



“It’s OK to Ask”

FINAL EVALUATION REPORT

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Contents

Background	3
The “It’s OK to Ask” Campaign	3
Method	5
Participants.....	5
Procedure	6
Findings.....	6
Theme 1: No Time To Ask.....	7
Theme 2: Campaign Visibility.....	9
Theme 3: Practicality and Readability	10
Theme 4: Responsibility and “It’s OK To Ask” culture	11
Discussion	13
Conclusion.....	15
References	16

**THE “IT’S OK TO ASK” CAMPAIGN EVALUATION
FINAL REPORT**

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Acknowledgments

We would like to thank the participants for their valuable contributions to this project and for the support of Saltbox, Trentham Over 75s, Healthwatch, and Breatheasy.

We also acknowledge UHNM for developing the original “It’s OK to Ask” campaign in Stoke-on-Trent.

Background

Health literacy can be defined “as the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health (WHO, 2015)”. The promotion of health literacy is a public health concern. Limited health literacy follows a social gradient that potentially reinforces existing health inequalities. Encouraging health literacy can provide several benefits for both patients and health care providers. Patients with adequate levels of health literacy are more likely to understand guidance given by health care providers and manage their own health more effectively than those with less than adequate health literacy, are more likely to participate in shared decision-making, are more likely to use screening services, and are less likely to rely on emergency services, thus reducing their chance of developing additional health problems (UCL Institute of Health Equity, 2015).

However, in a city-wide health literacy survey in Stoke-on-Trent, it was found that more than half (52%) of the population have less than adequate health literacy levels. Associations with higher rates of limited health literacy included older age, lower educational level, lower income, perceived poor health and lack of access to the Internet (Estacio, et al., 2017; Protheroe, et al., 2016).

It is important to consider health literacy as a factor when identifying and developing appropriate interventions in health and social care.

The “It’s OK to Ask” Campaign

University Hospitals of North Midlands (UHNM) began its “It’s OK to Ask” campaign in February 2017. Every patient admitted to hospital, arriving at A&E or visiting for an outpatient appointment was able to pick up a bookmark telling them “It’s OK to Ask”, which underlined the health benefits of asking three key questions:

1. What is my main problem?
2. What do I need to do?
3. Why is it important that I do this?

This was based on Ask Me 3, a campaign implemented in the USA to encourage patients to communicate effectively with their health care providers by asking useful health-related questions (Mika et al., 2007). Several evaluations of Ask Me 3 suggested the campaign provides a variety of benefits that can contribute to higher health literacy in patients, including: making patients feel more empowered to ask questions to their health care providers (Pender, Cusack, & Toibin, 2017); increasing the chance that patients will remember what questions they wish to ask to health care providers (Mika et al., 2007); and encouraging patients to take measures to help them understand what they are told by health care providers in appointments, e.g. bringing a friend along to take notes on their behalf (Miller et al., 2008).

The CCGs' Communications and Engagement Team, working closely with the City Council and the Hospital, decided to build on UHNM's excellent initiative and to use the "It's OK to Ask" logo and three questions approach but extend the work beyond UHNM hospital sites more widely across North Staffordshire and Stoke-on-Trent. Following the Health Literacy Training offered to health and social care staff in Stoke-on-Trent, the CCG launched their "It's OK to Ask" campaign on 3 July 2017 at the start of Health Information Week. Packs of the "It's OK to Ask" materials were distributed initially to:

- Pharmacists when they receive Health Literacy Training for use in their own pharmacies. The first tranche of 30 pharmacists received these on 19 September.
- Patient Participation Group Chairs when they receive Health Literacy Training. 8 GP practices PPG representatives were trained on 17 October. Those trained were from PPGs at Alton, Birches Head Medical Centre, Keele Practice, Mayfield, Norfolk Street, Talke Clinic and Wolstanton Medical Centre. The PPG members were asked to promote this initiative in their own practices and we will be following up with them to see how the materials have been received locally.
- GP practices whose staff have already received Health Literacy Training as part of their Quality Improvement Framework (QIF).

- Plans are in place to offer packs to those PPGs who did not send a representative to Health Literacy Training.

Included in the pack were a set of posters, postcards, badges, and pencils.



