Using co-creation to modify mindlines and improve childhood eczema care

Introduction

I'm red. I spread hate.
What's my name? It's eczema.
I am powerful.

Childhood atopic eczema impacts wellbeing and has a high self or parent-management demand requiring regular and consistent application of topical medication. National evidence-based guidance for childhood eczema exists. However, in common with much research-based evidence, application of this guidance is limited. We know that disseminating information and/or telling people what to do does not change practice.

Knowledge mobilisation (KM) seeks to get evidence into everyday practice, in essence KM is about sharing *knowledge* between different *communities* to catalyse *change* (Wye et al 2020). In an extensive search of KM techniques, I discovered mindlines, a concept that intuitively made sense to me as a nurse and fitted with my real-world experiences. In this chapter I recount how I used traditional and creative approaches to investigate lay and practitioner eczema mindlines and to co-create and implement strategies to alter and enhance these mindlines across lay-practitioner-wider society boundaries. My aims were to, i) use diverse and creative means to bring this evidence alive, ii) share simple, consistent, evidence-based messages, to instil shared language and understanding, iii) integrate reliable and useful knowledge and erase outdated or inaccurate information, and iv) ultimately, improve self-management practices and consultation experiences (see for example The Dragon in My Skin animation Dragon). This chapter illustrates how mindlines principles can inform effective KM strategies with wider application for other long-term conditions.

The challenge of childhood eczema

Atopic eczema affects around 20% of young children; it is a long-term relapsing condition which affects wellbeing and quality of life for children and their family. Key challenges are summarised in Box 1.

- Mainly treated by non-specialists in primary care
- Consultations often unsatisfactory for both parties
- High self/parent-management demand
- Treatment failure is common
- Concerns about topical steroid use is widespread
- Information quality is variable and overload commonplace

Box 1: Key challenges of childhood eczema

The fundamentals of caring for childhood eczema are straightforward but often, for a whole raft of reasons, not enacted as effectively as possible by health care practitioners (HCPs) or parents and children. Although high quality evidence exists (NICE eczema guidance) this does not take into account the complexity and constraints of everyday practice and self-care which are at the core of mindlines theory. Pragmatic guidance on eczema management is provided by clinical experts who speak of "*two things done well*[1]", referring to regular and consistent application of emollients and using topical steroids at times of flare, and "*get control, keep control*" referring to using topical steroids to reduce inflammation and regular and consistent application of emollients (Williams 2011).

The aims of my work were to:

- Understand existing lay and HCP eczema mindlines
- Work with lay people and HCPs to co-create affordable, practical, cost-effective, acceptable, safe and equitable (Michie et al 2014) strategies to alter and enhance existing mindlines.
- Deliver new 'interventions' to support changes in practice / health behaviours to enhance self-management practices and consultations experiences.

My approach was informed by the Socialisation, Externalisation, Combination and Internalisation (SECI) Spiral (Nonaka et al 2000) as explained by Gabbay and le May (2011) (Box 2)

- **Socialisation:** transfer of knowledge between people, often an implicit process that conveys day-to-day norms in a specific group or situation.
- **Externalisation:** tacit knowledge is made more explicit and people make collective sense of their own and others knowledge, often resulting in more widely comprehensible explicit knowledge
- **Combination:** other sources of knowledge (for example clinical guidelines) are melded with the explicit constructs from the original tacit knowledge.
- **Internalisation:** the individual transforms this combined knowledge into understanding that fits with their own knowledge and experience.

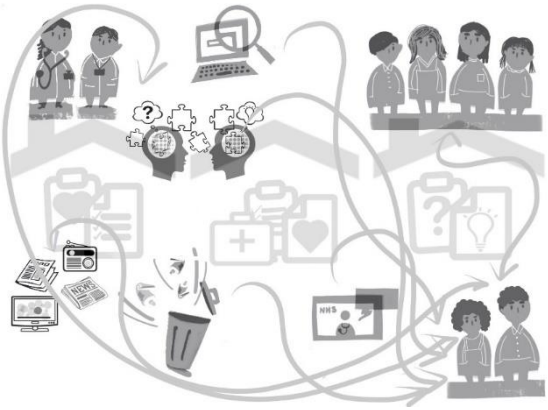
Box 2: The Socialisation, Externalisation, Combination and Internalisation (SECI Spiral) (Nonaka et al 2000) as explained by Gabbay and le May (2011)

[1] Provenance of this phrase is uncertain, I associate it with Professor Hywel Williams, Consultant Dermatologist and Sandra Lawton, Consultant Dermatology Nurse.

