Appendix 1. Focus group demographics

Note: This appendix is published as supplied and is unedited by *AJGP*.

Characteristic	N
Gender	
Female	11
Male	11
Geographical area	
NSW	7
VIC	7
QLD	4
SA	1
WA	3
Age (years)	
<29	10
30-54	5
65+	7
Highest level of education	
Secondary school	7
TAFE college	6
University degree	7
University post-graduate	2
Employment	
Working part time	4
Working full time	11
Retired	3
Unemployed - looking for work	2
Student	2

Appendix 2. Focus group guide

Note: This appendix is published as supplied and is unedited by *AJGP*.

6.30pm

1. **Introduction** (10 minutes)

- Welcome and thank you for coming
- Team first - introduce yourself and tell everyone what you will be doing – then mics and cameras off
- Today we are talking about **using the information that is held in general practice records for research purposes**
  Researchers often talk about this information as 'health data'. We will be using both words 'information' and 'data'.
- This focus group will last for about 1.5 hours, and we have a series of scenarios and activities to work through together.
- At the end we'll remind you about your gift cards
- Check to see if participants have their information pack[1] at hand
- Recording: We will be recording – we will delete the video file – audio kept secure – any identifying information removed.
- Reminder regarding group work – please remember that this is a confidential space and personal details should not be shared outside the group. It is best not to share personal details.
- No right or wrong answers
- Be respectful of other people and try to help other people to contribute.
- Questions?
- ALL OK TO PROCEED?
  WE'LL TURN THE RECORDING ON NOW BELINDA.

2. **People introductions and warm-up**

- Then participants:
    - Name & something that you like doing in your spare time
    - What made you decide to attend today?
    - When was the last time you gave someone data about yourself?
    - What is one piece of *health* data, generally speaking, that you have shared in the last year?

Today we will be working through a set of 3 scenarios or case studies about general practice data. You've received these scenarios in your information pack. Let's go to the first one now.

3. **6.40pm**
   GP data (20 minutes)

Scenario 1:

Maria is 65 years old. She has Type 2 Diabetes and Heart Disease. She and her husband have been attending the same general practice for thirty years. Today, she goes to see her GP to get repeat prescriptions for her diabetes and heart medications. The GP takes notes on the computer in Maria's health record.

---

[1] Documents sent about 1 week earlier

What information, in general, is held in Maria's health record?
Prompts

- *What personal information? (Age, gender, address)*
- *What about things in the past? (Medical history, lifestyle factors)*
- *Symptoms, Examination, test results (pathology and radiology)*
- *Diagnoses*
- *Treatment*
- *Referrals, hospital admissions information*
- *Social factors (family, employment, life stressors etc)*
- *Information about other people (family)*
- *Information from other professionals*

What information do GPs have about patients that they do ***not*** *include in their patients' health records? Why?*

Now, I would like to make the situation a little different. In your information pack this is scenario 2:

Scenario 2:

Maria returns to see her GP four weeks later with an injured and badly infected toe. Her GP refers her to the local hospital for admission because she is worried Maria may lose her toe.

Maria has visited the hospital a number of times, including to see a heart specialist. In the Emergency Unit the doctor makes notes in Maria's hospital record.

Now, I'd like you to think about the information in Maria's hospital record. What information in the hospital record will be similar to what is in the GP record?
What information would be different?

Reminder of information they have already discussed:
Prompts

- *What personal information? (Age, gender, address)*
- *What about things in the past? (Medical history, lifestyle factors)*
- *Symptoms, Examination, test results (pathology and radiology)*
- *Diagnoses*
- *Treatment*
- *Referrals, hospital admissions information*
- *Social factors (family, employment, life stressors etc)*
- *Information about other people (family)*
- *Information from other professionals*

If don't touch on broader contextual factors, consider these prompts:

- *Continuity*
- *Length of time*
- *Social information*
- *Information about other people in relation to patient*
- *Sensitive information*

4. 7.00pm

Sharing GP data (30 minutes)

*Now, we're going to talk about **sharing** the information in **general practice records**. We're going to talk specifically about a form of sharing which collects together health care records from lots of patients. This is scenario 3 in your information packs.*
This scenario has three specific examples of how information taken from GP records can be shared.

Scenario 3:

Maria's GP, along with all the other GPs in the practice and surrounding practices, has agreed to provide their patient records to contribute to a government funded program that aims to create a picture of all of the health care that people in Australia receive and the outcomes they experience. The names, addresses and dates of birth are removed from the individual patient records before they are shared.

At the moment, the program is particularly interested in patients with Type 2 Diabetes. Below are four examples of how information from people like Maria who have diabetes is shared.

a) The information about patients with diabetes (without their names, addresses and dates of birth) is shared with staff in a government department who compile a report for each GP taking part in the program. The GP receives a report comparing her patients diabetes outcomes are doing compared the patients of all other GPs in the state.

b) The information about patients with diabetes (without their names, addresses and dates of birth) is shared with staff in a government department. Government staff use information to prepare a report on planning where to put new diabetes services and what sorts of services to provide.

c) The information about patients with diabetes (without their names, addresses and dates of birth) is shared with researchers in a university. Researchers use information to see if they can predict what might make someone's diabetes get better or worse.

We will talk about each of these examples in turn.
I'm going to ask you what you think about sharing the information in these GP records for each of these examples.
You should also have some dots in your information pack –green, red and orange. I'd like you to use these when we're talking about each example.

Let's start with the first one – A.
Does anyone have any questions about the people and activities in this example?
Do you think it is okay to share the information from the GP records for this purpose?
If you think it is okay, put a GREEN dot next to the example; if you think it's not okay, use a RED dot.
If you're not sure, use an ORANGE dot.
GREEN: 'yes, okay to share'; RED: 'no, don't share'; ORANGE: 'not sure' categories

Ask who put a green dot? Then ask for one reason why.
Who put a red dot? Ask for one reason why.
Orange dot? Reason why.

Redo same activity for each example B and C.

Moderator assistance: Make a note / tally of the numbers of the participant responses for each example.

DISCUSS most green dots, most red dots, most orange dots and why?
Talk about patterns:
Spontaneous views / questions about how acceptable to share
Which examples most acceptable? Least acceptable?
How do each of the following shape views?

- *Who the data recipients are (government, researcher)*
- *What the data will be used for (quality assurance, health services, research, safety)*
- *Who is likely to benefit GP, government, researcher, community*)*
  **what sorts of possible benefits for the community?*
    - *Better diagnosis, treatment and cure of diseases*
    - *Prevention of ill health*
    - *Population health improvements*
    - *Improved allocation of resources*
    - *Economic growth*

What if the data shared were about mental health problems? Domestic violence? How would this shape views? Why?

What other things might be important to you in deciding whether it is okay to for this information to be shared?

What concerns do you have about sharing information?

- *Trust (in GP, government, other data recipients)*
- *Views on how well data are protected/safeguards*
- *Personal privacy*
- *Data security/loss*
- *Unauthorised access*
- *Re-identification*
- *Discrimination/prejudice*
- *Lack of control*
- *Data misuse*
- *Access to results by public*

If not already covered, ask about consent:
We haven't talked about getting consent from patients to use their information in these ways.
There are different ways you can seek consent to use people's health information.

- Opt-in – the GP asks Maria if she is happy for her information to be shared
- Opt-out – There is a poster on display in the practice that explains patients' information will be shared. Patients can tell someone in the practice that they don't want this to happen
- Waiver – There is a poster on display in the practice that explains patients' information will be shared.
- Waiver and no information

Ask about views on which of these options is most acceptable.

What if there were an oversight committee who made decisions about who should access data and under what circumstances, would you be happy to let them make decisions on your behalf?
Or would you want to be asked?

5. 7.30pm
Data linkage (25 minutes)

We have one more example of sharing information from GP records that we would like you to talk about.

Scenario 4:

A special coordinating unit brings together some of the general practice data about each patient with other health information about the same patient from other general practices, emergency departments, public and private hospitals, other health professionals such as physiotherapists and occupational therapists, and ambulance records. Remember that there are no names, addresses, and dates of birth included when this information is shared.

> 1) A researcher looking at outcomes for people with Type 2 diabetes and heart disease would like to analyse data covering all general practice visits by people with diabetes.
> **Q: Is it okay to link information about a person from one general practice with their information from another practice?**
>
> 2) Researchers want to combine data from hospital records, general practice records and other health professional records, to answer a wide range of questions about diabetes and heart disease in the community.
> **Q: Is it okay to link information about a person from all of these records (general practice, hospital, other health professionals and ambulance)?**

You should have two more sets of red, orange and green dots left. For this example, if you think it is okay to share the information in this way, use a GREEN dot; if you think it's not okay, use a RED dot. If you're not sure, use an ORANGE dot.
GREEN: 'yes, okay to link; RED: 'no, don't share'; ORANGE: 'not sure' categories

After participants have chosen, **DISCUSS** how many green dots, red dots, orange dots and why?

Moderator assistance: Make a note / tally of the numbers of the participant responses for each example.

Does the fact that general practice information will be linked to information from other sources make you think differently about sharing the GP information? Why? Why not?
Does reporting findings by, say, postcode make you think differently about sharing the GP information? Why? Why not?

6. 7.55pm
Influencing policy (5 minutes)

Imagine you had an opportunity to speak to the person who runs the government department that is collecting and sharing general practice information and linking it to other health, education and social service records.

