This article reports the findings from a qualitative service evaluation of health literacy resources for parents of children aged 0-4 on six common paediatric conditions (abdominal pain, asthma/wheeze, bronchiolitis, diarrhoea/vomiting, fever and head injury). These have been launched across Wessex as part of the Healthier Together (HT) project and consist of a website and paper-based resources designed to provide easily accessible facts about common childhood conditions, advice on actions to take in the event of certain symptoms and when and where to seek medical help. Eighteen semi-structured interviews were conducted to investigate parents' experiences of and reactions to the resources. We sought an understanding of perceived effects on parental understandings and feelings about childhood illness and help seeking behaviours. We discuss findings under four main headings: Parental interaction with HT resources, Parental anxiety, Positive evaluation and Areas for improvement. Parents positively evaluated the aims of the project and the information provided. A small number gave examples of resulting behaviour change and several anticipated future changes. Parents expressed anxiety about childhood illness and making treatment decisions. They required simple and easy to navigate resources including prominent risk assessment information. Communication by health professionals that reassures and empowers parents was also seen as important. Whilst this was a small study we believe that the findings are of relevance to others producing, disseminating and explaining health information aimed at parents and other patient groups.
INTRODUCTION

Emergency or unscheduled hospital admissions have been rising for several years\(^1\), a large proportion of which are attributed to inappropriate or non-urgent visits. This is of concern due to the high and rising costs of emergency admission compared with other forms of care, and the disruption caused to elective healthcare (e.g. inpatient waiting lists). The 0-4 age group has the second highest emergency admission rate in England after the 84+ age group\(^2\). Common conditions that this age group presents with include self-limiting acute conditions such as fever, upper or lower respiratory tract infections, and gastroenteritis\(^3\).

A 2010 review\(^2\), identified three broad interventions that appear effective at reducing emergency admissions: integrating health and social care, integrating primary and secondary care, and patient self-management. To the best of our knowledge, no peer-reviewed, systems-wide interventions to date have targeted paediatric populations\(^4\).

In response to this, the Healthier Together (HT) pilot project was established in Hampshire, Dorset, and the Isle of Wight. Alongside health literacy material for parents, standardised clinical and referral pathways were developed for six common paediatric conditions (abdominal pain, asthma/wheeze, bronchiolitis, diarrhoea/vomiting, fever and head injury) which were made available to child healthcare and community services (general practices, front-line hospital staff, pharmacists, child community services, NHS 111 staff) serving children aged 0-4. The aim is that parents of children aged 0-4 years receive consistent signposting to this information from the range of professionals with whom they come into contact. The information is designed to provide easily accessible facts about common childhood conditions, advising actions to take in the event of certain symptoms and when and where to seek medical help. The information also provides healthcare professionals with standardised clinical pathways and ‘safety netting’ material to assist in the delivery of consistent healthcare messages to parents. The Healthier Together resources (evaluated in this study) consist of:

2. Paper parent handouts (conditions sheets) which were made available to parents in the context of parental health literacy classes delivered in children’s centres (these are also available as links from the website).
3. Paper HT ‘safety netting’ sheets which can be given to parents by GPs or health professionals.

The information resources were piloted in one city-based location within the Wessex area. This paper reports findings from a qualitative service evaluation of this pilot that investigated parents’ experiences of and reactions to the resources. We also sought an understanding of perceived effects on parental understandings or feelings about childhood illness and help-seeking behaviours.

METHODS

We conducted semi-structured interviews as the main data collection method, carried out in participants’ homes (in all but one case). The topic guide encompassed questions about reasons
for participants’ visit to the GP/children centre on the occasion that they received the HT resources, immediate impressions of the resources, experiences and views on the way that they were ‘signposted’ to them, their subsequent use of the resources and any perceived learning or behaviour changes that had arisen.

The second half of the interviews included a ‘think aloud’ section, in which respondents were asked to look again at each of the resources outlined above and ‘think aloud’ as they read and navigated them. In the case of the website, the researcher asked the participant to demonstrate how they had/would find the HT website and then how they had/would access information on a particular condition (for example, ‘fever’) by navigating the website. Importantly, the researcher did not bring a device with her via which participants could access the website, rather they were asked to demonstrate the process they had already followed, (or would follow) including using the device of their own choice. Participants’ verbalizing of their thoughts as they interacted with the resources, particularly the website, provided a detailed insight into any ‘usability problems’ and their underlying causes.

