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**Article:**

Ahmed, S, Hayward, J and Ahmed, M (2016) Primary care professionals' perceptions of using a short family history questionnaire. *Family Practice*, 33 (6). pp. 704-708. ISSN 0263-2136

<https://doi.org/10.1093/fampra/cmw080>

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**Title:** Primary care professionals' perceptions of using a short family history questionnaire

**Running header:** Usability of a short family history questionnaire

**Article category:** Qualitative research

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## **Abstract**

**Background:** Improving access for relatives at-risk of genetic conditions by building referral systems from primary care to genetic services is well recognised.

**Objectives:** This study aimed to explore Primary Care Professionals' (PCPs) views about using a short, seven-item family history questionnaire (S-FHQ) as an intervention for identifying at-risk relatives of patients with a genetic condition in routine primary care for referral to genetic services.

**Method:** This qualitative study was conducted in the UK in 2013-14. Focus groups were held with 21 PCPs. The Normalisation Process Theory (NPT) was used during analysis as the theoretical lens for exploring potential implementation and sustainability of the intervention.

**Results:** In principle, participants were supportive of the S-FHQ. They initially expressed enthusiasm for the S-FHQ and identified benefits of its use. However, in discussions about its use in practice, they raised concerns about their expertise to deliver the intervention, implications for their workload, potential duplication with existing roles and services in secondary care, the ethical implications of its use in routine care, and its acceptability to patients.

**Conclusion:** This study shows why even a short family history questionnaire, as an intervention for identifying at-risk relatives, is unlikely to be implemented by primary care professionals.

## **Keywords**

Family History, Genetics, Normalisation Process Theory

## **Introduction**

There is a high incidence of autosomal recessive conditions, resulting in high rates of infant mortality and morbidity in certain areas of the UK (1). The 'Born in Bradford' (BiB) study reported rates of congenital anomaly as 306 per 10,000 live births compared with a national rate of 166 per 10,000 live births, and that 30.7% of congenital anomaly in babies born to mothers of Pakistani origin could be attributed to parental consanguinity (marriage/union between blood relatives) (2). In the BiB study, only 6% of the babies born to couples in cousin marriages had a congenital anomaly, but the absolute number of children born with a range of rare conditions raises the need for an active approach to communicating information about genetic risk to the relatives of an affected child in all ethnic groups to enable informed marital and reproductive decisions.

One such approach would be for Primary Care professionals (PCPs) to identify relatives of affected families, who may be at-risk of having a child with a genetic condition. For this purpose, there has been much research on developing family history questionnaires (FHQs) for use in primary care. However, systematic reviews show that few FHQs have been formally evaluated, most focus on a specific cancer, and there is no short generic version for use by PCPs (3).

Although PCPs may consider it within their remit to inform relatives at increased risk of having a child with a genetic condition (4), they do not view clinical genetics as a core component of their role (5). Furthermore, many are unprepared to discuss family history or assess familial risk (6), probably due to the lack of pragmatic approaches, guidelines and systematically integrated procedures (7). Therefore, we developed a short/seven-item family history questionnaire (S-FHQ, see Supplementary Information). This study aimed to explore PCPs' views about the usefulness and usability of this S-FHQ as an intervention for identifying at-risk relatives of patients with a genetic condition.

## **Method**

### **Intervention**

The S-FHQ was designed as a brief intervention for PCPs to identify potentially at-risk relatives during routine consultations. It was developed by a group of health professionals from a Genetics Service and included a general practitioner (GP), three senior genetic counsellors (each with over 15 years' experience), and two consultant geneticists. Based on existing FHQs, systematic reviews of family history risk assessment in primary care (8,9), and consultations with experts who had developed or were in the process of developing FHQs (10,11), the group agreed on a final set of seven questions.

### **Design**

Focus groups were conducted because they can show divergence or convergence between participants' views. The focus group topic guide explored participants' experiences and views about taking a family history, approaching relatives of affected individuals, referring these relatives to genetic services, and the potential use of a S-FHQ for this purpose. The association between consanguineous marriages and the incidence of autosomal recessive conditions was not explored because only a small percentage of affected babies are born to couples in cousin marriages (2).