What message would you want to give them about sharing and linking GP data?

7. Close (1 minute)

LC or BF to discuss gift vouchers (emailed tomorrow, please contact us if not received) Thanks Close

Appendix 3. COREQ

Note: This appendix is published as supplied and is unedited by *AJGP*.

Research team and reflexivity	
Personal characteristics	
Interviewer/facilitator	Lead author ABM facilitated all focus groups
Credentials	PhD (Bioethics) BMedSci
Occupation	Head of School of Health and Society, University of Wollongong
Gender	Female moderator x 1, female research assistants x 2, 2 x female observers, 2 x male observers
Experience and training	Professor Braunack-Mayer is a bioethicist, with extensive experience in the use of qualitative research methods to explore public health issues, including data linkage, obesity, immunization and pandemics. Previous work includes research on the place of privacy and confidentiality in medicine and public health, the role of ethics in the education of medical students, and the relationship between ethics and health technology assessment. Prof Braunack-Mayer's initial research training was in general practice ethics, which developed her sensitivity to the specific ethical issues that arise in general practice. Subsequently she provided research advice and evaluation support to general practice organisations and taught ethics to GP trainees. Her understanding of general practice may have influenced her interpretation of participants' views on information access in their medical records. Prof Braunack-Mayer's experience as a medical ethics teacher, including her focus on ensuring that students understand the importance of informed consent, may have led to her placing greater emphasis on the need for community understanding. Given her experience and position, it was crucial for her to respect participants' views and ensure their voices were authentically represented.
Relationships with participants	
Relationship established	No relationship prior to the focus groups
Participant knowledge of the interviewer	Participants received a Participant Information Sheet (PIS) which described the moderator's role and provided contact details e.g. 'lead Chief Investigator Professor Annette-Braunack-Mayer at abmayer@uow.edu.au'
Interview characteristics	Participants were provided with a brief introduction in the PI: 'We are undertaking focus groups to investigate community knowledge, attitudes and values with respect to use of people's general practice data being used for research purposes, as well as through linking general practice data to other data sources.'
Domain 2: Study design	
Theoretical framework	
Methodological orientation and theory	Focus groups have their methodological origins in marketing and social research. They are designed to encourage discussion in a supportive

	environment and non-confrontational way to understand people's perspectives, attitudes and values (Kitzinger, 1995, and Morgan, 1997). In this project, the theoretical framework for the focus groups is empirical bioethics, focusing on how the participants' knowledge, perspectives and values interact. **References** Kitzinger J. Qualitative Research: Introducing focus groups BMJ 1995; 311 :299 doi:10.1136/bmj.311.7000.299 Morgan, D. L. (1997). *Focus groups as qualitative research*. SAGE Publications, Inc., https://dx.doi.org/10.4135/9781412984287
Participant selection	
Sampling	Sampling for focus groups follows a qualitative (purposive) rather than a quantitative (representational) sampling strategy. Our aim was to constitute broadly inclusive groups, with a range of ages (18 years+), genders, SES and cultural backgrounds, from a range of geographic areas nationally, including urban, regional and rural), in order to recruit as diverse a sample as possible.
Method of approach	We employed an experienced Australian market research company, McNair yellowSquares (https://mcnair.com.au/), to recruit a sample of 24 participants from their opt-in online panel. McNair yellowSquares were asked to secure a diverse sample with respect to gender, age, geographic residential location (rural, regional and urban), national spread, educational qualifications, employment and cultural background. Only panel members 18 years and older were invited. We excluded potential participants with current or previous experience(s) employed in a general practice setting to limit the impact of firsthand knowledge of data sharing practices in general practice. Using a screening survey, participants were purposively selected from MacNair yellowSquare's panel to meet these requirements.
Sample size	24 participants were recruited (22 participants took part in the focus groups)
Non-participation	2 participants failed to attend on the day despite recording verbal consent to participate in the week before hand.
Setting	
Setting of data collection	On-line Focus group via Zoom
Presence of non-participants	The moderator (ABM) and two members of the research team (BF & LC) plus one observer per group
Description of samples	Focus Group 1 - All female group (25 years+), Focus Group 2 - All male group (25 years +), Focus Group 3 - Mixed group all ages (25 years +), Focus Group 4 - Young persons' group (18 – 25 years),
Data Collection	
Interview guide	A moderator guide was developed for the research team and moderator use. A participant information pack was posted out one week ahead of the focus groups.

	The focus group was pilot tested and minor amendments to the discussion/ moderator guide made after the pilot.
Repeat interviews	Four focus groups were held in total, within a 2-week period.
Audio/visual recording	All focus groups were audio recorded and transcribed.
Field notes	Notes were taken during the focus groups by a research team member.
Duration	Focus groups were 90 minutes in duration
Data Saturation	Data saturation was discussed, and determined to have been achieved by the fourth focus group
Transcripts returned	Transcripts were not returned to participants for comment and/ or correction
Domain 3: analysis and findings	
Data analysis	
Number of data coders	Two members of the research team (ABM & LC)
Description of the coding tree	The coding tree focused on concepts related to: awareness and understanding of the content of GP and hospital records; support for sharing and linkage (including the perceived benefits); concerns about sharing and linkage; conditions and controls on sharing and linkage
Derivation of themes	Themes were both proposed in advance and also derived from the data
Software	Microsoft Word, Excel and NVivo were used to manage the data
Participant checking	Participants did not provide feedback
Reporting	
Quotations presented	Quotations from focus group participants are presented to illustrate findings and are identified with a focus groups and participant number
Data and findings consistent	There was consistency between the data presented in the literature search and the focus group findings.
Clarity of major themes	Major themes are clearly presented in the findings.
Clarity of minor themes	Minor themes are clearly presented in the findings.

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Appendix 4. Online survey instrument

PAGE 1

Eligibility Criteria

We are asking the following three questions so that we can check how closely our sample matches the whole population of Australia

1. With which gender do you most identify? One response only

☐ Female
☐ Male
☐ I prefer not to say

☐ Non-binary
☐ I prefer to describe:___________(free text 50 characters)

2. How old are you? Insert numerals only. Please program for responses 17 and under to be immediately exited from the survey.

___________ in years

3. Where do you currently live? One response only

☐ Greater Sydney
☐ Rest of NSW
☐ Greater Melbourne
☐ Rest of VIC
☐ Greater Brisbane
☐ Rest of QLD
☐ Adelaide
☐ Rest of SA
☐ Perth
☐ Rest of WA
☐ TAS
☐ Northern Territory
☐ ACT

PAGE 2

Participant Information Sheet

Please read the Participant Information Sheet below:

(Participant information sheet will appear on this page within the survey)

☐ Please tick the box to indicate you have read and understood the Participant Information Sheet Participant to indicate by ticking box

If you would like to view and/or download and/or print the Participant Information Sheet please go here. This link will send participant to a PDF version of Participant Information Sheet.

PAGE 3

Section A: Patient information in general practice

Please watch this video before answering question 4 link to video 1 (mandatory – able to be replayed)

Video 1 text:
In Australia, general practitioners (GPs) are the first and primary source of health care for most people.
Information about you is recorded in your general practice record, mostly in computers.
The record may include your symptoms, what the GP finds when they examine you, your blood test results, diagnoses, medications and other treatments, and communications with other health professionals.
The record may also include non-medical information, such as aspects of your personal life, work life, and/or family situation.
GPs sometimes share the information in patient records with other people and organisations.
Everyone who handles your information is covered by privacy laws or privacy principles as well as other legal obligations to protect the information in your record.
Information in your general practice record can only be shared for specific purposes.
In answering the first set of questions, please assume that the GP and everyone your information is shared with will abide by all relevant laws and will do everything they can to minimise risks to your privacy.
However, it is still possible that you may be identified from some of the information shared about you.

We are interested in understanding who you think your general practice information is being shared with and whether you agree with this.

In answering these questions, please assume that the GP and everyone your information is shared with will abide by all relevant laws and will do everything they can to minimise risks to your privacy. However, it is still possible that you may be identified from some of the information shared about you.

4. Do you think information from your general practice record is being shared with the following people?

Answer all items. One response per row.

	Yes	No	I do not know
(a) Me			
(b) My immediate family members			
(c) Other staff in the general practice, e.g., other GPs, practice nurse,			
(d) Hospital health professionals e.g., doctors or nurses			

(e) Emergency personnel e.g., ambulance staff			
(f) Other medical specialists, e.g., surgeon, cardiologist			
(g) Allied health professionals, e.g., pharmacist or psychologist			
(h) Health administrators and planners in government			
(i) Researchers in a university			
(j) Researchers in a government department			
(k) Health researchers in private industry, e.g., a pharmaceutical company			

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Please click here if you would like to watch the video 1 again link to video 1 (not mandatory – able to be replayed)

5. To what extent do you agree with information from your general practice record being shared with the following people?

Answer all items. One response per row.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
(a) Me					
(b) My immediate family members					
(c) Other staff in the general practice, e.g., other GPs, practice nurse,					
(d) Hospital health professionals e.g., doctors or nurses					
(e) Emergency personnel e.g., ambulance staff					
(f) Other medical specialists, e.g., surgeon, cardiologist					
(g) Allied health professionals, e.g., pharmacist or psychologist					
(h) Health administrators and planners in government					
(i) Researchers in a university					
(j) Researchers in a government department					
(k) Health researchers in private industry, e.g., a pharmaceutical company					

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Section B: For what reasons can general practice information be shared?

