Big data or big risk: general practitioner, practice nurse and practice manager attitudes to providing de-identified patient health data from electronic medical records to researchers

Timothy Monaghan\textsuperscript{A,B}, Jo-Anne Manski-Nankervis\textsuperscript{A} and Rachel Canaway\textsuperscript{A}

\textsuperscript{A}Department of General Practice, Melbourne Medical School, The University of Melbourne, Vic. 3010, Australia.

\textsuperscript{B}Corresponding author. Email: tim.monaghan@unimelb.edu.au
Appendix S1. Interview schedule

Note that interview schedule is only indicative and will be tailored based on the interviewee e.g. GP, practice nurse or practice manager.

Hi, thanks very much for agreeing to participate in this study and for returning the Consent Form and Pre-Interview Questionnaire. Before we start, I wanted to clarify how much time you have available for this interview? I’d also like to remind you that we are audio [or video] recording this session. The recordings will be stored securely and separately from any identifying information and will only be used by the researchers.

The aim of this project is to explore general practitioners’, practice nurses’ and practice managers’:

(a) attitudes and beliefs about the sharing and use of deidentified patient health information for the purposes of research; and

(b) perceived barriers to and facilitators for the provision of deidentified patient health information for the purposes of research.

Do you have any questions before we start?

<table>
<thead>
<tr>
<th>Topic</th>
<th>Question/s</th>
<th>Prompts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline attitude to providing de-identified patient health information for research</td>
<td>How do you feel about research using de-identified patient health information from general practices?</td>
<td>- Aware of data extraction software that can automatically extract information from programs such as Medical Director?</td>
</tr>
</tbody>
</table>
| Understanding of the process of data-extraction from electronic medical records and consent requirements | a. What is your understanding of how patient data are de-identified and extracted from electronic medical records?  

b. What types of patient healthcare data do you believe are extracted?  

c. What, if any, type of consent do you think patients need to provide? How do you feel about this? | - Aware of what patient information is removed for de-identification? (e.g. names, DOB, address)  

- Examples of consent include individual written/verbal consent, being notified through a flyer etc in the practice. |
| Perceived utility of research using de-identified patient health information | a. How useful do you think the patient data in electronic medical records would be for research?  
  b. What do you think about research based on de-identified patient health information from electronic medical records? | - What kind of problems do you think there are with data in electronic medical records?  
  - What kinds of research do you think could be done using this patient data? |
| Perceived benefits from providing de-identified health information for research | Could you tell me about any key benefits you feel there are to providing de-identified patient information for research? | - Any benefits for your relationship with your patients?  
  - Any benefits for your clinical practice?  
  - Any benefits through contributing to the wider body of research?  
  - What, if any, benefits for patients do you anticipate? |
| Perceived risks and downsides of providing de-identified health information for research | a. Please tell me about any risks you are concerned about in providing de-identified patient health information for research?  
  Are there any other downsides you feel to agreeing to provide de-identified patient health information? (e.g. time and effort involved?) | - Any risks for your relationship with your patients?  
  - Any legal risks associated?  
  - Any concerns about confidentiality or re-identification?  
  - Any reputational risks associated? |
| If it was (or is) the participants decision, would they provide de-identified patient health information for research? | a. Do you know if your practice currently provides or has previously provided de-identified patient health information for research?  
  b. Who do you think in your practice is (or would be) involved in the decision to provide de-identified patient health information for research?  
  c. If you were (or are) in the position to decide whether to share de-identified patient health information for |
research, do you think you would do so?
- If so, what is the key driving factor for why you would?
If not, what is the key reason why you would not? In what ways, if any, could this issue be overcome?

<table>
<thead>
<tr>
<th>Opportunity to raise any other points</th>
<th>Is there anything else that you would like to say about sharing de-identified patient health information for research purposes?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Transcript</strong></td>
<td>Would you like to receive a copy of the transcript of this interview?</td>
</tr>
</tbody>
</table>