

‘I think we just do it once and leave it ...’ The collection and utility of family health history in general practice in Aotearoa New Zealand: a qualitative study

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ABSTRACT

Introduction. The value of family health history as a means to understanding health risk has been long known. Its value in a precision medicine context is also now becoming apparent. General practitioners (GPs) are considered to play a key role in the collection, and investigation, of family health history, but it remains widely reported as being both poorly and infrequently undertaken. Little is known about this practice in Aotearoa New Zealand (NZ). **Aim.** This study aimed to explore current practices in relation to the ascertainment of family health history, with a view towards precision medicine. **Methods.** Semi-structured interviews were conducted with 10 GPs recruited from one urban area of NZ. The interviews were subjected to a thematic analysis. **Results.** Family health history information was used to varying degrees in four areas – risk ascertainment, patient engagement with a diagnosis, social context and building relationships. Patient cultural considerations were rarely mentioned. Reliability of information provided by patients, resource constraints, context driven consults and electronic health record limitations are potential indicators of current limits of family health history. **Discussion.** Our findings present a baseline of current practice and echo larger studies from overseas. As precision medicine is not yet routine, a unique opportunity exists for consideration to be given to establishing specific roles within the NZ health system to enable equitable practice of, and subsequent health gains from, the use of family/whānau health history information as part of precision medicine.

Keywords: collection, equity, family/whānau health history information, General Practitioners, precision health, precision medicine, primary health care, utility.

Introduction

The value of family health history as a means to understanding health risk has long been known.^{1–3} Its value in a precision medicine context is also now becoming apparent.^{4,5} Precision medicine, as defined by the National Institute of Health (NIH), is an emerging approach for disease treatment and prevention that considers individual variability in genes, environment and lifestyle.⁶ Large general population based studies have shown that interpreting data from genomic/genetic screening and testing with a comprehensive family health history significantly increases the accuracy of disease risk estimation⁷ and the likelihood of detecting carriers for cancer syndromes⁸ than either approach would achieve alone. Indeed, family health history has been described as the first genetic test and the ‘fulcrum on which interpretation of precision genomic medicine turns’.⁹

General practitioners (GPs) are considered to play a key role in the collection, and investigation, of family health history, both as first contact with the healthcare system and as coordinator of care.¹⁰ As part of precision medicine, GPs are expected to act on relevant family health history information to identify patients for referral to genetic counselling, provide patient support and coordinate surveillance and management.⁵ This expectation is embedded in core competencies in genomic medicine for GPs and professional recommendations in many different countries.^{11–13}

WHAT GAP THIS FILLS

What is known about the topic: There has been a general expectation internationally that GPs are to play a central role in the collection of family health history as part of precision medicine. However, for more than 20 years it has remained widely reported as being both poorly and infrequently undertaken.

What this study adds: Family health history information was used to varying degrees – risk ascertainment, patient engagement with a diagnosis, social context and building relationships. Perceived low quality (unreliability) of family health history information and accessibility issues are potential indicators of current limits of family health history, especially as a part of precision medicine. An opportunity exists to establish specific roles to enable socio-culturally appropriate collection, storage and use of family health history information.

A comprehensive three-generation family health history is regarded as the ‘gold-standard’ in clinical practice.^{9,14} In addition, family – or whānau – in indigenous Māori as well as other Polynesian cultures, are multi-generational and often involve more distantly related individuals than just first cousins, linking back to common ancestors sometimes many generations beyond grandparents. Internationally the collection of family health history is reported as being variably and poorly done, and infrequently meets the three-generation gold-standard.¹ To date, little is known about this practice in Aotearoa New Zealand (NZ). Understanding this practice in NZ has taken on a new level of importance with moves towards a digital health identity, shared electronic health platforms and most recently a call from the Government about prioritising precision medicine.¹⁵ As such, this study aimed to explore established practices and views towards the collection and utility of family health history.

