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## Family health history as the first genomic test: (How) is it discussed in routine primary health care consultations?

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Family health history; genomics; primary health care; equity; family

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## Abstract

### Objectives

Family health history underpins genomic medicine. Our study aimed to explore language and patterns of communication relating to family health history observed in interactions between general practitioners (GPs) and their patients within routine primary care consultations.

### Design

Secondary analysis of patient and general practitioner (GP) routine consultation data (n=252).

### Participants

Consultations that included “family health history” were eligible for inclusion (n=58).

### Primary outcomes

A qualitative inductive analysis of the interactions from consultation transcripts.

### Results

46/58 conversations about family health history were initiated by the GP. Most discussions around family history lasted for between approximately 1 to 2 minutes. Patients were invited to share family health history through one of two ways: non-specific enquiry (e.g. by asking the patient about “*anything that runs in the family*”); or specific enquiry where they were asked if they had a “*strong family history*” in relation to a particular condition e.g. breast cancer. Patients often responded to either approach with a simple *no*, but fuller negative responses also occurred regularly and typically included an account of some kind (e.g. explaining family relationships/dynamics which impeded or prevented the accessibility of information).

### Conclusions

Family health history is regarded as a genomic test and is embedded in the socio-cultural norms of the patient from whom information is being sought. Our findings highlight that it is more complex than asking simply if “*anything*” runs in the family. As the collection of family health history is expected to be more routine, it will be important to also consider it from socio-cultural perspectives in order to help mitigate any inequities in how family history is collected, and therefore used (or not) in a person’s healthcare. Orientating an enquiry away from ‘*anything*’ and asking more specific details about particular conditions may help facilitate the dialogue.

### Strengths and limitations of this study

- The patient cohort was Euro-centric, and not fully reflective of the ethnic population of New Zealand (where the study was carried out).
- The extent to which the family health history information had been previously shared/documentated was not ascertainable.
- The study draws on range of routinely collected consultation studies with different purposes, and hence cover a wide range of GP contexts, without specifically having a focus on family history.

### Funding statement

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### Competing interests

The authors have no competing interests to declare.

For peer review only

## Introduction

Family health history has been described as the first genetic test.<sup>1</sup> A family health history is defined as “a record of health information about a person and his or her close relatives. A complete record includes information from three generations of relatives, including children, brothers and sisters, parents, aunts and uncles, nieces and nephews, grandparents, and cousins.” (NIH Genetics Home Reference). Such a detailed family health history is regarded as one of the most useful tools for risk assessment for common chronic diseases.<sup>2</sup> It is estimated that the relative risks and odds ratios for various cancers, stroke, type 2 diabetes, and cardiovascular diseases is twice that for people with an affected first degree relative, and more than four times greater for many of these diseases if there is more than one affected first degree relative.<sup>2 3</sup> Several professional organisations have recently made recommendations that general practitioners (GPs) routinely, and opportunistically, collect family health history for three generations.<sup>2 4</sup> However, current evidence would indicate that there may be barriers to achieving this level of information, and approach to its collection, as family health history is widely reported as being both poorly and infrequently collected.<sup>5 6</sup> Reported barriers to the collection of family health information include: poor reimbursement, provider’s lack of time and expertise, lack of guidelines and adequate tools, and limited functionality of electronic health information systems to capture and interpret data and unreliability of information provided by patients.<sup>7 8</sup> The potential to improve health care by being able to act on family health history information is thus not being fully realised. This is important as access to genomic becomes easier and cheaper, available direct to the public, and knowledge of family health history is imperative in wisely using this testing and interpretation of results.<sup>1 9 10</sup>

The exploration of the practice of collection of family health history has tended to focus on the practical side i.e. to garner better understandings around the barriers and facilitators to its collection, and the validation and implementation of tools to collect family health history.<sup>2 10 11</sup> How family health history is actually discussed in routine primary healthcare consultations has received less attention, and to our knowledge this is first study to observe conversations about family health history in routine primary care consultations. The aim of our study was to explore language and patterns of communication relating to family health history observed in interactions between general practitioners (GPs) and their patients within routine primary care consultations.

## Materials and Methods

### Data Source

Consultation data were sourced from the Applied Research on Communication in Health (ARCH) Corpus at the University of Otago, Wellington, New Zealand<sup>12</sup>, and have been previously described.<sup>13</sup> The Corpus houses a digitally stored collection of patient / practitioner consultation data that includes 458 video-recorded consultations, verbatim transcripts and selected medical notes.<sup>14</sup>

### Ethical approval

The collection of all Corpus data and guidelines for subsequent use have been approved by the New Zealand Health and Disability Ethics Committee and University of Otago Human

Ethics Committee (Health). Ethics approval for this study was given by the University of Otago Human Ethics Committee (Health) (H19/022).

### Identification of family health history consultations

The ARCH Corpus includes a Microsoft Access database populated with metadata including full demographic information about every participant, research site information and free text content logs of each consultation. The logs were prepared by a research nurse according to a standard template and include information about the main topics discussed, outcomes of the consultation (including prescriptions and referrals), and a minute by minute summary of key events and content. The logs thus capture any complaint or topic mentioned incidentally in a consultation, in addition to the main presenting complaint(s). The database and logs link electronically to full verbatim transcripts (including time measurements in minutes) and the original audio and video-recordings to facilitate subsequent more detailed analysis, but the latter cannot be queried directly via the database.<sup>14</sup>

A query was run on the Microsoft Access database of the logs of each GP consultation in the Corpus using the keyword “family health history” (Table 1). It is possible that not all relevant consultations in the Corpus were identified; however, the purpose was to collate a relevant dataset adequate for the purpose of undertaking a descriptive qualitative analysis, and not to investigate the frequency of occurrence of family health history. At the time of this study, the Corpus included 252 patient-GP consultations involving 36 GPs, collected as part of 5 studies between 2004 and 2018. The term ‘family health history’ was present in the logs of 71 individual patient consultations with GPs. Further review of the transcripts was undertaken and the consultations were excluded if family health history was not discussed. Additional terms were also included at this time to identify if family health history was mentioned in another context, and included “whānau” (family); “inherited”; and “condition”.

**Table 1** Overview of the study and number of patient-GP consultations where family health history was discussed.

Study	Brief description of the original study	Number of consultations included in the analysis	Number of patient-GP consultations in original study
Diabetes study (DS)	Tracking the contact of newly diagnosed patients with Type 2 diabetes with healthcare professionals over a six-month period	7	34
Interaction Study (IS);	Exploring clinical decision-making when rationing is explicit	11	58
Tracking Study (TS)	Exploring communication processes throughout a single complete episode of care of patients referred from primary to secondary care	31	125
TAbOO: Talking About	When and how GPs and patients discuss excess weight related issues (or not) during routine consultations	6	19



Overweight and Obesity			
Interpreting Study (IN)	Clinical risk and patterns of use and communication with/of interpreters	3	16
Total		252	58

## Patient and Public Involvement

Patients were not involved in any aspects of the study design, including plans for dissemination of the research findings. As part of the original consenting process, they would have been advised on the length of the time required to participate in the research.

