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Helping parents know when to seek help for an acutely ill child: Evidence based co-development of a mobile phone app using complex intervention methodology.

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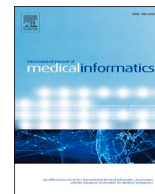
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A B S T R A C T

Background: Acute illness accounts for the majority of episodes of illness in children under five years of age and is the age group with the highest consultation rate in general practice in the UK. The number of children presenting to emergency care is also steadily increasing, having risen beyond pre-pandemic numbers. Such high, and increasing, rates of consultation have prompted concerns about parents' level of knowledge and confidence in caring for their children when they are ill, and particularly when and how to seek help appropriately.
Aim: The ASK SNIFF collaboration research programme identified parents' need for accurate and accessible information to help them know when to seek help for a sick child in 2010. This paper presents the resulting programme of research which aimed to co-develop an evidence-based safety netting intervention (mobile app) to help parents know when to seek help for an acutely ill child under the age of five years in the UK.
Methods: Our programme used a collaborative six step process with 147 parent and 324 health professional participants over a period of six years including: scoping existing interventions, systematic review, qualitative research, video capture, content identification and development, consensus methodology, parent and expert clinical review.
Results: Our programme has produced evidence-based content for an app supported by video clips. Our collaborative approach has supported every stage of our work, ensuring that the end result reflects the experiences, perspectives and expressed needs of parents and the clinicians they consult.
Conclusion: We have not found any other resource which has used this type of approach, which may explain why there is no published evaluation data demonstrating the impact of existing UK resources. Future mobile apps should be designed and developed with the service users for whom they are intended.

1. Introduction and background

Acute illness accounts for the majority of episodes of illness in children under five years of age, and is the age group with the highest consultation rate in general practice in the UK [1]. From the early 1990s until the onset of the COVID-19 pandemic in early 2020, the number of children presenting to emergency care and/or admitted to hospital had been steadily increasing [2–6], although the UK child population decreased over this time period [7]. Indeed, between 1999 and 2010 emergency admissions for children increased significantly, particularly

for those under 5 years (<1 year increased by 52 %, 1–4 years by 25 %) and for those with acute infections (by 30 %) [4]. This trend continued between 2007 and 2017 with a 1.6 %/year increase in emergency department visits for all children and 3.9 %/year for infants [8]. During the COVID-19 pandemic the numbers of children presenting to primary and emergency care dropped significantly [9–12], creating concerns that parents were not seeking health care expeditiously. Before and during the pandemic a small proportion of children were reported to present late in the course of an illness [12,13], although it was initially unclear whether this increased during the pandemic [13]. A comparative analysis found reductions in ED attendances across all 38 study sites in 16 European countries, with no evidence of disproportionate numbers of more severely ill children [14]. Since the lifting of pandemic restrictions the numbers of children presenting to emergency care increased and is now reported to be higher than pre-pandemic levels [15]. Children under five years of age constituted 11 % of emergency care attendances in March 2023, the same as those for patients over 80 years of age [16].

Such high and increasing rates of consultation have prompted concerns about parents' level of knowledge and confidence in caring for their children when they are ill, and particularly when and how to seek help appropriately. Parents and professionals can miss signs of serious illness in children [17,18], indeed children in the UK are more likely to die from preventable causes, such as pneumonia and meningitis, than in any similar European country [19].

The need for accurate and accessible information to help parents know when to seek help for their child has only been exacerbated with the pandemic and the increased pressure on services which has followed [20], making it even more important to provide information for both parents and professionals to facilitate timely treatment. The requirement for social distancing and the change from face-to-face to predominantly virtual consultations during the pandemic lockdowns in primary care highlighted a need for information which parents can access in the home. Information to help parents know when to seek help for a sick child is often referred to as 'safety netting'. We defined safety netting as the provision of information for families to enable them to know when to consult for an acutely sick child. It should include verbal and/or written information on warning symptoms, how & when to access further healthcare, arranging follow-up appointments and liaison with other healthcare professionals [21].

Safety netting is included in guidance from the National Institute for Health and Care Excellence [22–24] and is reported to be used routinely by health professionals across first contact services [25–27]. However, parents often report no specific advice being given ('*Bring her back if she gets worse*' [18]), or advice only being given verbally rather than in a printed form [18,28]. Retention of verbal information in consultations may be as low as 25 %, especially when the recipient is anxious [29,30], making it important to provide information in forms that parents can refer back to after a consultation.