Methods

Study setting

The study was carried out in a large urban centre in NZ. General practices were identified through our professional networks, an internet search of practices in the area and snowball sampling. Information and invitations to participate in the study were sent to 36 general practices in the area during 3 months in 2019. The interview was semi-structured with prompts to questions exploring views toward the value of family health history, enquiry and processes around collection and documentation (Supplementary Table S1). We specifically sought views about the following professional recommendations: ‘Ideally, a three-generation family history should be collected on all patients where possible, including first-degree relatives (ie children, siblings, parents) and

second-degree relatives (ie aunts, uncles, grandparents) ... including opportunistically’.¹² Interviews were undertaken by RJ and lasted up to 45 min.

Analysis

Transcripts from the recorded interviews were sent to participants for comments and correction. Themes were derived iteratively using a qualitative inductive approach based on the verbatim transcripts.¹⁶ Initially, open coding of transcripts was undertaken independently by RJ (practicing GP) and SF (health researcher). These codes were consolidated through an iterative process of discussion between RJ and SF and cross-reviewing codes with quotes to generate 16 codes, which formed the coding frame for subsequent review of the transcripts. The coding frame was shared with the co-authors and discussed in detail between SF, MS and RJ. The transcripts were then re-read and new codes emerged as preliminary themes. These themes were mapped across all of the transcripts, which were then reread and recoded until no further themes were identified and the final higher level main themes were derived (Supplementary Table S2).¹⁶ These were finalised as presented and agreed between the authors. Direct quotes are included. Analysis of the transcripts was undertaken in NVivo (Version 12).

Ethics

Ethical approval was granted by the University of Otago Human Ethics Committee (Health) Reference: H19/022.

Informed consent

Written informed consent was obtained from all participants.

Results

Ten GPs agreed to participate in the study, who had between 3 and 33 years in practice in primary care and were from practices varying in size and patient population. Of the GPs, nine were in urban practices (three in a high-income area, three in an area with high and low income and three in a low-income area). One GP worked exclusively in adolescent mental health in a rural and low-income area. Only two GPs stated they had received additional training in taking family health history since their primary medical degree.

Two main themes were derived from the iterative analysis (Supplementary Table S2): ‘Added value’ and ‘Accessibility’. Exemplar quotes are provided with further supporting quotes provided in Supplementary Table S3.

Added value

‘Added value’ describes how family health history was used, in particular whether it was seen to add value, or not, in

informing the consultation and treatment plans. The use of family health history information was seen in four areas: ascertaining risk, engaging patients in a diagnosis, potential to know a patient and establishing the social dynamics of a family.

The level of value that the GPs perceived patient family history information to have for informing the consultation and treatment plans was dependent on the degree to which the information shared by patients was seen as being reliable.

Well, I guess what makes it valuable is when it's accurate. Sometimes people give slightly vague family histories. (GP10)

That the information patients would share was unreliable appeared as a default position for GPs, and consequently, the information shared was considered as a guide rather than an absolute.

I think you know that a lot of information is not reliable. So, I don't worry about it. I accept that it's not expected to be reliable, it's an indicator not a proof. So I'm quite relaxed about that sort of stuff. Do not expect too much of it. (GP5)

What constituted reliable information was not directly enquired about. However, GPs commented that validating and/or filling in any gaps in family health history and family history information through input from other family members raised ethical concerns. They also raised that it would be logistically challenging, if not impossible, if family members were at different practices.

Conditions that were enquired about were the 'big stuff' such as cardiovascular history, eg strokes and ischemic heart disease, and chronic conditions such as diabetes. Perceived patient knowledge of cancer was more variable, and also appeared to be related to the type of cancer.

The lack of knowledge of what their family members have had, it's still just an issue as ever. Family members know they've had some kind of cancer [but] really [have] no idea what [type] it was. (GP9)

Family health history information was observed as a useful tool in helping patients understand a condition within a familial context to engage them with the diagnosis as the GP could explain the condition in terms of 'how it tied into their family history'.

In the context of a primary care youth service, the value of family health history extended beyond the collection of medical information and was used more in a social context to better understand a person's family dynamics.

