Australians' knowledge of general practice data sharing:

Findings from a focus group study and cross-sectional survey

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Background and objective

Relatively little is known about public understanding of the secondary use of general practice data. We investigated what the Australian public knows about the secondary use of information in their general practice records.

Methods

The investigation used a mixed methods approach with four focus groups (n=22) and a cross-sectional survey that was weighted to be nationally representative (n=2604).

Results

Participants broadly understood what was in their general practice record. Most believed it was shared with hospital health professionals and other medical staff to support their care. Fewer than 30% thought their health information was shared with health administrators, planners and researchers, and fewer than half believed it was used for planning, to improve health services generally or for research.

Discussion

The secondary use of general practice data outside the clinical encounter is poorly understood by the public. More and better information about how, where and with whom general practice data are shared is needed.

THERE IS AN IMPORTANT and increasing demand in Australia and internationally for access to administrative health data for secondary purposes, including for quality assurance, evaluation, health service planning and research. General practice data should be a rich resource for such purposes, particularly when combined with hospital and other health service data through data linkage.[1,2]

There are now over 100 primary care datasets available in Australia.[3] However, the potential of these datasets is not being realised. Alongside technical reasons related to poor data quality and the lack of standardisation of and interoperability between clinical software tools,[4] 'fear, reticence and lack of trust' among general practitioners (GPs) and patients are the most frequently cited reasons.[3]

Patients and the public do recognise the benefits of using general practice data for research, where the data are appropriately protected and the use is in the public interest.[5–9] However, even with protections in place, there is ongoing community concern about data security, the potential for misuse of data and the public's lack of control over their own health data.[5,10–12] There are also frequent calls for data custodians to build greater public awareness of and trust in the ways in which their agencies collect, share, protect and use administrative health data.[10–12]

The extent to which the public is aware of secondary uses of their health information varies.[13] There is some evidence that general practice patients are poorly informed about the use of their information outside of the clinical encounter.[8,14] However, this picture is not consistent, with a more recent study finding that participants were surprised to hear that specific research and data sharing practices were **not** happening on a routine basis.[9]

As the technical capacity to share and link general practice data grows, understanding what general practice patients know about the secondary use of their health data is crucial if we are to sustain trust in general practitioners and the health system. The launch and suspension of care.data – the UK initiative to extract data from general practice records with opt-out consent – is a salutary reminder of how important it is to understand what patients know about the use of their general practice data before implementing policy change.[15]

In this study, we explored what the Australian public knows about the content and use of the information in their general practice records. The findings reported in this paper are part of a larger study of community understandings of, and attitudes to, the use of general practice data for secondary purposes.

Methods

We used an exploratory sequential mixed methods design with focus groups (November to December 2021), followed by a cross-sectional survey (March to April 2022).

Recruitment

We employed an Australian market research company, McNair yellowSquares (Sydney, https://mcnair.com.au), to recruit Australian participants aged 18 years and over from their opt-in online panel for both the focus groups and survey. For the focus groups, McNair yellowSquares secured a diverse sample with respect to gender, age, residential location, educational qualifications, employment and cultural background. (Appendix 1, available online only). We aimed to recruit four focus groups with six participants in each; 22 participants took part, due to last-minute dropouts. We excluded people currently or previously employed in a general practice setting. For the survey, McNair yellowSquares aimed to recruit an opt-in sample of 2500 participants, selected to be nationally representative by age, gender and location. In recognition of their time, focus group participants received a $90 voucher and survey participants received up to $2.

Design

Focus groups

For the focus groups, we used case-based scenarios to prompt participants to discuss the types of information captured in general practice records and with whom and why general practice data are shared. We also sought their views on linking general practice records with other administrative health data and with administrative records outside the health sector. We piloted the discussion guide with a convenience sample of six adults. We made minor amendments to the discussion guide after the pilot (Appendix 2; available online only). The theoretical framework for the focus groups was empirical bioethics, focusing on how the participants' knowledge, perspectives and values interact.