## Data analysis

Themes were derived iteratively using a qualitative inductive approach based on the verbatim transcripts of interactions between patients and GPs.<sup>15</sup> Our overarching aim was to report on the emerging range of issues and communication styles without pre-conceived assumptions. SF identified and coded the collection of conversation sequences related to family health history identified in the transcripts, including the time in the consultation that it was first mentioned. Where additional clarity or interpretive information was required, the video recording of the consultation was reviewed. Initial interpretations of the themes were shared with the team and discussed in detail discussion between SF and RJ. MS, a researcher with experience in interactional sociolinguistics contributed to an additional round of discussion and interpretation. The themes were discussed and agreed by consensus with all of the authors. The sociodemographic information of the 71 patients was reviewed after the first round of analysis and self-identified ethnicity reported in Table 2, analysis by ethnicity was not undertaken.

**Table 2** Self-reported ethnicity of patients who participated in the original studies.

Self-reported ethnicity	Frequency
New Zealand European	41
New Zealand European/Māori	2
New Zealand European/Cook Island Māori	2
Māori/ Samoan/UK/US	2
New Zealand European /Samoan	2
Samoan	8
Tongan	2
Assyrian	1
Chinese	2
Dutch	2
Dutch/ New Zealand European	1

Indian	2
Italian	1
Somali	1
Sri Lankan	1
Thai	1
<b>TOTAL</b>	<b>71</b>

## Results

Fifty-eight out of a possible 252 (23%) patient-GP consultations involved at least one mention of family health history. Since most patients came to the consultation with more than one reason for their visit, the resultant interaction between the GP and the patient was a dynamic exchange of information, often covering several points of discussion. The length of each individual consultation ranged from 6 to 37 minutes duration. Sharing or updating family health history was never the presenting reason for the consultation. In the 58 consultations, 46 conversations about family health history were initiated by the GP. Most discussions around family history lasted for between 1 to 2 minutes. Two overarching themes were developed from the transcripts that described how family history was raised, and then subsequently discussed, in the consultation – non-specific and specific enquiry; and one theme which related to the situational context, multi-tasking (Table 3).

**Table 3** Thematic structure

Inductive codes	Preliminary themes	Final themes
Blindsiding	Open question	Non-specific line of enquiry
GP closed question	Closed question	Specific line of enquiry
GP contextualising	Health condition	
GP health promotion		
Knowing the GP		
Not knowing	Not getting very far	
Patient position		
Isolation		
Health condition	Why asked	
Lifestyle advice		
How asked	GP multi-tasking	Multi-tasking
GP position	Patient multi-task response	

### How Family Health History is raised in the consultation

The topic of family health history was presented initially to the patient in one of two ways, through a line of non-specific enquiry or through a specific context. Patients often responded to either approach with a simple *no*, but fuller negative responses also occurred regularly and typically included an account of some kind – e.g. that the patient was unable to be certain or to provide the requested information (e.g. explaining family relationships/dynamics which impeded or prevented the accessibility of information).

#### Non-specific enquiry

A non-specific line of enquiry was initiated through prompt questions that were tilted towards a 'no' answer, typically asking the patient if there was "*anything that runs in the family*" or if there was "*anything in the family we should know about?*".

The introduction of the topic through this form of non-specific enquiry, while sufficient to initially engage the patient, elicited two opposite types of responses, one where the patient disclosed very little or one where the patient disclosed a significant amount of information.

Where patients responded by not disclosing any information, this often ended any further discussion about family history, with no further details being drawn out by the GP. Following this, the direction of the consultation tended to change abruptly into a different topic, as illustrated by the following interaction:

**GP:** ... and anything that runs in your family at all on either your mum or dads side

**PT:** No not that I know of

1  
2  
3 GP: *Nope*

4 GP: *Fine, and have you ever had a smear test?*

5  
6 (ARCH:TS GP08-17)

7  
8 Those patients who responded positively to the initial response to the prompt to share  
9 'anything' or discuss 'any' history did so by presenting a picture of family health that had  
10 personal meaning to them, and at the same time oriented to the doctor's agenda by  
11 highlighting aspects that were clinically relevant. For example:  
12

13 GP: *I've got your details and medication, any history of*

14  
15 PT: *Parents are in the seventies and still alive*

16  
17 GP: *Good*

18  
19 PT: *Apparently my grandmother ended her life in the gas oven at home so I guess she  
20 would have lived a long life if she hadn't of done that*

21  
22 GP: *Mm*

23  
24 PT: *Grandfather on the other side was an alcoholic so that sort of explains why he's dead*

25  
26 GP: *Right*

27  
28 PT: *The other set of parents are fine*

29  
30 GP: *And the other grandparents*

31  
32 PT: *Oh grandparents? One died on the operating table and um, he was sixty odd, and my  
33 grandmother would have been in her seventies as well I think"*

34  
35 At this point of the consultation, the GP changed to a more specific line of enquiry (inferably  
36 following a checklist) by asking about the occurrence of specific health conditions, and it  
37 followed as:

38  
39 GP: *Anyone had diabetes in the family?*

40  
41 PT: *No*

42  
43 GP: *And high blood pressure?*

44  
45 PT: *No*

46  
47 GP: *Um alcoholism it was your mother's father or your father's father?*

48  
49 PT: *Oh my mother's father grandfather, but it's all largely hearsay*

50  
51 GP: *Yep*

52  
53 GP: *Any significant mental illness?*

54  
55 PT: *No, we seem to be pretty straight up*

56  
57 GP: *And familial degenerative disease, which I don't actually understand what that means,  
58 so we'll leave that blank*

59  
60 PT: *Once again they're all seventy they're not in the mental asylums and they're living in  
their own homes without nursing and wheelchairs so that's pretty good*

(ARCH:IS-GP02-08)

In this interaction initially it appeared that the patient wasn't going to share family health history information by stating "*Parents are in the seventies and still alive*", which suggests that they felt this was sufficient in describing a picture of family health. However, they went on to share more details, despite being prompted initially by a non-specific line of enquiry, with the patient disclosing that alcohol misuse and mental health conditions did exist in their family. Of note is that while this patient disclosed that a relative died by suicide, and that there was alcohol misuse, they did not appear to attribute this to poor mental health, instead discounting the reliability of the information passed down, by saying it was "*hearsay*". After several specific questions about the occurrence of particular health conditions, the GP ended the enquiry by saying "*And familial degenerative disease, which I don't actually understand what that means, so we'll leave that blank*" to which the patient augmented their initial response by stating "*Once again they're all seventy they're not in the mental asylums and they're living in their own homes without nursing and wheelchairs so that's pretty good*", and at which point the discussion changed topic. A more extended dialogue about family health was not established.