In adolescent health, family history is super important, but not ... from the perspective of genetics ... We don't

necessarily see lots of physical ill health. Family history and behaviour, in terms of what they struggle with and what the dynamic in the family is, is kind of vital for just about every one of the young people that we see. (GP8)

The potential for family health history information to help a GP know more about their patient was evident:

Patients that I don't know very well I tend to glance at [their] classifications. I don't always glance at the history, so I often don't know if that's where it's been classified. I often don't know it's there. (GP1)

This quote also speaks to how family health history information is classified and stored, which is as READ codes (standardised clinical terminology for diagnosis, procedural and symptomatic data) or in a history tab in the patient/practice management system. These classification and storage processes are linked to the theme 'Accessibility'.

Accessibility of family health history information

'Accessibility' refers to *how* family history information was collected; it relates to what information was available, the need to access the information and how accessible it was in subsequent visits or by different people in the practice.

The process of collecting family health history information varied among GPs and within the same practice. Sometimes practice nurses would collect the information, and the content of the information that was collected was not always known by the GP. The collection of family health history information was something that was often described as only being done once.

Every new patient that enrolls has a nurse consult. The nurses have a template they follow for that nurse consult, and one of them is family history. So, they ask is there any relevant family history? Then they'll record it in that initial consult template, or appointment block. If it's quite relevant they may put it into classifications but not [very] often. (GP4)

In terms of what was viewed as being relevant information, emphasis was placed on first degree relatives (information beyond first degree was not frequently enquired about). The approach to collecting this information was not systematic and described using terms such as 'pretty loose', and was often patient initiated.

Only one GP considered cultural aspects to the collection of family health history, which they felt may impact how information was collected.

So, I think that ... one of the things about gathering family information, a lot of it is about dealing with potential future stuff ... that's a culture bound

phenomenon, which does not apply for every culture ... there are some it applies to and some it does not. (GP7)

In terms of how the information was stored and subsequently accessed (accessible), all the GPs used MEDTECH® as their practice management system (PMS). This was not user-friendly and did not facilitate the collection of health history information:

... I'm always struggling to classify because it's not easy to do and particularly when you're in a rush. And the PMS [patient management system] does not make it easy. I think that's one of our biggest barriers. (GP5)

As indicated from the above quote, having the time to work within the constraints of the system was not always possible. Having time within the consultation to enquire about family health history information was also not always possible. As one GP shared:

... invariably because of pressures of time it [family health history] might be one of the last on the list that we will omit. (GP6)

If GPs were to, or did, construct a family tree (pedigree) of health history information it was/would be on a piece of paper with little or no further use.

... [Family pedigree is] a scanned document that never gets referred to again. Do you transfer that into classifications or what happens to that? It's just how it would practically work. (GP9)

However, the need for ready access (and therefore any value added) to a patient's family health history in the context of meeting their patient population needs was perceived to be minimal – 'in terms of everyday stuff, almost zero' (GP7), and further expanded:

Obviously if they come in with a stubbed toe, you're not going to go into a lot of family history. (GP3)

Additionally, the need for accessing family health history information was influenced by how well the GP knew the patient.

That would depend on the context. In your 15-minute consult there's a limited amount of time. So, if it was a new patient I'd go through it as part of the general history, but as we get to know the patient it kind of depends on what's brought up and what they come in with. (GP3)

As the above describes, enquiring about, or having access to, family health history information could help establish a

relationship with a new patient. Over time, such knowledge about a patient is established and is not necessarily formally documented, nor enquired about, after an initial consultation, given the aforementioned accessibility constraints and the degree of value this information would add to the consultation and treatment plans.

Precision medicine context

GPs were specifically asked about the recommendation that routine, opportunistic and systematic collection of family health history up to three generations is best practice in a precision medicine context. Any expectation that this would become normal practice in the current paradigm did not align with the lived realities of GPs and patient needs (as evidenced from the above) and further, was viewed as impeding their ability to provide care:

They can recommend anything they like. That fits into the number of other things that people tell me how to do my job, which if I tried to do them all I'd never see any patients ... the odds of me ever sitting down to write a beautiful family tree for three generations for any of my patients, versus seeing acutes, is about zero. (GP7)

Responses to this recommendation identified that specific funding with appropriate resourcing, including workforce capacity, would be needed in order to implement it. However, the value/need of having family health history information in a precision medicine context was not apparent to the GPs interviewed.