Using the Zoom platform, we conducted one female-only group (>25 years), one male-only group (>25 years) and two mixed-gender groups: one >25 years and one young persons' (18–25 years). Appendix 3 Consolidated criteria for reporting qualitative research (COREQ)[16] (available online only) provides more detail about the methods.

Survey

The online survey (Appendix 4; available online only) adapted questions from pre-existing tools with new questions and insights from the literature[6,7,11,17–19] and the focus group findings. The focus group findings alerted us to the possibility that participants were less familiar with secondary uses of the information in their general practice record than we had expected. Accordingly, the final survey explicitly sought to understand what participants knew about the uses of their general practice information.

The survey included two short videos to briefly explain the content of a general practice health record and how this information can be shared with other people and organisations, including the protections that are in place. The final survey examined community knowledge and views across four domains:

- knowledge of information sharing practices
- views about how information should be shared
- views on linking general practice records with other data sources
- views about the trustworthiness of GPs, identifiability and transparency.

We also collected sociodemographic characteristics, health status and general practice attendance for participants. A single open-ended question at the end of the survey invited additional comments. The Survey Reporting Guideline (SURGE)[20] provides more detail (Appendix 5; available online only.).

Data analysis

Focus groups

Focus groups were audio recorded and transcribed verbatim by a professional transcription service. We used thematic analysis to analyse the focus group data.[21] Two researchers (LC and ABM) coded transcript one, to develop and agree on a structure. The coding tree focused on:

- awareness and understanding of the content of GP and hospital records
- support for sharing and linkage (including perceived benefits)
- concerns about sharing and linkage
- conditions and controls on sharing and linkage.

We summarised group dynamics and content of group discussions, with particular attention to the ways each group was similar or different. In this paper, we present findings as they relate to what participants knew about how information held in their general practice record was used, and by whom.

Survey

We weighted data based on Australian Bureau of Statistics (ABS) census data[22] and used R Project for Statistical Computing[23] to analyse the data. Only completed survey data were analysed. 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 ABS census data[24] to obtain the Australian population characteristics of gender, age, state and education, and to calculate the survey weights based on the realised sample characteristics after combining categories with small sample counts. We used the rake method[25] because not all possible crossings of all possible levels of the variables chosen were observed in the data. All results in this paper except for participant demographics are obtained using such weights. Raw proportions are only reported on participants' demographic information. In this paper, we focus on those findings that relate to participants' knowledge of who the information in the general practice record was shared with and for what purposes.

Results

In total, 22 participants attended the four focus groups. There were equal numbers of female and male participants, with most aged 18–29 years (n=10), all but seven with post-secondary education, residing in New South Wales or Victoria (n=14), and working full time (n=11); refer to Appendix 1.

The survey was completed by 2604 participants. Full demographic information about participants is in Appendix 6 (available online only).

Familiarity with the content of health records

Participants in all focus groups explained that they believed that general practice records held reasons for presenting demographic information, symptoms, examination findings, medical and family histories, diagnoses, tests and referrals, treatment plans and medications, and Medicare and health insurance information. Some participants noted that GPs used their discretion in deciding what to record, and information about a patient's personality and attitudes would probably not be in the record. There were also some differences of view about social information such as family situations and major life events:

> *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.* (Participant [P] 1, all-female Focus Group [FG] 1)

> *Probably. There* [are] *probably some things about the person's personality or things they wouldn't see as being necessary to put in the health record, but they would just know as a part of their practice when treating the patient …* (P5, mixed-gender youth FG4)

> *If you had symptoms of, say, ADHD, your doctor wouldn't write it down until you, possibly, brought up the possibility of having that, but they'd know if they'd seen you for a long time, possibly.* (P2, mixed-gender youth FG4)

Across all focus groups, the participants also agreed that a hospital record would have less information and relate to a shorter period than a general practice record, and that information about social situations and mental health would not be in a hospital record. Again, the participants referenced their personal experience:

> *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, 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 …* (P1, all-male FG2)

Knowledge about general practice data-sharing practices

We asked three questions in the survey about knowledge of data-sharing practices: who the information was being shared with, for what purposes and whether participants had a My Health Record. We told participants to assume that the GP and everyone with whom information was shared would do everything they could to minimise privacy risks but that it was still possible that people could be identified from some of the information shared about them.