### **A more specific enquiry through context – highlighting the unknown**

In comparison, more specific lines of enquiry were evident when the GP was wanting to establish the occurrence of a particular condition, which in this cohort was mainly about the occurrence of heart disease, diabetes, cancers, and/or the existence of allergic reactions to particular medications. This line of enquiry was frequently premised by asking the patient if there was a "*strong family history*" of a particular condition; although the adjective 'strong' was never defined nor questioned by any of the patients. With a more specific enquiry, the patient was often asked to think about more than one condition, for example when this patient was seeking a repeat prescription for hormonal contraceptive:

GP: *You or your family have never had any sort of blood clot or thrombosis or a stroke or blood pressure is there a strong family history of breast cancer at all?*

PT: *No, not that I know of*

GP: *No, fine, fine.*

PT: *I live with my father so I don't really know much about my mother's side of the family*

GP: *Yeah okay. And have you had any medical problems in the past?*

PT: *No.*

(ARCH:TS-GP08-07)

Exploring this interaction further, the use of the words 'never' or 'any' in the first three-part question orientated the response to a negative, and the doctor left no space for a response, continuing straight on to the next question, suggesting this was a request for confirmation rather than a question seeking specific information. In all cases, as we see in the response to the doctor's second question here, a more specific line of enquiry placed an onus of recall on the patient, as with a non-specific line of enquiry, but had the additional effect of orientating the patient to wanting to be as accurate as possible. In this example we see the patient added 'not that I know of' and an explanation as to why they do not know all or some of the answer (at that given time). Estranged family relationships were frequently reported to account for why patients did not know about the occurrence of specific health conditions. As exemplified by another patient disclosing:

GP: *Yep so um well - apart from that is there anything that runs in your family that might trigger it thyroid problems or auto-immune problems or nothing else?*

1  
2  
3 *PT: Nothing that I know of um I mean I don't know my father that well but um, I've kind of*  
4 *asked him a few questions but he's had nothing he's only just got heart disease and*  
5 *stuff like that*  
6

7 *GP: Okay.*  
8

9 *(ARCH:TS-GP10-16)*  
10

11 Where patients indicated that they did not know (much) about their family health history, there  
12 was no indication that they would have been able to ascertain a more detailed family history  
13 if they knew they were going to be asked about it, nor did any patient say in the consultation  
14 that they would attempt to find out more. Once an estranged family had been raised by the  
15 patient, the GPs made no more enquiries to establish familial inheritance/occurrence, and the  
16 consultation was re-focussed to the individuals' health history.  
17

### 18 Multi-tasking

19 In reviewing the video recordings, the GP could often be observed multi-tasking during the  
20 consultation (e.g. looking at or adding to the electronic medical record, undertaking a physical  
21 examination), including at the time while asking the patient about their family health history.  
22 The patient was also expected to multi-task, from having to think about answering more than  
23 one line of enquiry, and having to undertake tasks at the same time. The following excerpt  
24 exemplifies such an interaction:  
25  
26

27  
28 *GP: I will need your height and weight please as well, and do you have a family history of*  
29 *heart attacks or strokes? Without shoes please*  
30

31 *PT: Um my mum she had a minor heart attack but she died um it'll be three years this year*  
32

33 *GP: Mm hm*  
34

35 *PT: Um from cancer*  
36

37 *GP: Mm what kind of cancer?*  
38

39 *PT: Um they're not really sure*  
40

41 *GP: Stand here please*  
42

43 *PT: Cos they don't know where it started*  
44

45 *GP: Yeah*  
46

47 *GP: Sometimes has that, okay, that's perfect*  
48

49 *PT: Oh okay, what height am I?*  
50

51 *GP: One fifty six*  
52

53 *(ARCH:DS-DP32-08)*  
54

55 This consultation commenced with a "so" to which the patient explained the reason for their  
56 visit. Within one minute the GP had turned their back to the patient, and started typing. Two  
57 minutes into the consultation, the GP started experiencing problems with the computer (data  
58 entry) and said to the patient "ahhh don't you hate computers?". The patient in this instance  
59 did not appear relaxed, they were wringing their hands and swinging their legs under the chair.  
60 The topic of family history was raised approximately five minutes into the 13-minute  
consultation, where the patient was given a statement of intent - that their height and weight

1  
2  
3 would need to be taken, asked a question - about their family history, and an instruction – to  
4 remove their shoes. In response to the doctor’s question about family history of heart attack  
5 or stroke, the patient disclosed that her mother had died three years ago. At this point the GP  
6 was not making eye contact with the patient, and during the explanation of what her mother  
7 had died from the patient was given another instruction to go and stand in a particular place.  
8 While family health history information was able to be shared, because it was done in a context  
9 of multi-tasking, it appeared to create a perfunctory transaction, rather than a discussion.  
10  
11

## 12 Discussion

13  
14 This paper reviewed how family history was discussed in a sample of archived primary  
15 healthcare consultations. To our knowledge, this study is the first to observe conversations  
16 about family health history in routine primary care consultations. The majority (46/58) of  
17 conversations about family health history were initiated by the GP. Most of these family history  
18 discussions lasted approximately 1 to 2 minutes. Patients were invited to share family health  
19 history through one of two ways; non-specific enquiry such as asking “*anything that runs in*  
20 *the family?*”, or in relation to a specific condition where patients were asked if they had a  
21 “*strong family history*” of a particular condition, like breast cancer. The majority of patients  
22 responded to either approach by replying ‘no’ or premising the negative reply by explaining  
23 family relationships or dynamics which would impede or prevent the accessibility of  
24 information. Of note is the influence of socio-cultural norms and the constraints of primary care  
25 consultations on family health history taking. ‘Multitasking’, and computer use also appeared  
26 to have an influence on how family history taking played out. These aspects have been noted  
27 in other areas of primary care performance and once understood strategies can be put in place  
28 to mitigate their impact.<sup>16</sup>  
29  
30  
31

32 Sharing family history information with family members and health-professionals is influenced  
33 by the socio-cultural norms of the family it pertains to and the purpose for which the information  
34 is being sought.<sup>17-20</sup> There are multiple meanings of ‘family’ and varying beliefs about what  
35 ‘health’ (and illness) means.<sup>18 19</sup> Furthermore there are different reasons for collecting family  
36 health history information, for example to establish genetic risk to identify which patients need  
37 referral for specialist genetics assessments;<sup>20</sup> to establish the prevalence of complex chronic  
38 diseases;<sup>3</sup> or to establish family systems genogram<sup>20</sup> or potentially for all of the  
39 aforementioned reasons. However if this is not established prior to the enquiry being made,  
40 the healthcare interaction may result in misaligned communication because there has been  
41 an assumed shared understanding of what is meant by ‘family health history’.<sup>19 21</sup> This was  
42 frequently observed in our study. Whilst no patient questioned why family health history was  
43 being enquired about, there was no indication given by the GPs as to why it was being asked  
44 about. It is not possible to ascertain whether indicating the purpose of the enquiry would have  
45 resulted in more aligned discussions and this would warrant further investigation.  
46  
47  
48