Discussion

This study explored established practices and views towards the collection and utility of family health history in a sample of GPs in NZ. The study also explored the views of these GPs towards the collection of family health history in relation to professional recommendations, with the view that such practice guides will be introduced as NZ moves towards precision medicine. Our findings highlighted four areas of current practice where family health history information was used to varying degrees – risk ascertainment, patient engagement with a diagnosis, social context and building relationships. However, the perceived low quality (unreliability) of family health history information that was ascertained, and accessibility issues, are potential indicators of current limits of family health history, especially as a part of precision medicine.

Strengths and limitations of the study

This was a small study, the findings from which may not be generalisable to other practices throughout NZ. The findings

from the research are Euro-centric, and future research needs to prioritise Māori and other Polynesian cultures (as discussed below). Nevertheless, although the study involved a small number of GPs, they work with diverse patient populations. Moreover, some clear themes emerged, consistent with those found in overseas studies, such as barriers relating to information technology and lack of reliability of patient information.^{14,17}

The PMS used by GPs in this study was limited to MEDTEC[®], and it will be important to explore how other electronic health records (EHRs) compare, and the quality of data entered into the health record. Health system constraints such as limited consultation time and limitation of information technology (specifically PMS) and EHRs are consistently, and universally, reported as the main barriers to the ascertainment of family health history information.^{18,19} Another barrier identified in our study is that GPs perceive that the information provided by some patients is vague and unreliable, also echoing findings from overseas.^{17,20,21} However, there is growing evidence that patient knowledge might be more accurate than perceived, especially for some conditions such as breast cancer.^{22–24}

It is important to discuss family/whānau health history in relation to the health initiatives that were raised in the Introduction, with particular contextualising of some socio-cultural considerations necessary to achieve the health equity that precision medicine promises.

Collecting family health history information is not straightforward. Enquiring can bring up a range of emotions, for example, anxiety if the patient is approaching a similar age to a family member who was diagnosed, and some conditions are not discussed openly within families. Socio-culturally there are also multiple meanings of 'family' – beyond a dominant Western view. There are also varying beliefs about what 'health' and 'illness' means.^{25–29} Efforts to facilitate dialogue and recollection of family health history information during a consultation should focus on socio-cultural responsiveness and appropriate styles of interaction.¹⁴ Such approaches consider peoples' (patients') perception of, and response to, a request for sharing information about members of their family.^{25–28,30} Ethical and privacy issues involving information on patients' records about family members were also raised in our findings which are complex to navigate and manage.^{9,31–33} Increasingly the expectation is that solutions are to be co-created and developed with patients/people.^{34–36} Such discussions, and the need for resolution, are gaining urgency in NZ particularly in light of moves toward a health and wellbeing information platform named 'Hira'.³⁷ Hira will enable information to be pulled from different sources, eg national datasets and GP PMSs, to create a persons' (personal) health record. This record would be accessible by healthcare providers and could be accessed by other people, such as family/whānau and third parties such as health insurers.³⁷

There is a particular consideration in NZ regarding Māori data sovereignty which 'recognises that Māori data should be subject to Māori governance. Māori data sovereignty supports tribal sovereignty and the realisation of Māori and Iwi aspirations'.³⁸ With a move towards a national health platform, and associated development of a Health Digital Identity (as My Health Account³⁹), it is currently unclear how the relationship between individuals, their family/whānau (extended kinship network) and healthcare practitioners and the use and access (including by third-parties) of family/whānau health history information, and any associated DNA information, will be managed.