Please click here if you would like to watch the video 1 again link to video 1 (not mandatory – able to be replayed).

There are a number of reasons why GPs share the information in your patient record with other people.

We are interested to know what you think are the reasons for your general practice information being shared and whether you agree with this.

In answering these questions, please assume that the GP and everyone your information is shared with will abide by all relevant laws and will do everything they can to minimise risks to your privacy. However, it is still possible that you may be identified from some of the information shared about you.

6. Do you think information from your general practice record is being shared for the following reasons?

Answer all items. One response per row.

	Yes	No	I do not know
(a) To directly support my personal health care			
(b)For my GP to improve the health services they provide			
(c) For the government to improve health services generally			
(d) For research in universities, hospitals or publicly funded research organisations			

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Please click here if you would like to watch the video 1 again link to video 1 (not mandatory, able to be replayed)

7. To what extent do you agree with information from your general practice record being shared for the following reasons?

Answer all items. One response per row.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
(a) To directly support my personal health care					
(b)For my GP to improve the health services they provide					
(c)For the government to improve health services generally					
(d) For research in universities, hospitals or publicly funded research organisations					

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Section C: Sharing and linking general practice information for research

Please watch this video before answering question 8 Link to video 2 (mandatory, able to be replayed)

Video 2
We would like to know more about your views on sharing information from your general practice record specifically for research.
Researchers can do more valuable research if they can bring together information, not just from your GP, but also from other places such as hospital, education, and social services records.
When your general practice information is used for research, there are special safeguards.
A Human Research Ethics Committee must consider each research project to ensure that the researchers will protect the privacy and security of your general practice information by, for example, not sharing the information with anyone outside the research team and not publishing anything that would identify individual patients.
To answer the questions which follow, we would like you to assume that the researchers will not have your name and address. However, it is still possible that the researchers may be able to work out who you are from information provided about you.

We would like to know what you think about information from your general practice record being linked with other information about you from other sources for specific research purposes. Please remember that the researchers will not have your name or address. However, it is still possible that the researchers may be able to work out who you are from information provided about you.

8. To what extent do you agree with information from your general practice record being linked with information about you from the following sources for specific research purposes?

Answer all items. One response per row.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
(a) Other health service records, e.g., hospital and ambulance records					
(b) Education department records					
(c) Social service records, e.g., disability, housing and childcare services					
(d) Criminal justice records					

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SECTION D: Trust in GP and general practice records

9. To what extent do you agree with the following statements about your GP and sharing information from your general practice record?

Please remember, the GP and everyone your information is shared with will abide by all relevant laws and will do everything they can to minimise risks to your privacy. However, it is still possible that you may be identified from some of the information shared about you.

Answer all items. One response per row.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
(a) I am confident that my GP will take care of the information in my general practice record appropriately					
(b) There are some aspects of the information in my general practice record I would rather my GP did not share with anyone else					
(c) I would want to know when the information in my general practice record is being shared					
(d) I would want to know who the information in my general practice record is being shared with					
(e)I would want to know why the information in my general practice record is being shared					
(f) I would be willing to let my GP decide who can see information from my health record without informing me					
(g) My name, address and date of birth must be removed before my general practice information is shared					

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10. If you have anything else to tell us about your views on using information from your general practice records, please comment below?

☐ No
☐ Yes (please respond below)

Open text 2000 characters

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Demographics

11. In general, how would you rate your health?

One response only

☐ My health is poor
☐ My health is fair
☐ My health is good
☐ My health is very good
☐ My health is excellent

12. About your health status:

Answer all items. One response per row.

	Yes	No	I am not sure/I do not know
(a) I have a chronic health condition			
(b) I care for someone with a chronic health condition			
(c) I take prescribed medication(s)			
(d) I have a My Health Record electronic health record			

13. In what type of setting did you most often see a GP in the last year, including face-to-face, online or by telephone?

One response only

☐ General practice
☐ Community centre, e.g., Women's Health Centre, Aboriginal Medical Service
☐ Residential or nursing care home
☐ Hospital or rehabilitation
☐ Other (please specify):

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14. How many times did you see a GP in the last year, including face-to-face, online or by telephone?

One response only

☐ I did not see a GP in the last year
☐ 1-3 times in the year
☐ 4-12 times in the year
☐ 13-52 times in the year
☐ More than once a week

15. Which best describes the highest educational qualification you have obtained?

One response only

☐ No formal qualifications
☐ Year 10 or school certificate
☐ Year 12 or leaving certificate
☐ Trade/apprenticeship
☐ Other TAFE/Certificate
☐ University degree/Higher degree
☐ I prefer not to answer/I am not sure

16. What best describes your current employment status?

One response only

☐ Full time employed
☐ Part-time employed
☐ Unemployed
☐ Home duties
☐ Student/Training
☐ Retired
☐ Unable to work (e.g., disability/Work Cover)
☐ I prefer not to answer/I am not sure

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17. What is your household's combined income?

One response only

☐ $1 - $19,999 per year ($1 - $379 per week)
☐ $20,000 - $39,999 per year ($380 - $769 per week)
☐ $40,000 - $59,999 per year ($770 - $1149 per week)
☐ $60,000 - $99,999 per year ($1150 - $1919 per week)
☐ $100,000 - $124,999 per year ($ 1920 - $2399 per week)
☐ $125,000 - $149,999 per year ($2,400 - $2879 per week)
☐ $150,000 - $199,999 per year ($2880 - $3839 per week)
☐ $200,000 or more per year ($3840 or more per week)
☐ I prefer not to answer/I am not sure

18. Have you worked, or do you currently work in the health industry and/or in health services or research?

Tick all that apply (maximum 3 answers)

☐ Yes, in a general practice
☐ Yes, in the health industry (other than general practice)
☐ Yes, in conducting research (this does not include being part of a research panel)
☐ No
☐ I am not sure
☐ I prefer not to answer

Thankyou for completing our survey

If you would like to view and/or download and/or print the Participant Information Sheet please go here. This link will send participant to a PDF version of Participant Information Sheet.

Appendix 5. SURGE: Data abstraction quality criteria (1)

Note: This appendix is published as supplied and is unedited by *AJGP*.

Category	Item
Title and abstract	
Is the design of the study stated in the title and/or abstract?	Yes. The design of the study, a 'cross-sectional survey', is stated in the title of the manuscript.
Is there an explanation of why the research is necessary, placing the study in context of previous work in relevant fields?	Yes. In the manuscript an explanation of why the research is necessary is stated in the introduction.
Is the purpose or aim of the paper explained?	Yes. In the manuscript the aim of the paper is explained in the introduction, "we explored what the Australian public knows about the secondary use of the information in their general practice records".
Method	
Research tools	
Is the questionnaire described?	Yes. We developed our online survey by initially reviewing the existing literature on public understandings of, and attitudes towards, using the information captured in general practice records for secondary purposes. We examined peer reviewed and grey literature to identify quantitative and qualitative tools measuring public views, with a focus on instruments examining sharing for purposes beyond patient care or quality assurance. We combined questions from pre-existing tools with new questions and insights from the literature (2-12), overseen by the research team's knowledge and expertise. We also incorporated findings from the focus groups, particularly concerning participants' knowledge of when, why and with whom general practice data were shared. Two videos were included in the survey to enhance participants' understanding of data sharing in general practice. (13) The first introduced the survey and explained: the types of information captured in general practice records; how information in general practice records may be shared with other people or organisations and for what purposes; privacy principles and privacy laws; and the very small risk of identifiability. The second video explained how information from general practice records could be linked with other records, the role of a Human Research Ethics Committee, privacy protections and again

	mentioned the small risk of identifiability. Introductory Video 1 can been viewed here: (link to be provided). Video 2 can be viewed here: (link to be provided) The final survey (including videos) took approximately 10 minutes to complete. The 18-question instrument examined community knowledge and views across four domains (See Appendix 3 for our survey instrument): 1. Knowledge of how information held in general practice records was shared with specific people or organisations and for specific purposes 2. Views about whether information held in general practice records should be shared with specific people or organisations and for specific purposes 3. Views on linking general practice records with other data sources for research purposes 4. Views about the trustworthiness of GPs, identifiability and transparency with respect to sharing information in general practice records We also collected sociodemographic characteristics, health status and GP attendance for participants. A single open-ended question at the end of the survey invited additional comments.
If an existing tool was used, are its psychometric properties presented?	Not applicable. We did not use an existing tool.
If an existing tool was used, are references to the original work provided?	Not applicable. We did not use an existing tool.
If a new tool was used, are the procedures used to develop and pre-test provided?	Yes. We piloted a hardcopy version of the survey with a convenience sample of the general population (n=9) aged 34 years and over. (14) Pilot participants were diverse with respect to age, gender, education and ethnicity. The survey was then amended based on participants' feedback before being programmed by the research company, McNair yellowSquares, on the Web Survey Creator survey platform. The research team checked the survey for usability and technical functionality before launching.
If a new tool was used, have its reliability and validity been reported?	No. As this tool did not aim to evaluate or measure a construct such as "knowledge" (for example), as such no strict psychometrics on reliability and validity have been performed.
Is a description of the scoping procedures provided?	Not applicable
Sample selection	