The data collection approach also included a supplementary element of participant observation. As described below, recruitment was partly accomplished by attendance at a number of children’s centres where HT information had been displayed and introduced to parents by workers, during the preceding weeks. As part of the recruitment process, the researcher spent time at several parent/child sessions at these children’s centres interacting with parents and observing the way that the resources were being displayed and explained, as well as gaining a broader understanding of the activities and interactions taking place within these settings. Similarly, semi-structured interviews were carried out within participants’ homes and respondents were asked to demonstrate how they had (or would) use online resources. This allowed the researcher to observe the familial scene and to gain an impression of the context in which participants were using and accessing HT resources. In combining interviewing with ‘think aloud’ evaluation of resources and observation of daily contexts, we sought understanding of how people would interact with the health literacy resources in their own homes and lives. This was in contrast to asking them to review material in a more formal ‘laboratory-like’ setting, which would have been one possible alternative approach to this research. The ‘naturalistic’ approach (i.e. carrying out research out in ‘natural settings’) is in line with the aims of qualitative evaluation and yielded useful information that may not have emerged from other approaches.

**Data analysis**

Following respondent consent, the interviews were audio recorded and supporting field/observation notes taken as data. Firstly, transcripts were read through by a researcher and preliminary impressions observed. Hereafter, the data were entered to NVivo11, where following two separate readings by different researchers, codes representative of the emerging themes were generated. After a further reading of the data additional codes were created by the two researchers that captured the complexity of the respondents’ narratives. This process of thematic analysis is
a recognised methodology for reducing and categorising qualitative data. As well as seeking to identify themes across the data set, analysis also identified the steps taken in navigating the website which was achieved through the compiling of detailed case descriptions for each think aloud section. This allowed a deeper understanding of the processes followed by individual respondents and the similarities and differences across the data set.

Sample and recruitment
The HT pilot was carried out in a city with an increasingly diverse population for whom English is either not their first language, or who can speak no English at all. It contains areas of considerable socioeconomic deprivation, the sample for the current study represents respondents from a range of backgrounds.

A purposive sample was recruited via three local children’s centres and one GP surgery. These were chosen because they were locations at which the materials were known to have been actively promoted prior to the evaluation. At the children’s centres the HT information had been promoted in the three weeks prior to data collection. At the GP surgery, the information had also been introduced to parents of children aged 0-4 years presenting with any of the key childhood conditions targeted by the HT literature, as part of the consultation.

The study’s recruitment criteria were:
- Parents/carers of children aged 0-4 resident in the HT pilot location,
- who had received, or were signposted to, HT information from one or more of the participating sites, in the 3 months prior to recruitment.

The recruitment criteria were broadened as the study progressed. It was the initial intention to recruit parents to interview who had already been signposted to and accessed the HT resources. However it became apparent in recruitment from children’s centres that whilst parents attended the centres when the HT information was being marketed and displayed, the majority of parents stated that they were not familiar with the HT resources and had not accessed them. Therefore the recruitment criteria were broadened to include ‘parents who had attended a children’s centre/GP surgery at which HT was being promoted in the 3 months prior to recruitment’.

Interviews recruited
In all, a sample size of 18 were recruited; as shown in table one below.

ETHICS
The project was classified as Service Evaluation and approved by University Hospital Southampton NHS Foundation Trust. Each respondent received a project information sheet and signed a consent form before being interviewed.
Table 1: Interviewee demographic details

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<th>Occupation (F/T = full time)</th>
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FINDINGS

The evaluation yielded a great deal of detail regarding participants’ views of the HT resources including specific recommendations for changes to the layout and information included. In this paper, rather than presenting all of the resource-specific findings, we highlight the particular themes that are likely to have broader relevance to health literacy information in general. We discuss these findings under four main headings: Parental interaction with HT resources, Positive evaluation, Parental Anxieties, and Areas for improvement. Respondents are numbered to ensure anonymity. The CC or GP after the number denotes whether the participant was recruited from the GP surgery or a children’s centre.