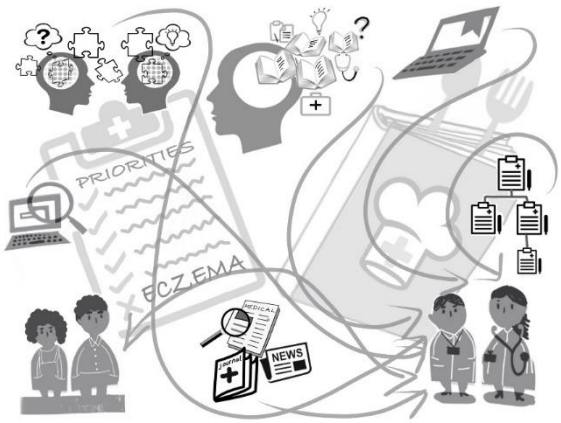
Understanding eczema mindlines

To understand ***socialisation*** processes and uncover the complexity of how and why HCP and parent-child lay eczema mindlines develop, evolve and are transmitted I used ethnographic observation, informal conversations, interviews and documentary review to build up a rich picture of day-to-day practice. I spent several months working alongside general practitioners (GPs) including trainees and locums, nurses and health visitors, receptionists and community pharmacy staff observing numerous interactions. The essence of lay and HCP eczema mindlines is illustrated in Boxes 3 and 4:

- *Care informed by "trial and error", "I've tried everything … I know what works for me"*
- *Family, friends and wider society influential, offering sometimes unsolicited advice*
- *"Old wives tales" assimilated, "just knowing", "steroids … back of your mind, bad for the skin, thins it, don't know where from".*
- *New knowledge from NHS Choices and patient.co.uk trusted but too generic and not applicable for their circumstances and needs.*
- *"Googling" frequent, ability to judge the value of information varied, degrees of caution and all had a line which they would not cross in terms of acting on information*
- *Poor consultation experiences, "not worth consulting".*



Box 3: Essence of lay eczema mindlines (Cowdell 2018)



- *Low priority condition which is simple to manage, "eczema is simple to treat, nothing much has changed over the years", "the recipe doesn't change"*
- *Prescribing limited by local formularies*
- *Limited motivation to change current practice*
- *Management as a long-term condition rare*
- *Approach automatic, often unthinking, likened to a "satnav ……you stop thinking, the little NHS boxes [on the computer] tell you what to prescribe"*
- *Value given to patient experience varied "listen and learn", "actually taking notice of what they're telling me" to "patient experience stuff can be counterproductive"*

Box 4: Essence of HCP eczema mindlines (Cowdell 2019)

Lay people and HCPs alike struggled to ***externalise*** their tacit knowledge to make it explicit; the interview process provoked deep thinking about where knowledge and beliefs had come from and whether they were valid. Surfacing eczema mindlines exemplified the key role tacit knowledge plays in guiding decision making and actions for lay people and HCPs alike. Nonaka and Takeuchi (1995) point to two types of tacit knowledge, i) technical know-how an "informal craft-based skill" that cannot readily be articulated, and unconscious schemata "the schemata, mental models, beliefs and perceptions so ingrained that we take them for granted" (Gabbay and le May 2010 p99). The patients and HCPs in my study illustrated how this informal knowledge is far more influential than formal codified guidance.

Eczema mindlines were relatively static, people had tacit knowledge that informed brief and often unhelpful interactions. One powerful influencer was the low priority afforded to eczema by many HCPs and the impact this had on lay people who often chose to stop consulting or bring eczema as a secondary complaint in a consultation. Eczema knowledge is deeply embedded in social norms and so is rarely externalised. HCPs in particular had limited motivation to combine their existing tacit knowledge with external, codified knowledge sources such as clinical guidelines and thus internalisation (with improvement in practice) was infrequent. Understanding mindlines, and importantly the relationships of mindlines between stakeholders, offers the promise of opportunity for people to engage in the type of social processes which are far more likely to change practice than the production of yet more codified information (Gabbay and le May 2011).

