and

differentiating between the colours used in the response options. Therefore, you may need to present the questions and response options verbally.

*Cover sheet*

- Ensure the individual with IDD can see a copy of the cover sheet.
- Support the individual with IDD to read the information on the cover sheet out loud themselves if able. Alternatively, read out the information on the cover sheet to the individual with IDD.
- Fill in the name of the ward.
- Ask the individual with IDD if they have any questions.

*Sequencing Task*

- Cut out the large-scale response format so that each response option (heading and associated visual representation) is presented on a single card.
- Shuffle the cards and place them upside down on the table.
- Ask the individual with IDD to turn over the cards and place them in order from the card depicting the lowest level of agreement to the highest level of agreement.
- If the individual completes this task correctly, then move on to completion of the EssenCES-IDD questions.
- If the individual completes this task incorrectly, then demonstrate the correct order and explain this to the individual before moving on to complete the EssenCES-IDD questions.

*Questionnaire Items*

- Ensure the individual with IDD can see a copy of the questionnaire. You may print large, single, sheets with each individual question on if required.
- Reiterate to the individual with IDD that the EssenCES-IDD is not a test:
    - They can tell you if they don't understand a question.
    - There are no right or wrong answers.
    - It is okay if they don't know the answer to a question.
- Ensure the questions are asked and answered in the order in which they are presented. Do not return to a question later.
- **Do not deviate from the wording of the questions.** This ensures that all individuals with IDD are receiving the same explanation of the questions.
- Do not provide any examples of events that may help demonstrate the meaning of a question, as this can increase bias and lead to inaccurate results.

If it is clear that the individual with IDD is not understanding the questions, please use your clinical judgement to decide whether or not to continue. For some individuals with IDD, distress may be caused by continuing; however, for others, ceasing completion may have a negative impact. If it is deemed more appropriate to continue, then please use the feedback

box at the end of the questionnaire to indicate that the data may be unreliable due to a lack of understanding by the individual with IDD.

*Responding to the EssenCES-IDD Questions*

- Ensure the individual with IDD can see the response format. Use the large-scale response format if required.
- Read through the response options with the individual with IDD.
- Response choices can be communicated in any way (i.e., ticking their chosen option on the questionnaire, saying the word out loud, pointing, or holding up a card depicting their chosen option).
- If the individual with IDD does not know the answer to a question then support them to select the 'I don't know' response option.
- Encourage the individual with IDD to take ownership of their response choices by ticking their chosen option or providing support for them to do this when required.
- If the individual with IDD wishes to provide additional information within the comment boxes please allow them to write this themselves if able. If they are not able to write this themselves, then please write down exactly what they have said in their own words.
- Comment boxes can still be used even if the individual with IDD answers 'I don't know' to the question.

*Additional information*

- Please note in the feedback box at the end of the questionnaire if:
    - The individual with IDD experienced difficulties completing the sequencing task correctly.
    - You feel that the individual with IDD has not understood the questions.
    - You observe a pattern of responses indicative of response bias (i.e., selecting the last option provided for each question, selecting the same option for each question).
    - **Of note is that difficulties understanding the sequencing task or EssenCES-IDD questions, or the presence of response biases, must not result in any individuals' responses being excluded from the dataset.**

**Large Scale Response Format**