49 As part of realising the use of family health history more routinely, there is starting to be an  
50 expectation that people will collect their family health information through the use of online  
51 family health history tools.<sup>2 11 22</sup> In 2010 the US Surgeon General suggested from a health  
52 perspective that Thanksgiving Day be also called “Family Health Day” because families often  
53 get together and this therefore provides an opportunity to discuss and collect family health  
54 history from several family members.<sup>23</sup> In parallel the US Surgeon General released a free  
55 online tool for the collection of family health history.<sup>24</sup> As with other family health history tools,  
56 this tool reflects a narrow biomedical definition of the family<sup>19</sup> which raises questions about  
57 the relevance and potential acceptability of such tools for many families, including for those  
58 observed in our study. Multiple approaches that incorporate both social and biological  
59  
60

1  
2  
3 elements are likely to result in more equitable access to and greater benefit from family history  
4 information in healthcare.  
5

6 In our study, enquiring about family health history lasted between 1-2 minutes. A “full” family  
7 history includes three generations of relatives, health problems with age of onset for each  
8 family member, and age of each relative at death with cause has been estimated to take up  
9 to 30 minutes.<sup>25</sup> Dedicated consultations for the collection and documentation of family health  
10 history have been proposed as potential solutions to these system level constraints.<sup>2</sup> However,  
11 this approach could potentially create inequities in access to (and therefore benefit from) family  
12 history collection for those people who are unable to pay for and/or attend additional  
13 consultations.  
14

15  
16 In previous studies, GPs have reported that the information that patients do provide about their  
17 family history is unreliable.<sup>7 26 27</sup> Our study demonstrates that the way GPs enquire about family  
18 health history may also contribute to the amount and type of information that is gathered. In  
19 another study exploring how GPs could meet patients unmet needs in acute care consultation  
20 by changing the orientation of the enquiry, it was found that GPs who used the question “Is  
21 there *something* else you want to address in the visit today?” led to significantly more unmet  
22 needs being eliminated than when GPs used the question “Is there *anything* else you want to  
23 address in the visit today?”.<sup>28</sup> In another study, when patients were asked to consider family  
24 health history, the addition of ‘extended’ to family health history yielded patients reporting  
25 positive family history for 8 of 11 medical conditions.<sup>25</sup> The abrupt shift in consultation topic  
26 observed in our data analysed here after a negative initial response to family history is  
27 indicative of many interactions in primary care where there are competing demands in a  
28 checklist driven consulting environment.<sup>29</sup> There are opportunities to enhance the interaction  
29 and obtain more information if these communication devices are noted and explored, and  
30 which would need to be considered with the increase in expectation that this information be more  
31 routinely and/or opportunistically collected.  
32  
33

34  
35 A limitation of this study is that the patient cohort was Euro-centric, and not fully reflective of  
36 the ethnic population of New Zealand (where the study was carried out). We have not  
37 undertaken any analysis by ethnicity, and this is warranted in future research. Another  
38 limitation of this study that it was not possible to ascertain the extent to which the family health  
39 history information that was shared was taken into account in any clinical decision making by  
40 the GP. It was also not possible to ascertain whether other healthcare practitioners had had  
41 prior discussions with patients about their family history, and if this information had been  
42 collected and recorded elsewhere in the patient records. A strength of this study is that these  
43 examples are taken from a range of routinely collected consultation studies with different  
44 purposes, and hence cover a wide range of GP contexts, without specifically having a focus  
45 on family history.  
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48 This study has highlighted areas where inequities may arise with existing methods of routine  
49 collection of family health history. The opportunistic enquiry into family health history is more  
50 complex than asking if “*anything runs in the family*” and with attention to linguistic devices and  
51 acknowledgment of patient social and cultural norms there is an opportunity to expand history  
52 taking to the point at which the history can become an effective genomic tool.  
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## 9 Author's Contributions

10 SF conceived the idea, led the analysis and drafted all versions of the manuscript.

11 MS contributed to the study design, analysis and manuscript preparation.

12 RG contributed to the study design, analysis and manuscript preparation.

13 BR contributed to the study design, analysis and manuscript preparation.

14 KP contributed to the study design, analysis and manuscript preparation.

15 PW contributed to the study design, analysis and manuscript preparation.

16 RJ contributed to the study design, analysis and manuscript preparation.

17 TD contributed to the study design, analysis and manuscript preparation.  
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## COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
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<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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## How is family health history discussed in routine primary healthcare? A qualitative study of archived family doctor consultations

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# How is family health history discussed in routine primary healthcare? A qualitative study of archived family doctor consultations

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## Key words

Family health history; genomics; primary health care; equity; family

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## Abstract

### Objectives

Family health history underpins genetic medicine. Our study aimed to explore language and patterns of communication relating to family health history observed in interactions between general practitioners (GPs) and their patients within routine primary care consultations.

### Design

Secondary analysis of patient and general practitioner (GP) routine consultation data (n=252).

### Participants

Consultations that included “family health history” were eligible for inclusion (n=58).

### Primary outcomes

A qualitative inductive analysis of the interactions from consultation transcripts.

### Results

46/58 conversations about family health history were initiated by the GP. Most discussions around family history lasted for between approximately 1 to 2 minutes. Patients were invited to share family health history through one of two ways: non-specific enquiry (e.g. by asking the patient about “*anything that runs in the family*”); or specific enquiry where they were asked if they had a “*strong family history*” in relation to a particular condition e.g. breast cancer. Patients often responded to either approach with a simple *no*, but fuller negative responses also occurred regularly and typically included an account of some kind (e.g. explaining family relationships/dynamics which impeded or prevented the accessibility of information).

### Conclusions

Family health history is regarded as a genetic test and is embedded in the socio-cultural norms of the patient from whom information is being sought. Our findings highlight that it is more complex than asking simply if “*anything*” runs in the family. As the collection of family health history is expected to be more routine, it will be important to also consider it from socio-cultural perspectives in order to help mitigate any inequities in how family history is collected, and therefore used (or not) in a person’s healthcare. Orientating an enquiry away from ‘*anything*’ and asking more specific details about particular conditions may help facilitate the dialogue.

### Strengths and limitations of this study

- The patient cohort was Euro-centric, and not fully reflective of the ethnic population of New Zealand (where the study was carried out).
- The extent to which the family health history information had been previously shared/documented was not ascertainable.
- The study draws on range of routinely collected consultation studies with different purposes, and hence cover a wide range of GP contexts, without specifically having a focus on family history.

### Funding statement

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### Competing interests

The authors have no competing interests to declare.