In summary, parents and children acquire knowledge and beliefs from many sources including personal experience, family, friends and wider society, trial and error, online and from practitioners. Quality of HCP advice is variable with the most trusted, useful and personalised being given by dermatology specialist nurses (although few participants had benefited from such consultations). HCPs' actions are built on the belief that eczema is simple to treat, and prescribing options limited. Knowledge is based on early education, interactions with colleagues, practical experience and patients. Therefore, efforts to alter and enhance mindlines need to be a mutual endeavour which transcends lay–practitioner-wider society boundaries to develop shared and consistent language and understanding; this required a co-creation approach.

Combination through co-creation

Co-creation in healthcare is increasingly seen as a 'good thing' and, more importantly, is essential in moving beyond socialisation and through ***externalisation*** to ***combination***. Co-creation is a logical approach to finding strategies to alter and enhance mindlines, given the complexity, context specificity and intertwined nature of lay-HCP mindlines and the need to consider the wider social milieu. The goal in co-creation was to i) find strategies to help others internalise reliable, useful and contextually appropriate knowledge and erase outdated or inaccurate information and ii) to offer shared language and understanding across boundaries. Although language and

definitions of co-creation vary, the idea that it should involve lay people and professionals working as equals at each stage of the research process is consistent (Co-create 2021; NIHR 2021). Fundamental questions in preparation for co-creation include: who is participating, in what and for whose benefit (Cornwall 2008).

Co-creation workshops

Co-creation work was guided by eight principles of the 'Gold Standard' Coproduction Matrix (Co-create 2021); all activities should be holistic, resourced, transparent, inclusive, iterative, positive, equal and sustainable. The co-creation group comprised lay people with, and parents of children with, atopic eczema, HCPs, a researcher and a facilitator (n=22). We met face-to-face three times with iterative email communication before, between and after sessions. Before workshop one co-creators received the original mindline publication of Gabbay and le May (2004) with illustrations and explanation of lay and HCP practitioner eczema mindlines. Each workshop started with a discussion about mindlines, which intuitively "made sense" to all. Data included facilitator notes, flip charts documenting individual and group presentations and artefacts. Data collection and analysis were iterative. Between workshops data summaries were sent to all participants for comment, amendment, and supplementation.

Workshops one and two

HCPs attended workshop one and lay people workshop two where the purpose was to externalise existing tacit knowledge allowing participants to make collective sense of their own and others knowledge thus increasing understanding. To remain close to context and give participants a familiar and comfortable starting point, two core questions were posed to generate rich discussion, i) what makes a good eczema consultation in primary care[2] and ii) what should lay people and practitioners start, stop and continue if they are to improve eczema consultations and self-management? Question two elicited the interactions and approaches to treatment that work well and should be continued, what new ones should be initiated and which are unhelpful and should be stopped. A summary of co-creators' thoughts are provided in Boxes 5 and 6.

Lay people

- *HCP who empathised with the impact that eczema had on quality of life and made time to talk*
- *HCPs being open about their knowledge and its limitations, provided they could signpost to required information*
- *HCPs to value their expertise*
- *"Help manage long-term rather than short-term solutions for flares"*
- *Working in partnership with HCPs to "come to an understanding, work together" to self-manage as effectively as possible*

[2] Thoughts here were primarily around GP consultations but also included interactions with other HCPs in particular community pharmacists, pharmacy counter assistants, nurses and health visitors who many suggested may be better placed to provide eczema care.

HCPs

- *Based on empathy*
- *Involving a reciprocal conversation between "equals" to generate shared understanding of eczema and treatment history so that both parties understand and "play the same tune, be on the same page".*
- *Delivering consistent messages to reduce misunderstandings and enhance patient's confidence*
- *Agreeing goals to "get control and keep control"*
- *Accommodating patient and family preferences for treatments, whilst acknowledging this could be challenging within the confines of local prescribing guidelines*

Box 5: Summary of thoughts on Q1, what makes a good eczema consultation in primary care?

Lay people and HCPs

- Treat eczema as a long-term condition
- Be prepared for the appointment
- Prioritise eczema
- Engage in shared decision-making
- Use topical treatments consistently

Box 6: Summary of thoughts on Q2, what should lay people and practitioners start, stop and continue to improve eczema consultations and self-management?

Data from workshops one and two and subsequent email exchanges were collated and analysed to identify priority areas to alter and enhance lay and HCP eczema mindlines. These were i) prioritise eczema, ii) manage eczema as a long-term condition, iii) prepare for each consultation, iv) be consistent with treatment, v) work together, vi) get the right emollient and vii) use steroids appropriately.

