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Knowledge mobilisation: an exploratory qualitative interview study to confirm and envision modification of lay and practitioner eczema mindlines to improve consultation experiences and self-management in primary care in the United Kingdom

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Title Page

Article title: Knowledge mobilisation: an exploratory qualitative interview study to confirm and envision modification of lay and practitioner eczema mindlines to improve consultation experiences and self-management in primary care in the United Kingdom

Author information:

Fiona Cowdell
DProf, RN
Professor of Nursing and Health Research
Faculty of Health, Education and Life Sciences
Birmingham City University
220 Ravensbury House
Westbourne Road
Edgbaston
Birmingham
B15 3TN
UK
Telephone: +44 (0)121 300 4345
Email: Fiona.cowdell@bcu.ac.uk
orcid.org/0000-0002-9355-8059

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3 **Knowledge mobilisation: an exploratory qualitative interview study to confirm and envision**
4 **modification of lay and practitioner eczema mindlines to improve consultation experiences and**
5 **self-management in primary care in the United Kingdom**
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9 **Abstract**
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11 **Objectives:** To investigate whether initial eczema mindlines, “collectively reinforced, internalised,
12 tacit guidelines”, are an accurate representation of the experiences of lay people and practitioners in
13 primary care and to explore how these mindlines may best be revised to improve eczema care.
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16 **Design:** Exploratory qualitative interviews with constant comparative analysis and data mining.
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18 **Setting:** United Kingdom, primary care
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20 **Participants:** People with eczema or parents of children with eczema (n=19) and primary care
21 practitioners (n=13).
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24 **Results:** Interview data were analysed using constant comparison of new data with existing initial
25 eczema mindlines to identify areas of agreement and disagreement. Data were mined for
26 participant’s thoughts about *whose* mindlines should be modified, *how* this may be achieved and
27 *what* core content is essential. Eczema mindlines and the spiral of knowledge creation, from which
28 they evolved, intuitively made sense. Participants offered examples of how their eczema knowledge
29 is continually produced and transformed as they interact with others. They reported diverse and
30 wide-ranging influences on their thinking and recognised the critical relationship between lay and
31 practitioner mindlines. For this reason they advocated modifying lay and practitioner mindlines in
32 parallel. Participants advised amendment based on consistent information directed to all who
33 influence eczema care. Information should come from trusted sources and be easy to access,
34 distilled, practical, contextually relevant and amenable to assimilation.
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37 **Conclusions:** The purpose here is to improve primary care consultation experiences and self-
38 management in eczema. The remaining challenge is to find novel, simple and pragmatic methods of
39 modifying eczema mindlines to instill shared and consistent understanding. Given the prevalence of
40 eczema and the scope of people who influence self-care, interventions should transcend patient-
41 practitioner boundaries and address the wider community. One conceptually congruent approach is
42 to create a *Ba*, which in this case would be a virtual space for generating and sharing eczema
43 knowledge.
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Strengths and limitations

- Novel study confirming and extending existing lay and practitioner eczema mindlines
- Diverse sample of UK patients and parents of children with eczema and primary care practitioners
- Enhanced understanding of *whose* mindlines should be modified and *when* and *how* offers a starting point for the complex process of mindline amendment.
- Combining of parent and adult with eczema data and data from different practitioner groups may have limited recognition of nuanced differences in mindlines

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Introduction

Eczema is a common and burdensome long-term skin condition (1) predominantly treated in primary care (2). People seek advice from general practitioners (GPs), nurses, health visitors and pharmacy staff. Consultations with GPs can be frustrating for both patient (3) and practitioner (4, 5) and there may be considerable differences between beliefs about assessment and treatment (6). Nurse consultations tend to be more positively regarded (7, 8). Research into the role of pharmacy staff is limited (9).

The essence of eczema treatment in primary care is the regular application of emollients, at least daily and often for many years, with or without intermittent use of topical corticosteroids (TCS). Non-adherence is common due to high self-management demand (10) and limited, sometimes conflicting, information (11). Effective self-management can improve disease outcomes and quality of life (12). Interventions to support eczema self-management are poorly understood, are not available to all, can be resource intensive and have varying impact (13). Eczema is not formally categorised as a long-term condition (14).

Knowledge mobilisation (KM) is concerned with the creation and movement of new knowledge to where it can be most useful (15). To be effective KM activity must be relational, constructed from social interaction and context-specific (16-18). One method of mobilising knowledge is amending mindlines. Mindlines were developed from the work of Polyani (19) and Nonaka & Takeuchi (20) specifically the concept of the **S**ocialization, **E**xternalization, **C**ombination, **I**nternalization (SECI) spiral in which knowledge is perpetually produced and transformed as users interact, collaborate and learn (17). Mindlines are “collectively reinforced, internalised tacit guidelines”. They lie beneath clinical decision-making (21) and are underpinned by acceptance that tacit knowledge (knowledge that is implicit and hard to simply transfer to another person) is a more powerful influencer of action than formal codified knowledge (knowledge that can easily be articulated, accessed and shared through mainstream approaches such as documents, educational videos and the like) (19, 20). Mindlines are predicated on the notion of a flexible, embodied and intersubjective understanding of knowledge, the existence of multiple realities and acceptance of knowledge being context-specific (17). In their seminal work Gabbay and LeMay identified mindlines amongst practitioners in primary care (21); this and subsequent work has been frequently cited. However, minimal investigation has been undertaken on condition specific mindlines or the existence of the lay (patient) equivalent of mindlines (22).

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3 A recent ethnographic study investigated the construction of healthcare practitioner and lay eczema
4 mindlines in primary care (3, 23). From this, initial models of eczema mindlines were developed. For
5 practitioners eczema was a low priority condition for which the “*recipe doesn’t change*”. Their
6 mindlines were built on brief and limited early career education, general and focused internet
7 searches, local formularies and guidance, tacit knowledge and interactions with patients and, to
8 some extent, other practitioners. Differences in mindline development were noted between
9 professions (23). On the whole they perceived limited need to update their eczema knowledge. The
10 initial model of lay (person with eczema or caring for a child with the condition) mindlines indicated
11 that, like practitioners, their knowledge was built up over time from multiple sources. They comprise
12 interactions with family, friends and the wider community and with practitioners, general and
13 focused internet searches, media coverage, trial and error and tacit knowledge. The desire for
14 knowledge was most marked when people were self-managing by default, those who had become
15 disillusioned and had disengaged from primary care (3).

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27 The purpose of the study reported here is to: (i) investigate whether the initial practitioner and lay
28 mindlines are an accurate representation of the realities experienced by practitioners and lay people
29 in primary care and (ii) consider how eczema mindlines may best be revised or modified by adding
30 reliable and useful knowledge and by erasing outdated or inaccurate information thus potentially
31 improve quality of eczema consultations and self-management.
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37 **Methods**

38 *Aims*

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40 To: (i) investigate whether initial eczema mindlines, developed from previous research by the author
41 of this paper (3, 23), are an accurate representation of the realities experienced by practitioners and
42 lay people in primary care and (ii) consider how they may best be revised or modified.
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46 *Design*

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48 Exploratory qualitative interviews (24) with constant comparative data analysis (25).
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51 *Setting, participants and process*

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53 Data were collected by the author, a nurse and researcher, from December 2017-May 2018.

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55 Practitioners were recruited via the local Clinical Research Network and word of mouth and lay
56 participants through a higher education institute website with mass sharing via word of mouth and
57 media posts in an effort to recruit hard-to-reach groups who may not realise their value in this type
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of study (26). Maximum variation purposive sampling was applied (27); characteristics were broad and focused on participant's ability and willingness to discuss eczema mindlines by virtue of their knowledge and experience. Single, individual, semi-structured, audio-taped interviews using a topic guide (table 1) were conducted. The topic guide was based on previous research by the author (3, 23) and questions likely to elicit thoughtful and detailed responses to address the research questions. Participants comprised lay people (n=19, table 2) and practitioners with between one and 26 years clinical experience (n=13, table 3) and lasted from 16 – 55 minutes. Interviews continued to the point of data sufficiency; that is until the depth and detail in the data gathered fully addressed the research questions (28). Most interviews were face-to-face, in the participant's workplace, and a small number via telephone. In preparation, participants were sent a brief explanation of mindlines and illustrations of the relevant initial eczema mindline (3, 23).

At the beginning of each interview the concept of mindlines and illustrations were discussed.

- How does this eczema mindline make sense to you?
- What are the similarities and differences in the way in which you know and think about eczema?
- How could eczema mindlines best be amended?
- Do you think there particular information that needs to be added or erased from existing mindlines?