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## Introduction

Family health history has been described as the first genetic test.<sup>1</sup> A family health history is defined as “a record of health information about a person and his or her close relatives. A complete record includes information from three generations of relatives, including children, brothers and sisters, parents, aunts and uncles, nieces and nephews, grandparents, and cousins.” (NIH Genetics Home Reference). Such a detailed family health history is regarded as one of the most useful tools for risk assessment for common chronic diseases.<sup>2</sup> It is estimated that the relative risks and odds ratios for various cancers, stroke, type 2 diabetes, and cardiovascular diseases is twice that for people with an affected first degree relative, and more than four times greater for many of these diseases if there is more than one affected first degree relative.<sup>2,3</sup> The value of health records from relatives has been recently demonstrated in research aimed at providing accurate predictions of disease risk: Truong et al., (2020) showed that including health information from first degree relatives of those with both genomic and health records, had similar accuracies in polygenic risk scores with 44-fold larger population samples consisting of only genomic data and health information.<sup>4</sup> Several professional organisations have recently made recommendations that general practitioners (GPs) routinely, and opportunistically, collect family health history for three generations.<sup>2,5</sup> However, current evidence would indicate that there may be barriers to achieving this level of information, and approach to its collection, as family health history is widely reported as being both poorly and infrequently collected.<sup>6,7</sup> Reported barriers to the collection of family health information include: poor reimbursement, provider’s lack of time and expertise, lack of guidelines and adequate tools, and limited functionality of electronic health information systems to capture and interpret data and unreliability of information provided by patients.<sup>8</sup> The potential to improve health care by being able to act on family health history information is thus not being fully realised. This is important as access to genetic and genomic testing becomes easier and cheaper, available direct to the public, and knowledge of family health history is imperative in wisely using this testing and interpretation of results.<sup>1,10,11</sup>

The exploration of the practice of collection of family health history has tended to focus on the practical side i.e. to garner better understandings around the barriers and facilitators to its collection, and the validation and implementation of tools to collect family health history.<sup>2,11,12</sup> How family health history is actually discussed in routine primary healthcare consultations has received less attention, and to our knowledge this is first study to observe conversations about family health history in routine primary care consultations. The aim of our study was to explore language and patterns of communication relating to family health history observed in interactions between general practitioners (GPs) and their patients within routine primary care consultations.

## Materials and Methods

### Data Source

Consultation data were sourced from the Applied Research on Communication in Health (ARCH) Corpus at the University of Otago, Wellington, New Zealand<sup>13</sup>, and have been previously described.<sup>14</sup> The Corpus houses a digitally stored collection of patient / practitioner consultation data that includes 458 video-recorded consultations, verbatim transcripts and selected medical notes.<sup>15</sup>

## Ethical approval

The collection of all Corpus data and guidelines for subsequent use have been approved by the New Zealand Health and Disability Ethics Committee and University of Otago Human Ethics Committee (Health). Ethics approval for this study was given by the University of Otago Human Ethics Committee (Health) (H19/022).

## Identification of family health history consultations

The consultations analysed in this paper were derived from five different studies that comprise the ARCH Corpus; in none of these was family health history the focus (Table 1). At the time of this study, the Corpus included 252 patient-GP consultations involving 36 GPs, collected between 2004 and 2018. The ARCH Corpus includes a Microsoft Access database populated with metadata including full demographic information about every participant, research site information and free text content logs of each consultation. The logs were prepared by a research nurse according to a standard template and include information about the main topics discussed, outcomes of the consultation (including prescriptions and referrals), and a minute by minute summary of key events and content. The logs thus capture any complaint or topic mentioned incidentally in a consultation, in addition to the main presenting complaint(s). The database and logs link electronically to full verbatim transcripts (including time measurements in minutes) and the original audio and video-recordings to facilitate subsequent more detailed analysis, but the latter cannot be queried directly via the database.<sup>15</sup>

A query was run on the Microsoft Access database of the logs of each GP consultation in the Corpus using the keyword “family health history” (Table 1). The term ‘family health history’ was present in the logs of 71/252 individual patient consultations with GPs. Further review of the transcripts was undertaken and the consultations were excluded if family health history was not discussed. Additional terms were also included at this time to identify if family health history was mentioned in another context and included “family history”; “family”; “whānau” (family); “inherited”; and “condition”. It is possible that not all relevant consultations in the Corpus were identified; however, the purpose was to collate a relevant dataset adequate for the purpose of undertaking a descriptive qualitative analysis, and not to investigate the frequency of occurrence of family health history.

**Table 1** Overview of the study and number of patient-GP consultations where family health history was discussed.

Study	Brief description of the original study	Number of consultations included in the analysis	Number of patient-GP consultations in original study
Diabetes study (DS)	Tracking the contact of newly diagnosed patients with Type 2 diabetes with healthcare professionals over a six-month period	7	34
Interaction Study (IS);	Exploring clinical decision-making when rationing is explicit	11	58
Tracking Study (TS)	Exploring communication processes throughout a single complete episode of care of	31	125

	patients referred from primary to secondary care		
TAbOO: Talking About Overweight and Obesity	When and how GPs and patients discuss excess weight related issues (or not) during routine consultations	6	19
Interpreting Study (IN)	Clinical risk and patterns of use and communication with/of interpreters	3	16
Total		58	252

## Patient and Public Involvement

Patients were not involved in any aspects of the study design, including plans for dissemination of the research findings. As part of the original consenting process, they would have been advised on the length of the time required to participate in the research.

## Data analysis

Themes were derived iteratively using a qualitative inductive approach based on the verbatim transcripts of interactions between patients and GPs.<sup>16</sup> Our overarching aim was to report on the emerging range of issues and communication styles without pre-conceived assumptions. SF (health services researcher) read all of the transcripts (n=71) several times and identified the conversation sequences that related to family health history, including the time in the consultation that it was first mentioned. A subsample of transcripts were read by RJ (GP and health services researcher). Twelve initial inductive themes were derived (Table 2) which formed the coding frame, the transcripts were then reread and new codes emerged as preliminary themes. These themes were mapped across all of the transcripts, reread and recoded until no further themes emerged and the final themes derived (Table 2). Where additional clarity or interpretive information was required, the video recording of the consultation was reviewed. Initial interpretations of the themes were shared with the team and discussed in detail discussion between SF and RJ. MS, a researcher with experience in interactional sociolinguistics contributed to an additional round of discussion and interpretation. The themes were discussed and agreed by consensus with all of the authors. The sociodemographic information of the 71 patients was reviewed after the first round of analysis and self-identified ethnicity reported in Table 3 analysis by ethnicity was not undertaken.

### Table 2 Thematic structure

Inductive codes	Preliminary themes	Final themes
Blindsiding	Open question	Non-specific line of enquiry
GP closed question	Closed question	Specific line of enquiry
GP contextualising	Health condition	
GP health promotion		
Knowing the GP		
Not knowing	Not getting very far	
Patient position		
Isolation		
Health condition	Why asked	
Lifestyle advice		
How asked	GP multi-tasking	Multi-tasking
GP position	Patient multi-task response	

**Table 3** Self-reported ethnicity of patients who participated in the original studies.

Self-reported ethnicity	Frequency
New Zealand European	41
New Zealand European/Māori	2
New Zealand European/Cook Island Māori	2
Māori/ Samoan/UK/US	2
New Zealand European /Samoan	2
Samoan	8
Tongan	2
Assyrian	1
Chinese	2
Dutch	2
Dutch/ New Zealand European	1
Indian	2
Italian	1

Somali	1
Sri Lankan	1
Thai	1
<b>TOTAL</b>	<b>71</b>

## Results

Fifty-eight out of a possible 252 (23%) patient-GP consultations involved at least one mention of family health history. Since most patients came to the consultation with more than one reason for their visit, the resultant interaction between the GP and the patient was a dynamic exchange of information, often covering several points of discussion. The length of each individual consultation ranged from 6 to 37 minutes duration. Sharing or updating family health history was never the presenting reason for the consultation. In the 58 consultations, 46 conversations about family health history were initiated by the GP. Most discussions around family history lasted for between 1 to 2 minutes. Two overarching themes were developed from the transcripts that described how family history was raised, and then subsequently discussed, in the consultation – non-specific and specific enquiry; and one theme which related to the situational context, multi-tasking (Table 2).