<table>
<tr>
<td>Is there a description of the survey population and the sample frame used to identify this population?</td>
<td>Yes. Members of the Australian public may opt in to sign up to be part of a McNair yellowSquares (15) online research panel. McNair yellowSquares aimed to recruit an opt-in sample of 2,500 Australian participants drawn from its online panel, selected to be nationally representative by age, gender and location. While potentially less ideal than probability sampling, this methodology had the practical advantage of ease of implementation and was considered appropriate for this exploratory study. (16)</td>
</tr>
<tr>
<td>Do the authors provide a description of how representative the sample is of the underlying population?</td>
<td>Yes. To support population inference, we analysed the survey data using post stratification using gender, age, place of residence, and highest educational attainment weights. We used the 2016 Australian Bureau of Statistics census data (17) to obtain the Australian population characteristics of gender, age, state and education and calculate the survey weights based on the realised sample characteristics after combining categories with small sample counts. The rake method (18) was used due to the fact that not all possible crossings of all possible levels of the variables chosen were observed in the data. Hence the marginal tables of Sex and Age, Sex and Residence, Age and Highest education attained, Sex and Highest Education attained, were all used for the Rake method. All results in this paper except for participant demographics are obtained using such weights.
Analysis: A note on Australian Bureau of Statistics weighting
Australian Bureau of Statistics only has in their most recent 2016 Census available for use with the table builder Sex as Male and Female, hence the 12 participants in our data that did not identify directly with either of these, had to be excluded as otherwise they would not be receiving a weight. Weighting was planned taking into account of the following variables:
<table>
<tr><th>Values considered</th><th>ABS equivalent</th></tr>
<tr><td colspan="2">Age in groups</td></tr>
<tr><td>18-24 years, 25-29 years, 30-34 years, 35-39 years, 40-44 years, 45-49 years, 50-54 years, 55-59 years, 60-64 years, 65-69 years, 70-74 years, and 75 or more
Of Note, our data only had a maximum observed age of 88, and so “75 or more” is, in reality, 75-88. Otherwise, we would be falsely giving much more weight to that group</td><td>Same</td></tr>
<tr><td colspan="2">Gender</td></tr>
<tr><td>Female, Male</td><td>Same</td></tr>
<tr><td colspan="2">Place of residence</td></tr>
<tr><td>Sydney, NSW other than Sydney, Melbourne, VIC other than Melbourne, Brisbane, QLD other than Brisbane, Perth, WA other than Perth, Adelaide, SA other than Adelaide, NT, TAS, ACT.</td><td>Pretty much the same except for labelling e.g., “Greater Sydney”, “NSW not Greater Sydney”, etc</td></tr>
<tr><td colspan="2">Highest attained education</td></tr>
</table>
</td>
</tr>
</table>

Based on survey	Based on Australian Standard Classification of Education (ASCED), 2001
"No formal, not described" formed from: "No formal qualifications", "I prefer not to answer/I am not sure")	622- Year 9 623- Year 8 624- Year 7 (excluding SA) All 7, 8 and 9 levels
"Year 10 or school certificate"	621 -year 10 613- year 11 612- Bridging and Enabling Course at Senior Secondary Level
"Year 12 or leaving certificate"	611- Year 12
"TAFE/Certificate/Trade" formed from: "Trade/apprenticeship", "Other TAFE/Certificate"	All 4 and 5
"University degree/Higher degree"	All 1, 2 and 3

Is a sample size calculation or rationale/justification for the sample size presented?	Yes. The rationale for the sampling approach to recruit 2,500 participants was based on our previous research using a national online survey. (19) As our questions resulted in categorical variable measures for each question, we knew we would be estimating proportions. Before any weighting, and for a crude estimate of proportions, the sample of 2500 was appropriate as it would allow for a worst-case scenario Margin of Error of 2% in constructing 95% confidence intervals.
Survey administration	
Mode of administration?	Yes. McNair yellowSquares emailed participants of their online panel an invitation to participate in the closed online survey via a unique one-time use link. Once the survey was completed, the link was disabled to prevent duplicates and the panel was regularly checked for duplication with various data points. Upon completing the introductory section to establish the quotas, participants were directed to the Participant Information Sheet which described the researchers, purpose of the study, risks and benefits, time involved to complete and data protection and storage. Participants were asked to indicate that they understood the information sheet; on assenting to this, they were directed to the first page of the survey. All quantitative questions were mandatory, and some items provided an 'I do not know' or 'I prefer not to answer' response option. Participants were not able to view their responses by moving backwards. There was no randomisation of items, and all responses were captured on the McNair yellowSquares Web Survey Creator survey platform.
Do the authors provide information on the type of contact and how many attempts were made to contact subjects (i.e.,	Yes. The survey was not advertised in any manner. Up to two reminder emails were sent over the three-week period during which the survey was open (18th March to 7th April 2022).

prenotification by letter or telephone, reminder postcard, duplicate questionnaire with reminder)?	
Do the authors report whether incentives were provided (financial or other)?	Yes. Participation was voluntary and participants received a small reward on completion of all items in the survey.
Is there a description of who approached potential participants (e.g., identification of who signed the covering letter)?	Yes. McNair yellowSquares approached individuals who had signed up to be part of a McNair yellowSquares online research panel.
Analysis	
Is the method of data analysis described?	Yes. We used R Project for Statistical Computing (20) to analyse the data. Only completed survey data were analysed. First, we provided a descriptive summary of the survey outcomes by showing a frequency table with relative frequencies for each question of interest.
Do the authors provide methods for analysis of nonresponse error?	Not applicable. The dataset only contains responses from participants who completed the full survey.
Is the method for calculating response rate provided?	Not applicable. A response rate cannot be calculated. The online survey was emailed to 24, 787 members of the McNair yellowSquares online research panel. 3,785 responded within 21 days. The survey was closed once the quotas for age, gender and location were met.
Are definitions provided for complete versus partial completions?	Not applicable. All quantitative questions were mandatory, and some items provided an 'I do not know' or 'I prefer not to answer' response option. The dataset contains responses from participants who completed the full survey.
Are the methods for handling item missing data provided?	Not applicable. All quantitative questions were mandatory, and some items provided an 'I do not know' or 'I prefer not to answer' response option. The dataset contains responses from participants who completed the full survey.
Results	
Is the response rate reported?	Yes. In total, 2,604 participants were included in our survey sample.
Are all respondents accounted for?	Yes. The dataset only contains responses from participants who completed the full survey.
Is information given on how nonrespondents	No. The concept of non-responders is less relevant for surveys conducted with panels. The online survey was open to all members of

differ from respondents?	the McNair yellowSquares online research panel. The survey was closed once the quotas for age, gender and location were met. Demographic information about the non-respondents and those who commenced but did not complete the survey was not captured.
Are the results clearly presented?	Yes. In the manuscript the results are presented objectively in tables and figures.
Do the results address the objective(s)?	Yes. In the manuscript we aligned our results to the study aims.
Discussion	
Are the results summarized with reference to the study objectives?	Yes. In the manuscript the results are summarised with reference to the study objectives.
Are the strengths of the study stated?	Yes. In the manuscript the strengths of the study are summarised in the discussion and abstract.
Are the limitations of the study (taking into account potential sources of bias or imprecision) stated?	Yes. There are number of limitations in this study related to the use of an online panel. The survey respondents were members of the Australian public who had expressed interest and willingness to participate in research and may be considered more likely to be supportive of research, or at least more interested, than the general public. Participating in online research activities may also indicate our respondents have a reasonable level of confidence in using information technology and the internet, although what this may mean for their attitudes to sharing information from their general practice record is unclear. Content validity of our survey was developed using a variety of items found in the literature overseen by experts in the field. A full formal validation exercise of our instrument was not undertaken, and our literature review did not identify a 'gold standard' tool to replicate. (21) In addition, despite our best efforts to explain concepts of data collection, sharing and linkage, and anonymity, we do not know the extent respondents in our online survey fully understood this complex topic. The challenges in explaining these concepts effectively in surveys and the variable understanding amongst community members have been noted as limitations in many other surveys on views about data sharing. (2, 7, 19, 22) Additional deliberative methods would be useful to fully explore the views and concerns of an informed community. (14)
Is there explicit discussion of the generalizability (external validity) of the results?	Yes. Our survey is limited to the Australian healthcare landscape and did not include the views of Australians under 18 years old.
Ethical quality indicators	

Is study funding reported?	Yes. This project received funding support from the Digital Health CRC Limited (DHCRC) and Population Health Research Network. The Digital Health CRC Limited is funded under the Commonwealth's Cooperative Research Centres (CRC) Program. The Population Health Research Network is a capability of the Australian Government National Collaborative Research Infrastructure Strategy.
Research Ethics Board (REB) review reported?	Yes. This study was approved by the University of Wollongong (UOW) Ethics Committee (Ethics number: 2022/012).
Reporting of subject consent procedures?	Yes. All participants provided tacit consent before participating by indicating that they had reviewed an online participant information sheet.

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Appendix 6. Online survey demographics

Note: This appendix is published as supplied and is unedited by *AJGP*.