Although some parents say they prefer hard copy information, most would like information on their mobile phones for easy access [31]. While the vast majority (96 %) of UK adults aged 16–34 years) own a smartphone (https://www.statista.com/topics/4606/uk-smartphone-market/), fewer of those on lower incomes have pay monthly contracts, unlimited data plans or home WiFi [32,33]. Furthermore, eHealth literacy is rarely considered in developing eHealth interventions for socially disadvantaged groups [34], including those living in rural areas or among individuals with low levels of digital skills (ability to navigate, use and understand digital information) [32,33,35–37].

Safety netting was originally conceived as a tool to reduce health care professionals' risk of missing serious illness in patients where there was diagnostic uncertainty [21,38] rather than with patients' or parents' educational needs in mind. Spotting the Sick Child (www.spottingthesickchild.com), an internet based learning platform hosted by the Royal College of Paediatrics and Child Health, was developed to help UK health professionals identify sick children – parents also need a similar

resource.

2. Aim

We describe a programme of research which led to the co-development of the content, format and delivery methods for an evidence-based safety netting intervention (mobile app) co-designed to help parents know when to seek help for an acutely ill child under the age of five years in the UK. This research programme is the work of the Acutely Sick Kid Safety Netting Interventions for Families (ASK SNIFF) collaboration first set up in 2010. Although mobile apps are now pervasive, we have been unable to find any reports of evidence-based processes for the development of apps with parents of young children. In this paper we share our process and experiences to guide future app development. We are currently developing a prototype app in collaboration with parents and health professionals. Where possible, without risk to the intellectual property of the resulting content for the app, we have published, and referenced herein, papers on each stage of the work.

3. Methods and results

3.1. Guiding principles: Collaborative co-design

The need for an intervention for parents was identified by the research programme leads, in 2010 [39,40] and the launch of spottingthesickchild.com for health professionals, which highlighted the need for a similar resource for parents. Our next step was to discuss the concept with parents of young children and, when the idea proved to be popular, to develop our parent panel, to guide the development of each stage of the work. Working with families with young children brings its own challenges (the subject of a separate paper in preparation) which we sought to address in order to capture the views of a diverse range of parents. Collaborative co-design has been the guiding principle for this work, reflecting good practice principles for public involvement in research [41–43], and evidence of their greater effectiveness [44–48]. Where necessary we secured ethical approval from NHS Research Ethics Committees and all our projects were conducted following Health Research Authority ethical principles for best practice (www.hra.nhs.uk).

3.2. Steps in the development process

We initially followed the Medical Research Council (MRC) [49,50] framework for development and evaluation of complex interventions but latterly found, post-hoc, that O'Cathain et al.'s [51] framework reflects the steps we followed, reflected in their statement that the '*key principles of intervention development are that it is dynamic, iterative, creative, open to change and forward looking to future evaluation and implementation.*' [51 p2].

Our intervention was developed in a 6-step process:

1. Scoping of existing interventions
2. Systematic review: identification of the evidence base
3. Mapping clinical evidence: identification of the evidence base
4. Qualitative research: theory development
5. Co-development of the content using consensus methodology and video capture
6. Web-based content review and expert panel review

3.2.1. Scoping of existing interventions

We initially planned a scoping review of all information resources on childhood illness available for parents in the UK on the internet. We quickly ascertained that there was an overwhelming amount of information available on the internet for parents. This was mirrored by our parent panel who reported that they found the internet to be generally

unhelpful as most of the information is presented by diagnosis, forcing parents to guess what is wrong with their child and they also found it difficult to determine which information sources to trust. We therefore opted not to perform a formal scoping review, and given that phone apps were emerging during our research programme, we conducted an environment scan of UK child health apps which include information on acute childhood illness. This focussed search identified 14 apps providing a wide range of information, similar to an information-based website, which makes access to the relevant information more complex, especially at a time of stress. This greater complexity decreases perceived ease of use (PEOU). PEOU decreases intention to use apps, i.e. more complex apps are less likely to be used [52]. Our initial analysis also identified only two apps reporting any co-production with parents, and the extent to which this co-production used an evidenced approach is not clear. An international environment scan of apps for acute childhood illness [53] found that only 5/53 (9 %) apps had any evidence of usability or efficacy testing, only one of which was from the UK (Handi app).