Table 1: Interview topic guide

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Self / child	Age	Gender
Self	28	Female
Self	36	Male
Child	6	Female
Self	53	Male
Self	34	Female
Children	13 and 15	Female
Self	75	Female
Self	26	Female
Self	49	Male
Self	28	Female
Self	39	Female
Child	5	Female
Self	24	Male
Child	7	Female
Children	17 and 20	Female
Self	22	Female
Self	56	Male
Self	38	Male
Self	48	Female

Table 2: Demographic details of lay interview participants

Role	Gender
Dermatology nurse in primary care	Female
Dermatology nurse in primary care	Female
Community pharmacist	Female
Trainee general practitioner	Male
Practice nurse	Female
Nurse practitioner	Male
General practitioner	Male
General practitioner	Male
General practitioner	Female
General practitioner	Male
General practitioner	Male
Practice nurse	Female
Practice nurse	Female

Table 3: Demographic details of practitioner interview participants

Data analysis

Data collection and analysis were iterative processes (29, 30). Audio-data was professionally transcribed and transcripts proof read against recordings for accuracy. Data were analysed in two ways. Firstly in a constant comparison approach (25) incoming data was compared with data from the two previous studies from which initial eczema mindlines had been developed (3, 23). Here the focus was on identifying similarities and differences in the ways that mindlines are generated,

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3 embedded and transformed over time. Secondly, through subsequent readings of the transcripts,
4 data were mined for participant's thoughts about how mindlines may best be amended and their
5 beliefs about specific information that should be added or erased.
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9 10 *Reflexivity*

11 A reflexive attitude was maintained throughout, acknowledging own subjectivity and positioning as a
12 nurse and skin health researcher and the influence that this may have on the study (31).
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15 16 *Ethical issues*

17 The study was approved by a University Ethics Committee and the Health Research Authority.
18 Written consent was taken for interviews and participants consented to publication of anonymised
19 quotes.
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24 25 *Patient and public involvement*

26 Lay people were involved in developing the research question and designing the study. Results will
27 be communicated to participants in a brief summary.
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31 **Results**

32 The results are presented in four sections. Firstly the extent to which lay and then practitioner
33 eczema mindlines were perceived as being an accurate representation of their realities is
34 considered. Areas of individual similarity and difference are considered. Secondly areas of
35 connection are identified, followed by examples of synergy and dissonance between lay and
36 practitioner mindlines. Finally a synthesis of *whose* mindlines should be amended with *what*
37 information and *how* this could best be achieved is offered.
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45 *1a) Are lay eczema mindlines a reasonable representation of realities?*

46 Lay participants reported that the concept of mindlines intuitively made sense and noted broad
47 congruence in sources of knowledge and beliefs. They reviewed each element of the existing lay
48 eczema mindline, that is: interactions with family, friends and the wider community and with
49 practitioners, general and focused internet searches, media coverage, trial and error and tacit
50 knowledge within the context of being content to self-manage or accept practitioner management
51 or self-managing by default. Lay participants spoke at length about the presented mindline and
52 provided examples and nuanced insights into the how, why and when their mindlines had been
53 constructed.
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5 Interactions with family and friends and the wider community were experienced by all. The most
6 influential information was advice from mothers. Others reported picking up “snippets” of
7 information, sometimes unbidden “I’ve had someone on the Tube recommending a moisturiser”
8 (Female, 22). Suggestions could be overwhelming “they were telling me their regimes or oh try this
9 cream. Everybody had a cream to recommend and it got to the point where I was using so many
10 things, you didn’t know what was working from what wasn’t” (Female, 27) and often unfounded
11 “hearsay ... ‘oh well so and so tried this’, ‘oh I know someone who did this’” (Female, 28). Advice
12 from practitioners was sometimes externally validated with other lay people before making a
13 decision about treatment use.
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22 Participants mainly spoke about GP consultations which were frequently viewed as unsatisfactory.
23 GPs were perceived as having limited expertise “sometimes I get the impression that they’re doing
24 no more than you would by Googling it” (Female, 34) and working on a trial and error basis “it’s
25 generally a bit of chuck everything at the wall and see what sticks” (Male, 36). In contrast to the
26 initial mindline the pathway of knowledge between lay people and practitioners was perceived as
27 one-way. People experienced their views and experiences as being undervalued and suggested that
28 they were provided with standard, often unhelpful, information, “I think doctors think everyone’s
29 stupid I know the advice is well meant but it’s generalistic” (Male, 56). Some mentioned power
30 differentials as the cause of their expertise being dismissed “I interact with them as equal but he
31 couldn’t have that” (Male, 53).
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40 Lay participants also consulted with nurses, pharmacy staff, health visitors and a physician’s
41 assistant. These meetings were more positively evaluated, for example after seeing a nurse “I felt
42 much more confident that they know in detail what they were dealing with they seemed to have
43 a lot more knowledge about products” (Female, 27). Pharmacists were another source of practical
44 and personalised advice “I saw the pharmacist at the practice she was actually very, very helpful, she
45 came out with this keep the creams in the fridge, stroke them on the two saviours were the
46 pharmacists really” (Female, 75).
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53 Most lay participants had searched the internet, the focus was invariably on finding new treatments
54 or cure rather than understanding the condition. Most had used trusted sources such as NHS
55 Choices, but for some this was “a lovely set of generic blandishments” (Male, 36). Many had
56 “Googled” but were selective in using this information, “lot of self-censoring, you know a filter”
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3 (Female, 34). Finding reliable information electronically was challenging and some withdrew *"I'm*
4 *wary of Google in case you get frightened by things that you don't need to see"* (Female, 34).

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7 Other media sources, including leaflets, newspapers and magazines, television programmes and
8 social media, were used to a lesser degree and also treated judiciously. Few people read patient
9 information leaflets enclosed with medications describing them as of little practical value. Leaflets in
10 GP surgeries and pharmacies were infrequently taken and poorly evaluated. A few read newspapers
11 and magazines but were sceptical *"I'm quite an avid newsreader, periodically there are articles ...*
12 *don't always believe 100% because I think there could be something sponsored"* (Female, 39).

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17 Participants reported seeing occasional television programmes that influenced their thinking but not
18 often their actions; the BBC was considered most trustworthy. Participant's valued social media for
19 example Facebook and Twitter, the value here was perceived reality, *"a fellow sufferer saying 'this*
20 *works for me'"* [Female, 34]. As with other knowledge sources participants filtered information, *"the*
21 *critical eye that I have definitely makes me check and double check, are these valid sources and cross*
22 *referenced?"* (Female, 26).

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29 Trial and error was a familiar and frustrating experience for every lay participant *"you build up this*
30 *medicine cabinet full of every ointment and then you have a set of stories about each one"* (Male,
31 53). Tacit knowledge was viewed as an amalgamation of personal experience accrued over time and
32 hearsay from unknown or unremembered sources often from the wider community. Universal tacit
33 knowledge was that TCS *"thin the skin"* and should be avoided as far as possible. No participants
34 could trace how this thought had entered their mindline, *"I just grew up with that 'oh you have to be*
35 *careful with this'"* (Female, children 13&15) and *"umm ... I'm trying to think who told me"* (Female
36 34).

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44 Participants identified with being content to self-manage or accept practitioner management or self-
45 managing by default. Most described moving back and forth between these states, for example, at
46 times of eczema flare, treatment failure or unsatisfactory consultations. These circumstances
47 triggered fresh attempts to find new ways of managing their eczema sometimes with clouded
48 judgment, *"we just jump to unreliable sources or do irrational things because you can be tempted to,*
49 *when you've got a really bad flare up"* (Female, 26).

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56 Eczema mindlines instinctively made sense to lay participants and the content presented resonated
57 with their thoughts, beliefs and experiences. They recognised the multiple influences, including the
58 power of social interactions. Their analysis of personal eczema mindlines reinforced the complexity
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3 and difficulty in unravelling how all the elements coalesce particularly as, although content is similar
4 for each individual, the way in which mindlines have developed over time had subtle variations. Lay
5 participants linked efforts to amend mindlines closely with different phases of self-management and
6 for this reason suggested that this should be integrated into the mindlines image (see figure 1).
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11 *1b) Are practitioner eczema mindlines a reasonable representation of realities?*

12 Practitioners agreed with the initial mindline but offered less discussion, for example *“so I think it’s*
13 *nice model actually, I think it’s all fair, everything you’ve said is fair and reasonable and appropriate”*
14 (Male GP). All agreed that eczema is not perceived as a priority in primary care, that treatment is
15 limited by their local emollient formulary and that they exercised caution in prescribing TCS. A
16 dominant influence on the mindlines of the four practitioners with self-reported expertise in eczema
17 care was exposure to dermatology experts in secondary care. The trusted and structured guidance
18 given had become firmly embedded leading to increased knowledge, skills and confidence and
19 *“braver”* prescribing of non-formulary emollients (when clinically appropriate) and TCS. These
20 experts contested the backdrop of low priority but concurred with the relative straightforwardness
21 of treatment regimens whilst viewing these not as a *“recipe”* but as principles that should be
22 individualised. The practitioner mindline illustration was amended for clarity (figure 2).
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33 *2) Areas of lay and practitioner mindline connection*