Research is underway in NZ that explores the combination of genomic data and health records from relatives in a Māori community context, potentially expanding the utility of whakapapa (genealogical histories) (see <https://www.genomics-aotearoa.org.nz/projects/rakeiora-pathfinder-genomic-medicine>) which will help inform such practice. Decision making within whānau is often – but not always – collective,^{40,41} necessitating further considerations regarding who has the right to collect and access such information. Similarly, posthumous use of EHRs across all ethnicities also requires additional consideration which may involve developing bespoke protocols.⁴² For example, in te ao Māori the central unit is often the whānau, rather than the individual. Whānau span across and over multiple generations, thus the maintenance and incorporation of posthumous information from tūpuna (ancestors) may be more relatable to Māori than non-Māori. There are also specific applications of family health history that can improve risk estimation for clinical and/or research applications. For example, estimating polygenic (disease) risk scores using health information from non-genotyped relatives is significantly more cost effective than establishing large biobank-scale populations typically required for sufficiently accurate disease risk estimates from unrelated individuals,⁷ and thus more appropriate for tribal populations whose members share (often multiple) common ancestors.

Our findings present a baseline of current practice. The advantages of taking a more detailed type of health history collection are becoming more apparent as genetic risk knowledge increases and cost of testing decreases, all of which may facilitate timely access to genetic investigation/treatment and potentially inform lifestyle changes.^{5,10,43} It is likely from overseas experience that guidelines for standards for family/whānau health history ascertainment will be developed in NZ as part of practice in the future. With that in mind, and informed by the aforementioned research and socio-cultural considerations, we have outlined current practice, challenges and implications of, and proposed some ideas to develop capability around, the ascertainment of family health history in the context of moving towards precision in primary health care (as summarised in Table 1).

Table 1. Summary of current practice, challenges and implications of, and ideas for developing capability around, the ascertainment of family health history in the context of moving towards precision medicine.

Four areas of current practice	Challenges in Current practice	Implications	Embedded health equity and culturally safe solutions
1. Risk ascertainment 2. Patient engagement with diagnosis 3. Social context 4. Building relationships	<p>Patient level</p> <ul style="list-style-type: none"> Perceived unreliable information provided by patients <p>Healthcare professional level</p> <ul style="list-style-type: none"> Usually collected at first patient enrolment by GPs during consult or by practice nurse Mostly restricted to common conditions Infrequent collection and inconsistent or no updating Resource constraints eg time for information collection <p>Health service provider/practice level</p> <ul style="list-style-type: none"> Accessibility issues (eg IT, electronic record) Resource constraints eg time Variation between and within practice regarding what data are collected Inability to collate information across practices <p>System level</p> <ul style="list-style-type: none"> No standardised tools for data collection No contribution of family health history information to national-level database or risk estimation tools No ascertainment of family health information across practices No tools to facilitate standard contribution to diagnoses 	<ul style="list-style-type: none"> Patients placed in credibility deficit Missed opportunity for actionable family health history Variation in socio-culturally safe practice Inequity in use and potential health gain 	<p>Patient level</p> <ul style="list-style-type: none"> Patient/family/whānau informed health history collection initiatives <p>Healthcare professional level</p> <ul style="list-style-type: none"> Increase attentiveness to enhance and enable recollection among patients eg linguistic devices Continuing education programmes eg ethical, socio-cultural and legal competencies <p>Health service provider level/practice level</p> <ul style="list-style-type: none"> Change how family/whānau health history is collected in practice eg advance notice given to patients that may be asked about family health history; opportunity to add information whilst in the waiting room Standardise collection Explore familial/whānau level confidentiality <p>System level</p> <ul style="list-style-type: none"> Public engagement National family/whānau health information promotion strategy Establish system readiness eg socio-cultural license around data use, access and storage Develop effective digital tools and interoperability with and among electronic health records, national datasets and risk estimation tools

Conclusion

As precision medicine is not yet routine, a unique opportunity exists for consideration to be given to establishing specific roles within the NZ health system to enable equitable practice of, and subsequent health gains from, the use of family/whānau health history information as part of precision medicine – we must not miss it.

Supplementary material

Supplementary material is available [online](#).

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