3.2.2. Systematic review: Acutely Sick Kid Safety-netting Review and Analysis (ASK SaRA)

Our systematic review aimed to identify the effectiveness of information resources to help parents decide when to seek medical care for an acutely sick child under five years of age, including the identification of factors influencing effectiveness [54]. This was the identification of the evidence base stage of the MRC framework. Our review concluded that information resources for parents are more likely to be effective if they are relevant, address assessment of all key symptoms of acute illness and include information on how to care for the child [54]. Interventions which did not include these components appeared to leave parents needing further help and advice. Interventions were also more likely to be effective if they were co-produced with parents and introduced by health professionals in non-stressful environments.

Since this review was published, the number of digital interventions has increased significantly; 53 identified for parents with an acutely ill child internationally [53]. However, a further systematic review identified only three published studies evaluating interventions for parents with an acutely ill child, none from the UK [55] and none providing evidence of effectiveness. Our updated systematic review [56] (in progress), focussed on digital interventions for parents, has identified only six papers (none from the UK) demonstrating the lack of research evaluating such interventions.

3.2.3. Mapping clinical evidence: Identification of the evidence base

Clinical standards and guidelines relevant to the five most common presenting symptoms of acute childhood illness (breathing difficulty, fever, diarrhoea, vomiting and rash [57]), were analysed and indicators of illness severity mapped into a single document. These five symptoms were identified as the most clinically significant by our expert clinicians. These indicators of illness severity were expressed as traffic light colours; green, amber and red (the most serious) flags. This mapping was regularly revised when clinical guidelines were updated and used in the later stages of the work for expert clinical review panels to ensure consistency of content with national guidance.

3.2.4. Qualitative theory development research: Acutely Sick Kid Parent/ Professional InformationProject (ASK PIP)

Our next step was to develop the theory for our intervention through grounded theory informed qualitative research with key potential stakeholders and end users: parents and first-contact services clinicians. In ASK PIP we conducted focus groups with 27 parents and, separately, 16 first contact health care professionals (HCPs) [25,28,31,58]. First contact HCPs include Emergency Care (Emergency Department (ED) Clinicians, Paramedics), Community Paediatricians, General Practitioners (GPs), Health Visitors (HVs), Community Children's Nurses, and Practice Nurses. We sought to identify what information parents and first contact HCPs were using to help parents know when to seek help for a sick child, what they liked or disliked and what information resources they wanted in the future.

Our findings showed that parents wanted information before, during and after consultation with a HCP to inform their own care seeking and safety netting decisions [28,58]. Parents' pre-consultation information seeking was dominated by the internet, albeit with limited success, often raising anxiety levels. When they did consult, parents reported that information was not routinely offered, the content was inconsistent, and the delivery method usually only verbal. National Institute for Health and Care Excellence (NICE) information for the public was not mentioned at all. We noted that neither hard copy nor the internet were accessible for parents with low levels of literacy, and NICE or other printed safety netting advice was rarely received.

HCPs reported safety netting practices that included information on what to look for, when and where to seek help [25,31]. Delivery of safety netting, whether verbal and/or printed, was inconsistent, rarely documented and left to individual preference. None of the clinician participants had received any training in giving safety netting information. The way in which safety netting was provided was reported to be influenced by clinician's experience, confidence, time, knowledge, their own parental status, assumptions of individual parent's knowledge and confidence, and practical factors such as access to functioning printers. Professionals recognised that safety netting is limited by not knowing if it has been understood, parents' desire for face-to-face reassurance irrespective of any prior information provided, and worries about the potential for over-reassurance.

Parents and HCPs expressed a desire for safety netting with the following characteristics:

- **Content:** Signs and symptoms of serious and common illnesses, illness management, where and when to seek help.
- **Presentation:** Basic, simple to use, containing simple symbols.
- **Delivery:** multiple methods from face-to-face to written materials and digital media, including audiovisual.
- **Validation:** Professional endorsement was a key criterion, alongside reliability, consistency and being up-to-date.

3.2.5. Co-development of content, format and delivery methods for a standardised safety netting intervention: Acutely sick Kid safety-netting intervention development (ASK SID)

This phase of the project aimed to build on the findings of ASK SaRA and ASK PIP to develop the content for a safety netting information resource for parents to use to help them determine when to see a HCP with an acutely sick child. The objectives were to identify the clinical features that parents and HCPs consider essential for safety netting advice related to the five most common presenting symptoms of childhood illness, and identify the optimal content, format and delivery mechanisms for a safety netting resource for acutely sick children.

During the study, 28 parents and 23 HCPs participated, separately, in focus groups or interviews to identify the content list, format and delivery methods for the safety netting resource. Analysis of the data generated extensive lists of possible options which required prioritisation.