34 Unprompted participants considered mindlines of the *“other”* and the interplay between these
35 entities. Lay participants suggested a need for change in practitioner mindlines but focused on
36 amending lay mindlines. Practitioners were certain about the best targets for mindline amendment.
37 GPs stated that their own and lay mindlines should be amended but considered the former unlikely
38 due to the low priority given to eczema. This view was reinforced by an expert nurse, *“GPs are*
39 *entrenched in their views”* and a lay participant, *“it’s a challenge with the entrenched stubbornness*
40 *of the medical profession, people will not change their beliefs once they ‘know something’”* (Lay
41 male, 36). Other practitioners advised that health visitors, nurses and community pharmacy staff
42 should be targeted given their relative accessibility for patients.
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51 A challenge for all participants was the volume of often contradictory information from a multitude
52 of sources available to lay people. A GP recounted trying to persuade a patient to use TCS properly,
53 *“I validate it with something and say, look I do extra work in dermatology, please just trust me, this is*
54 *fine”*. However his efforts were thwarted by the patient’s existing mindlines and standard advice
55 given by pharmacists which generated fear.
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Practitioners almost universally identified the key reliable and useful knowledge that should be added to, and outdated or inaccurate information that should be erased from, existing mindlines. Core content is summarised in quotations from participants (table 4). Lay participants were less certain about the essential content but agreed key issues included understanding and accepting that eczema may be a long-term condition requiring ongoing treatment with emollients and that TCS have a place in the treatment of flares.

- *“never let anyone say to you again that eczema is just a bit of dry skin”*
- *“treat as a long term condition”*
- *“eczema needs maintenance treatment”*
- *“mantra of the best emollient is the one that [is used]”*
- *“don’t be frightened [of] steroids and use them properly”*
- *“when it does flare up you’ve got to hit it hard quickly with your steroid”*

Table 4: Core eczema mindline content from practitioners

3) Examples of synergy and dissonance between lay and practitioner mindlines

Returning to the original definition of mindlines as “collectively reinforced, internalised tacit guidelines” participants demonstrated both the complexity in development and the influential interplay between lay and practitioner mindlines. Participants identified areas of synergy and dissonance across and between mindlines. A key finding is that eczema knowledge does not involve just people living with the condition and practitioners but rather there is a pervasive social element, for example the received wisdom or “old wives tale” that TCSs “thin the skin” causing irreparable damage.

Perceived need to update was low among most practitioners and this pervaded some lay mindlines “there’s no point in wasting the doctors time” (Male, 53). As a result eczema was sometimes relegated to an additional concern rather than the primary reason for consultation and then necessarily given limited attention by practitioners, thus reinforcing its low priority. Practitioners reported “we don’t often think about it as a chronic condition which needs regular follow up and a defined plan” (Male, trainee GP), leading to reactive treatment with few follow-up appointments. Lack of maintenance therapy impacted on self-management leading to a cycle of flare management rather than a long-term, agreed management plan.

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5 *4) Mindline amendment: whose, what and how?*

6 Mindline amendment proved a conundrum to all. Lay participants reflected on the futility of simply
7 providing more information. Immediate suggestions including predictable approaches such as
8 websites media and leaflets were made but rapidly dismissed. For example, *"website ... but who*
9 *would go on it?"* (Male, 53) and *"leaflets in GP surgeries, but then you just get information fatigue"*
10 (Male, 49). Similarly suggestions about using social media and 'apps' were voiced and rejected within
11 the same sentence. Interactive fora were vetoed due to the need for leadership and moderation.
12 One participant favoured a *"Facebook group specifically for eczema care, I'd probably be part of*
13 *that ... good to have a safe place for people to talk"* (Female, 22) although she acknowledged that
14 sustained participation was unlikely.
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23 Pivotal factors in lay mindline amendment included "realness", exemplified by *"that's the stuff that*
24 *I'm interested in and that I'll home in on are the forums where you've got people telling their stories"*
25 (Male, 53) and *"people work off stories don't they, like, I'm living proof"* (Male, 36). Other people's
26 stories were persuasive for some and disliked by others. Trustworthiness, ease of access and
27 applicability to self were important, *"quick trusted and easy to access"* (Female, 34) from trusted
28 sources *"pharmacies, a credible source of information"* (Female, children 17&20). All lay participants
29 disliked the generic nature of current information *"eczema is very particular, people regard it as part*
30 *of who they are, because it does shape what you're doing"* (Male, 53). Disillusionment and lack of
31 motivation to change was identified as a challenge to mindline amendment. Interactions and
32 relationships were addressed on several levels. Engagement was one hurdle *"you need a way of*
33 *hooking people in, people who are likely to walk past and go 'I haven't got time to care about that'"*
34 (Female, 34). The impact of social and relational factors suggested a need for wider amendment *"an*
35 *effective way would be to normalise this thing, there's still a shame element around it, bringing it*
36 *into normal conversations, everyday discussions, so it's not a thing that you're just hiding away"*
37 (Female, 26). Shared, consistent information could be powerful in eradicating influential *"old wives*
38 *tales"*.
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51 Practitioners proposed existing educational mechanisms for amending mindlines including: free
52 taught sessions with *"really, really practical, emollient testing"* (Female, nurse) and information
53 which can readily be applied in everyday practice; free online education; sessions during protected
54 learning time. Practitioners rarely accessed available eczema education and were *"wary of messages*
55 *from pharma or perceived messages from pharma"* (Female, GP). Expert practitioners were
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exasperated by the lack of motivation for change amongst generalist colleagues and the continued provision “*outdated and wrong*” advice (Female, nurse). Practitioners were aware of existing patient-focused resources, for example NHS Choices, patient.co.uk, the Primary Care Dermatology Society and the British Association of Dermatologists Patient Information Leaflets, but rarely signposted or used these in consultations.

Participants pointed to the need for shared understandings and consistent advice through synergistic mindlines. Reflection on mindlines brought to the fore the diversity and magnitude of influencing factors and the extent to which knowledge was accessed in different circumstances, for example during an eczema flare. The need for consistency of information was a high priority and one best addressed by seeking to modify the multiple channels of information that contribute to lay and practitioner eczema mindlines in primary care with straightforward, evidence based messages.

Discussion

The first aim of this study was to investigate whether initial eczema mindlines are an accurate representation of the experiences of practitioners and lay people in primary care. Mindlines intuitively made sense to, and were confirmed by, all participants. Areas of synergy and dissonance were identified, as was the interplay between lay and practitioner eczema mindlines. Secondly mindline amendment was investigated. The need to modify and unify mindlines by adding reliable and useful knowledge and by erasing outdated or inaccurate information was universally agreed. However, strategies to achieve amendment proved elusive. The prevalence of eczema, the diversity of *how* and *when* mindlines are developed suggests a need to find focused strategies for wide-reaching, societal amendment to ensure simple, consistent messages to improve consultation experiences and self-management in primary care. Practitioners offered suggestions about essential areas for amendment.

This study is one of few to apply mindline theory to a specific condition and is original in identifying the relationship between lay and practitioner mindlines. The study conforms to the conventions of qualitative research in being rigorous (externally auditable thorough clear reporting), relevant (enhancing understanding of the subject), resonant with reader’s experiences and understandings and reflexive (31). The study has deepened understanding of *whose* mindlines should be modified and *when* and *how* this may best be achieved. This offers a robust starting point for the complex amendment process. Limitations of the study include parent and adult with eczema data being combined, potentially limiting nuanced differences in mindlines. Similarly practitioner mindlines have been viewed as a whole. That said, mindlines are individual and can change over time.