**Parental interaction with HT resources**

In this section we highlight a number of themes that arose in relation to the way that parents interacted with the HT information, or their preferences for doing so. These are likely to have implications for other areas of health information, beyond this project.
1. Points of likely receptiveness to health resources

An important finding that emerged from data collection (as alluded to above) was that despite being in children’s centres at which the HT information was on display, the majority of parents approached did not appear to have noticed the resources. Insight into this was afforded in interview, where parents stated that they would not look for, or access health information until their child was actually unwell:

‘I’d not seen these before, no, but maybe it’s because I wasn’t looking out for them, that I didn’t see them’. R20 CC

‘When your baby is preferably fine, you’re just not wondering what would happen if something would happen. What it happens, then you do a bigger research on it’. R19CC

On the other hand, all parents recruited from GP surgeries recalled being signposted to the HT resources and had accessed the resources ahead of the interview, reinforcing that parents may be more receptive to health literacy resources at a point when they have concerns about their children’s health.

This also provided an important insight about the likely state of mind of parents when they do access health resources -that is to say, when they are feeling anxious because their child is unwell.

‘I would probably only look at it if I was worried about something…I probably, to be honest with you, wouldn’t actually download it until I was worried about something with Lily*, then I might be more likely to download it’. R41CC (*pseudonym used)

The implications of this are drawn out further below:

2. Need for effective ‘signposting’ communication

There are indications from the data about the importance of a good communication/consultation style amongst health professionals who signpost parents to health resources. A number of respondents expressed reservations about the introduction or explanation that they had received – respondents 28 and 24 below felt the delivery was rushed, without enough attention being given.

‘He was very brief and very quick about it, which I understood why he was doing it, but he could have done it a little bit more friendlier, I would have thought…He was rushed. He was very rushed and I guess he had other appointments to see as well’. R28GP

‘They said, “Oh just go to that website, it has everything on there like when you have to go to hospital or GP”, and I was like, “Okay”. I was quite upset with her because I was…wanting her to do a check-up properly on my baby’. R24CC

On occasions a web link was written on a piece of paper without further explanation – which was not always a helpful strategy.
‘a couple of months down the line she was poorly again and I’d lost the piece of paper and I’d forgotten what it was called’. R29GP

However, as the respondent below shows, a more detailed and friendlier explanation was appreciated and reassuring:

‘She had a poster on the wall I think that had sort of an example page from the website. I think she talked us through bits on that that were relevant and just wrote down the website address and said to go see that…She was absolutely lovely and very reassuring. Yes, and it was really useful to have somewhere you can go and actually check these things out’. R30GP

3. Format of resources: paper versus web based resources

Another contextual issue that affected people’s interaction with the HT resources was their preferences (and confidence levels) around using the internet to access information versus paper-based information.

Of those expressing a preference, 7 preferred paper and 6 the internet. Those stating a preference for paper often referred to a lack of trust, or confidence in using the web to access information, meaning that for them, paper based information would be easier to find and refer to. However, this was not universally the case as one participant expressing a preference for paper based resources worked as a web designer.

‘I’m not very good with technology’. R36CC

‘on internet, you have so much information that you don’t know what to follow first’. R19CC

On the other hand, a common reason for accessing the resources via the website is that people would be unlikely to keep (or find) information in paper form.

‘I’m probably more likely to go to the internet just because you’ve always got your phone with you or your iPad or a computer. I’m probably more likely to reach for that than to go and try and look for some leaflets that I knew I was given once’. R41CC

It was not possible to draw conclusions about any shared characteristics of respondents with preferences for paper or the internet as each group contained a mix of those with English not as the first language, those with post 16 educational qualifications and none, and a mix of age ranges. A mix of information formats is likely to be necessary to meet the range of preferences people hold.

4. Choice of device via which to access the website

As described above, the ‘think aloud’ section of the interview involved asking participants to access information about certain conditions using the HT’ website. The large majority of participants (15) opted to use a smart phone to access the website during the interview. Two respondents accessed
the information via a tablet device. Phones were often seen as the most convenient method for accessing web based information.

‘I prefer my phone, being able to access it quite quickly’. R40CC

‘I do most things now on my phone’. Respondent 28, GP

For respondent 27, this convenience was likely to be particularly important when dealing with a child who is unwell.