Characteristic	N (%)
Gender	
Male	1,270 (48.8%)
Female	1,322 (50.8%)
Non-binary	2 (0.1%)
I prefer to describe*	1 (0.0%)
I prefer not to say	9 (0.3%)
Age	
Gen Z/iGen/Centennials (1996-2010)	325 (12%)
Gen Y/Millennials (1977-2010)	962 (37%)
Gen X (1965-1976)	413 (18%)
Baby Boomers (1946-1964)	573 (22%)
Traditionalists/Silent Gen (1928-1945)	319 (12%)
Residential location	
Sydney	536 (20.6%)
NSW other than Sydney	290 (11.1%)
Melbourne	508 (19.5%)
VIC other than Melbourne	155 (6.0%)
Brisbane	251 (9.6%)
QLD other than Brisbane	262 (10.1%)
Perth	218 (8.4%)
WA other than Perth	60 (2.3%)
Adelaide	147 (5.6%)
SA other than Adelaide	43 (1.7%)
NT	27 (1.0%)
TAS	56 (2.2%)
ACT	51 (2.0%)
Employment	
Full-time employed	1,115 (42.8%)
Part-time employed	546 (21.0%)
Unemployed	104 (4.0%)
Home duties	162 (6.2%)
Student/Training	96 (3.7%
Retired	474 (18.2%)
Unable to work (e.g., disability/Work Cover)	87 (3.3%)
Highest level of education	
No formal qualifications	50 (1.9%)
Year 10 or school certificate	233 (8.9%)
Year 12 or leaving certificate	409 (15.7%)
Trade/Apprentice	160 (6.1%)

Characteristic	N (%)
Other TAFE/Certificate	633 (24.3%)
University degree/higher degree	1,103 (42.2%)
I prefer not to answer/I am not sure	16 (0.6%)
Combined household income	
$1 - $19,999 per year ($1 - $379 per week)	101 (3.9%)
$20,000 - $39,999 per year ($380 - $769 per week)	375 (14.4%)
$40,000 - $59,999 per year ($770 - $1149 per week)	334 (12.8%)
$60,000 - $99,999 per year ($1150 - $1919 per week)	601 (23.1%)
$100,000 - 124,999per year ($1920 - $2399 per week)	320 (12.3%)
$125,000 - $149,999 per year ($2,400 - $2879 per week)	238 (9.1%)
$150,000 - $199,999 per year ($2880 - $3839 per week)	231 (8.9%)
$200,000 or more per year ($3840 or more per week)	168 (6.5%)
I prefer not to answer/I am not sure	236 (9.1%)

Appendix 7. Indicative quotes from all groups (F1 – F4)

Awareness of content of general practice records

I don't know about major life events because the doctor doesn't ask those questions. I don't know if it's recorded or not. Maybe it is but I have no idea, because they don't ask us those questions. They ask you illness. The GPs don't have much time. It's quite quick over here. (P1, 43 yrs.. - all female FG1)

I've been going to my female doctor for many, many years and in that time I had been divorced. So, she knows. That was something that she asked and I shared. She asked me how I was feeling and I said, "I'm getting divorced and I'm a little bit sad". She may not write it down, though probably does, I would imagine. I wouldn't have a problem if she did. (P2, 59 yrs.. - all female FG1)

I just recently went to ED for the first time based on my own decision. When I went there, they had to ask me a lot of things because no one referred me there and they're working basically on a blank piece of paper. (P4, 29 yrs.. - all female FG1)

What Phillip says is absolutely right. When you go to a hospital, because in most cases you're going fairly rarely and at long intervals, that you've got to go through the whole process of telling them exactly what's happened all over again. (P3, 64 yrs.. – all male FG2)

All the medications she would be on which, if she's got heart medication and asthma medication, that would be a lot, so you'd have to really, probably keep a pretty good eye on something like that if you're taking multiple medications. The doctors would have to link up together, to work together because otherwise it just wouldn't go, I would think.

Q: Do you think they link up and work together?

You'd hope so. (P2, 59 yrs.. - all female FG1)

I don't think they do. I think the hospital treats you and then discharges you back to your GP with notes. (P3, 74 yrs.. - all female FG1)

Support for sharing data for quality assurance, service planning and research

Public benefit

I think so. If you can work out a blood type of people or age groups or anything like that and work out a particular type of medicine or medication is good for that particular problem, that's the only way they're going to find that out, isn't it? By just a big group of people and all their records. (P2, 59 yrs.. - all female FG1)

I think it should be used for research purposes that further benefit patients and work to improve their healthcare, either on an individual level or on a more systemic level. I don't think it should be used for other reasons, like just for the GP practice, to get them different funding from the government or things like that. (P5, female 24 yrs. – mixed gender youth FG4)

Absolutely. How long does research take when they just do it with individual people? If everybody was a research subject, it would certainly make things go a lot quicker and you would find things out, I would imagine, a lot faster with a diverse group of people. (P2, 59 yrs.. - all female FG1)
It doesn't make a difference in my perspective. You can do it. The thing is, it's good to opt in, but before that I think it should be some sort of campaign or awareness should be made, just for telling people that, "We have used your data to do these good things, and we are trying to improve it," so that people can know what sort of things are being done with the data, so that they will be further happy to opt in, things like that. (P1, male 28 yrs.. – mixed gender group FG3)
Maybe, Carol, that might speak to you. If you could see some of the results of having this data, this information, what the results were – I don't know what I'm talking about now. If you could see what comes out of having access to this sort of data, the differences in treatment and the provision of facilities, maybe that might be more encouraging to you. I don't know. Give you a reason why you're doing it. This is the reason. (P4, male 65 yrs.. – mixed gender group FG3)
I think something similar. If the researcher is able to use our information in a way that both us and the researcher are contributing to a small step towards the greater good, that's similar to what Jenny says. Use it properly because who knows what the future might bring? We may be working towards the future with pills that can cure Diabetes, pills that can cure heart disease, cancer, everything. Just to be a part of that tiny bit of future of mankind. (P4, 29 yrs. - all female FG1)
Individual benefits
I would have thought, if through this you can identify an area where there's a lot of people with diabetes that don't have a sufficient service to deal with it, this would help promote new services, new clinics, new diabetes treatments for these people. How else are you going to do it? (P4, male 65 yrs. – mixed gender group FG3)
Yeah, because we live in a siloed society. Information's not centralised, and so a GP has information on me, a hospital has certain information on me, maybe the ambulance has – I've been to a number of other GPs throughout my life, and they've got different information, so I think it's crucial that we bring it all together to build the bigger picture. (P1, 59 yrs. – all male FG2)
This is, I think, what we talked about earlier because when one person goes from one GP to another GP, so if that person has access to this data he will know the history when he answers the person, the patient. It will be helpful for both the patient and the GP. (P1, 43 yrs. - all female FG1)
Yeah. You don't have to keep going over your past history. (P2, 59 yrs. - all female FG1)
Yeah, because we live in a siloed society. Information's not centralised, and so a GP has information on me, a hospital has certain information on me, maybe the ambulance has – I've been to a number of other GPs throughout my life, and they've got different information, so I think it's crucial that we bring it all together to build the bigger picture. (P1, 59 yrs. – all male FG2)

Well, for me, I didn’t do good in school. I dropped out earlier. I didn’t do that good in school, but I think giving my school records to my GP is actually quite important to me, only because I knew I had trouble learning and stuff, even [1:15:44] getting an idea which I could then pursue. So, I showed my report card, my grades and all that, and then, from what they saw, they had an idea of what could be the problem, and I had to pursue that and find out that was really the cause, or [1:16:04] thing is [1:16:08], honestly – for me, mine was more like the behavioural part of school, but GPs are always aware of behaviour part of it, and any change of schools, or go to a behaviour school. Having that kind of support – giving that image to them gives them a better understanding of what to put behind you to help you get [1:16:30] the schools (P7, male 19 yrs. – mixed gender youth FG4)
Concerns about sharing data
Lack of benefit
I’m not sure if you should be compared to everybody else, because you're not everybody else. (P2, female 22 yrs. – mixed gender group FG3)
Over to you. I just don’t see why my educational record would benefit them in regard to my health record. It’s got nothing to connect it to – no need for it. (P5, 29 yrs. – all male FG2)
Yeah, but that’s for me. I’m not sure. Just ‘cause you’ve got and someone else has got that, there might be other things that go along with it. (P2, female 22 yrs. – mixed gender group FG3)
Concerns about who information is shared with
I’m just concerned that the right people that should be getting the information aren’t getting it, because I think it should be going back to the GP, because if it stays with the government, how can the GPs, if you go – and all specialists as well – how can you get the latest advice if it doesn’t go back to the people that are on the frontline. [0:31:52] some sort of government department, that’s not getting to the people that need it. I go to see a GP or a specialist and they haven’t got this data – how are they supposed to recommend the correct stuff on the later studies? (P4, 52 yrs. – all male FG2)
But that would come out of the services that get set up, so then GPs will have access to those services, I’m assuming. (P1, 59 yrs. – all male FG2)
I don’t have any issues with scientific research, and I think it’s highly relevant, and I think you need it. I don’t think GPs are capable, they’ve got the time or the means to do the research. They rely on everyone else’s research to draw conclusions. That’s why they’re general practitioners. They’re not specialists. So, I don’t agree with John, but I’m in total agreement with giving out that information to researchers to - - -we’ve been doing it for hundreds of years, and I don’t have an issue with it, so I’ve given it two thumbs up. (P1, 59 yrs. – all male FG2)
I put orange, and a lot of what Kevin said as well is what I thought, but in addition to that, you don’t necessarily know the medical expertise of the people in the government department, so whether they actually are using the information to do what should be done ideally, whereas previously it was people who at least were in the medical profession, so you would assume that they would have some sort of knowledge that they could use to actually understand the statistics that were given and the information that they collected.(P6, male 20 yrs. - mixed gender youth FG4)