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5 To date little attention has been given to the construction of lay (or patient) mindlines. Gabbay and
6 LeMay (17) suggest a patient equivalent, but this possibility is poorly represented in other literature
7 (22). The term clientlines appears in one study (32) but is not fully explored. However, the notion
8 that knowledge creation inevitably happens in patients is not contested (33) and is extended here in
9 the breadth of influences on lay eczema mindlines. This could be attributable to prevalence, with
10 most people knowing someone with eczema and the perception that it is a “health problem which is
11 not an illness” (34) and therefore perceived as open to treatment suggestions from anyone.
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18 Amendment of mindlines is rarely reported, a synthesis of 10 years of literature (n=340) identified
19 28 related to practitioner amendment. These emphasise the importance of collaborative learning,
20 relationship building and effective leadership in the development of valid, collective, evidence-based
21 mindlines (22). Repeating the search strategy used for this review in August 2018 revealed an
22 abundance of new literature (n=422) but still little directly addressing how mindlines may best be
23 amended. Allied literature indicates the need for a judicious approach to amending practitioner
24 mindlines. Primary care practitioners are necessarily expert generalists (35) and have to know about
25 many conditions. It is clearly impossible for any individual to process all available information.
26 Practitioners use coping strategies such as “satisficing” that is, curtailing the amount of information
27 gathered to enable them to make a “good enough” decision (36). Given the view that eczema is
28 straightforward with treatment being standard and unchanging over the years, motivation to change
29 practice is limited (23). Likewise treatment decisions are apparently made rapidly, perhaps fitting
30 somewhere between fast, automatic, System 1 thinking and the more deliberative, conscious slow
31 and effortful System 2 approach (37) and instead accessing knowledge from a well-worn path. The
32 danger here is that *this* path may not lead to the best outcomes.
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45 Mindlines evolved from the work of Polyani and Nonaka & Takeuchi, in particular, the SECI spiral (17)
46 in which knowledge is perpetually produced and transformed as users interact, collaborate and learn
47 (38). Gabbay and LeMay (21) point to the critical nature of knowledge-in-practice-in-context, in
48 which in each context new knowledge is converted by complex social processes. This current study
49 concurs, finding that eczema knowledge is founded in a wider community (39, 40), sometimes
50 facilitated by others (41) and often influenced by numerous, interacting personal and social factors
51 (42). To date moves to improve eczema self-management and consultation experiences largely
52 comprise educational and psychological interventions (13, 43). This study offers an alternative
53 socially-mediated approach. Returning to the work of Nonaka offers new insights into mindline
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3 amendment drawing on the relationship between the SECI spiral and *Ba*. *Ba*, originally discussed by
4 the Japanese philosopher Nishida (44, 45) and later refined by Shimizu (46), is a shared space for
5 knowledge generation and sharing. *Ba* is not about the space per se (47), rather it is a shared
6 context-in-motion which advances over time and has no fixed boundaries or membership. It is about
7 the here-and-now and thrives on people with different viewpoints (48). *Ba* space occurs naturally, is
8 not prescribed, relationships are fluid, permeable and iterative (49, 50). It has four characteristics:
9 originating (face-to-face, individual communications), interacting (face-to-face group dialogue),
10 cyber (virtual group interactions) and exercising (virtual individual interactions) (50). In the main *Ba*
11 has been considered in business organisations (51-56). More recently attention has been given to its
12 application in other contexts, for example in making “big data” widely useful (57) and in supporting
13 educational endeavours (50, 58, 59). To date there is no evidence of attempting to create *Ba* across
14 lay-practitioner-community boundaries. Given the need to amend mindlines, both lay and
15 practitioner, across the community the notion of deliberately creating *Ba* and integrating
16 innovative approaches to addressing each of the four characteristics in a specific geographic area
17 offers a new opportunity for eczema knowledge mobilisation. This work is currently underway and
18 will be the focus of future publications.
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32 In some respects core treatment of eczema in primary care is relatively straightforward. Experts in
33 the field propose “getting control” and “keeping control” (60) which requires emollient maintenance
34 to reduce incidence and severity of flares and need for sufficient use of the right potency TCS when
35 required. The key to effective self-management is supporting people to do these two things well and
36 addressing the enormous challenges they face on a day-to-day enduring basis (61-64).
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42 This study offers a new approach to improving consultation experiences and self-management
43 through active and community-wide mindline amendment to develop consistent and shared
44 understandings. Core reliable and useful knowledge that needs to be integrated, and outdated and
45 inaccurate knowledge to be erased is identified. Mechanisms for change need to be socially-
46 mediated, multi-faceted, tailored to specific groups and convey consistent, evidence based, core
47 messages.
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5 **Contribution statement**

6 FC is the sole contributor to this paper

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9
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13 or the Department of Health.
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18 **Ethical approval**

19 The study was approved by a University Ethics Committee. Written consent was taken for
20 interviews. Participants consented to publication of anonymised information.
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25 **Competing interests**

26 None to declare

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30 **Acknowledgements**

31 Thanks to Jay Nolan-Latchford for the mindline illustrations and to all the participants who shared
32 their time and thoughts.
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37 **Data sharing statement**

38 The datasets generated and/or analysed during the current study are not publicly available as they
39 are not designed to be re-analysed by others but are available from the corresponding author on
40 reasonable request.
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Table 1: Interview topic guide

Table 2: Demographic details of lay interview participants

Table 3: Demographic details of practitioner interview participants

Table 4: Core eczema mindline content from practitioners

Figure 1: Lay eczema mindline

Revised lay eczema mindline

Figure 2: Practitioner eczema mindline

Revised practitioner eczema mindline

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Title Page

Article title: Knowledge mobilisation: an exploratory qualitative interview study to confirm and envision modification of lay and practitioner eczema mindlines to improve consultation experiences and self-management in primary care in the United Kingdom

Author information:

Fiona Cowdell
DProf, RN
Professor of Nursing and Health Research
Faculty of Health, Education and Life Sciences
Birmingham City University
220 Ravensbury House
Westbourne Road
Edgbaston
Birmingham
B15 3TN
UK
Telephone: +44 (0)121 300 4345
Email: Fiona.cowdell@bcu.ac.uk
orcid.org/0000-0002-9355-8059

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3 **Knowledge mobilisation: an exploratory qualitative interview study to confirm and envision**
4 **modification of lay and practitioner eczema mindlines to improve consultation experiences and**
5 **self-management in primary care in the United Kingdom**
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9 **Abstract**
10

11 **Objectives:** To investigate whether initial eczema mindlines, “collectively reinforced, internalised,
12 tacit guidelines”, are an accurate representation of the experiences of lay people and practitioners in
13 primary care and to explore how these mindlines may best be revised to improve eczema care.
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16 **Design:** Exploratory qualitative interviews with constant comparative analysis and data mining.
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18 **Setting:** United Kingdom, primary care
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20 **Participants:** People with eczema or parents of children with eczema (n=19) and primary care
21 practitioners (n=13).
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23 **Results:** Interview data were analysed using constant comparison of new data with existing initial
24 eczema mindlines to identify areas of agreement and disagreement. Data were mined for
25 participant’s thoughts about *whose* mindlines should be modified, *how* this may be achieved and
26 *what* core content is essential. Eczema mindlines and the spiral of knowledge creation, from which
27 they evolved, intuitively made sense. Participants offered examples of how their eczema knowledge
28 is continually produced and transformed as they interact with others. They reported diverse and
29 wide-ranging influences on their thinking and recognised the critical relationship between lay and
30 practitioner mindlines. For this reason they advocated modifying lay and practitioner mindlines in
31 parallel. Participants advised amendment based on consistent information directed to all who
32 influence eczema care. Information should come from trusted sources and be easy to access,
33 distilled, practical, contextually relevant and amenable to assimilation.
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36 **Conclusions:** The purpose **here is to** improve primary care consultation experiences and self-
37 management in eczema. The remaining challenge is to find novel, simple and pragmatic methods of
38 modifying eczema mindlines to instill shared and consistent understanding. Given the prevalence of
39 eczema and the scope of people who influence self-care, interventions should transcend patient-
40 practitioner boundaries and address the wider community. One conceptually congruent approach is
41 to create a *Ba*, which in this case would be a virtual space for generating and sharing eczema
42 knowledge.
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Strengths and limitations

- Novel study confirming and extending existing lay and practitioner eczema mindlines
- Diverse sample of UK patients and parents of children with eczema and primary care practitioners
- Enhanced understanding of *whose* mindlines should be modified and *when* and *how* offers a starting point for the complex process of mindline amendment.
- Combining of parent and adult with eczema data and data from different practitioner groups may have limited recognition of nuanced differences in mindlines

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Introduction

Eczema is a common and burdensome long-term skin condition (1) predominantly treated in primary care (2). People seek advice from general practitioners (GPs), nurses, health visitors and pharmacy staff. Consultations with GPs can be frustrating for both patient (3) and practitioner (4, 5) and there may be considerable differences between beliefs about assessment and treatment (6). Nurse consultations tend to be more positively regarded (7, 8). Research into the role of pharmacy staff is limited (9).

The essence of eczema treatment in primary care is the regular application of emollients, at least daily and often for many years, with or without intermittent use of topical corticosteroids (TCS). Non-adherence is common due to high self-management demand (10) and limited, sometimes conflicting, information (11). Effective self-management can improve disease outcomes and quality of life (12). Interventions to support eczema self-management are poorly understood, are not available to all, can be resource intensive and have varying impact (13). Eczema is not formally categorised as a long-term condition (14).