Methods used to determine prioritisation were informed by consensus methodology [59–62]. Workshops, using an adaptation of dotmocracy and nominal group technique (see Appendix 1 for an example of the scoring sheets used), and surveys were used for the initial stages of prioritisation with a further 49 parents and 234 health care professionals. Participants were asked to rate each item as: essential; not essential but would be good to have; not important to include. A preference was not always clearly identified, consequently these items were presented to expert clinician and parent review panels to develop consensus on the content to be included in the safety netting resource. Keeping parent review panels separate from clinician review prevented parents from being influenced by clinicians' responses.

Prioritisation data on presentation, delivery and advertising of the intervention were analysed to identify items with the highest levels of agreement. The outcome of this project was consensus on a detailed list of the content required for the safety netting intervention and on the ways in which this information should be presented, delivered and advertised.

The output of this project included a comprehensive list of the content required on each of the five commonest presenting symptoms of acute childhood illness. Dehydration was added as a sixth symptom to prevent repetition as it was identified within each of the other symptom lists. Dehydration is also a clinically important symptom in acutely ill children. We also identified parents' and HCPs' preferences for the delivery, presentation/format and advertising of the intervention.

Parents and HCPs wanted information on symptoms in three main areas: assessment of the child's illness, management and care of the child/illness, and explanation of illness causation. The findings identified a range of different ways in which the information resources could be presented, delivered and advertised, suggesting that multiple formats should be considered during the development of the intervention. However, there was a preference for the intervention to be presented as a mobile app, as parents wanted something they could hold in their hand, and that written information needed to be augmented by short video clips of real children showing visual and auditory examples of the symptoms concerned.

3.2.5.1. Video capture and review: Acutely Sick Kid Video Capture (ASK ViC). The aim of ASK ViC was to capture video footage of acutely sick children which could then be edited into short video clips showing symptoms of acute illness in real children. Parents throughout our projects had expressed a desire to be able to see symptoms in real children, rather than diagrams or cartoons. ASK ViC ran concurrently with both ASK SID and ASK PETra projects. Parents in a children's emergency department in London were approached for consent to film their child in the emergency department. We aimed to include children from a wide range of racial and ethnic groups. Parents were provided with information about the project and how the resulting video footage would be used, prior to providing consent to allow video footage of their child to be used. Additional video footage of children being given medication and having their temperature taken at home was provided (with parents' consent) by a parallel project, led by the Health Innovations Network in London, that developed short videos on managing a child with a fever and identifying signs of sepsis.

All video footage was reviewed and edited by our emergency care clinical expert (DR) in conjunction with a video editing company. These edited videos were reviewed during ASK PETra as mentioned above and by the Parent Panel, leading to revisions where necessary. Feedback from parents highlighted the need to remove potentially distracting clinical features implying severe illness, such as intravenous lines or electrocardiograph leads, so that the symptoms would remain the focus of attention.

3.2.6. Development and review of the written content for a safety netting intervention: Acutely Sick Kid Parent Education and Training intervention (ASK PETra)
The next step was the development of the safety netting intervention, which aimed to translate the findings from ASK SID into structured algorithms for providing information to parents on the six core symptoms of acute childhood illness in language appropriate for parents, write the specific content to be included within the safety netting resource for all six symptoms of acute childhood illness, and finally, solicit parents' and HCP' reviews and consensus on the algorithms and written content.

The research team and the Parent Panel worked together to develop the content and the flow of information (content map) for the six symptoms, with a wider group of parents and HCPs involved in reviewing the content developed. The red and amber flag mapping

(referred to above) was used, alongside more recently published guidance, NICE information for the public and NHS online, to ensure that the scripted content was consistent with the latest national guidance. An online review platform was developed by an SME specialising in development of digital health interventions, then managed by the research team to ensure the review process was secure, anonymous and accessible. The Parent Panel contributed to the development of the review platform by providing feedback on the appearance and function of the review platform.

A total of 95 participants, 43 parents and 51 HCPs, participated in this phase of the project. Most (39 parents and 46 HCPs) were involved in online reviewing of the content map, and the written and audio-visual content developed for each of the six symptoms. Parents and first contact HCPs were recruited from a range of social groups and practice backgrounds.

Reviewers provided feedback on content, including wording, use of traffic lights to indicate level of severity of the symptom, sequencing of information, and use of audio and/or visual content. The results were then presented to our expert panels (five parents and five HCPs) to review areas of consensus and address each area where consensus had not be achieved. Finally, clinical experts within the research team reviewed the results from consensus meetings to ensure that the resulting content was relevant, accurate, consistent with national guidelines and within the scope of the safety netting intervention.