Workshop three

In workshop three, co-creators came together to consider ***combination*** of tacit and codified knowledge. They emphasised the core challenges of eczema being a low priority condition, views about treatment being deeply entrenched, and some reluctance to engage in shared decision-making. Commonalities in thinking included

- Interventions to alter and enhance the mindlines of either group in isolation would not be effective as they are intertwined and co-dependent and so must be addressed in parallel
- Eczema mindlines are influenced by a wider social milieu, this may reinforce powerful messages, such as children "grow out of eczema" and the myth that topical steroid preparations are necessarily "dangerous".

Changes in mindlines would only occur in the context of trust and 'realness' for lay people and practical, locally relevant, hints and tips, tailored, 'no faff' approaches for HCPs. Simply providing more information would not influence mindlines; information overload was already problematic. We revisited existing evidence-based NICE eczema guidance and consulted with the National Eczema Society to ensure that when ***combination*** occurred it integrated reliable evidence in user-friendly language. To meet identified need we developed five key, consistent, evidence-based messages to become the bedrock of eczema mindlines alteration and enhancement:

i. Eczema is more than just dry skin,
ii. Eczema does not just go away,
iii. Moisturisers are for every day,
iv. Steroid creams are okay when you need them and
v. You know your child's eczema best.

Creating this firm foundation could enable shared language and understandings and support more equal interactions between lay people and HCPs. Each priority was underpinned by a set of simple, illustrated messages. Potential approaches to alter and enhance mindlines included, for example, 'pop up' events in public arenas, sharing the messages in skincare sections of supermarkets, targeting information in 'Healthy Living Pharmacies', using 'Steroid Sam the emoji' in information to illustrate benefits of topical steroids when needed and using the Patient Oriented Eczema Measure/Children's and Dermatology Life Quality Index to improve confidence in 'proving' impact of eczema during consultations. As each idea was discussed, the strengths and weaknesses were identified. Many were abandoned as not being feasible due to lack of time and funding.

In summary co-creators agreed five key, consistent eczema messages should be shared across lay-practitioner-wider society boundaries using accessible, engaging, easy to understand formats to promote shared language and understanding. Co-creation work was necessarily time limited, I left the sessions with a set of key messages and ideas about how these may best be shared.

Internalisation: altering and enhancing mindlines

To date, relatively little has been written about strategies to alter and enhance mindlines particularly approaches that attempt to bridge lay-HCP-wider society boundaries. In the course of the workshops co-creators combined their eczema knowledge, the challenge here was to find ways to support ***combination*** and ***internalisation*** at a wider level. Co-creators thinking aligned closely with Gabbay and le May's (2011) analysis of uptake of new evidence. They point to the inherent messiness of the adoption of new evidence demonstrating the chasm between the orderly, linear and rational route sometimes espoused in evidence-based practice and the reality of day-to-day practice. Equally, whilst valuing the SECI spiral, Gabbay and le May (2011) emphasise that mindlines take into account a more complex view of how internalisation occurs and offer valuable pointers:

i. Certain types of evidence and the way in which this evidence is presented are better accepted than others. Personal experiences and views of locally respected experts, often shared through stories and anecdotes, are powerful currency. Immediate credibility and relevance trumps perceived scientific validity. Information that can be transformed and linked to existing knowledge supports reformulation of new information in a way that makes sense to individuals

ii. People need to surface and communicate existing tacit knowledge and combine and internalise (or reject) new information and assess this for relevance and fit with their situation

iii. The fate of information is influenced by negotiation, how accessible and plausible it is to all involved, and the credibility of the bearer

iv. The desirability and possibility of putting new knowledge into practice depends on roles, power differentials and individuals' credibility, all of which are in a state of perpetual flux.

Strategies to alter and enhance eczema mindlines were informed by four elements: i) knowledge brokering, ii) Social Marketing, iii) 'Ba' and iv) the Ripple Effect model. Each is described briefly below.

Knowledge brokering

My role was as a knowledge broker, "one who connects science and society by building networks and facilitating opportunities among knowledge producers and knowledge users" (Thompson & Schwartz Barcott, 2019 p26). Activity is based on five elements: i) establish - identifies potential stakeholders, ii) engage - recognises stakeholders' cultural norms and practices, iii) educate - facilitates multidirectional knowledge exchanges, iv) empower - builds capacity for shared decision making and v) evaluate – considers processes, outcomes, and impacts.