Knowledge mobilisation (KM) is concerned with the creation and movement of new knowledge to where it can be most useful (15). To be effective KM activity must be relational, constructed from social interaction and context-specific (16-18). One method of mobilising knowledge is amending mindlines. Mindlines were developed from the work of Polyani (19) and Nonaka & Takeuchi (20) specifically the concept of the Socialization, Externalization, Combination, Internalization (SECI) spiral in which knowledge is perpetually produced and transformed as users interact, collaborate and learn (17). Mindlines are “collectively reinforced, internalised tacit guidelines”. They lie beneath clinical decision-making (21) and are underpinned by acceptance that tacit knowledge (knowledge that is implicit and hard to simply transfer to another person) is a more powerful influencer of action than formal codified knowledge (knowledge that can easily be articulated, accessed and shared through mainstream approaches such as documents, educational videos and the like) (19, 20).

Mindlines are predicated on the notion of a flexible, embodied and intersubjective understanding of knowledge, the existence of multiple realities and acceptance of knowledge being context-specific (17). In their seminal work Gabbay and LeMay identified mindlines amongst practitioners in primary care (21); this and subsequent work has been frequently cited. However, minimal investigation has been undertaken on condition specific mindlines or the existence of the lay (patient) equivalent of mindlines (22).

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A recent ethnographic study investigated the construction of healthcare practitioner and lay eczema mindlines in primary care (3, 23). From this, initial models of eczema mindlines were developed. For practitioners eczema was a low priority condition for which the “*recipe doesn’t change*”. Their mindlines were built on brief and limited early career education, general and focused internet searches, local formularies and guidance, tacit knowledge and interactions with patients and, to some extent, other practitioners. Differences in mindline development were noted between professions (23). On the whole they perceived limited need to update their eczema knowledge. The initial model of lay (person with eczema or caring for a child with the condition) mindlines indicated that, like practitioners, their knowledge was built up over time from multiple sources. They comprise interactions with family, friends and the wider community and with practitioners, general and focused internet searches, media coverage, trial and error and tacit knowledge. The desire for knowledge was most marked when people were self-managing by default, those who had become disillusioned and had disengaged from primary care (3).

The purpose of the study reported here is to: (i) investigate whether the initial practitioner and lay mindlines are an accurate representation of the realities experienced by practitioners and lay people in primary care and (ii) consider how eczema mindlines may best be revised or modified by adding reliable and useful knowledge and by erasing outdated or inaccurate information thus potentially improve quality of eczema consultations and self-management.

Methods

Aims

To: (i) investigate whether initial eczema mindlines, **developed from previous research by the author of this paper (3, 23)**, are an accurate representation of the realities experienced by practitioners and lay people in primary care and (ii) consider how they may best be revised or modified.

Design

Exploratory qualitative interviews (24) with constant comparative data analysis (25).

Setting, participants and process

Data were collected by the author, a nurse and researcher, from December 2017-May 2018.

Practitioners were recruited via the local Clinical Research Network and word of mouth and lay participants through a higher education institute website with mass sharing via word of mouth and media posts in an effort to recruit hard-to-reach groups who may not realise their value in this type

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of study (26). Maximum variation purposive sampling was applied (27); characteristics were broad and focused on participant's ability and willingness to discuss eczema mindlines by virtue of their knowledge and experience. Single, individual, semi-structured, audio-taped interviews using a topic guide (table 1) were conducted. The topic guide was based on previous research by the author (3, 23) and questions likely to elicit thoughtful and detailed responses to address the research questions. Participants comprised lay people (n=19, table 2) and practitioners with between one and 26 years clinical experience (n=13, table 3) and lasted from 16 – 55 minutes. Interviews continued to the point of data sufficiency; that is until the depth and detail in the data gathered fully addressed the research questions (28). Most interviews were face-to-face, in the participant's workplace, and a small number via telephone. In preparation, participants were sent a brief explanation of mindlines and illustrations of the relevant initial eczema mindline (3, 23).

At the beginning of each interview the concept of mindlines and illustrations were discussed.

- How does this eczema mindline make sense to you?
- What are the similarities and differences in the way in which you know and think about eczema?
- How could eczema mindlines best be amended?
- Do you think there particular information that needs to be added or erased from existing mindlines?

Table 1: Interview topic guide

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Self / child	Age	Gender
Self	28	Female
Self	36	Male
Child	6	Female
Self	53	Male
Self	34	Female
Children	13 and 15	Female
Self	75	Female
Self	26	Female
Self	49	Male
Self	28	Female
Self	39	Female
Child	5	Female
Self	24	Male
Child	7	Female
Children	17 and 20	Female
Self	22	Female
Self	56	Male
Self	38	Male
Self	48	Female

Table 2: Demographic details of lay interview participants

Role	Gender
Dermatology nurse in primary care	Female
Dermatology nurse in primary care	Female
Community pharmacist	Female
Trainee general practitioner	Male
Practice nurse	Female
Nurse practitioner	Male
General practitioner	Male
General practitioner	Male
General practitioner	Female
General practitioner	Male
General practitioner	Male
Practice nurse	Female
Practice nurse	Female

Table 3: Demographic details of practitioner interview participants

Data analysis

Data collection and analysis were iterative processes (29, 30). Audio-data was professionally transcribed and transcripts proof read against recordings for accuracy. Data were analysed in two ways. Firstly in a constant comparison approach (25) incoming data was compared with data from the two previous studies from which initial eczema mindlines had been developed (3, 23). Here the focus was on identifying similarities and differences in the ways that mindlines are generated,

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3 embedded and transformed over time. Secondly, through subsequent readings of the transcripts,
4 data were mined for participant's thoughts about how mindlines may best be amended and their
5 beliefs about specific information that should be added or erased.
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10 *Reflexivity*

11 A reflexive attitude was maintained throughout, acknowledging own subjectivity and positioning as a
12 nurse and skin health researcher and the influence that this may have on the study (31).
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16 *Ethical issues*

17 The study was approved by a University Ethics Committee and the Health Research Authority.
18 Written consent was taken for interviews and participants consented to publication of anonymised
19 quotes.
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25 *Patient and public involvement*

26 Lay people were involved in developing the research question and designing the study. Results will
27 be communicated to participants in a brief summary.
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31 **Results**

32 The results are presented in four sections. Firstly the extent to which lay and then practitioner
33 eczema mindlines were perceived as being an accurate representation of their realities is
34 considered. Areas of individual similarity and difference are considered. Secondly areas of
35 connection are identified, followed by examples of synergy and dissonance between lay and
36 practitioner mindlines. Finally a synthesis of *whose* mindlines should be amended with *what*
37 information and *how* this could best be achieved is offered.
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45 *1a) Are lay eczema mindlines a reasonable representation of realities?*