‘But if you’ve got a screaming child in the middle of the night that are ill and you’re not sure what’s wrong with them, and you’ve got your phone in your hand and you’re looking on the internet and you’re probably on a mobile site, because again, people aren’t going to go and power up a laptop or whatever’. Respondent 27, GP

The Think aloud section of the interview, revealed that the lay-out on the HT mobile site was different to that appearing when loaded on a PC or tablet and resulted in several problems navigating the site and searching for information. Pictorial links to main web pages were prominent on the PC/tablet version which allowed respondents using tablets to easily find information by following these links. However, on the phone version the most prominent feature was the search bar, which led respondents to try to navigate the site by inputting search terms – which often did not yield helpful results. Whilst further details about the specificities of navigation problems are beyond the remit of the paper, these findings highlight that many people will access web-based health literacy resources via their smartphones and it is therefore important that consistency and ease of navigation is ensured across all interfaces (phone, PC, tablet etc).

Parents’ anxieties concerning their children’s health

Parental anxiety concerning childhood illness was a prominent theme that emerged over the course of this evaluation. Words that parents used to describe their feelings when their children were unwell included ‘stressed out’, ‘anxious’, ‘worried’, ‘in a bit of a panic’, ‘scared’ and even ‘petrified’. Anxieties were heightened when illness was amongst a baby or very young child.

‘people do tend to panic especially when it’s with their children’. R40

‘I think when they are very young, you get more worried’. R43

Respondents reported specific anxieties relating to what best to do to help their child, particularly about whether or not they should take the child to see a doctor.

‘…as mums they are always anxious, “Oh I don’t know if I should be riding it out, if I shouldn’t be riding it out?” And things like that’. R29GP

This appeared to be a particular dilemma for newer parents:

‘especially for new mums…everything is new for us and you’re always thinking, oh my God, is my
baby all right? Is he not? What should I do? Should I go straightaway to A&E? Should I go to a GP?.
R22CC

Some parents expressed specific anxieties associated with taking their child to the GP surgery or hospital. These included exposure to more germs but also the fear of being judged as a nuisance by the doctor.

‘I see if it’s really necessary to go to the doctors because I don’t want to be around bugs and people who is more sick than her’. R24GP

‘It was one of the things I was really worried about was taking her to the doctors with a cough, and getting a doctor who was sort of very much, “Don’t bring your child here for a cough”’. R30GP

Whilst these concerns may put people off from visiting the doctor, respondents recognized that fears for the safety of one’s children could lead parents to panic and seek help in cases that may not actually require urgent attention.

‘I think there’s a percentage of people, they just worry too much and they think, oh my gosh, my child needs to be seen by a doctor or a nurse…people panic and that’s why they then rush up to A&E and the doctors’. R35

The data revealed that periods of child illness could lead parents to weigh up which of their worries was worse – going to the doctor inappropriately, or the fear of not going to the doctor when their child might be seriously ill. As shown in R29’s comment, respondents felt that information that could help them feel more confident in making these decisions were welcomed. This is discussed further below.

‘A lot of my friends have definitely been made to feel small about wasting their time at the GP, and so they’ve gone without going to see the GP for their little ones, and the little one has been all right, but it would have been a less stressful situation if they had the support without having to see that GP, than seeing them and being made to feel like that. If they had access to it (the HT information)…then at least they know that they don’t have to get that appointment. It’s not the end of the world if they don’t have that appointment before five o’clock that day. Do you see what I mean?’. R29GP

Positive evaluation

Many of the positive comments about the resources appeared to relate to their potential role in mitigating the anxieties outlined above.

Respondents appreciated the advice regarding ‘what to do when’ in terms of caring for their child, especially advice on whether it is necessary to see a doctor or if they can treat their child at home.

‘It’s like a mini doctor for you at home, that’s how it is, that’s how I see it. It gives all information, what should I do, in what cases I need to go to hospital or how I can treat my baby at home’. R19 CC
Several respondents mentioned the reassurance that this information offered to parents that they are taking the right course of action for their child.

‘Yes, I think that’s the point of it is to help people just reassure themselves that they’re not avoiding going to the doctors when they should be, or not going, or going when they shouldn’t be’. R30 GP

As well as reassurance, the resources were seen as providing parents with confidence that they were making the right choices and providing them with knowledge about how to best help their child. A small number of parents had already implemented some of the learning they acquired from the resources.