## How Family Health History is raised in the consultation

The topic of family health history was presented initially to the patient in one of two ways, through a line of non-specific enquiry or through a specific context (Table 4). Patients often responded to either approach with a simple *no*, but fuller negative responses also occurred regularly and typically included an account of some kind – e.g. that the patient was unable to be certain or to provide the requested information (e.g. explaining family relationships/dynamics which impeded or prevented their access to information).

**Table 4** Supporting quotes

Theme	Interaction	ARCH Original Study
Non-specific enquiry	GP: Okay, and is there anything that runs in your family any medical problems at all? PT: In my family? GP: Yeah anything in your parents or brothers or sisters or grandparents? PT: No. PT: Er mum .....yeah she got asthma or something like that GP: Yep PT: Yeah yeah GP: Okay but you've never had any problems like this fine and do you drink any alcohol or smoke PT: No no	TS-GP08-01
	GP: Well what about your family any um illness run in your family? PT: Um no GP: Um okay now what about bees	IS-GP05-05
	GP: ... we'll examine you today and make sure that's okay. What about in your family any of those things run in your family at all? DA: Um nothing runs in the family... we, my aunt told me	TS-GP08-21
	GP: ...anything that runs in your family? PT: Nope, my family's GP: Yeah good PT: My husband's well my ex husband's would be a different story	TS-GP08-23



		<p>GP: But your fam- there's no strong family history of any type of cancer or anything like that</p> <p>PT: Nope</p> <p>PT: Nothing</p> <p>GP: Fine</p>	
Enquiry context through		<p>GP: Any family history with bowel problems?</p> <p>PT: Um my aunty had bowel cancer but um that's all</p> <p>GP: How old was she when she got it?</p> <p>PT: She was late sixties</p> <p>GP: Right</p> <p>PT: But nothing you know my parents both died of smoking related diseases</p> <p>GP: Mm mm</p> <p>PT: So but apart from that there was nothing</p>	TS-GP03-07a
		<p>GP: Does anyone else in your family have diabetes?</p> <p>PT: No</p> <p>GP: Okay</p> <p>PT: No it's not in the family</p>	DS-GP19-02a
		<p>GP: Is um whether there's any significant family history of heart disease, anything there in your family?</p> <p>PT: Not sure about heart, so leukaemia's different isn't it?</p> <p>GP: Angina or heart, yeah</p> <p>PT: Yeah</p> <p>GP: Angina or heart attack, parents or grandparents</p> <p>PT: Yeah, my grandfather did have a heart attack</p>	IS-GP02-02
		<p>GP: ...it's just a little, it's a small spot that's bleeding on your chest a bleeding spot on your chest, yep, there's no family history of skin cancer that I should be aware of or any skin problems?</p> <p>PT: Not that I know of</p> <p>GP: No that's fine, that's okay</p>	IS-GP06-08
Multiple conditions enquiry, and patient		<p>GP: ...and anything that runs in your family? Any strong history of heart disease or cancers or</p>	TS-GP08-19

<p>contextualising response</p>	<p>blood pressure problems, diabetes, anything?</p> <p>PT: No</p> <p>GP: ...like that</p> <p>PT: Um no, nothing like that just my granddad</p> <p>PT: Yeah well my grandparents were pretty old when they died</p> <p>GP: Mmm</p> <p>PT: Um except for one, there was an accident so, yes nothing really pretty, pretty, pretty good genetics although I've got poor hearing from my mother's side but yeah I mean that's something I've known about for years, might need to get a hearing aid one day...</p>	
<p>Enquiry through context – highlighting the unknown</p>	<p>GP: Can I ask you a few more questions... is there any family history of any cancers in your family?</p> <p>PT: Um yes</p> <p>GP: Which ones?</p> <p>PT: On my father's side I don't know much, he was an only child with elderly parents so I never even met them and um so I don't know much about that except his cousin had cancer, um started with er testicles I think and then carried on um he's now passed</p>	<p>DS-GP32-05_Taboo</p>
	<p>GP: Any er cancer in your family? Especially breast cancer</p> <p>PT: Possibility of breast cancer my mum's side</p> <p>GP: Who?</p> <p>PT: My mother's, my grandmother</p> <p>GP: Your grandmother?</p> <p>PT: Yep</p> <p>GP Had breast cancer</p> <p>PT: Yep um, yeah yep she had one breast removed about, it's all a bit it's from quite a long time ago, they're a bit unsure as to how accurate the diagnosis was yeah so</p>	<p>TS-GP14-02</p>
	<p>GP: ...have either you or your family had a history of any skin cancer or anything like that?</p> <p>PT: No. Not that I'm aware of but I've got very narrow family I've only got mum, dad, and they've got no brothers or sisters there's no</p>	<p>TS-GP08-02</p>

	aunty or uncles and, much above that don't really know to be honest	
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### Non-specific enquiry

A non-specific line of enquiry was initiated through prompt questions that were tilted towards a 'no' answer, typically asking the patient if there was *"anything that runs in the family"* or if there was *"anything in the family we should know about?"*.

The introduction of the topic through this form of non-specific enquiry, while sufficient to initially engage the patient, elicited two opposite types of responses, one where the patient disclosed very little or one where the patient disclosed a significant amount of information.

Where patients responded by not disclosing any information, this often ended any further discussion about family history, with no further details being drawn out by the GP. Following this, the direction of the consultation tended to change abruptly into a different topic, as illustrated by the following interaction:

GP: ... and anything that runs in your family at all on either your mum or dad's side?

PT: No not that I know of

GP: Nope

GP: Fine, and have you ever had a smear test?