46 Lay participants reported that the concept of mindlines intuitively made sense and noted broad
47 congruence in sources of knowledge and beliefs. They reviewed each element of the existing lay
48 eczema mindline, that is: interactions with family, friends and the wider community and with
49 practitioners, general and focused internet searches, media coverage, trial and error and tacit
50 knowledge within the context of being content to self-manage or accept practitioner management
51 or self-managing by default. Lay participants spoke at length about the presented mindline and
52 provided examples and nuanced insights into the how, why and when their mindlines had been
53 constructed.
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5 Interactions with family and friends and the wider community were experienced by all. The most
6 influential information was advice from mothers. Others reported picking up “snippets” of
7 information, sometimes unbidden “I’ve had someone on the Tube recommending a moisturiser”
8 (Female, 22). Suggestions could be overwhelming “they were telling me their regimes or oh try this
9 cream. Everybody had a cream to recommend and it got to the point where I was using so many
10 things, you didn’t know what was working from what wasn’t” (Female, 27) and often unfounded
11 “hearsay ... ‘oh well so and so tried this’, ‘oh I know someone who did this’” (Female, 28). Advice
12 from practitioners was sometimes externally validated with other lay people before making a
13 decision about treatment use.
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22 Participants mainly spoke about GP consultations which were frequently viewed as unsatisfactory.
23 GPs were perceived as having limited expertise “sometimes I get the impression that they’re doing
24 no more than you would by Googling it” (Female, 34) and working on a trial and error basis “it’s
25 generally a bit of chuck everything at the wall and see what sticks” (Male, 36). In contrast to the
26 initial mindline the pathway of knowledge between lay people and practitioners was perceived as
27 one-way. People experienced their views and experiences as being undervalued and suggested that
28 they were provided with standard, often unhelpful, information, “I think doctors think everyone’s
29 stupid I know the advice is well meant but it’s generalistic” (Male, 56). Some mentioned power
30 differentials as the cause of their expertise being dismissed “I interact with them as equal but he
31 couldn’t have that” (Male, 53).
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40 Lay participants also consulted with nurses, pharmacy staff, health visitors and a physician’s
41 assistant. These meetings were more positively evaluated, for example after seeing a nurse “I felt
42 much more confident that they know in detail what they were dealing with they seemed to have
43 a lot more knowledge about products” (Female, 27). Pharmacists were another source of practical
44 and personalised advice “I saw the pharmacist at the practice she was actually very, very helpful, she
45 came out with this keep the creams in the fridge, stroke them on the two saviours were the
46 pharmacists really” (Female, 75).
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53 Most lay participants had searched the internet, the focus was invariably on finding new treatments
54 or cure rather than understanding the condition. Most had used trusted sources such as NHS
55 Choices, but for some this was “a lovely set of generic blandishments” (Male, 36). Many had
56 “Googled” but were selective in using this information, “lot of self-censoring, you know a filter”
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3 (Female, 34). Finding reliable information electronically was challenging and some withdrew *"I'm*
4 *wary of Google in case you get frightened by things that you don't need to see"* (Female, 34).
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8 Other media sources, including leaflets, newspapers and magazines, television programmes and
9 social media, were used to a lesser degree and also treated judiciously. Few people read patient
10 information leaflets enclosed with medications describing them as of little practical value. Leaflets in
11 GP surgeries and pharmacies were infrequently taken and poorly evaluated. A few read newspapers
12 and magazines but were sceptical *"I'm quite an avid newsreader, periodically there are articles ...*
13 *don't always believe 100% because I think there could be something sponsored"* (Female, 39).
14
15 Participants reported seeing occasional television programmes that influenced their thinking but not
16 often their actions; the BBC was considered most trustworthy. Participant's valued social media for
17 example Facebook and Twitter, the value here was perceived reality, *"a fellow sufferer saying 'this*
18 *works for me'"* [Female, 34]. As with other knowledge sources participants filtered information, *"the*
19 *critical eye that I have definitely makes me check and double check, are these valid sources and cross*
20 *referenced?"* (Female, 26).
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30 Trial and error was a familiar and frustrating experience for every lay participant *"you build up this*
31 *medicine cabinet full of every ointment and then you have a set of stories about each one"* (Male,
32 53). Tacit knowledge was viewed as an amalgamation of personal experience accrued over time and
33 hearsay from unknown or unremembered sources often from the wider community. Universal tacit
34 knowledge was that TCS *"thin the skin"* and should be avoided as far as possible. No participants
35 could trace how this thought had entered their mindline, *"I just grew up with that 'oh you have to be*
36 *careful with this'"* (Female, children 13&15) and *"umm ... I'm trying to think who told me"* (Female
37 34).
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45 Participants identified with being content to self-manage or accept practitioner management or self-
46 managing by default. Most described moving back and forth between these states, for example, at
47 times of eczema flare, treatment failure or unsatisfactory consultations. These circumstances
48 triggered fresh attempts to find new ways of managing their eczema sometimes with clouded
49 judgment, *"we just jump to unreliable sources or do irrational things because you can be tempted to,*
50 *when you've got a really bad flare up"* (Female, 26).
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56 Eczema mindlines instinctively made sense to lay participants and the content presented resonated
57 with their thoughts, beliefs and experiences. They recognised the multiple influences, including the
58 power of social interactions. Their analysis of personal eczema mindlines reinforced the complexity
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3 and difficulty in unravelling how all the elements coalesce particularly as, although content is similar
4 for each individual, the way in which mindlines have developed over time had subtle variations. Lay
5 participants linked efforts to amend mindlines closely with different phases of self-management and
6 for this reason suggested that this should be integrated into the mindlines image (see figure 1).
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10 11 *1b) Are practitioner eczema mindlines a reasonable representation of realities?*

12 Practitioners agreed with the initial mindline but offered less discussion, for example *“so I think it’s*
13 *nice model actually, I think it’s all fair, everything you’ve said is fair and reasonable and appropriate”*
14 (Male GP). All agreed that eczema is not perceived as a priority in primary care, that treatment is
15 limited by their local emollient formulary and that they exercised caution in prescribing TCS. A
16 dominant influence on the mindlines of the four practitioners with self-reported expertise in eczema
17 care was exposure to dermatology experts in secondary care. The trusted and structured guidance
18 given had become firmly embedded leading to increased knowledge, skills and confidence and
19 *“braver”* prescribing of non-formulary emollients (when clinically appropriate) and TCS. These
20 experts contested the backdrop of low priority but concurred with the relative straightforwardness
21 of treatment regimens whilst viewing these not as a *“recipe”* but as principles that should be
22 individualised. The practitioner mindline illustration was amended for clarity (figure 2).
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33 *2) Areas of lay and practitioner mindline connection*

34 Unprompted participants considered mindlines of the *“other”* and the interplay between these
35 entities. Lay participants suggested a need for change in practitioner mindlines but focused on
36 amending lay mindlines. Practitioners were certain about the best targets for mindline amendment.
37 GPs stated that their own and lay mindlines should be amended but considered the former unlikely
38 due to the low priority given to eczema. This view was reinforced by an expert nurse, *“GPs are*
39 *entrenched in their views”* and a lay participant, *“it’s a challenge with the entrenched stubbornness*
40 *of the medical profession, people will not change their beliefs once they ‘know something’”* (Lay
41 male, 36). Other practitioners advised that health visitors, nurses and community pharmacy staff
42 should be targeted given their relative accessibility for patients.
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51 A challenge for all participants was the volume of often contradictory information from a multitude
52 of sources available to lay people. A GP recounted trying to persuade a patient to use TCS properly,
53 *“I validate it with something and say, look I do extra work in dermatology, please just trust me, this is*
54 *fine”*. However his efforts were thwarted by the patient’s existing mindlines and standard advice
55 given by pharmacists which generated fear.
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Practitioners almost universally identified the key reliable and useful knowledge that should be added to, and outdated or inaccurate information that should be erased from, existing mindlines. Core content is summarised in quotations from participants (table 4). Lay participants were less certain about the essential content but agreed key issues included understanding and accepting that eczema may be a long-term condition requiring ongoing treatment with emollients and that TCS have a place in the treatment of flares.

- *“never let anyone say to you again that eczema is just a bit of dry skin”*
- *“treat as a long term condition”*
- *“eczema needs maintenance treatment”*
- *“mantra of the best emollient is the one that [is used]”*
- *“don’t be frightened [of] steroids and use them properly”*
- *“when it does flare up you’ve got to hit it hard quickly with your steroid”*

Table 4: Core eczema mindline content from practitioners

3) Examples of synergy and dissonance between lay and practitioner mindlines

Returning to the original definition of mindlines as “collectively reinforced, internalised tacit guidelines” participants demonstrated both the complexity in development and the influential interplay between lay and practitioner mindlines. Participants identified areas of synergy and dissonance across and between mindlines. A key finding is that eczema knowledge does not involve just people living with the condition and practitioners but rather there is a pervasive social element, for example the received wisdom or “old wives tale” that TCSs “thin the skin” causing irreparable damage.

Perceived need to update was low among most practitioners and this pervaded some lay mindlines “there’s no point in wasting the doctors time” (Male, 53). As a result eczema was sometimes relegated to an additional concern rather than the primary reason for consultation and then necessarily given limited attention by practitioners, thus reinforcing its low priority. Practitioners reported “we don’t often think about it as a chronic condition which needs regular follow up and a defined plan” (Male, trainee GP), leading to reactive treatment with few follow-up appointments. Lack of maintenance therapy impacted on self-management leading to a cycle of flare management rather than a long-term, agreed management plan.

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4) Mindline amendment: whose, what and how?

Mindline amendment proved a conundrum to all. Lay participants reflected on the futility of simply providing more information. Immediate suggestions including predictable approaches such as websites media and leaflets were made but rapidly dismissed. For example, *"website ... but who would go on it?"* (Male, 53) and *"leaflets in GP surgeries, but then you just get information fatigue"* (Male, 49). Similarly suggestions about using social media and 'apps' were voiced and rejected within the same sentence. Interactive fora were vetoed due to the need for leadership and moderation. One participant favoured a *"Facebook group specifically for eczema care, I'd probably be part of that ... good to have a safe place for people to talk"* (Female, 22) although she acknowledged that sustained participation was unlikely.

Pivotal factors in lay mindline amendment included "realness", exemplified by *"that's the stuff that I'm interested in and that I'll home in on are the forums where you've got people telling their stories"* (Male, 53) and *"people work off stories don't they, like, I'm living proof"* (Male, 36). Other people's stories were persuasive for some and disliked by others. Trustworthiness, ease of access and applicability to self were important, *"quick trusted and easy to access"* (Female, 34) from trusted sources *"pharmacies, a credible source of information"* (Female, children 17&20). All lay participants disliked the generic nature of current information *"eczema is very particular, people regard it as part of who they are, because it does shape what you're doing"* (Male, 53). Disillusionment and lack of motivation to change was identified as a challenge to mindline amendment. Interactions and relationships were addressed on several levels. Engagement was one hurdle *"you need a way of hooking people in, people who are likely to walk past and go 'I haven't got time to care about that'"* (Female, 34). The impact of social and relational factors suggested a need for wider amendment *"an effective way would be to normalise this thing, there's still a shame element around it, bringing it into normal conversations, everyday discussions, so it's not a thing that you're just hiding away"* (Female, 26). Shared, consistent information could be powerful in eradicating influential *"old wives tales"*.