The evaluation team from Keele University facilitated a series of focus group discussions with patient groups in Stoke-on-Trent to gather feedback from service users. This report summarises findings from these discussions.

Method

PARTICIPANTS

A total of 40 participants took part. They were recruited with the support of patient groups such as Saltbox, Trentham Over 75s, Healthwatch, and Breatheasy. All are living in the Stoke-on-Trent area. Age ranged between 22 and 90 years old with a mean age of 69.23 years. The majority of participants were female (65%) and White British (with only one patient identifying as African Caribbean). HLS-EU6 scale was used to measure health literacy levels. Based on Pelikan et al.'s (2014) guidelines for interpreting the results of the HLS-EU-Q6, 37.5% of participants in this sample had sufficient levels of health

literacy; 37.5% had problematic levels of health literacy; and 25% had inadequate levels of health literacy. Overall, 62.5% of patients had less than sufficient levels of health literacy.

PROCEDURE

Four focus group discussions were facilitated as part of the evaluation process. Before they could take part, all participants were required to read an information sheet and complete a consent form. Once all participants had completed the consent forms, they were asked to complete the HLS-EU-Q6 scale. Assistance was provided for those who had questions, did not understand the materials, or could not read the materials due to poor eyesight.

After completing the forms, participants took part in a focus group discussion lasting between 30 and 120 minutes. Patients were encouraged to discuss their experiences freely, with prompts being given by the researcher only when needed (e.g. during periods of silence, to clarify certain points, or when the current discussion was not relevant to the campaign or health literacy). Participants were asked for their feedback on the campaign materials. They also shared their experiences about asking questions to healthcare providers.

Group discussions were audio recorded. After each session, all recordings were transferred to the researchers' password-protected computer accounts and deleted from the digital recorder. Recordings were then transcribed verbatim. The focus group transcripts were then analysed using thematic analysis (Braun & Clarke, 2014). Ethics approval for this evaluation was gained from the School of Psychology Ethics Committee at Keele University.

Findings

Four themes were identified from the focus group discussions:

- **Theme 1 (“No Time To Ask”)** suggested that patients are discouraged from and/or feel unable to ask questions to GPs specifically due to the “ten-minute limit” placed on appointments.

- **Theme 2 (“Campaign Visibility”)** examined feedback and suggestions from patients on the visibility of the campaign materials.
- **Theme 3 (“Practicality and Readability”)** described positive feedback from patients on the materials’ practicality along with suggestions on how to improve their readability.
- **Theme 4 (“Responsibility and “It’s OK to Ask” Culture”)** emphasised that while asking questions to health care providers was seen as important, patients felt that their providers were not always listening, answering, or explaining things clearly enough, emphasising a need to target both patients *and* health care providers in the campaign and embed this into the culture of health and social care.

THEME 1: NO TIME TO ASK

While many patients agreed that asking questions to their healthcare providers was important, several felt that there was a lack of time to ask questions, especially in GP appointments. One explicitly stated that the ‘ten-minute slot’ for appointments adhered to by most practices was “*a big fault in the system*” (male, Group 4, line 16). Multiple patients reported feeling too rushed during their appointments to ask questions, with one patient describing how some GPs tend to “*clock watch*” (female, Group 2, line 149) and refused to exceed the limit, “*that’s your ten minutes, out*” (female, Group 2, line 152).

One patient also noted that the ten-minute limit placed psychological constraints on patients to ask questions: “*when you go to the doctors, you’re always conscious, the waiting room’s full, you know, you only have ten minutes, and... you know, your conscience is there*” (female, Group 2, lines 163-165). This indicated that the limit might affect patients’ willingness to ask questions even when they were not being explicitly rushed.

Patients with multiple conditions or complex health problems faced additional time constraints. One noted that “[...] *you can only talk about one thing when you go to the doctors now. You can’t talk about anything else*” (male, Group 4, lines 312-313). Another pointed out that some couldn’t “*go with just one problem ‘cause lots of your issues are linked*” (male, Group 3, line 678). Even for patients whose conditions were not linked, the ten-minute limit created problems, as described by one service provider:

“I took a lady recently, um, one of our service users and, she had a number of conditions. Um, and the first thing her doctor said is, “right I’ve got ten minutes so tell me wh- you know, which thing you want to talk about”. But to me, you know, she didn’t know which- which was the most important. I mean they were interacted and some of them were waiting for test results which she hadn’t had. Um, and you know, all the way through the doctor said “no, I’ve only got ten minutes, I’m not a miracle worker!” (female, Group 1, lines 189-194)

In this case, the patient was limited by both the ten-minute slot and uncertainty about which conditions should take priority. While creating a list could have helped this patient remember to ask relevant questions, she may not have had time to ask all of them, reducing their potential usefulness if the patient is left with gaps in their understanding due to unanswered questions.