Over 80% of participants believed that information from their general practice record was being shared with hospital staff, other medical professionals or themselves (Figure 1). Over half thought that information was being shared with other health professionals outside these settings. In contrast, fewer than 30% of participants thought their information was being shared with people outside the health professions, including health administrators and researchers.

Almost 90% of participants believed that information was being shared to directly support their own health care and 70% thought that GPs used the information to improve the general practice services they provided (Figure 2). Around one-third believed that information was not being shared to improve health services generally or for research, and over a quarter said they did not know. For both questions, a noteworthy number, though a minority, of participants were unsure or did not know what was happening with their information.

We also asked participants if they had a My Health Record. Approximately one in 10 Australians opted out of the My Health Record system when it was amended in 2018. In our survey, 48% of participants said they had a My Health Record, 32% said they did not and 20% were unsure.

In the focus groups, there were also mixed views about whether general practice and hospital records were linked to each other:

> *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 [work], I would think.* (P2, all-female FG1)

Participants responded as follows when asked if they thought the hospital and GP would link up and work together:

> *You'd hope so.* (P2, 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, all-female FG1)

See Appendix 7 (available online only) for the indicative focus group quotation table.

Patterning of responses

In the survey, we investigated the impact of age, gender and educational background on participants' knowledge. We grouped participants into generational cohorts: Traditionalists (born 1928–1945), Baby Boomers (1946–1964), Gen X (1965–1976), Gen Y (1977–1995) and Gen Z (1996–2010). Younger generational groups were more likely to say their information was being shared with allied health services (60% Gen Z compared with 35% Traditionalists), but also more likely to say it was **not** being shared within the general practice (21% Gen Z compared to 7% Traditionalists) or with other medical specialists (20% Gen Z compared with 4% Traditionalists). Fewer Baby Boomers than any other generation said that their general practice information was being shared with researchers. For example, 7% of Baby Boomers said their information was being shared with private sector researchers compared with between 16% and 25% in