Practitioners proposed existing educational mechanisms for amending mindlines including: free taught sessions with *"really, really practical, emollient testing"* (Female, nurse) and information which can readily be applied in everyday practice; free online education; sessions during protected learning time. Practitioners rarely accessed available eczema education and were *"wary of messages from pharma or perceived messages from pharma"* (Female, GP). Expert practitioners were

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exasperated by the lack of motivation for change amongst generalist colleagues and the continued provision “*outdated and wrong*” advice (Female, nurse). Practitioners were aware of existing patient-focused resources, for example NHS Choices, patient.co.uk, the Primary Care Dermatology Society and the British Association of Dermatologists Patient Information Leaflets, but rarely signposted or used these in consultations.

Participants pointed to the need for shared understandings and consistent advice through synergistic mindlines. Reflection on mindlines brought to the fore the diversity and magnitude of influencing factors and the extent to which knowledge was accessed in different circumstances, for example during an eczema flare. The need for consistency of information was a high priority and one best addressed by seeking to modify the multiple channels of information that contribute to lay and practitioner eczema mindlines in primary care with straightforward, evidence based messages.

Discussion

The first aim of this study was to investigate whether initial eczema mindlines are an accurate representation of the experiences of practitioners and lay people in primary care. Mindlines intuitively made sense to, and were confirmed by, all participants. Areas of synergy and dissonance were identified, as was the interplay between lay and practitioner eczema mindlines. Secondly mindline amendment was investigated. The need to modify and unify mindlines by adding reliable and useful knowledge and by erasing outdated or inaccurate information was universally agreed. However, strategies to achieve amendment proved elusive. The prevalence of eczema, the diversity of *how* and *when* mindlines are developed suggests a need to find focused strategies for wide-reaching, societal amendment to ensure simple, consistent messages to improve consultation experiences and self-management in primary care. Practitioners offered suggestions about essential areas for amendment.

This study is one of few to apply mindline theory to a specific condition and is original in identifying the relationship between lay and practitioner mindlines. The study conforms to the conventions of qualitative research in being rigorous (externally auditable thorough clear reporting), relevant (enhancing understanding of the subject), resonant with reader’s experiences and understandings and reflexive (31). The study has deepened understanding of *whose* mindlines should be modified and *when* and *how* this may best be achieved. This offers a robust starting point for the complex amendment process. **Limitations of the study include parent and adult with eczema data being combined, potentially limiting nuanced differences in mindlines. Similarly practitioner mindlines have been viewed as a whole. That said, mindlines are individual and can change over time.**

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To date little attention has been given to the construction of lay (or patient) mindlines. Gabbay and LeMay (17) suggest a patient equivalent, but this possibility is poorly represented in other literature (22). The term clientlines appears in one study (32) but is not fully explored. However, the notion that knowledge creation inevitably happens in patients is not contested (33) and is extended here in the breadth of influences on lay eczema mindlines. This could be attributable to prevalence, with most people knowing someone with eczema and the perception that it is a “health problem which is not an illness” (34) and therefore perceived as open to treatment suggestions from anyone.

Amendment of mindlines is rarely reported, a synthesis of 10 years of literature (n=340) identified 28 related to practitioner amendment. These emphasise the importance of collaborative learning, relationship building and effective leadership in the development of valid, collective, evidence-based mindlines (22). Repeating the search strategy used for this review in August 2018 revealed an abundance of new literature (n=422) but still little directly addressing how mindlines may best be amended. Allied literature indicates the need for a judicious approach to amending practitioner mindlines. Primary care practitioners are necessarily expert generalists (35) and have to know about many conditions. It is clearly impossible for any individual to process all available information. Practitioners use coping strategies such as “satisficing” that is, curtailing the amount of information gathered to enable them to make a “good enough” decision (36). Given the view that eczema is straightforward with treatment being standard and unchanging over the years, motivation to change practice is limited (23). Likewise treatment decisions are apparently made rapidly, perhaps fitting somewhere between fast, automatic, System 1 thinking and the more deliberative, conscious slow and effortful System 2 approach (37) and instead accessing knowledge from a well-worn path. The danger here is that *this* path may not lead to the best outcomes.

Mindlines evolved from the work of Polyani and Nonaka & Takeuchi, in particular, the SECI spiral (17) in which knowledge is perpetually produced and transformed as users interact, collaborate and learn (38). Gabbay and LeMay (21) point to the critical nature of knowledge-in-practice-in-context, in which in each context new knowledge is converted by complex social processes. This current study concurs, finding that eczema knowledge is founded in a wider community (39, 40), sometimes facilitated by others (41) and often influenced by numerous, interacting personal and social factors (42). To date moves to improve eczema self-management and consultation experiences largely comprise educational and psychological interventions (13, 43). This study offers an alternative socially-mediated approach. Returning to the work of Nonaka offers new insights into mindline

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3 amendment drawing on the relationship between the SECI spiral and *Ba*. *Ba*, originally discussed by
4 the Japanese philosopher Nishida (44, 45) and later refined by Shimizu (46), is a shared space for
5 knowledge generation and sharing. *Ba* is not about the space per se (47), rather it is a shared
6 context-in-motion which advances over time and has no fixed boundaries or membership. It is about
7 the here-and-now and thrives on people with different viewpoints (48). *Ba* space occurs naturally, is
8 not prescribed, relationships are fluid, permeable and iterative (49, 50). It has four characteristics:
9 originating (face-to-face, individual communications), interacting (face-to-face group dialogue),
10 cyber (virtual group interactions) and exercising (virtual individual interactions) (50). In the main *Ba*
11 has been considered in business organisations (51-56). More recently attention has been given to its
12 application in other contexts, for example in making “big data” widely useful (57) and in supporting
13 educational endeavours (50, 58, 59). To date there is no evidence of attempting to create *Ba* across
14 lay-practitioner-community boundaries. Given the need to amend mindlines, both lay and
15 practitioner, across the community the notion of deliberately creating *Ba* and integrating
16 innovative approaches to addressing each of the four characteristics in a specific geographic area
17 offers a new opportunity for eczema knowledge mobilisation. **This work is currently underway and**
18 **will be the focus of future publications.**

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32 In some respects core treatment of eczema in primary care is relatively straightforward. Experts in
33 the field propose “getting control” and “keeping control” (60) which requires emollient maintenance
34 to reduce incidence and severity of flares and need for sufficient use of the right potency TCS when
35 required. The key to effective self-management is supporting people to do these two things well and
36 addressing the enormous challenges they face on a day-to-day enduring basis (61-64).

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42 This study offers a new approach to improving consultation experiences and self-management
43 through active and community-wide mindline amendment to develop consistent and shared
44 understandings. Core reliable and useful knowledge that needs to be integrated, and outdated and
45 inaccurate knowledge to be erased is identified. Mechanisms for change need to be socially-
46 mediated, multi-faceted, tailored to specific groups and convey consistent, evidence based, core
47 messages.
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5 **Contribution statement**

6 FC is the sole contributor to this paper
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9

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13 or the Department of Health.
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17

18 **Ethical approval**

19 The study was approved by a University Ethics Committee. Written consent was taken for
20 interviews. Participants consented to publication of anonymised information.
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25 **Competing interests**

26 None to declare
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32 their time and thoughts.
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37 **Data sharing statement**

38 The datasets generated and/or analysed during the current study are not publicly available as they
39 are not designed to be re-analysed by others but are available from the corresponding author on
40 reasonable request.
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3 **Table 1:** Interview topic guide

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5 **Table 2:** Demographic details of lay interview participants

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7 **Table 3:** Demographic details of practitioner interview participants

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9 **Table 4:** Core eczema mindline content from practitioners

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11 **Figure 1:** Lay eczema mindline

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13 Revised lay eczema mindline