Social marketing

Social marketing (SM), used internationally in healthcare since the mid-1970s, melds concepts from commercial marketing and social sciences (Walsh et al 1993). SM goes beyond providing information, encompassing health communication techniques based on mass media. Messages can be mediated through other sources, in our case potentially practitioners and lay influencers. Communication approaches are varied and may include targeted message placement, health promotion, dissemination, and community outreach (Evans 2006). SM works here given the high prevalence of childhood eczema, the aim of changing practices and the need to get simple, consistent messages to a diverse range of people who may influence treatment including those living with eczema, HCPs and members of the wider community, for example grandparents, friends and influencers such as community leaders.

'Ba'

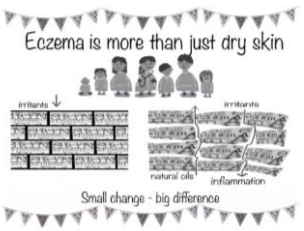
Mindlines build on the work of Polanyi (2009) and Nonaka & Takeuchi (2007), in particular, the SECI spiral in which knowledge is perpetually produced and transformed as users interact, collaborate and learn. Gabbay and le May (2011) emphasise knowledge-in-practice-in-context, recognising that in each context new knowledge is transformed by complex social processes. The work of Nonaka offers new insights into altering mindlines, drawing on the relationship between the SECI spiral and *Ba. Ba* originates from philosophers Nishida & Dilworth (1970) and was advanced by Shimizu (1995), it is a shared space for knowledge creation and sharing. *Ba* is not about the space itself (Bartolacci et al 2016) but instead is a shared context-in-motion which progresses over time and has no firm boundaries or membership. It is about the here-and-now and flourishes with people who contribute diverse viewpoints (Nonaka & Toyama 2003). *Ba* space occurs naturally, is not preordained, relationships change over time (Nonaka & Konno 2003). Communication flows iteratively back and forth between *Ba* members and can be face-to-face or virtual, involving individuals or groups according to need and opportunity (Krahe et al 2014). Given the need to alter and enhance mindlines, both lay and HCP, across communities the notion of deliberatively creating *Ba* and integrating innovative approaches to communication offers new opportunities.

Ripple Effect Model

Language of the ripple effect is varied but in essence refers to the spreading effect or series of consequences caused by a single action or event (Newman 2003), akin to a series of waves. Although mainly referenced in supply-chain literature, the ripple effect is documented in healthcare, for example in the diffusion of health education messages from nursing students via primary school children to their parents and onward to neighbours (Nambozi 2014). The ripple effect may also have a reciprocity characterised by mutual sharing of expertise, experience, attitudes, beliefs, and skills. An example many will relate to is the reciprocity we use when driving, if another driver helps us, we are more likely to help others and vice-versa (Tennant 2016). Just as considerate driving can generate a ripple effect of safer journeys (Tennant 2016), so clear, consistent messages and shared understandings may support better eczema care.

Mindline alteration and enhancement

Initially my focus was on the small, deprived, multicultural area of an East Midlands city in the UK where I collected early data. Box 7 provides exemplars of activity and illustrations of the five key messages which were used in advertising for events and illustrated and printed on postcards with supplementary information on the back.

    	*Venue: community pharmacies* *Target group: customers and pharmacy staff* *Intervention: posters and postcards* *Evaluation method: feedback from staff* *Venue: shopping centre* *Target group: passing shoppers and staff* *Interventions: i) brief consultation with expert dermatology nurses ii) trying emollient products and iii) postcards* *Evaluation method: footfall, observation of responses and nature of interaction with nurses* *Venue: primary school* *Target group: children aged 5-6 years, teachers and parents* *Intervention: story reading, drawing activity and conversations. Information for parents* *Evaluation method: response from children, feedback from staff* *Venue: healthcare facilities* *Target group: Health visitors, community public health nurses, general practitioners and other HCPs* *Intervention: workplace based, mindline informed case-study based interactive sessions* *Evaluation method: informal conversations, qualitative interviews and post session questionnaire* *Venue: online* *Target group: people seeking further information* *Intervention: website with further information and animation* *Evaluation method: visits to site and views of animation* *Venue: place of worship* *Target group: children and their parents* *Intervention: storytelling and conversations with children and parents* *Evaluation: feedback from children and parents*

Box 7: Exemplars of activity and illustrations of the five key messages

Later I expanded the reach of activity with a focus on continuing to share key messages and sharing with the wider community to normalise eczema amongst children aged 5-7 years and their teachers. The latter was influenced by lay feedback about the need to educate the educators and help others understand the impact of living with eczema and promote empathy.