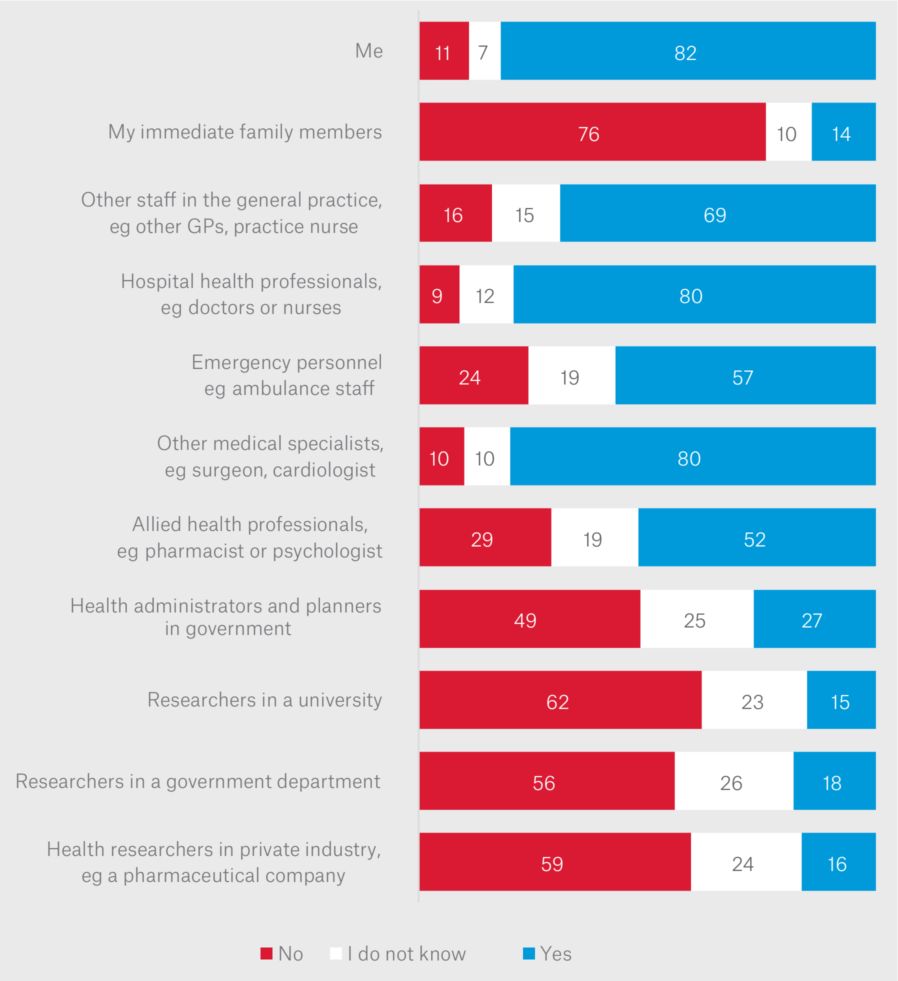

Figure 1. Participant responses (%) to the question 'Do you think information from your general practice is being shared with the following people?'

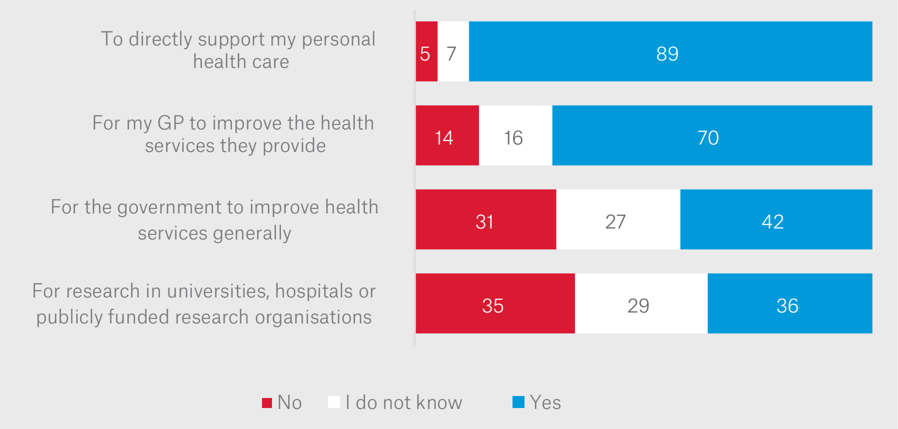

Figure 2. Participant responses (%) to the question 'Do you think information in your general practice record is being shared for the following reasons?'

other generational cohorts (see Appendix 8 and Appendix 9; available online only).

In general, gender and educational differences were small. More men than women said that their health information was being shared with other family members (19% compared with 9%), health administrators (32% compared to 22%) and researchers (20–23% compared to 11–13%); see Appendix 10 (available online only). Other differences between men and women were small; see Appendix 11 (available online only). Participants with education at Year 10 or below were more unsure about whether their health information was being shared with health administrators and researchers (32–35% compared with 17–21% with university education); refer to Appendix 12 and Appendix 13 (both available online only).

We also explored the relationship between knowledge of data sharing and measures of the participants' health status. People with poorer self-reported health status tended to be less sure about whether their health information was being shared, particularly with emergency personnel (31%) and with planners and researchers (4% to 12%); refer to Appendix 14 and Appendix 15 (both available online only). Participants who saw a GP more often were more likely to report that they thought their information was being shared outside the general practice (78% to 97%); refer to Appendix 16 and Appendix 17 (both available online only).