### **Setting and participants**

The study was conducted in a UK city with a high incidence and range of autosomal recessive conditions. Participants were recruited by Author 2 (GP) from Primary Care general practices by initially emailing practice managers about the study. Purposive sampling was used to select participants who were PCPs, had contact with patients who were likely to benefit from the S-FHQ and worked in inner city practices. PCPs were defined as GPs, practice nurses, health visitors, healthcare assistants and practice managers. Different

PCPs were included to explore the potential use of the S-FHQ at different contact points with patients in primary care. Twenty-two PCPs participated in three focus groups, each group consisting of 6-8 participants, which were conducted in the three different practices from which they were recruited.

## Procedure

Following written consent from all participants, focus groups were facilitated by Author 2 and Author 3 (Principal Genetic Counsellor with expertise in qualitative research). Groups were composed of different PCPs. The facilitators encouraged participants to express different perceptions and views, and any quiet participants were asked for their views. The focus groups lasted about 60 minutes, were audio recorded and transcribed verbatim. Author 1 (experienced qualitative researcher) assured the quality of the transcripts. Each transcript was analysed, and changes were made to the topic guide based on this analysis, before conducting subsequent focus groups. The study was conducted in 2013-14.

## Analysis

Thematic analysis was initially conducted to ensure (a) emergent themes were data driven, reflecting participants' accounts (inductive analysis) rather than theory-driven, and (b) data was organised according to themes identified a priori (deductive analysis): perceptions of the usefulness of a S-FHQ, experiences/views about identifying, approaching and referring patients to genetic services, and the role of PCPs (12). Normalisation Process Theory (NPT) was then used as the theoretical lens for exploring potential implementation and sustainability of the intervention (13). NPT provides a conceptual framework consisting of four interrelated theoretical constructs believed to shape the process of successful intervention implementation: coherence – how stakeholders' make sense of the intervention; cognitive participation – how they get involved, commit and contribute to the intervention; collective

action – how they make the intervention work in practice; and reflexive monitoring – how they assess whether it is worth using the intervention and how it could be improved.

The findings from the thematic analysis were mapped onto a NPT framework consisting of the four constructs and 16 sub-constructs with sensitising questions to guide interpretative analysis (see Table 1) (14). All themes identified through thematic analysis fell within the four NPT constructs. The raw data was also reanalysed using the NPT framework to identify any further issues on implementation. Some sensitising questions could not be used on the data collected, particularly those under ‘reflexive monitoring’. Author 1 analysed the data, discussed themes with authors 2 and 3 (following thematic analysis and then following use of the NPT framework), then refined and discussed them again to ensure consistency in interpretation.

## **Results**

The three focus groups included a total of 21 participants: 13 GPs, 4 practice nurses, 1 healthcare assistant and 3 practice managers. The initial thematic analysis is summarised in Table 2. The following are the findings after mapping the data onto the four main NPT concepts. Although most of the 16 sub-constructs are represented in the findings, the data collected does not enable representation of contextual integration, systemisation, and individual appraisal.

### **Clarifying the Role of PCPs (Coherence)**

Participants understood the purpose of the S-FHQ as enabling them to identify relatives of affected individuals for referral to genetic services and were initially supportive of its use in Primary Care. Participants could see how the S-FHQ would fit into their current practice, but believed that the task of identifying at-risk relatives overlapped with the role of health professionals in secondary care, such as, those with responsibility for the healthcare of

affected individuals. More importantly, there was a misconception that referral pathways from secondary care to genetic services already existed for such relatives:

*...(paediatricians) usually refer them to the geneticist. (GP1/FG1)*

*...we didn't do anything...with the assumption that the haematologist would pick up on this... (GP/FG2)*

Overall, PCPs raised concerns over potential duplication with existing roles and uncertainty over the boundaries of the role of PCPs.