I wouldn't think this sort of information would be just spilled to insurance companies, though – distributed to insurance companies. I would've thought that this sort of stuff would go to the appropriate departments, the appropriate areas only, not anyone and everyone. -(P4, 52 yrs. – all male FG2)
I'd certainly change it to green if that was the case. As long as the GPs and the specialists get it, then I'd go to green, but you know what? I wouldn't want it to be restrictive as well to GPs and specialists in a certain scenario that aren't with the program, because I think it's for the greater good, these sort of results. It should be for everyone, regardless, but that goes back to the mandate, doesn't it? -(P4, 52 yrs. – all male FG2)
Concerns about risk of harm
I think, maybe, sometimes information might be misused. Say, for example, insurance companies might turn around and say, "Look, we've got this report from the government saying that 50 percent of people who live in this area have experienced this problem." We might jack up the premiums just to cover ourselves, just in case a claim's been made. That's high-level. (P1, 59 yrs. – all male FG2)
Reflecting on everybody's comment, I think it's also for the purpose and outcomes – how this information is being used. I think, the perfect example of insurance companies finding reasons to increase the premiums. (P2, 37 yrs. – all male FG2)
I've gone orange. I think that the idea of researchers using the information and drawing on that information to make predictions – I think that's a little bit – what's the word I'm looking for? I think it's a little risky, maybe. (P3, 64 yrs. – all male FG2) ***Q: Why are you thinking that?*** I guess a lot of it's going to depend on the qualifications of the researchers, of course, but it occurs to me that, maybe, the best person to decide whether someone's condition gets better or worse would, in fact, be the GP, I would've thought. (P3, 64 yrs. – all male FG2)
Over to you. I just don't see why my educational record would benefit them in regards to my health record. It's got nothing to connect it to – no need for it. -(P5, 29 yrs. – all male FG2)
I agree. I don't see the relevance, unless they're looking at people's wealth and demographics due to their wealth. If they live out in a certain area and their education is poor or something, are they going to be discriminated against? Even though there's anonymity, like the other guys are saying – if the data gets in the wrong hands, then certainly, you're likely to be discriminated against based on – your health might be poor if you can't get the right food, you can't get this and that, or the right education. -(P4, 52 yrs. – all male FG2)
I think, in this case, it's just kind of too nebulous there. The kind of safeguards you'd need on this would just be immense, and I don't think it'd actually be achievable, because at least in the fourth scenario, I think it could be achievable, but in this sort of case, I'm not sure what information's being shared, because let's say, if it's information about health outcomes – if you have a certain health outcome, and you might compare it to ATO data about taxable income there, there might be a little bit of danger. I know you don't have the exact address there, but you might have a specific geographical region there, and I'm not very confident in terms of that kind of data being held as well. I'm not sure that it should be held at all in conjunction with each other. Things

like that. And, there’s a lot of areas there that I can’t really think of, but that’s one of the first that comes to mind, for instance [1:13:38] (P1, male 21 yrs. – mixed gender youth FG4)
Concerns about privacy and data breaches
I was thinking – what sort of information does the researchers will have access, and what is the source of the information? Is it actually being collected from GPs or from government? Basically, we are actually going further layers away from the customer, which raises, sometimes, some privacy concerns – how that actual information is – where is my information (P2, 37 yrs. – all male FG2)
I don’t agree with that. Information’s easily hacked, and then time and time again, we know about huge data breaches. You can’t protect information, and so if you link all the information, then it’s greater exposure. (P1, 59 yrs. – all male FG2)
I agree with that. Hackers don’t need too much information. They can start piecing it together over education. You’ve got this, you’ve got (P4, 52 yrs. – all male FG2)
That’s right. They can create a profile (P1, 59 yrs. – all male FG2)
For me, my address is very important to me – it’s where I live, and my area where I am. …The census last year got hacked, and people had names, their addresses in all the censuses of themselves run by the government. It was hacked before. (P7, male 19 yrs. – mixed gender youth FG4)
Information’s easily hacked, and then time and time again, we know about huge data breaches. You can’t protect information, and so if you link all the information, then it’s greater exposure. (P1, 59 yrs. – all male FG2)
I agree with that. Hackers don’t need too much information. They can start piecing it together over education. You’ve got this, you’ve got (P4, 52 yrs. – all male FG2) That’s right. They can create a profile. (P1, 59 yrs. – all male FG2)
You're trusting the safety of their computer system in the surgery to keep it secure. (P4, male 65 yrs. – mixed gender group FG3)
I wouldn’t want to entrust it to the MyGov Health Record, because I just don’t think it’s got to that stage yet where you could trust it. (P4, male 65 yrs. – mixed gender group FG3)
I agree. I don’t see the relevance, unless they’re looking at people’s wealth and demographics due to their wealth. If they live out in a certain area and their education is poor or something, are they going to be discriminated against? Even though there’s anonymity, like the other guys are saying – if the data gets in the wrong hands, then certainly, you’re likely to be discriminated against based on – your health might be poor if you can’t get the right food, you can’t get this and that, or the right education. (P4, 52 yrs. – all male FG2)
I think that, if governments were to legislate and create laws that ensured people’s privacy, or that information would be deidentified, I think all of us have to work on governments to ensure that they have those sort of checks in place. (P3, 64 yrs. – all male FG2)

I don’t agree with that. Information’s easily hacked, and then time and time again, we know about huge data breaches. You can’t protect information, and so if you link all the information, then it’s greater exposure. (P1, 59 yrs. – all male FG2) I agree with that. Hackers don’t need too much information. They can start piecing it together over education. You’ve got this, you’ve got (P4, 52 yrs. – all male FG2)
Q: Peta, you had a red as well? I think that they shouldn’t be combined, like how My Health Record brings things together. I think they should be kept separate. If someone wanted to do research, they should ask the participant, “Can I get the data from your GP, and can I get the data from your school records?” and then they use that data together. I think they shouldn’t be linking them in any other way. (P5, female 24 yrs. – mixed gender youth FG4)
Q: Sally, you were really quick to go orange. Why was that? I’ve got three points in my brain. A kid can’t really consent, but my main idea is – in school, you can have good grades and all that, but your mental health may not be exactly prevalent, but if you’re a girl and you have bad grades, and all your report cards say, “Inattentive,” it might be easier for someone to diagnose you with ADHD since girls don’t get diagnosed until later in life, but it’s prevalent – the inattentive ADHD – in their school records, but there’s also bias, like if your kid doesn’t do well in school and it’s like, “They’re lazy,” and – no, but yes (P2, female 22 yrs. – mixed gender youth FG4)
Data Security
I have no problem with it – just make sure that the servers and all the information is very secure. (P5, female 24 yrs. – mixed gender youth FG4)
Make sure my information is safe. (P3, female 48 yrs. – mixed gender group FG3)
Security, I think, just secure information. I'm basically saying what Carol just said, but I do agree. (P6, female 57 yrs. – mixed gender group FG3)
I would like to say basically to whoever runs data security and making sure that the anonymous data doesn’t come back and identify me. (P1, male 28 yrs. – mixed gender group FG3)
Conditions on sharing data
Anonymisation
I really think with the anonymity of all the information, it doesn’t really bother me. I don’t really know what they share about me anyway, even if they are, so my name is not there. (P4, 29 yrs. - all female FG1)
Yeah. No one knows you. That's right. It’s anonymous… Because it’s anonymous it’s an easy way to gather a lot of information quite quickly and literally quite unobtrusively too. Because of the anonymity, I think everyone is protected (P2, 59 yrs. - all female FG1)

Imagine the end result might just be your data like 80 percent of WA citizens in the area have Diabetes and then if they want to link it somehow to education or they want to link it to physiotherapists, then I think such a wide data wouldn't be able to track unless they're doing case studies. (P4, 29 yrs. - all female FG1)
Yeah. Case studies. Exactly. I think they could probably keep it quite anonymous. (P2, 59 yrs. - all female FG1)
Again I can't see it being a problem, again because it's anonymous. It would show if there are patterns or if it's linked to a certain area. It could be linked to water, it could be linked to where they live, it could be linked to what they eat. Literally, some places have had contaminated water that makes people sick. They live on contaminated housing estates and stuff. That can't be a bad thing. Otherwise, it might take a while for something like that to click and work out that there is a problem or, 'Why is this area having so many?' That's my personality. I think it's a very personal thing. I think it's a good thing. (P2, 59 yrs. - all female FG1)
To me, it's been green all the way …. as long as the appropriate people get the results – the GPs and the specialists. The anonymity is the main core element for me. -(P4, 52 yrs. – all male FG2)
That it stays anonymous, that no one can hack and find out, especially if they're bringing in education and things like that, there has to be some very foolproof way that no one's information can be hacked or tapped into because there are people out to do bad everywhere. Somebody could hack into somebody's record and it's all there, then use it for evil, not good. Unfortunately, we live in that society, don't we? There would have to be very strict regulations on that. (P2, 59 yrs. - all female FG1)
Transparency
It doesn't make a difference in my perspective. You can do it. The thing is, it's good to opt in, but before that I think it should be some sort of campaign or awareness should be made, just for telling people that, "We have used your data to do these good things, and we are trying to improve it," so that people can know what sort of things are being done with the data, so that they will be further happy to opt in, things like that. (P1, male 28 yrs. – mixed gender group FG3)
I think, in general, if the government is transparent about how they use that data and what kind of data they collect, then I think it could be okay, but it all depends on the situation. (P2, female 22 yrs. – mixed gender youth FG4)
I'm thinking of a bit more transparency in terms of what information is being provided to those other GPs as well, just in terms of that consent thing as well with doctor-patient confidentiality as well, as some patients might not like certain details to be shared. (P1, male 21 yrs. – mixed gender youth FG4)
Consent
I was thinking about the whole transparency thing, and also in terms of consent as well. Just as I'm thinking that – might be better as an opt-in system with that sort of thing, and also, with that report, is that going to be shared to the public, or is it going to be an internal affair, let's say, within that government department? Because if funding gets allocated and I don't know the basis of why the funding was allocated to those particular locations for those diabetes

