

## Supplementary Material

### **‘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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## Supplementary Table S1. Topic guide

1. What makes family history a valuable tool in your opinion?
2. When and how would collect family history information?
3. What information are you enquiring about and how much detail do you go into?
4. How is it recorded? (e.g. family tree drawing or in notes, updates in classifications, etc.)
5. How do you interpret the data in regards to possible genetic risk?
6. What issues have you encountered when discussing or collecting family history information, especially in varying cultural contexts?
7. Are there barriers to collecting and/or interpreting family history for you?
8. What are your views about the the following professional recommendations from the Royal Australian College of General Practitioners: *“Ideally, a three-generation family history should be collected on all patients where possible, including first-degree relatives (i.e., children, siblings, parents) and second-degree relatives (i.e. aunts, uncles, grandparents) ...including opportunistically”*

**Supplementary Table S2. Thematic structure**

| <b>Initial inductive codes</b>  | <b>Initial themes</b>  | <b>Final themes</b> |
|---|--|---------------------|
| <b>Application</b>  | Collection   | Added value         |
| <b>Collection</b>   |  |                     |
| <b>More than genes</b>  | Utility  |                     |
| <b>Disease</b>  | Low priority   |                     |
| <b>Different views</b>  | Goes nowhere   |                     |
| <b>Facilitator</b>  |  |                     |
| <b>Patient driven</b>   | Patient condition  |                     |
| <b>Patient acceptability</b>  | Confidentiality<br>Unreliable<br>Vague   |                     |
| <b>Barriers</b><br><b>Confidentiality</b><br><b>Education</b><br><b>Goes nowhere</b><br><b>Overstretched</b><br><b>Resource poor</b><br><b>Time</b><br><b>The mechanics</b> | Overstretched<br>Resource poor<br>Time<br>The mechanics<br>Ethical and cultural considerations | Accessibility       |

**Supplementary Table S3. Exemplar quotes by main and sub-themes**

|   |  |
|---|--|
| <b>Value added</b>  |  |
| <b>Ascertaining risk</b>                                      | “And when I’m seeing <b>people with particular issues</b> , so in my practice- so skin- if I’m seeing someone with a skin thing I always ask if there’s a family history of skin cancer and melanoma.” GP1   |
|   | “That might be passed down through the generations...common ones would be something like <b>bowel cancer, early heart disease</b> , some people will present with odd conditions that also have a genetic thing...cystic fibrosis might be one..., thyroid disease...things that you think will run in a family and therefore are worth knowing about because that would be to look earlier in those others coming through.” GP10  |
| <b>Unreliable and vague information</b>                       | “So, patients will bring in that stuff. And patients often I think...overestimate too how that stuff works, so they’ll often throw in unrelated cancers, mix them all together and say I’ve got a high risk of cancer...talking about that stuff is often helpful or it might be,... my great great-grandparent, someone quite a long way removed from them, but they’ve imported that as a high risk when it’s not really because say the diseases are common,... <b>that they’ve got a third degree relative is not particularly relevant...</b> ” GP2 |
| <b>Accessibility</b>  |  |
| <b>Information sought</b>                                     | “ <b>I normally just do the big stuff.</b> I find out number of siblings, whether parents were alive or dead, what their parents died of and what age...just throw in an extra question about heart disease, diabetes, cancers primarily. People will often offer other things.” GP 2  |
| <b>Collection</b>   | “...when the patients are enrolled there’s <b>some gathering</b> of information on their enrolment form....” GP 10   |
|   | “We’d generally discuss back to grandparents... then it would come down to what people offer probably more than... in terms of aunts, uncles, brothers and sisters....depending on the disease and what’s prompted the discussion,... as a general history particularly a new one,...we would- <b>in a broad sense...it’s ...pretty loose</b> , wouldn’t probe particularly what was this person, that person, the other.” GP9   |
|   | “...we don’t have the time or resources but to update it. ...we’ve asked family history on people who’ve been in our practice 20 years ago and things have moved on a lot. <b>We don’t update it unless it is patient issue initiated...we’re not really being systematic. I think we just do it once and leave it ...</b> ” GP5   |
|   | “I would say <b>I find that the relevance is more first degree</b> ...my grandma had a heart attack’, I don’t really think that’s of that high importance... unless grandma was very young or her daughter or the patient’s mother had an issue....” GP4   |
| <b>Electronic health record and patient management system</b> | “... <b>the PMS is dreadful on family trees</b> , I was trying to do one in my last practice and we just couldn’t manage it,...we tried to put a family tree in place ...and it’s got to be made easy for us to be able to use it...I’ve tried and failed on that.” GP5  |
|   | “...the fact that the ways of documenting it, whether it’s done through a READ   |

|                                    |  |
|------------------------------------|--|
|                                    | code classification or it's put in the tab for history, are <b>not necessarily the same for everybody.</b> " GP10  |
| <b>Within practice variability</b> | "...the other GPs are putting it in history, so <b>I'm now starting to put it in both if I remember...</b> but classifications is the one I always go to so that's where I historically have always put I,t and that's where I go to look for it." GP1   |
| <b>Privacy</b>                     | "The major one is that if you have an important trait is how you do a genogram...and where it sits... it contains information about more than one patient and <b>we're very individual patient focused here and consent... is valued, and access to notes means that if I put information into this patient's notes that includes information from someone else they have a right,</b> actually to the content of the information when they notice it applies to them." GP7  |
| <b>Precision medicine context</b>  |  |
|                                    | "I guess it would be somewhat useful to have ( <i>family tree</i> ) that kind of thing, but in reality, not many people would have time to do that. Having a discussion to help a patient put things in perspective in their family history. That's more important to me than following a college guideline that says do a three- generation family tree. I think that's kind of a nonsensical- unless they wanna' pay us for half an hour of time to do that, and patients necessarily gonna', wanna' do that." GP2 |