An author and illustrator embedded the five key messages in a children's book 'The Dragon in My Skin'. We then ran a series of co-creation workshops with children living with eczema aged 4-10 years and their parents. The children, alongside the team, developed words and sounds for a Dragon song. Children recorded themselves reading the book and singing the song, this was merged with professional vocals and backed by an orchestra to create a Dragon animation. The film premiered at an online event in March 2021 and is now freely available

online. Taking this content as a starting point a group of education academics developed a series of illustrated, curriculum linked activities relating to each primary school subject area: English, maths, science, physical education and dance, music and personal, social, health and economic education, each at three graduated levels of complexity, which we have called 'hatch, grow and fly' in keeping with the Dragon theme.

Impact

Assessing the impact of using KM techniques to alter and enhance eczema mindlines is inevitably messy and multi-factorial. To aid clarity I have drawn on two schools of thought. Firstly, the contributions approach, accepting this work is just one of many factors which contribute to change (as opposed to attribution which claims change is due to the intervention alone) (Morton 2015). Secondly the Social Impact Framework (SIF) which promotes a broad and inclusive notion of impact across the domains of individual, group and interpersonal, organisation, society and infrastructure and paradigm (Beckett et al 2018). Proving change is limited as it may be subtle and go unseen. At the time of writing indications of impact are promising. Practitioners, parents and children have given concrete examples of changes in thinking and/or action. Over 500 trainee teachers are using the teacher resource pack and a copy of the book with links to resources has been sent to over 800 schools. Online resources have been shared across national and international teaching communities via existing extensive online networks. Through a web of connectivity, largely word of mouth, resources have been requested by healthcare colleagues at individual, departmental and organisational levels. Likewise resources have been sent to educators, particularly those with a focus on mental health and wellbeing. Additionally, we are translating resources to French and Portuguese. Engagement with project specific social media was modest but webpages had good view quality, users engaged with the content and spent time reading it, as indicated by an average time of five minutes compared with the norm of 35 seconds to one minute. In Box 8 I present exemplars of feedback and indicators of mindline changes.

- *"I use the postcards in practice and in teaching my students about care of the skin on a regular basis" (Health Visitor)*
- *"Evie wanted me to tell you that she has put her spray on all over to look after her dragon" (Mother with daughter aged 5 years)*
- *"Main things I took away …. using one application of steroids is just as good as two. Go big, go early with the steroid" (GP)*
- *"I am so glad that this will now be shared in schools to raise awareness amongst children of what some of their friends are going through and to hopefully encourage more parents to talk about this and share experiences of what treatments have worked for their children" (Mother)*
- *"It's certainly made me more confident in prescribing" (Nurse Practitioner)*
- *"I've double checked that they've got enough of the emollients" (GP)*
- *"My daughter is a primary teacher and I was telling her about it last night. Her response was, 'that sounds great - I'll definitely use it. It would have made me feel so much better in school if we'd had something like that'" (Mother and teacher).*
- *"We shared the information with parents via our weekly Newsletter last week and have included the book in our family information 'lending library'. We have already had a request from a parent to 'borrow' the book and I have forwarded details of the website" (Teacher)*

- *Your film and music are absolutely fab! You've taken a debilitating but common and overlooked problem and made it come alive! I loved it all and found it very moving (Nurse)*
- *I have attached some posters the children in my year 1 class did today leading on from our 'Dragon in My Skin' lesson last week. They really enjoyed the lesson and loved the song! We had a lot of discussion around the topic of eczema and we then went on to talk about feelings and how things such as eczema can affect our moods (Teacher).*

- *The children had some really mature discussion during this lesson and I have to say I was impressed, a couple of children with eczema were heavily involved in this and told other pupils some of their experiences (without being prompted or pressured to do so) (Teacher).*

Box 8: Exemplars of feedback and indicators of mindline changes.

Reflections on altering and enhancing eczema mindlines

Uncovering eczema mindlines exposed some dispiriting facts. In particular: the burgeoning amount of variable quality information available, a sense that practitioners had limited motivation to change practice, the micro level 'gloom à deux' with lay people, HCPs sharing a perception of hopelessness (Dodd n.d.), and a wider view that eczema is a "health problem which is not an illness" (Cornwell 1984) and therefore perceived as low priority and open to treatment suggestions from anyone.