‘When (name of baby) been struggling to eat for two or three days, and it was clearly stated …on the website that don’t worry about babies not eating, little and often might be a better way than standard meals. That kind of put my mind at rest actually yesterday, because I was getting a little bit stressed that he wasn’t eating the meals in the times that he usually did. Yesterday I changed my strategy and I was feeding him bits here and there, and he ended up eating the same amount, but it was a lot less stressful for me and probably for (name of baby) as well. That’s probably a good example’. R20CC

A number of respondents suggested that the provision and advice for parents at home should reduce unnecessary trips to the GP. A number also reflected on how they may change their behaviour in future as a result of these resources.

‘I think it’s very good, to be honest. It’s very good that you’re having this kind of help to the people because I know that A&Es and GPs, they can get really busy with simple stuff that you can fix at home. It is much better for you and your baby if you can help just staying at home’. R22CC

‘Yes, I think definitely if we’d had the website before we actually took her to the doctors that time we wouldn’t have taken her’. R30GP

Areas for improvement

There were nevertheless a number of recommendations for changes to HT resources. These related particularly to the need for simple and easy to access information at times of anxiety.

‘When you’re in a bit of a panic because your little one’s not very well, you just want something very simple’. R32CC

1. Higher prioritization of risk assessment information

Risk assessment information was seen as very important for worried parents. Respondents recommended that web based information, across all interfaces, should be re-organised so that risk assessment information is the first thing seen, without needing to scroll through other information first, as the quote from R43CC reveals:

‘This bit at the bottom, “When should you worry?... Maybe that should be a bit higher up because
obviously, if your child has got any of these symptoms, you don’t want to be reading through loads of stuff and then, if it’s got a worrying symptom and you actually need to do something about it'. R43CC (phone user)

Conversely, an attraction of the safety netting sheets (a one page sheet including risk assessment information only) was the instant accessibility of assessment criteria for their child’s state of health.

2. Need for easier access/navigation across all formats and interfaces

The think aloud section of the interviews revealed that the use of search terms on the HT website did not always yield the most relevant information, something which would hinder parents especially when searching for information at times of anxiety. They suggested that this should therefore be rectified to improve web based resources.

’It’s too much stuff there…If you’re panicking, your child’s got a fever and unwell…you just want information there quick. What do I do…tell me what temperature is a fever, what medication could you do, what treatment should you give. Should you take your child to the doctor straightaway or yes, you want advice like that. …you need it just simple, basic, information’. R35CC

3. Concise and simple information

Similarly, parents also suggested that shorter, more concise information would be preferable. This was a comment levelled at the conditions sheets and particularly the website.

’… I think you’ve just got to remember that people that are reading this are worried parents normally. You probably don’t look this stuff up until you’re worried about something, so people that are reading this are worried parents and I think when you’re worried, you’re not thinking straight, you probably aren’t taking in a massive chunk of writing like that. I think you’re much more likely to be reassured by short, bullet points’. R41CC

4. Enhanced targeting/adaptation of resources

Several respondents made suggestions about a more targeted distribution of paper-based resources or links to web based information to first time/inexperienced parents, who because of heightened anxiety (highlighted earlier) may be more likely to consult health professionals unnecessarily. A suggested way of targeting new parents was via maternity packs or red books.

’So you know when you get a pack when you leave the maternity?…You could have it in there, so you get all this gumpf, don’t you, leaflets about this, leaflets about that…I would definitely, as the midwife or whoever is discharging you, just get them to give them and point it out and say, ‘Pop it on your fridge. If you need it, this is a good first port of call. Obviously if you are concerned contact the GP, but this is a good first port of call’. R29GP

Some issues related to low literacy also emerged – suggesting that resources need further
adaptation to enhance their accessibility for all potential recipients. One respondent who did not have English as a first language reported difficulties understanding the website.

‘The only time I looked at the website was just once… but the problem is reading, if there’s something I don’t understand it will be like nothing I can do’. R24GP

She went on to explain that although she had struggled to understand how to use the resources initially, extra support and explanation by health professionals helped her, indicating the importance of additional explanation for those with language difficulties.

‘the nurses they come to the house and do a check-up on the baby….so they came here and they gave me but when they gave it to me they read it all out for me and explained how… Like if there’s something wrong to go straightaway to the red but if not, that one, this section, to stay at home and just ring the doctors, explain she’s got worse or something…It was good because I was glad…It made me feel better because I was scared because it’s my first baby…’. R24GP

A number of respondents suggested that the use of colours and symbols in health information is important to enhance comprehension amongst those with less grasp of the English language.