### Commitment to using the S-FHQ (Cognitive Participation)

Participants initially expressed enthusiasm for the S-FHQ and discussed various PCPs who could implement it at different patients contact points:

*...when I do six to eight week checks, I usually ask them about family history... that's a good time. (GP3/FG3)*

*...new patient health screening with the healthcare assistants (Practice nurse/F1)*

*The health visitors... because they know most of the families... (GP2/FG1)*

However, further discussion showed little commitment to using the S-FHQ. Participants understood that using the S-FHQ would identify patients needing referrals to genetic services, and believed that decisions about such referrals required clinical expertise. Therefore, participants agreed that the S-FHQ would need to be implemented by GPs:

*...it's more about what does that ('yes' response) mean for the family, so very complicated. (Practice nurse/FG2)*

*...it's quite deep for somebody who hasn't got any clinical knowledge. (Practice Manager/FG3)*

Participants also believed that a decision to refer should be explained to patients and/or may result in patients asking questions that PCPs may find difficult to answer. They agreed that knowledge of genetic conditions and inheritance patterns was essential to using the S-FHQ



and that GPs were unlikely to have this expertise. This lack of specialist knowledge was seen as a barrier to using the S-FHQ:

*If you're... talking about risk of an illness, then we're not the right people (GP3/FG2)*

Overall, most participants did not see it as their role to identify and approach relatives. They believed it health professionals in secondary care were better placed pursue relatives via affected individuals, because of their expertise and knowledge:

*...that's not our area of expertise. (GP2/FG2)*

*...if genetic services' limit of input is purely to advise them (affected individuals to contact relatives) and not take it any further with the wider family, then they're really missing a trick. (GP4/FG2)*

Participants also believed that relative may be more receptive to being approached about genetic inheritance by consultants caring for the affected families than PCPs, hence distancing themselves from the responsibility of identifying relatives:

*...if the consultant is saying we need to refer relatives to genetic services, I think it has more of an impact. (GP1/FG1)*

Participants briefly discussed whether the questions within the S-FHQ looked valid or formed a robust measure. However, they focused on the use of the S-FHQ more broadly, and accepted that any such tool would need to be validated. For example, participants clarified that it was not practically possible to use the S-FHQ with all patients. Therefore they questioned how to select patients with whom it should be used:

*...we wouldn't be doing this on a day-to-day basis because we wouldn't have time to do anything else. (GP2/FG2)*

Overall, participants gave little priority to the usefulness of the S-FHQ and focused on barriers to implementing it in primary care. Participants made few constructive suggestions for addressing the potential challenges raised, showing their lack of commitment and interest in implementing the S-FHQ.

Using the S-FHQ in routine practice (Collective Action)

Time constraints were recurrently mentioned as a barrier to implementing the S-FHQ.

Participants explained that routine consultations were time restricted, and while it may not take long to ask seven questions, a 'yes' response to any of the questions was likely to require time. This was because PCPs would need to: discuss the condition with the patient; determine whether the condition was genetically inherited; decide whether the patient should be referred; and explain the need for this referral to patient in a sensitive way, given that patients were unlikely to be aware of the possibility of being at-risk of having a child with a genetic condition:

*...as soon as you hit one or two 'yes' responses, covering all the points that you want to cover within the time constraints... I don't think it would work. (GP2/FG3)*

*...they might not know about it, so it would need to be managed sensitively.*

*(GP4/FG1)*

Participants also explained that the limited time they had for consultations compared to the time needed to discuss a patient's family history, made it difficult for them to support an intervention that could potentially increase their workload:

*...sometimes we're dealing with a few problems, and then we've got this (intervention) on top... (GP4/FG3)*

*I don't want to be the one chasing those families. It would just shoot the workload through the roof. (GP3/FG2)*

Furthermore, participants questioned the ethical implications of using the S-FHQ to engage patients in discussion of relatives affected with a genetic condition. Participants felt patients were likely to visit GPs for minor concerns and were unlikely to expect or want to engage in such discussions. Participants also believed maintaining confidentiality of the affected family would be a major ethical challenge to approaching relatives. They agreed the need for prior

agreement to disclose information about the condition from the affected family, but suggested that affected families may not be interested in such disclosure:

*'Come in for a cold and she's asked me all these dodgy questions'. It's not the right place ...the agendas just don't match. (GP3/FG3)*

*...you'd have to get consent from the parents of the children with the disorder (Practice Nurse/FG1)*

*...they (affected families) don't like to discuss it with extended families... how do you broach that with relatives? (GP1/FG2)*

Overall, it was evident that most participants believed the S-FHQ would result in more work for them in routine practice. Participants appeared hesitant to invest time and effort in using the S-FHQ. Participants' perceptions of the 'fit' of the S-FHQ with PCPs routine practice raises concerns about whether primary care is the right setting for an intervention to identify at-risk relatives.