At the core of this KMb activity is ***connectivity***, a complex spider's web, between people and across organisations and wider society. People are at the heart of this work. Of note was the time, determination, inter-personal skills, belief and creativity required to be an effective knowledge broker. Not all areas were receptive to my offer and in some cases it took persistence and negotiation to be allowed in. Reasons to decline included, from schools "the curriculum allows no space for extras", from supermarkets "we only support one charity each year" (highlighting a fundamental misunderstanding of this work despite several conversations and emails) and suspicion from some gatekeepers of the message that steroid creams are okay when you need them. The most effective approach was to personally visit leaders in my capacity as a nurse (and so presumably viewed as trustworthy). Personal connections were pivotal, starting with my need to connect with a person rather than an organisation to deliver events. As I met people they introduced me to their networks, for example a GP invited me to his Mosque where

I met a community pharmacist, and so it went on by word of mouth allowing me to create a density of coverage in the small geographical area. Similarly spreading of the teacher resource pack was through a web of contacts. Once access was secured, the sessions were of value. In the shopping centre, 94 people had brief nurse consultations about their own, their child's or wider family or friend's eczema. Over 60 HCPs attended mindline informed sessions, a significant number given the low priority of eczema and work pressures.

Alongside face-to-face events, Twitter and Facebook accounts were started and a website set up. After an initial flurry of interest these were of limited value although people enjoyed the series of Haiku (see top of chapter). Information overload is a common phenomenon, in the early 2000s information production was increasing at 50% per year but consumption at less than 2% (Brown and Dugiud 2002). Two decades on, production continues apace and volume is overwhelming us. Globally there are well over three billion internet users with an estimated two billion using social media (SoMe). Whilst being free and easy to use, these media can also lead to rapid, widespread transmission of misinformation (Welch et al 2018). The value of SoMe in this work was in raising the profile of eczema and starting conversations. Links between people spiralled, people are good at identifying others and whilst systems offer generalities people address particularities (Brown and Duguid 2002) and can adapt engagement to individuals and context. That is not to say SoMe cannot also contribute directly to mindline alteration; judicious use has supported development of innovative and creative ways to share the five key messages. This more widespread distribution, particularly the teacher resource pack, plays to the strengths of SoMe in creating interactive, collaborative networks which are dynamic and embedded in social contexts (Luca et al 2015). These networks have been built from individuals in the core team and have rippled out more widely than anticipated, for example resources are in the process of being translated to other languages.

A core feature of eczema mindlines was emotion, also a central factor in *Ba* in terms of both shared experiential knowledge and as context for socialisation processes (Nonaka et al 2000). Efforts to alter eczema mindlines have invoked positive emotion, for example through valuing each and every person's contribution, bringing together groups of people to better understand each other's worlds and by working together to develop creative ways to share simple messages and sharing these messages using accessible and attractive media. Using mindline informed sessions for HCPs allowed us not only to work with them to uncover their tacit knowledge and link new nuggets to this but also privileged and respected their expertise and created an atmosphere of positive emotion. There are suggestions that positive emotion inspires resourcefulness and innovation (Hodgins & Dadich 2017 influences how knowledge is assimilated (Forgas and Smith 2007), shapes sense-making (Steigenberger 2015) and provides a powerful stimulus to action (Sebrant 2014). The mindline-alteration strategies used here promoted positive emotion whilst offering digestible nuggets of knowledge which early evaluation suggests have been integrated into eczema mindlines. Ultimately securing shared language and understanding through integration of the five key messages has the potential to improve consultation experience and self-management practice in childhood eczema. In healthcare emphasis is placed on self-management of long-term conditions (DH

2014) and shared decision making (Légaré et al 2018). Both benefit from shared language and understanding between lay people and HCPs. Although this work focuses on altering and enhancing eczema mindlines the approach could equally be applied to other long-term health conditions.

Summary

- Effective self or parent-management of childhood eczema requires shared language and understanding between child, parent and healthcare practitioner
- Entrenched beliefs, such a steroid preparations being harmful, are powerful and can lead to sub-optimal health care practices
- Changing practice requires externalisation *and* reflection on these tacit beliefs
- New and already available codified information needs to be linked with existing knowledge and experience and adapted to local context to be combined, internalised and change mindlines
- Multiple, low-cost approaches have been successful in altering and amending eczema mindlines across lay-practitioner-wider society boundaries
- These approaches may equally be applied to other long-term conditions

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