(ARCH:TS GP08-17)

Those patients who responded positively to the initial response to the prompt to share 'anything' or discuss 'any' history did so by presenting a picture of family health that had personal meaning to them, and at the same time oriented to the doctor's agenda by highlighting aspects that were clinically relevant. For example:

GP: I've got your details and medication, any history of

PT: Parents are in the seventies and still alive

GP: Good

PT: Apparently my grandmother ended her life in the gas oven at home so I guess she would have lived a long life if she hadn't of done that

GP: Mm

PT: Grandfather on the other side was an alcoholic so that sort of explains why he's dead

GP: Right

PT: The other set of parents are fine

GP: And the other grandparents

PT: Oh grandparents? One died on the operating table and um, he was sixty odd, and my grandmother would have been in her seventies as well I think"

At this point of the consultation, the GP changed to a more specific line of enquiry (inferably following a checklist) by asking about the occurrence of specific health conditions, and it followed as:

1  
2  
3 GP: *Anyone had diabetes in the family?*

4  
5 PT: *No*

6  
7 GP: *And high blood pressure?*

8  
9 PT: *No*

10 GP: *Um alcoholism it was your mother's father or your father's father?*

11  
12 PT: *Oh my mother's father grandfather, but it's all largely hearsay*

13  
14 GP: *Yep*

15  
16 GP: *Any significant mental illness?*

17  
18 PT: *No, we seem to be pretty straight up*

19  
20 GP: *And familial degenerative disease, which I don't actually understand what that means, so we'll leave that blank*

21  
22  
23 PT: *Once again they're all seventy they're not in the mental asylums and they're living in their own homes without nursing and wheelchairs so that's pretty good*

24  
25  
26 (ARCH:IS-GP02-08)

27  
28 In this interaction initially it appeared that the patient wasn't going to share family health history  
29 information by stating "*Parents are in the seventies and still alive*", which suggests that they  
30 felt this was sufficient in describing a picture of family health. However, they went on to share  
31 more details, despite being prompted initially by a non-specific line of enquiry, with the patient  
32 disclosing that alcohol misuse and mental health conditions did exist in their family. Of note  
33 is that while this patient disclosed that a relative died by suicide, and that there was alcohol  
34 misuse, they did not appear to attribute this to poor mental health, instead discounting the  
35 reliability of the information passed down, by saying it was "*hearsay*". After several specific  
36 questions about the occurrence of particular health conditions, the GP ended the enquiry by  
37 saying "*And familial degenerative disease, which I don't actually understand what that means, so we'll leave that blank*" to which the patient augmented their initial response by stating "*Once again they're all seventy they're not in the mental asylums and they're living in their own homes without nursing and wheelchairs so that's pretty good*", at which point the discussion changed topic. A more extended dialogue about family health was not established.

### 43 44 **A more specific enquiry through context – highlighting the unknown**

45  
46 In comparison, more specific lines of enquiry were evident when the GP was wanting to  
47 establish the occurrence of a particular condition, which in this cohort was mainly about the  
48 occurrence of heart disease, diabetes, cancers, and/or the existence of allergic reactions to  
49 particular medications (Table 4). This line of enquiry was frequently premised by asking the  
50 patient if there was a "*strong family history*" of a particular condition; although the adjective  
51 'strong' was never defined nor questioned by any of the patients. With a more specific enquiry,  
52 the patient was often asked to think about more than one condition (Table 4), for example  
53 when this patient was seeking a repeat prescription for hormonal contraceptive:

54  
55 GP: *You or your family have never had any sort of blood clot or thrombosis or a stroke or blood pressure is there a strong family history of breast cancer at all?*

56  
57  
58 PT: *No, not that I know of*

59  
60 GP: *No, fine, fine.*

1  
2  
3 *PT: I live with my father so I don't really know much about my mother's side of the family*

4  
5 *GP: Yeah okay. And have you had any medical problems in the past?*

6  
7 *PT: No.*

8  
9 *(ARCH:TS-GP08-07)*

10 Exploring this interaction further, the use of the words 'never' or 'any' in the first three-part  
11 question orientated the response to a negative, and the doctor left no space for a response,  
12 continuing straight on to the next question, suggesting this was a request for confirmation  
13 rather than a question seeking specific information. In all cases, as we see in the response to  
14 the doctor's second question here, a more specific line of enquiry placed an onus of recall on  
15 the patient, as with a non-specific line of enquiry, but had the additional effect of orientating  
16 the patient to wanting to be as accurate as possible. In this example we see the patient added  
17 'not that I know of' and an explanation as to why they do not know all or some of the answer  
18 (at that given time). Estranged family relationships were frequently reported to account for why  
19 patients did know about the occurrence of specific health conditions. As exemplified by  
20 another patient disclosing:  
21  
22

23 *GP: Yep so um well - apart from that is there anything that runs in your family that might*  
24 *trigger it thyroid problems or auto-immune problems or nothing else?*

25  
26 *PT: Nothing that I know of um I mean I don't know my father that well but um, I've kind of*  
27 *asked him a few questions but he's had nothing he's only just got heart disease and*  
28 *stuff like that*

29  
30 *GP: Okay.*

31  
32 *(ARCH:TS-GP10-16)*

33  
34 Where patients indicated that they did not know (much) about their family health history, there  
35 was no indication that they would have been able to ascertain a more detailed family history  
36 if they knew they were going to be asked about it, nor did any patient say in the consultation  
37 that they would attempt to find out more. Once an estranged family had been raised by the  
38 patient, the GPs made no more enquiries to establish familial inheritance/occurrence, and the  
39 consultation was re-focussed to the individuals' health history.  
40  
41

## 42 Multi-tasking

43 In reviewing the video recordings, the GP could often be observed multi-tasking during the  
44 consultation (e.g. looking at or adding to the electronic medical record, undertaking a physical  
45 examination), including at the time while asking the patient about their family health history.  
46 The patient was also expected to multi-task, from having to think about answering more than  
47 one line of enquiry, and having to undertake tasks at the same time. The following excerpt  
48 exemplifies such an interaction:  
49  
50

51 *GP: I will need your height and weight please as well, and do you have a family history of*  
52 *heart attacks or strokes? Without shoes please*

53  
54 *PT: Um my mum she had a minor heart attack but she died um it'll be three years this year*

55  
56 *GP: Mm hm*

57  
58 *PT: Um from cancer*

59  
60 *GP: Mm what kind of cancer?*

1  
2  
3 PT: *Um they're not really sure*

4  
5 GP: *Stand here please*

6  
7 PT: *Cos they don't know where it started*

8  
9 GP: *Yeah*

10  
11 GP: *Sometimes has that, okay, that's perfect*

12  
13 PT: *Oh okay, what height am I?*

14  
15 GP: *One fifty six*

16  
17 (ARCH:DS-DP32-08)

18  
19 This consultation commenced with a "so" to which the patient explained the reason for their  
20 visit. Within one minute the GP had turned their back to the patient, and started typing. Two  
21 minutes into the consultation, the GP started experiencing problems with the computer (data  
22 entry) and said to the patient "*ahhh don't you hate computers?*". The patient in this instance  
23 did not appear relaxed, they were wringing their hands and swinging their legs under the chair.  
24 The topic of family history was raised approximately five minutes into the 13-minute  
25 consultation, where the patient was given a statement of intent - that their height and weight  
26 would need to be taken, asked a question - about their family history, and an instruction - to  
27 remove their shoes. In response to the doctor's question about family history of heart attack  
28 or stroke, the patient disclosed that her mother had died three years ago. At this point the GP  
29 was not making eye contact with the patient, and during the explanation of what her mother  
30 had died from the patient was given another instruction to go and stand in a particular place.  
31 While family health history information was able to be shared, because it was done in a context  
32 of multi-tasking, it appeared to create a perfunctory transaction, rather than a discussion.  
33  
34