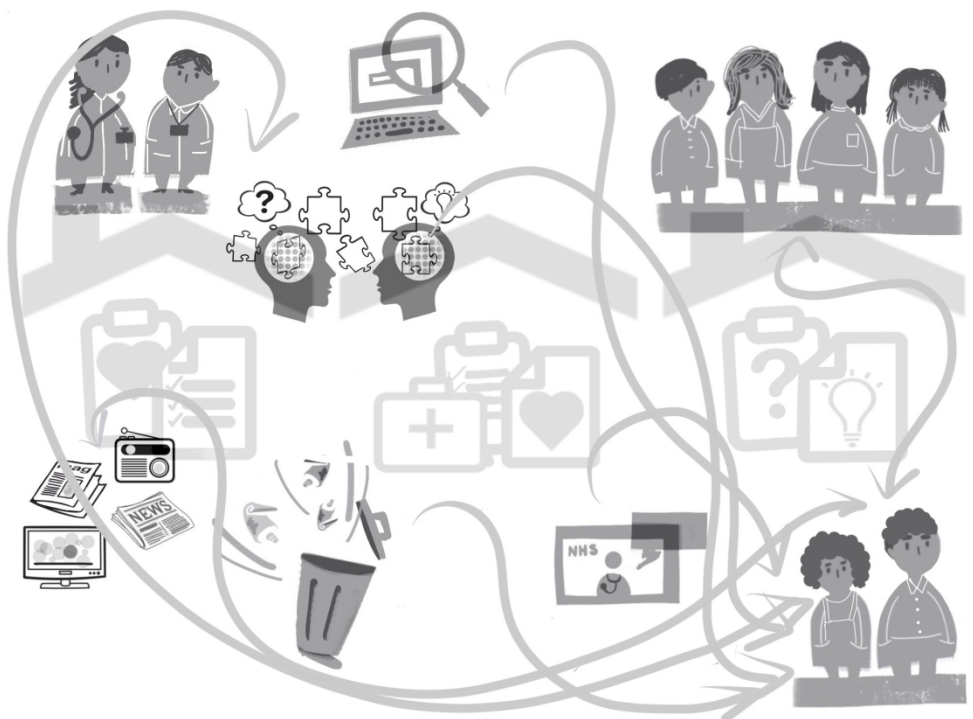
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15 **Figure 2:** Practitioner eczema mindline

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17 Revised practitioner eczema mindline

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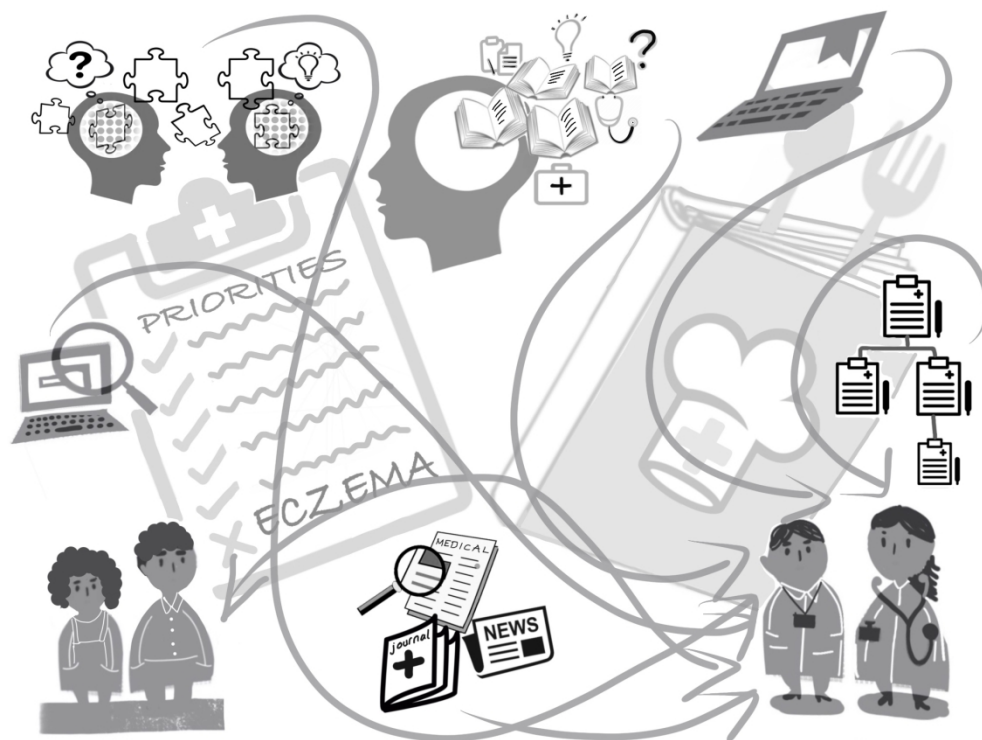
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Lay eczema mindline

394x295mm (132 x 132 DPI)



Practitioner eczema mindline

394x295mm (132 x 132 DPI)

BMJ Open Eczema mindlines COREQ 27.11.18

COREQ Statement

Knowledge mobilisation: an exploratory qualitative interview study to confirm and envision modification of lay and practitioner eczema mindlines to improve consultation experiences and self-management in primary care in the United Kingdom

Statement	Page no
Domain 1: Research team and reflexivity	
<i>Personal Characteristics</i>	
1. Interviewer/facilitator Which author/s conducted the interview or focus group? <i>I conducted all observation and interviews</i>	5
2. Credentials What were the researcher's credentials? E.g. PhD, MD <i>DProf, RN</i>	Title page
3. Occupation What was their occupation at the time of the study? <i>Professor of Nursing and Health Research</i>	Title page
4. Gender Was the researcher male or female? <i>Female</i>	Title page
5. Experience and training What experience or training did the researcher have? <i>I have extensive experience in qualitative research.</i>	Title page
<i>Relationship with participants</i>	6
6. Relationship established Was a relationship established prior to study commencement? <i>I established rapport with each participant at the time of interview.</i>	
7. Participant knowledge of the interviewer What did the participants know about the researcher? e.g. personal goals, reasons for doing the research <i>I sent participants an information sheet prior to interviews and answered any questions, I reiterated this information at the beginning of each interview.</i>	6
8. Interviewer characteristics What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic <i>Participants were aware, and it is reported in the manuscript, that I am a Registered Nurse with an interest in how eczema knowledge is developed and shared between patients and clinicians in primary care and that this was a publically funded study.</i>	5
Domain 2: study design	5 and 6
<i>Theoretical framework</i>	
9. Methodological orientation and theory What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis <i>In the methods section I explain that this is an exploratory qualitative study and that data analysis mainly involved constant comparison.</i>	
Participant selection	5
10. Sampling How were participants selected? e.g. purposive, convenience, consecutive, snowball <i>I selected participants using maximum variation purposive sampling to ensure a mix of ages, gender and ethnic background.</i>	
11. Method of approach How were participants approached? e.g. face-to-face, telephone, mail, email <i>Practitioners were recruited via the local Clinical Research Network and word of mouth and lay participants though a higher education institute website with mass sharing via word of mouth and media posts</i>	5
12. Sample size How many participants were in the study? <i>32 interviews were completed</i>	5
13. Non-participation How many people refused to participate or dropped out? Reasons? <i>No participants dropped out.</i>	NA
<i>Setting</i>	6
14. Setting of data collection Where was the data collected? e.g. home, clinic, workplace <i>Interview data were collected in workplaces or on the telephone</i>	

BMJ Open Eczema mindlines COREQ 27.11.18

16. Description of sample What are the important characteristics of the sample? e.g. demographic data, date Interview participants were sampled by age, gender and ethnicity.	Tables 2 and 3 5
<i>Data collection</i> 17. Interview guide Were questions, prompts, guides provided by the authors? Was it pilot tested? <i>A topic guide was used for interviews</i>	Table 1 5
18. Repeat interviews Were repeat interviews carried out? If yes, how many? <i>No repeat interviews were carried out</i>	NA
19. Audio/visual recording Did the research use audio or visual recording to collect the data? <i>Interviews were audio recorded</i>	5
20. Field notes Were field notes made during and/or after the interview or focus group? <i>No</i>	NA
21. Duration What was the duration of the interviews or focus group? <i>Interviews lasted from 16-55 minutes</i>	6
22. Data saturation Was data saturation discussed? <i>Yes</i>	6
23. Transcripts returned Were transcripts returned to participants for comment and/or correction? <i>No</i>	NA
Domain 3: analysis and findings <i>Data analysis</i>	6
24. Number of data coders How many data coders coded the data? <i>I analysed the data independently.</i>	
25. Description of the coding tree Did authors provide a description of the coding tree? <i>No</i>	NA
26. Derivation of themes Were themes identified in advance or derived from the data? <i>Findings were derived inductively from the data</i>	7
27. Software What software, if applicable, was used to manage the data? <i>No</i>	NA
28. Participant checking Did participants provide feedback on the findings? <i>No</i>	NA
<i>Reporting</i> 29. Quotations presented Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number <i>Quotations are provided and attributed to individuals.</i>	6-12
30. Data and findings consistent Was there consistency between the data presented and the findings? <i>Yes.</i>	6-12
31. Clarity of major themes Were major themes clearly presented in the findings? <i>Yes.</i>	6-12
32. Clarity of minor themes Is there a description of diverse cases or discussion of minor themes? <i>Yes, I present a broad spectrum of participant's views.</i>	6-12