‘I think that’s good. I think that’s internationally identifiable, traffic lights. I think everyone understands red, green and amber, so even if English isn’t really strong for you, I think you’d probably understand the traffic light system, so I think that’s quite good’. R41CC

Difficulties in comprehending the resources was also apparent in recruitment when three parents with English as a second language refused to participate in interview due to poor English skills and two further parents (with English as their first language) refused to participate because they could not read the information.

LIMITATIONS

Whilst the intention had been to recruit a larger sample, some parents were reluctant to participate or withdrew before being interviewed. Many cited competing child care commitments and work. As discussed above, a number refused participation feeling that their reading or English language skills were too poor. Some data was lost because of high levels of background noise in the interview. These challenges limited the data that we were able to collect/use. A further limitation related to participants recruited from children’s centres in the main not having seen the HT resources previously, which was contrary to the original sampling strategy. The original intention was for participants to have had the chance to refer to resources when their child was ill, or in the period preceding the interview. That being the case, interviewees may have reported actual learning and behaviour change, whereas as stands the majority of respondents could only comment on anticipated learning and behaviour arising from HT resources.
DISCUSSION

Despite the limitations highlighted above, a number of our findings could have relevance beyond the confines of the immediate study. Some of these are practical issues regarding when and how parents are most likely to want to interact with health information regarding their children. For example, parents did not tend to read health information except when their child was unwell – and were therefore unresponsive to marketing or invitations to engage with it outside of the health setting. Our findings also suggest that a mix of formats is likely to be preferable including a mix of paper based and online resources and that websites should work well across all interfaces, notably smart phones.

The theme of anxiety was prevalent in this evaluation, and resonates with findings from previous research\textsuperscript{7,8,9}. A range of conflicting worries acted as ‘push’ and ‘pull’ factors either encouraging or deterring parents from visiting the GP or A&E\textsuperscript{9}. From this perspective, health information that could help parents make decisions in an informed way was positively received.

Heightened anxiety affected parents’ health literacy information needs in two main ways. Firstly, parents felt that worry would negatively reduce their ability to read and process complicated information – meaning that health literacy resources should be as concise, simple and easy to navigate as possible. Research from the field of risk communication\textsuperscript{10} reveals that people under stress experience a form of ‘mental noise’ that leads to difficulties understanding and remembering information and reduces the ability to process information by several levels. This is in line with messages reported by parents in this evaluation. As a result of these findings, HT web based resources have been simplified and the process for navigation enhanced. These issues are likely to be even more important for those who struggle to read English either due to low literacy or because English is not their first language and it is important to consider how the needs of these particularly vulnerable groups can be met\textsuperscript{11}.

Secondly, to counteract their feelings of anxiety, parents appreciated reassuring, unrushed and personable communication from health professionals who introduce health resources to them. Research shows that people under stress are predisposed to focus on any negative aspects of communication and interpret non-verbal cues negatively\textsuperscript{10} and that to overcome this, and to build trust, requires good listening, and a caring manner as well as competence, expertise and knowledge\textsuperscript{10}. Our data suggests that where communication worked well parents have felt reassured and empowered to use health resources, whereas where communication felt rushed or unfriendly patients were less satisfied. This resonates with the call for health professionals to act as ‘infomediaries’ to support their patients to access the information they need to enable the best self-care\textsuperscript{11}. Our findings suggest that this is likely to be particularly important for patients with poorer English or literacy skills.
CONCLUSION

In this paper we have outlined the findings from a small scale qualitative evaluation of health information for parents about common childhood conditions. Parents positively evaluated the aims of the project and the information provided. They appreciated advice on what to do when, the reassurance and increased confidence that the resources could provide. A small number of parents gave examples of things they had done differently as a result of reading the resources and several anticipated future behaviour change and a reduction of unnecessary GP visits. Parents expressed much anxiety about childhood illness and making treatment decisions. To help alleviate this anxiety, they required simple and easy to navigate resources including prominent risk assessment information. Communication by health professionals that reassures and empowers parents was also shown to be important. Whilst this was a small study we believe that the findings are of relevance to others producing, disseminating and explaining health information aimed at parents and other patient groups.

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Statement of Interest: This study was funded in full by the Wessex Academic Health Sciences Network (AHSN) primary care project stream grant identifier: Wessex Healthier Together (26/7/2016).

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