This example raised the issue of whether the “It’s OK to Ask” materials will be as useful for patients who do not have time to ask all questions relevant to their health. Indeed, several patients felt that the ten-minute limit and ‘one problem only’ system conflicted with the advice provided by the “It’s OK to Ask” campaign materials. One argued that writing down multiple questions on the campaign cards may not be helpful if they do not have time to ask, *“two or three of these questions and your ten minutes are up.”* (male, Group 4, line 559). Another echoed this sentiment:

“[...] the doctor says you can only go in with one thing. Here it says it’s okay to make a list of things! You couldn’t go in with a list of things. They’d say you have to make more appointments.” (female, Group 2, lines 570-573)

It has been noted that many practices offer double appointments, lasting longer than 10 minutes and allowing patients to discuss more than one health concern. Three patients were used to double booking; however, two patients claimed that their practices did not allow patients to request double appointments. Patients who find it difficult to book double appointments might not benefit as much from the materials, but this issue is likely outside of the scope of the “It’s OK to Ask” campaign.

THEME 2: CAMPAIGN VISIBILITY

Overall, patients gave positive feedback on the campaign materials, particularly its noticeability. One praising the materials' attractive colours: *"It's got to be eye catching, I think this is eye catching"* (female, Group 4, line 711). Another noted that creating the cards using good quality material may encourage people to make use of them: *"If this were a crappy thing, you know if they saw a piece of paper stuck on a thing, they'd probably wouldn't bother anyway"* (male, Group 4, lines 644-645).

However, while the materials themselves were seen as colourful enough to attract attention, patients raised concerns about the visibility of the campaign. One expressed confusion over the purpose of the badge, stating that it was unclear whether the badge was related to health care or a charity, suggesting that the NHS logo should be placed on the badge to make its purpose less ambiguous. Another noted that the campaign poster would be competing with many others in GP reception areas: *"I've sat in a waiting room this big, there's thirty-five posters up, can't mostly read it, just imagine that I see that "It's OK To Ask" and then my name's called to go in"* (male, Group 3, lines 542-544).

Several patients suggested ways to overcome this issue. One recommended encouraging GP staff to play an active role in distributing the materials: *"For me, if- if you want to... It's also about getting the staff on board with this"* (male, Group 3, lines 538-539). Another echoed this sentiment, suggesting that *"[...] the receptionist could hand one over, couldn't they and say "would you like to make some notes about wh- what you want to see your doctor for?"* (male, Group 4, lines 755-756). Involving practice receptionists and/or volunteers in the campaign – for instance, by asking receptionists to point out the materials to patients – may encourage more patients to take note of the materials, ideally increasing the likelihood that they will make use of them.

Several patients also proposed including the materials in a wide variety of public places. This included both places related to health care, such as *"GP, clinics, outpatients"* (male, Group 3, line 544) and pharmacies as well as places *"where people go"* including post offices and shops.

THEME 3: PRACTICALITY AND READABILITY

Positive feedback was also given on the practicality of the materials. The card size was seen as convenient, especially as it could easily fit in a patient's bag or pocket. While concerns were raised over the cards being too small to write all questions on, participants agreed that taking two cards into appointments would solve this issue. Cardboard was seen as the best material for the cards as it was "*easier to write on*" (male, Group 4, line 648). Furthermore, patients felt the materials contained the right amount of information, with one stating they were "*clear, concise, and it does what it says*" (male, Group 4, line 811).