services there, then I'm going to have some trust issues with that as well, as I don't know if my data was taken into account if I opted in. (P1, male 21 yrs. – mixed gender youth FG4)
I agree. I think you need to have an informed discussion with your GP and the GP needs to outline what information's going to be shared and for what reasons, and we're not medical people, and we need to understand – well, I certainly do want to understand – what am I going to share? So, I need to make an informed decision. That's why opt-in is a no-brainer for me. (P1, 59 yrs. – all male FG2)
I think I agree with the opt-in option, but often the cases what we have seen is the consent waiver, so basically, the GPs just get a blanket consent waiver from the patients – whoever is visiting the GP – and that's what the reality is. I don't think the GPs have time or the patience to actually explain to each and every patient about the opt-in process. (P2, 37 yrs. – all male FG2)
Yeah. I wouldn't have a problem if, again, I knew that the practice I was going to did that, as long as I was made aware. I didn't need to be asked every time but again how do you know that? Then if you choose to not go there, that's your choice, but how do they make all their patients aware that it's a sharing information practice? (P2, 59 yrs. - all female FG1)
I think it should definitely still be opted in by the patient. They have to give informed consent about what their information's going to be used for, especially if it's a more sensitive topic. (P5, female 24 yrs. – mixed gender youth FG4)
For the second one, I put red because it doesn't sound right for them to use all their data from the doctors and hospital and things. As long as the patient gives their consent for it, then it's fine for them, but as long they got their consent for things. (P3, male 21 yrs. – mixed gender youth FG4)
Governance
I think that, if governments were to legislate and create laws that ensured people's privacy, or that information would be de identified, I think all of us have to work on governments to ensure that they have those sort of checks in place. (P3, 64 yrs. – all male FG2)

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Appendix 8. Participant responses to 'Do you think information from your general practice record is being shared with the following people?' by generational age.

Generational age by response	Number of participants (%)	Me	My immediate family members	Other staff in the general practice, e.g., other GPs, practice nurse	Hospital health professionals e.g., doctors or nurses	Emergency personnel e.g., ambulance staff	Other medical specialists, e.g., surgeon, cardiologist	Allied health professionals, e.g., pharmacist or psychologist	Health administrators and planners in government	Researchers in a university	Researchers in a government department	Health researchers in private industry, e.g., a pharmaceutical company
Generational age by 'Yes' response												
GenZ/iGen/Centennials	325 (12%)	88	17	61	77	63	70	60	28	17	23	25
GenY/Millennials	962 (37%)	82	13	72	83	62	78	59	28	15	18	17
GenX	413(18%)	74	17	65	75	55	81	48	31	14	17	16
Baby Boomers	573 (22%)	83	11	71	80	51	86	48	23	11	11	7.3
Traditionalists/Silent Gen	319 (12%)	86	16	72	76	46	88	35	21	27	27	24
Generational age by 'I do not know' response												
GenZ/iGen/Centennials	325 (12%)	5	14	18	14	19	10	12	23	21	24	24
GenY/Millennials	962 (37%)	5.1	9.1	11	8	15	10	16	21	17	22	20
GenX	413(18%)	12	11	18	11	18	9.7	20	25	27	28	29
Baby Boomers	573 (22%)	4.5	6.9	14	13	21	9.1	19	31	28	29	29
Traditionalists/Silent Gen	319 (12%)	8.1	11	22	18	30	7.9	35	25	25	29	22
Generational age by 'No' response												
GenZ/iGen/Centennials	325 (12%)	7	68	21	8	18	20	28	49	63	53	51
GenY/Millennials	962 (37%)	13	78	17	9	23	12	25	51	68	60	63
GenX	413(18%)	13	72	18	14	28	10	32	43	59	55	55
Baby Boomers	573 (22%)	12	82	16	7	28	5	33	46	61	60	63
Traditionalists/Silent Gen	319 (12%)	6	73	7	6	24	4	30	54	48	44	54

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Appendix 9. Participant responses to ‘Do you think information from your general practice record is being shared for the following reasons?’ by generational age.

Generational age by response	Number of participants (%)	To directly support my personal health care	For my GP to improve the health service they provide	For the Government to improve health services generally	For research in universities, hospitals or publicly funded research organisations
Generational age by 'Yes' response					
GenZ/iGen/Centennials	325 (12%)	86	72	49	48
GenY/Millennials	962 (37%)	89	70	41	34
GenX	413(18%)	82	65	35	35
Baby Boomers	573 (22%)	91	68	43	31
Traditionalists/Silent Gen	319 (12%)	96	81	49	44
Generational age by 'I do not know' response					
GenZ/iGen/Centennials	325 (12%)	10	15	21	21
GenY/Millennials	962 (37%)	6	16	23	28
GenX	413(18%)	12	19	34	33
Baby Boomers	573 (22%)	5	16	29	35
Traditionalists/Silent Gen	319 (12%)	1	7	30	23
Generational age by 'No' response					
GenZ/iGen/Centennials	325 (12%)	5	12	31	31
GenY/Millennials	962 (37%)	5	14	36	38
GenX	413(18%)	6	16	31	33
Baby Boomers	573 (22%)	4	16	28	35
Traditionalists/Silent Gen	319 (12%)	3	12	22	33

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Appendix 10. Participant responses to the ‘Do you think information from your general practice record is being shared with the following people?’ by gender.

Gender by response	Number of participants (%)	Me	My immediate family members	Other staff in the general practice, e.g., other GPs, practice nurse	Hospital health professionals e.g., doctors or nurses	Emergency personnel e.g., ambulance staff	Other medical specialists, e.g., surgeon, cardiologist	Allied health professionals, e.g., pharmacist or psychologist	Health administrators and planners in government	Researchers in a university	Researchers in a government department	Health researchers in private industry, e.g., a pharmaceutical company
Gender by 'Yes' response												
Female	1322 (51%)	84	9	70	79	55	82	51	22	11	13	13
Male	1270 (49%)	81	19	68	81	58	78	53	32	20	23	20
Gender by 'I do not know' response												
Female	1322 (51%)	5	8	14	13	19	7.4	18	27	23	27	25
Male	1270 (49%)	8	12	15	10	19	12	20	23	22	24	24
Gender by 'No' response												
Female	1322 (51%)	11	83	15	9	26	11	30	52	65	60	61
Male	1270 (49%)	11	69	17	9	23	10	28	45	58	53	57

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Appendix 11: Participant responses to ‘Do you think information from your general practice record is being shared for the following reasons?’ by gender.

Gender by response	Number of participants (%)	To directly support my personal health care	For my GP to improve the health service they provide	For the Government to improve health services generally	For research in universities, hospitals or publicly funded research organisations
Gender by 'Yes' response					
Female	1322 (51%)	90	72	40	36
Male	1270 (49%)	87	68	44	36
Gender by 'I do not know' response					
Female	1322 (51%)	5	13	26	25
Male	1270 (49%)	8	18	28	33
Gender by 'No' response					
Female	1322 (51%)	5	15	34	39
Male	1270 (49%)	5	13	28	31

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Appendix 12. Participant responses to ‘Do you think information from your general practice record is being shared with the following people?’ by highest level of education.