## 35 Discussion

36  
37 This paper reviewed how family history was discussed in a sample of archived primary  
38 healthcare consultations. To our knowledge, this study is the first to observe conversations  
39 about family health history in routine primary care consultations. The majority (46/58) of  
40 conversations about family health history were initiated by the GP. Most of these family history  
41 discussions lasted approximately 1 to 2 minutes. Patients were invited to share family health  
42 history through one of two ways; non-specific enquiry such as asking "*anything that runs in*  
43 *the family?*", or in relation to a specific condition where patients were asked if they had a  
44 "*strong family history*" of a particular condition, like breast cancer. The majority of patients  
45 responded to either approach by replying 'no' or premising the negative reply by explaining  
46 family relationships or dynamics which would impede or prevent access to such information.  
47 Of note is constraints of primary care consultations on family health history taking.  
48 'Multitasking', and computer use also appeared to have an influence on how family history  
49 taking played out. These aspects have been noted in other areas of primary care performance  
50 and, once understood, strategies can be put in place to mitigate their impact.<sup>17</sup>  
51  
52

53  
54 Sharing of family history information with family members and health-professionals is  
55 influenced by the socio-cultural norms of the family it pertains to and the purpose for which  
56 the information is being sought.<sup>18-21</sup> There are multiple meanings of 'family' and varying beliefs  
57 about what 'health' (and illness) means.<sup>19 20</sup> Furthermore there are different reasons for  
58 collecting family health history information, for example to establish genetic risk to identify  
59 which patients need referral for specialist genetics assessments;<sup>21</sup> to establish the prevalence  
60

1  
2  
3 of complex chronic diseases;<sup>3</sup> or to establish family systems genogram<sup>21</sup> or potentially for all  
4 of the aforementioned reasons. However if this is not established prior to the enquiry being  
5 made, the healthcare interaction may result in misaligned communication because there has  
6 been an assumed shared understanding of what is meant by 'family health history'.<sup>20 22</sup> This  
7 was frequently observed in our study. Whilst no patient questioned why family health history  
8 was being enquired about, there was no indication given by the GPs as to why it was being  
9 asked about. It is not possible to ascertain whether indicating the purpose of the enquiry would  
10 have resulted in more aligned discussions and this warrants further investigation.

11  
12  
13 As part of realising the use of family health history more routinely, there is an emerging  
14 expectation that people will collect their family health information through the use of online  
15 family health history tools.<sup>2 12 23</sup> In 2010 the US Surgeon General suggested that Thanksgiving  
16 Day be also called "Family Health Day" because families often get together, providing an  
17 opportunity to discuss and collect family health history from several family members.<sup>24</sup> In  
18 parallel the US Surgeon General released a free online tool for the collection of family health  
19 history.<sup>25</sup> The use of family health history tools has been shown to improve the detection of  
20 inherited conditions and cancer in research studies.<sup>2</sup> However there are considerations for the  
21 use of such tools in routine practice. As with other family health history tools, this tool reflects  
22 a narrow biomedical definition of the family<sup>20</sup> which raises questions about the relevance and  
23 potential acceptability of such tools for many families, including for those observed in our  
24 study. Multiple approaches that incorporate both social and biological/medical elements are  
25 likely to result in more equitable access to and greater benefit from family history information  
26 in healthcare.

27  
28  
29 In our study, enquiring about family health history lasted between 1-2 minutes. A "full" family  
30 history includes three generations of relatives, health problems with age of onset for each  
31 family member, and age of each relative at death with cause has been estimated to take up  
32 to 30 minutes.<sup>26</sup> Dedicated consultations for the collection and documentation of family health  
33 history have been proposed as potential solutions to these system level constraints.<sup>2</sup> However,  
34 this approach could potentially create inequities in access to (and therefore benefit from) family  
35 history collection for those people who are unable to pay for and/or attend additional  
36 consultations.

37  
38  
39 In previous studies, GPs have reported that the information that patients do provide about their  
40 family history is unreliable.<sup>8 27 28</sup> Our study demonstrates that the way GPs enquire about family  
41 health history may also contribute to the amount and type of information that is gathered.  
42 Another study exploring how GPs could meet patients unmet needs in acute care consultation  
43 found that changing the orientation of the enquiry by using the question "Is there *something*  
44 else you want to address in the visit today?" led to significantly more unmet needs being  
45 eliminated than when GPs used the question "Is there *anything* else you want to address in  
46 the visit today?"<sup>29</sup> Although the paper reports a randomised controlled trial that was  
47 conducted in the context of eliciting additional concerns, but its relevance extends beyond this  
48 topic – the key point is that choosing '*anything*' rather than '*something*' in asking the question  
49 signals that that the expected answer is 'No'. Hence this finding is relevant to history taking as  
50 well as problem presentation. It would be worth exploring if such attention to linguistics would  
51 help improve the collection of family health history. In a further study, when patients were  
52 asked to consider family health history, the addition of 'extended' to family health history  
53 yielded patients reporting positive family history for 8 of 11 medical conditions.<sup>26</sup> In our data,  
54 the abrupt shift in consultation topic after a negative initial response to family history is  
55 indicative of many interactions in primary care where there are competing demands in a  
56 checklist driven consulting environment.<sup>30</sup> With increasing expectations that family health  
57  
58  
59  
60

1  
2  
3 history is collected, such communication devices may help to enhance interactions and obtain  
4 more relevant information  
5

6 A limitation of this study is that the patient cohort was Euro-centric, and not fully reflective of  
7 the ethnic diversity of New Zealand (where the study was carried out). We have not  
8 undertaken any analysis by ethnicity, and this is warranted in future research. It was also not  
9 possible to ascertain the extent to which the family health history information that was shared  
10 was taken into account in any clinical decision making by the GP. Nor was it possible to  
11 ascertain whether other healthcare practitioners had had prior discussions with patients about  
12 their family history, or if this information had been collected and recorded elsewhere in the  
13 patient records. A strength of this study is that these examples are taken from a range of  
14 routinely collected consultation studies with different purposes, without a specific focus on  
15 family history, and hence cover a wide range of GP contexts.  
16  
17

18 This study has highlighted areas where inequities may arise with existing methods of routine  
19 collection of family health history. The opportunistic enquiry into family health history is more  
20 complex than asking if “*anything runs in the family*” and, with attention to linguistic devices and  
21 acknowledgment of patient social and cultural norms, there is an opportunity to expand history  
22 taking to the point at which the history can become an effective genomic tool.  
23  
24

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30 New Zealand.  
31  
32

## 33 Data Availability Statement

34 No additional data available.  
35  
36

## 37 Author's Contributions

38 SF conceived the idea, led the analysis and drafted all versions of the manuscript.  
39

40 MS contributed to the study design, analysis and manuscript preparation.

41 RG contributed to the study design, analysis and manuscript preparation.

42 BR contributed to the study design, analysis and manuscript preparation.

43 KP contributed to the study design, analysis and manuscript preparation.

44 PW contributed to the study design, analysis and manuscript preparation.

45 RJ contributed to the study design, analysis and manuscript preparation.

46 AD contributed to the study design, analysis and manuscript preparation.  
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## COREQ (CONsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**