Others felt that the advice offered by the materials was particularly useful for patients during difficult appointments. One patient described how she struggled to listen to the doctor after being diagnosed with cancer:

"I think that is important, that you take someone with you, especially with serious diagnoses because (.) erm, sometimes... You- you don't hear what the doctor's saying. You know. I remember when I had my cancer diagnosis and the doctor, they sat down, they were explaining an- I didn't hear half of what they were saying to me!"
(female, Group 3, lines 471-474)

The same patient later described how her daughter took notes during the appointment. Presumably, the patient read the notes taken by her daughter later, allowing her to understand what the doctor had told her despite her inability to pay attention during her appointment.

Additionally, patients felt that encouraging people to ask questions could save time, for example by cutting down the number of people returning to appointments to clarify misunderstood information. It was also recommended that the cards should include a "what the doctor said?" heading so that patients can make notes on what the doctor tells them.

That said, there were some suggestions to improve the readability of materials. Specifically, several patients emphasised that the headings on the card should be larger.

One suggested that, ideally, the text should be large enough that it can be read without glasses by most patients, as many may not remember to bring their glasses with them.

Others identified that the poster and cards may create issues for those with reduced literacy, “*considering this comes under health literacy, there’s an awful lot of people out there who can’t read*” (male, Group 3, lines 651-652). However, another patient suggested that “*the best part of this if you’re not very literate is to take a friend or someone*” (female, Group 3, lines 487-488), which may solve the issue for less literate patients. Even then, it may be important for health care providers, receptionists, and volunteers to explain and recommend the advice given by the materials to patients verbally, rather than assuming patients will be able to read the materials.

Further complicating the issue of literacy, one patient noted there is “*a hundred and forty languages spoken in Stoke-on-Trent*” (male, Group 3, line 500). While a source for this exact number could not be found, a 2013 report suggested that approximately 119 languages are spoken by children in Stoke-on-Trent schools (JSNA, 2013). Several patients agreed that providing the materials in multiple languages would be beneficial, though one acknowledged that due to the number of languages spoken in some areas of Stoke-on-Trent, “*you couldn’t have a poster for every [language]*” (male, Group 3, line 497).

THEME 4: RESPONSIBILITY AND “IT’S OK TO ASK” CULTURE

Although some acknowledged that not all patients will be confident enough to ask questions, three agreed that the materials may make people feel “*empowered*” to ask questions to their healthcare providers (female, Group 4, lines 725-733). One acknowledged that patients had a responsibility to ask questions about their health, noting that “*asking is taking responsibility for your health*” (male, Group 3, line 546).

However, this same participant – a former health care provider – argued that the responsibility is also on doctors to explain:

“I have a duty of care to you [...] if you’re my patient... Therefore I have a duty of care, and part of that is explaining what I’m going to say to you, why I’m prescribing medication, why I’m coming up with this diagnosis or this change in therapy or whatever it happens to be.” (male, Group 3, lines 552-555)

This participant emphasised that *“it’s OK to be asked, it’s OK to explain”* (male, Group 3, line 708), arguing that health literacy is a *“two-way thing”* (male, Group 3, line 552). A different patient emphasised that doctors should also *“make sure that they ask if you’re okay. [...] To check you understand. [...] Rather than just assume you do”* (male, Group 2, lines 369-376).

Another participant felt that the materials placed too much responsibility on patients to ask questions:

“I just think if you’re gonna... Put up posters like this, this sort of feels like... It’s up to every single patient to ensure that they get all the information they need on their own. [...] it just feels a little bit like “you do this, you do that, you should do this, you bring someone, you bring the list”. It’d be nice to have some information about what their side of it is going to be. For me.” (female, Group 3, lines 639-644)

Importantly, several participants discussed how they did ask questions to their GP but received vague answers or were promised follow-up information to their questions that they never received. Others felt ignored by their doctors, claiming they tended to focus on their computers more than the patient or were made to feel like *“a nuisance”* for having a list of questions. One felt that *“it’s listening and communicating that’s the biggest problem”* (male, Group 4, line 445): even if patients were asking questions, they were not receiving satisfactory answers – if any – from GPs.

There appears to be a conflict between the behaviour of doctors with the advice given by the *“It’s OK to Ask”* materials: *“Cause you can say it’s okay ‘till you’re blue in the face, a lot of people still feel like “it might be okay to ask, but I’m never gonna get an answer, so””* (male, Group 3, lines 713-714). While the focus of *“It’s OK to Ask”* is to get patients to ask questions to their healthcare providers, the experiences of patients in the evaluation groups suggest that more training may need to be directed towards health care providers.