The process of content development, review and consensus enabled the robust development of final content ready to be developed into a prototype safety netting intervention for six symptoms of acute childhood illness.

4. Outcome and conclusion

We took a structured and evidence based approach in line with the MRC Complex Interventions Framework [MRC 49, MRC 50, 63] and O'Cathain et al's [51] guidance to co-develop a safety netting resource for parents with acutely ill children under 5 years of age (see Fig. 1). Our systematic review established what factors were known to affect the impact of existing interventions [54]. Building on this with qualitative research, we gathered contemporaneous data on safety netting practices in the UK setting alongside parents' experiences [25,58,64,65]. These two projects created evidenced theoretical foundations for the development of the intervention. The next two projects extended this work to co-develop the desired content, format and delivery methods. The content developed was checked against NHS sources of information for families to ensure consistency, and all final content was reviewed by
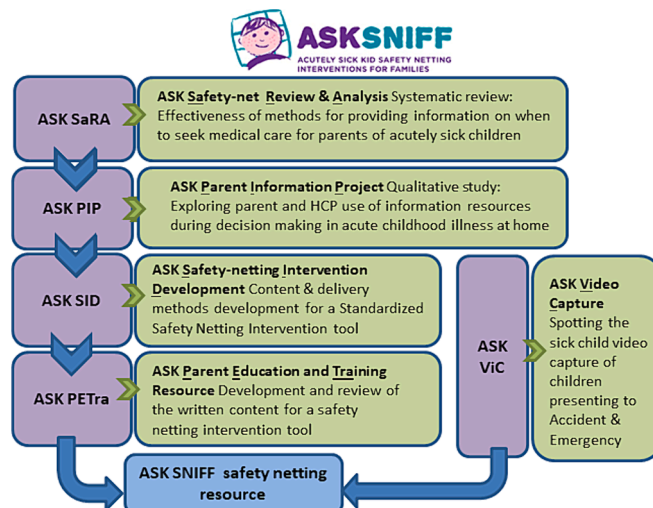

Fig. 1. ASK SNIFF research programme (colour online only).

parent and clinician panels. The resulting materials were augmented by short video clips illustrating the symptoms. The end result was evidence-based content for an app supported by video clips.

Our collaborative approach has supported every stage of our work, ensuring that the end result reflects the experiences, perspectives and expressed needs of parents and the clinicians they consult. We have not found any other resource which has used this type of approach, which may explain why there is no published evaluation data demonstrating the impact of existing UK resources [53,55]. Resources developed with the end users are inherently designed to meet their needs in ways that resources developed for them, based on assumptions about what is required, cannot. Our next steps are to co-create the digital prototype safety netting app and iteratively develop it using feedback from parents and first contact HCPs concerning presentation, functionality, ease of use and impact on decision making for an acutely ill child. Concomitantly, we will plan our implementation and evaluation strategy designed to capture data to determine how the app needs to function to be effective in supporting parents to care for children under five years of age with acute childhood illness.

Authors contributions

SN and ML were the originators of the research programme. SN and NB led the collaborative work with parents, supported for specific projects by CS and HSM (see Acknowledgments). The ASK SNIFF parent panel contributed to all but the data collection stages of each project. ML and SN led the systematic review with significant contributions from DR and CS. ML, MT and SN led ASK PIP with data collection support form HSM. CJ contributed to study design, data collection, analysis and publication writing for ASK PIP. SN and ML led ASK SID with CJ and NB contributing to data collection, analysis and report writing and MH mapping clinical guidelines. General practice expertise was provided by MT for ASK SARa, ASK PIP and ASK SID. ASK PETra was led by SN and ML. SN wrote and revised content with input from parents and clinicians via a digital review platform created by OCB Media and NB. General practice expertise was provided by JUS (see Acknowledgements). ASK ViC was led by ML with video capture by MH (see Acknowledgements) and clinical expert video editing by DR. During every project in the programme the core team of SN, ML, MT, and DR contributed to project design, development and delivery, including writing publications. NHS Research and Development support was provided by SPH.

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CRediT authorship contribution statement

Sarah Neill: . **Natasha Bayes:** . **Matthew Thompson:** Writing – review & editing, Writing – original draft, Methodology, Funding acquisition, Formal analysis. **Caroline Croxson:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation. **Damian Roland:** Writing – review & editing, Writing – original draft, Methodology, Investigation, Formal analysis, Data curation. **Monica Lakhanpaul:** .

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary material

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijmedinf.2024.105459.

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