#### *Perceptions of patients' values (Reflexive Monitoring)*

Participants believed some relatives would be interested in being referred to genetic services, while others would not because of their lack of understanding of genetics and implications for themselves and their family, or because of their religious or fatalistic beliefs:

*They think it's God's way. ...there's quite a few barriers with some Asian families (Practice Manager/FG1)*

Participants said that relatives of affected individuals rarely approached PCPs about genetic inheritance and, therefore, suggested the need for awareness campaigns to educate at-risk relatives:

*...not GPs talking about it... There needs to be a campaign to get the community to discuss it. (GP1/FG1)*

## Discussion

Participants were initially supportive of a primary care based intervention to enable identification of at-risk relatives of affected families. However, participants went on to highlight various factors which they believed would hinder implementation of the S-FHQ in primary care. Factors included: practical difficulties in using the S-FHQ in routine practice; perceptions of limited knowledge of genetics themselves to deliver the intervention; implications for their workload; potential duplication with existing roles and services in secondary care; the ethical implications of using the S-FHQ and its acceptability to patients.

PCPs in our study were concerned about their limited expertise and knowledge of clinical genetics (15), and little mention of training as a solution to address this issue or to use the S-FHQ, suggests little commitment on PCPs' part for implementing the S-FHQ. The need to explain referrals to patients also raised concerns about the limited time that PCPs had to address patients' health concerns, implications for their workload and, therefore, the 'fit' of the S-FHQ with the culture of primary care. The S-FHQ was developed to ensure minimal impact on PCPs workload, but our findings raise concerns about the extent to which even a brief intervention for identifying potentially at-risk relatives is likely to be implemented and sustained into everyday primary care practice (4).

Participants discussed the overlap of their role with health professionals in secondary care. These findings suggest the need for research on collaborative approaches between primary and secondary care professionals to develop more targeted and sustainable interventions for identifying at-risk relatives. One approach could be to utilise e-consultation technology, which is already used for other health issues (16). E-consultations could support PCPs by allowing quick access to advice from genetic services, hence addressing concerns about lack of expertise and increasing confidence in dealing with unclear family histories and symptoms. Another approach would be genetics liaison nurses: trained by genetic services

and based in primary care (17) or trained health advocates (18). Further research is needed to identify collaborative interventions to facilitate referral of at-risk relatives from primary care to genetic services.

Similar to others (4), PCPs also raised concerns about patients' reactions to being approached about their family history, particularly emotional (undue anxiety) and ethical (confidentiality and disclosure) implications. The ethical challenges for genetic health professionals and their role in informing relatives of their familial genetic risk have been long debated (19), and many guidelines exist on this issue for genetic health professionals (20). Similar guidelines are needed for PCPs to clarify their role in communication of genetic information with at-risk relatives.

Participants also suggested the need for public health education and awareness campaigns.

The idea here is that an S-FHQ may be sustainable if patients are proactive as oppose to passive recipients of genetic information. Therefore, public health campaigns could focus on raising patient awareness about the availability of genetic testing for at-risk relatives to enable them to approach PCPs.

### Strengths and limitations

A strength of this study was the engagement of various PCPs, although the GPs were most vocal during the focus groups, possibly due to power dynamics within such teams. Running focus groups separately with GPs may have enabled other PCPs to voice their views more openly. Another strength of this study is the use of various approaches to data analyse.

Thematic analysis enabled identification of participants' main concerns, while subsequent interpretation of these concerns using the NPT as a conceptual framework enabled identification of implementation and sustainability issues, lending more credibility to the findings. Furthermore, our findings are highly likely to be transferable to practices in other

geographical locations, both within and outside the UK, because the principles for identifying at-risk relatives are likely to be similar irrespective of patients' ethnic background or healthcare setting. Our study focused on PCPs' views about the usefulness and usability of the S-FHQ, hence the long-term implications of introducing this intervention into primary care are not known. Overall, NPT provided a useful framework for assessing potential implementation of the S-FHQ, although the focus was on the views of PCPs. Similar studies should also explore service-users views.

## Conclusion

Primary Care Professionals in our study recognised the benefits of a S-FHQ, but also highlighted significant barriers to its uptake, because of their recurrent concerns about its use in routine practice and their own willingness to discuss genetics generally.