Highest level of education by response	Number of participants (%)	Me	My immediate family members	Other staff in the general practice, e.g., other GPs, practice nurse	Hospital health professionals e.g., doctors or nurses	Emergency personnel e.g., ambulance staff	Other medical specialists, e.g.. surgeon. cardiologist	Allied health professionals, e.g., pharmacist or psychologist	Health administrators and planners in government	Researchers in a university	Researchers in a government department	Health researchers in private industry, e.g., a pharmaceutical company
Highest level of education by 'Yes' response												
No formal, not described	63 (12%)	85	14	63	76	31	82	35	24	22	22	17
Year 10 or school certificate	233 (16%)	82	20	67	80	56	79	57	23	17	18	20
Year 12 or leaving certificate	406 (18%)	82	18	70	80	64	77	57	26	15	18	16
TAFE/Certificate/Trade	789 (29%)	81	10	69	81	57	80	52	29	14	19	18
University degree/Higher degree	1101 (26%)	83	12	72	80	63	83	52	28	13	15	12
Highest level of education by 'I do not know' response												
No formal, not described	63 (12%)	7	5	22	21	28	12	26	16	12	15	15
Year 10 or school certificate	233 (16%)	7	14	14	15	22	8	19	35	32	35	32
Year 12 or leaving certificate	406 (18%)	7	9	12	8	14	9	16	26	26	30	29
TAFE/Certificate/Trade	789 (29%)	9	11	17	10	21	11	20	25	25	28	26
University degree/Higher degree	1101 (26%)	4	8	11	10	14	8	16	21	17	20	19
Highest level of education by 'No' response												
No formal, not described	63 (12%)	8	81	15	4	41	7	39	60	66	63	68
Year 10 or school certificate	233 (16%)	11	66	19	6	22	13	23	41	51	47	48
Year 12 or leaving certificate	406 (18%)	11	74	18	12	22	14	27	48	59	52	55
TAFE/Certificate/Trade	789 (29%)	11	79	14	9	22	9	27	46	60	53	56
University degree/Higher degree	1101 (26%)	13	79	17	10	23	9	31	51	70	65	68

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Appendix 13. Participant responses to ‘Do you think information from your general practice record is being shared for the following reasons?’ by highest level of education.

Highest level of education by response	Number of participants (%)	To directly support my personal health care	For my GP to improve the health service they provide	For the Government to improve health services generally	For research in universities, hospitals or publicly fundec research organisations
Highest level of education by 'Yes' response					
No formal, not described	63 (12%)	82	61	43	37
Year 10 or school certificate	233 (16%)	89	69	39	38
Year 12 or leaving certificate	406 (18%)	88	75	44	40
TAFE/Certificate/Trade	789 (29%)	88	70	39	33
University degree/Higher degree	1101 (26%)	93	71	46	36
Highest level of education by 'I do not know' response					
No formal, not described	63 (12%)	14	21	26	19
Year 10 or school certificate	233 (16%)	9	23	31	33
Year 12 or leaving certificate	406 (18%)	5	11	25	26
TAFE/Certificate/Trade	789 (29%)	6	15	31	34
University degree/Higher degree	1101 (26%)	4	13	22	27
Highest level of education by 'No' response					
No formal, not described	63 (12%)	4	18	31	44
Year 10 or school certificate	233 (16%)	2	8	30	29
Year 12 or leaving certificate	406 (18%)	7	14	31	35
TAFE/Certificate/Trade	789 (29%)	6	15	30	34
University degree/Higher degree	1101 (26%)	4	16	33	37

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Appendix 14. Participant responses to ‘Do you think information from your general practice record is being shared with the following people?’ by self-reported health status.

Self-reported health status by response	Number of participants (%)	Me	My immediate family members	Other staff in the general practice, e.g., other GPs, practice nurse	Hospital health professionals e.g., doctors or nurses	Emergency personnel e.g., ambulance staff	Other medical specialists, e.g., surgeon, cardiologist	Allied health professionals, e.g., pharmacist or psychologist	Health administrators and planners in government	Researchers in a university	Researchers in a government department	Health researchers in private industry, e.g., a pharmaceutical company
Health status by 'Yes' response												
My health is poor	119 (4.6%)	70	15	65	79	31	69	46	21	4	9	10
My health is fair	572 (23%)	80	11	71	83	56	83	56	27	12	14	14
My health is good	1046 (42%)	84	13	69	78	57	83	52	28	18	20	17
My health is very good	665 (24%)	83	17	70	79	62	78	49	26	17	19	18
My health is excellent	190 (5.9%)	85	14	63	77	52	68	51	25	12	16	16
Health status by 'I do not know' response												
My health is poor	119 (4.6%)	6	24	15	12	27	11	26	19	27	27	28
My health is fair	572 (23%)	7	12	16	11	22	10	19	30	28	30	28
My health is good	1046 (42%)	6	8	15	11	18	8	20	24	20	24	21
My health is very good	665 (24%)	6	7	12	13	16	10	17	24	22	25	27
My health is excellent	190 (5.9%)	7	12	16	11	18	15	15	20	23	22	22
Health status by 'No' response												
My health is poor	119 (4.6%)	23	62	20	10	42	19	28	60	69	64	62
My health is fair	572 (23%)	12	76	13	6	22	7	25	43	60	56	58
My health is good	1046 (42%)	10	78	16	10	24	9	28	48	62	55	61
My health is very good	665 (24%)	11	76	18	8	22	12	34	50	61	55	55
My health is excellent	190 (5.9%)	8	74	20	12	30	17	33	55	65	62	62

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Appendix 15. Participant responses to 'Do you think information from your general practice record is being shared for the following reasons?' by self-reported health status.

Self-reported health status by response	Number of participants (%)	To directly support my personal health care	For my GP to improve the health service they provide	For the Government to improve health services generally	For research in universities, hospitals or publicly funded research organisations
Health status by 'Yes' response					
My health is poor	119 (4.6%)	89	49	21	12
My health is fair	572 (23%)	83	68	42	32
My health is good	1046 (42%)	91	73	43	36
My health is very good	665 (24%)	88	70	46	45
My health is excellent	190 (5.9%)	95	74	40	34
Health status by 'I do not know' response					
My health is poor	119 (4.6%)	7	42	52	53
My health is fair	572 (23%)	11	20	30	38
My health is good	1046 (42%)	5	13	25	26
My health is very good	665 (24%)	6	12	21	19
My health is excellent	190 (5.9%)	3	13	30	32
Health status by 'No' response					
My health is poor	119 (4.6%)	3	9	27	35
My health is fair	572 (23%)	5	12	28	30
My health is good	1046 (42%)	4	14	33	38
My health is very good	665 (24%)	6	18	32	36
My health is excellent	190 (5.9%)	3	14	29	34

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Appendix 16. Participant responses to ‘Do you think information from your general practice record is being shared with the following people?’ by number of visits to the GP.

Number of visits to the GP by response	Number of participants (%)	Me	My immediate family members	Other staff in the general practice, e.g., other GPs, practice nurse	Hospital health professionals e.g., doctors	Emergency personnel e.g., ambulance staff	Other medical specialists, e.g., surgeon, cardiologist	Allied health professionals, e.g., pharmacist or psychologist	Health administrators and planners in government	Researchers in a university	Researchers in a government department	Health researchers in private industry, e.g., a pharmaceutical company
Number of visits to the GP by 'Yes' response												
I did not see a GP in the last year	240 (9.8%)	73	15	67	77	59	68	46	30	14	13	16
1-3 times in the year	1301 (50%)	83	15	67	77	56	80	49	28	19	22	18
4-12 times in the year	913 (35%)	85	13	71	82	56	83	56	24	11	13	12
13-52 times in the year	132 (4.9%)	81	12	80	86	63	86	66	24	13	21	26
More than once a week	6 (<0.1%)	100	17	86	92	97	92	78	81	10	10	78
Number of visits to the GP by 'I do not know' response												
I did not see a GP in the last year	240 (9.8%)	14	20	15	15	24	17	32	31	27	39	35
1-3 times in the year	1301 (50%)	7	9	16	13	19	10	19	22	20	21	22
4-12 times in the year	913 (35%)	4	9	13	10	19	7	17	27	26	27	26
13-52 times in the year	132 (4.9%)	6	3	9	6	11	9	14	26	21	30	22
More than once a week	6 (<0.1%)	0	0	0	3	3	3	7	3	71	68	0
Number of visits to the GP by 'No' response												
I did not see a GP in the last year	240 (9.8%)	13	65	18	8	17	15	22	39	59	48	49
1-3 times in the year	1301 (50%)	11	76	17	10	25	9	33	50	61	57	60
4-12 times in the year	913 (35%)	11	78	16	8	25	11	27	49	63	59	61
13-52 times in the year	132 (4.9%)	13	85	11	8	26	5	20	50	66	49	51
More than once a week	6 (<0.1%)	0	83	14	5	0	5	16	16	19	22	22

Note: This appendix is published as supplied and is unedited by *AJGP*.

Appendix 17. Participant responses to ‘Do you think information from your general practice record is being shared for the following reasons?’ by number of visits to the GP.

Number of visits to the GP by response	Number of participants (%)	To directly support my personal health care	For my GP to improve the health service they provide	For the Government to improve health services generally	For research in universities, hospitals or publicly funded research organisations
Number of visits to the GP by 'Yes' response					
I did not see a GP in the last year	240 (9.8%)	83	68	45	29
1-3 times in the year	1301 (50%)	88	71	42	40
4-12 times in the year	913 (35%)	89	67	41	31
13-52 times in the year	132 (4.9%)	98	85	51	44
More than once a week	6 (<0.1%)	97	81	15	10
Number of visits to the GP by 'I do not know' response					
I did not see a GP in the last year	240 (9.8%)	13	19	28	37
1-3 times in the year	1301 (50%)	7	14	27	25
4-12 times in the year	913 (35%)	5	18	26	32
13-52 times in the year	132 (4.9%)	2	4	27	28
More than once a week	6 (<0.1%)	3	0	71	74
Number of visits to the GP by 'No' response					
I did not see a GP in the last year	240 (9.8%)	4	13	27	34
1-3 times in the year	1301 (50%)	5	15	31	35
4-12 times in the year	913 (35%)	5	15	33	36
13-52 times in the year	132 (4.9%)	0	11	23	29
More than once a week	6 (<0.1%)	0	19	14	16