Discussion

This focus group study and survey weighted to be nationally representative provides preliminary evidence that Australians, even when they understand the content of their general practice record, are not clear about whether the contents are shared with other individuals and organisations, and why this occurs. Most of our participants believed that their information was shared with hospital health professionals and other medical staff to support their health care. Beyond this understanding, though, there was little consensus about who GPs share the information in patient records with and for what purposes. A noteworthy minority of people in the focus groups and national survey did not know what happened with their information or whether or not they had a My Health Record. Although these findings likely represent relatively uninformed positions, they suggest that many people in Australia would greet with surprise any public reporting of data sharing in general practice.

Much of the data sharing described in this paper is already occurring. Information is shared within general practices and with other health professionals and hospitals. Many general practitioners also share data that have had identifiers removed with government and researchers, and such sharing is likely to increase. The Australian Government's recently released blueprint for the next decade of primary health care[26] and the recent General Practice Crisis Summit White Paper from The Royal Australian College of General Practitioners (RACGP)[27] both argue that the primary health care system of the future must be underpinned by comprehensively and systematically gathered primary care and general practice data. The key finding of this paper is that some Australians do not know how their health information is already being shared related to their clinical care, and a greater proportion do not know that their health information is being shared for purposes that are not directly related to their care.

Recent research about public views on using health data for secondary purposes emphasises the importance of building and maintaining trust between the public and governments.[3] Central to trust is transparency – trust cannot be maintained if people do not know their health information is being shared and do not understand the measures taken to protect privacy and minimise the risk of harm.[27] Public awareness cannot exist without data transparency – without information about which data are collected and held, who they are shared with, when, how and for what purposes.[28]

However, the relationship between public awareness, transparency and trust is not straightforward. By itself, transparency does not secure patients' awareness, nor does being aware of information mean that it will be read and understood.[29] In addition, data transparency is not a guarantee of trust. Onora O'Neill famously pointed out in her Reith lectures in 2007 that 'trust seemingly has receded as transparency has advanced'. As we have access to more and more information, it becomes paradoxically more difficult to decide whether the information is trustworthy. We do not trust because we have lots of information but because we link the information we have to sources which we trust.[30] GPs are often regarded as trustworthy, in part because the GP–patient relationship is grounded in openness and reliability built over time. This creates both opportunities and risks as general practice data begin to be shared more widely. On the one hand, GPs are ideally placed to build trust in the secondary use of general practice data. In our recent research we have also found that patients, in general, trust that their GP will take care of the information in their general practice record appropriately.[10] On the other, as the UK care.data experience shows,[15] discovering secondhand that information from one's general practice record is being shared, even without identifiers, might have a profound effect on trust in the health system, general practices and GPs. In Australia, these effects could delay or even derail the use of a key and vital future resource for planning, service delivery and research.

The responsibility for ensuring that Australians are well informed about the secondary uses of the information in their general practice record cannot rest solely on GPs and general practices. Well-funded public engagement and consultation will be important to establish what Australians want to know about the secondary use of general practice data, and to provide this information in timely and meaningful ways. In addition, as the secondary use of general practice data grows, careful attention will need to be paid to the regulatory environment to ensure that it supports the conditions needed to share general practice data with confidence.

Limitations

The survey and focus groups were conducted using an online panel of members of the public who had signed up to participate in research and marketing activities, and this therefore has limitations. The participants in these panels might have been more likely to understand research uses of information. They also probably had a reasonable level of confidence in using information technology and the internet, although what this meant for their knowledge about sharing their health data was unclear.

Conclusion

There is a growing demand to use general practice data for purposes outside of patient care. This study has shown that current data-sharing practices in Australia are not transparent and that patients are not well informed about how their data are shared, with whom and for what purposes. Securing legitimacy for sharing general practice data will require careful attention to patient and public understanding of data-sharing practices. While this must involve providing more and better information for patients, equally there must be attention to the means through which that information is provided. General practitioners have a central role to play in these activities.

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