Discussion

Findings from this evaluation show how well-received the “It’s OK Campaign” materials were to the patients, particularly for its practicality (ideally sized, easy to write on), use of quality materials, and attention-grabbing characteristics. However, concerns were raised about whether the posters and cards would be noticeable in GP surgeries due to the number of other posters, leaflets, and other information materials already on display.

To help improve the visibility of the campaign, it was suggested placing the materials in settings other than GP surgeries, to include pharmacies and other public places such as post offices and local shops. Some also recommended involving receptionists and/or volunteers in pointing out the materials to those signing in for appointments. If receptionists or volunteers recommend the materials (e.g. by asking patients if they would like a card to write notes on before and during their appointment), patients may be more likely to take notice and consider making use of them. This could also be beneficial for patients who have issues with literacy or eyesight and may not be able to read the materials. For example, receptionists could provide the advice given by the campaign verbally, e.g. by recommending to patients that they bring another person along to take notes if necessary, rather than assume patients will be able or willing to read the materials.

Although most agreed that the advice provided by the materials was useful, some participants felt it conflicted with the attitudes of GPs and the way their local practices are managed. The ten-minute limit and ‘one problem at a time’ systems at practices were identified as barriers to asking questions, making patients feel rushed or unable to ask all their questions. Furthermore, some patients argued that the materials placed too much responsibility on patients to ask, with not enough emphasis on encouraging health care providers to give clear, understandable answers when asked.

One possible solution could be to make patients aware of health professionals other than their GP who can answer their questions. For instance, while many patients in the evaluation groups were aware that pharmacists could offer them advice on medication

and managing minor illnesses, some were unsure of what they could ask pharmacists. The campaign could consider clarifying what questions pharmacists (and any other suitable health care providers) are able to answer. Encouraging patients to ask a wider variety of health care providers may also help patients who feel rushed by the ten-minute limit on GP appointments, though this could also be improved by informing patients (via the campaign materials) on when and how to book an extended appointment.

Another solution could be to provide more training for health care providers, specifically GPs by raising awareness of this campaign and making clear the importance of double-checking that they have answered questions in a way that patients have understood before they leave their appointment. While this might be outside of the scope of the “It’s OK to Ask” campaign, advice provided by the campaign such as “don’t rush” may not be suitable in certain health care settings where appointment times are restricted, which could limit the usefulness of the materials in some contexts. Rephrasing the advice or tailor the materials to different contexts (e.g. creating separate posters explaining the roles of doctors, practice nurse, pharmacists, etc. in answering questions) could be considered.

It was also noted that, in some areas of Stoke-on-Trent, there may be a high volume of patients whose primary language is not English. These patients may face additional barriers to their health literacy if they are unable to fully understand the campaign materials or service providers’ answers to their questions.

Moving forward, it could be beneficial to conduct another evaluation with patients whose primary language is not English. The sample used in the current evaluation predominantly identified as White British, with only one person identifying as African Caribbean. Repeating the evaluation with patients whose first language is not English may provide some insight into how the campaign could account for those who might struggle to understand the current campaign materials. Moreover, as migrants and people from BME groups have been identified as having disproportionately low levels of health literacy in the UK (UCL Institute of Health Equity, 2015), such a study could provide insight into the experiences of BME patients in Stoke-on-Trent who may face barriers to health

literacy not identified by the (predominantly White British) sample in the current evaluation.

It was acknowledged that this campaign could encourage service users to ask questions and that there is no shame to ask. If embedded well into the culture, this campaign can make asking questions simply part of the practice (i.e., make it the norm). Asking questions is particularly easier when there is trust, good inter-personal relationship, and rapport between service providers and users. Embedding “It’s OK to Ask” into the health and social care culture will enable this campaign to have a real and lasting impact. This means good patient experience is not limited just to the GP practice but is reflected across the entire health and social care system.

Conclusion

This evaluation has shown that many patients felt that the materials and advice provided by the “It’s OK to Ask” campaign were fit for purpose. It is a good step to encouraging patients to ask questions, although the responsibility to be understood needs to be shared with health and social care professionals equally.

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