## **Declaration**

Funding: Bradford and Airedale teaching PCT

Ethical approval: University of Leeds

Conflict of interest: none

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**Table 1:** NPT constructs, sub-constructs and sensitising questions (14)

<b>NPT constructs</b>			
<p><b>Coherence:</b> How PCPs make sense of the S-FHQ</p>	<p><b>Cognitive Participation:</b> Whether PCPs would ‘buy into’ and ‘sustain’ the S-FHQ</p>	<p><b>Collective Action:</b> Action needed to make the S-FHQ work in practice</p>	<p><b>Reflexive Monitoring:</b> How the S-FHQ would be monitored and evaluated</p>
<b>16 Sub-constructs and sensitising questions</b>			
<p><b>Differentiation:</b> Do PCPs see how the S-FHQ differs from current practice/previous FHQs?</p> <p><b>Individual specification:</b> Do PCPs understand their role and responsibilities in achieving the aim of the S-FHQ?</p> <p><b>Communal specification:</b> Do all those involved agree about the aims and objectives of the S-FHQ?</p> <p><b>Internalization:</b> Do PCPs understand the potential benefits and future value of the S-FHQ?</p>	<p><b>Enrolment:</b> Do PCPs believe they are the correct people to implement the S-FHQ? Are they prepared to invest time and energy in it?</p> <p><b>Initiation:</b> Are PCPs willing and able to engage themselves and others in the S-FHQ?</p> <p><b>Activation:</b> Can PCPs identify tasks and activities to sustain the S-FHQ?</p> <p><b>Legitimation:</b> Do PCPs believe it is appropriate for them to be involved in the S-FHQ? Do they ‘buy into’ it?</p>	<p><b>Contextual integration:</b> Do local and national resources and policies support the S-FHQ?</p> <p><b>Skill-set workability:</b> Do PCPs have the necessary skills and training to implement the S-FHQ?</p> <p><b>Relational integration:</b> Do PCPs have confidence in using the S-FHQ?</p> <p><b>Interactional workability:</b> Does the S-FHQ make it easier or harder to complete routine tasks?</p>	<p><b>Systematisation:</b> How will PCPs assess the effectiveness or usefulness of the S-FHQ?</p> <p><b>Individual appraisal:</b> How will PCPs appraise the effects of the S-FHQ on themselves and their work?</p> <p><b>Communal appraisal:</b> How will patients assess the value of the S-FHQ?</p> <p><b>Reconfiguration:</b> What changes would need to be made for the S-FHQ to be adapted it in practice?</p>

**Table 2:** Initial thematic analysis

<b>Main theme</b>	<b>Sub-theme</b>	<b>Illustrative data</b>
Using a short FHQ	Practical difficulties	<i>I don't think this is practical ...trying to squeeze that into a normal ten minute consultation.</i>
	Appropriate referrals	<i>If we referred everybody... you'd be totally inundated, so we'd have to narrow down the criteria...</i>
	Other contact points	<i>...when I do eight week checks ...during a new patient health check</i>
Barriers to identifying/referring relatives	Identifying relatives	<i>...you don't know who's related to who If patients don't know the name or the diagnosis, what are GPs going to put on the referral?</i>
	Confidentiality	<i>You'd have to get consent from the parents of the children with the disorder.</i>
	Impact on relatives	<i>...you don't want to frighten the patient... 'come in for a cold and she's asked me all these dodgy questions' ...the agendas just don't match. They might not know about it (inherited condition), so it would need to be managed sensitively.</i>
	Impact on workload	<i>It's quite labour intensive, chasing people up...and in primary care, we've got enough labour intensive things to be doing.</i>
	Religious beliefs	<i>They think it's God's way... there's quite a few barriers with some Asian Muslim families, and taking on board the advice.</i>
Role of PCPs versus others	Secondary care	<i>... they (paediatricians) usually refer them to the geneticist. ...haematologist would pick up on this... refer to genetic services.</i>
	Intermediary outreach service	<i>There should be a third party service, like (genetic services), provided as a link between secondary and primary care.</i>
	Genetic services	<i>if your (genetic services) limit of input is purely just to advise them (affected individuals to contact relatives)... then you're really missing a trick</i>
	Public Health	<i>...do some sort of awareness campaign, either in the media or in practices</i>