

# Australian General Practitioner Perceptions to Sharing Clinical Data for Secondary Use: A Mixed Method Approach

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## Research Article

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# **Abstract**

## **Objective**

The potential for data collected in general practice to be linked and used to address health system challenges of maintaining quality care, accessibility and safety, including pandemic support, has led to an increased interest in public acceptability of data sharing, however practitioners have rarely been asked to share their opinions on the topic. This paper attempts to gain an understanding of general practitioners' perceptions on routinely sharing practice data for both population health planning and healthcare research both from an Australian and international perspective.

## **Materials and Methods**

A mixed methods approach combining an initial online survey followed by face-to-face interviews (before and during COVID-19), designed to identify the barriers and facilitators to sharing data, were conducted on a representative sample of general practitioners across Western Australia (WA).

## **Results**

Eighty online surveys and ten face-to-face interviews with general practitioners were conducted from Nov 2020 – May 2021. Although respondents overwhelmingly identified the importance of population health research, their willingness to participate in data sharing programs was determined by a perception of trust associated with the organisation collecting and analysing shared data; a clearly defined purpose and process of collected data; including a governance structure providing confidence in the data sharing initiative simultaneously enabling a process of data sovereignty and autonomy.

## **Discussion**

Results indicate strong agreement around the importance of sharing patient's medical data for population and health research and planning. Concerns pertaining to lack of trust, governance and secondary use of data continue to be a setback to data sharing with implications for primary care business models being raised.

## **Conclusion**

To further increase general practitioner's confidence in sharing their clinical data, efforts should be directed towards implementing a robust data governance structure with an emphasis on transparency and representative stakeholder inclusion as well as identifying the role of government and government funded organisations, as well as building trust with the entities collecting and analysing the data.

## **Background**

General practice is considered the cornerstone of healthcare and provides the foundations of a health system designed to protect and improve the health of the population (1, 2). To assist in managing an increasingly complex patient demographic, general practices have taken advantage of advancements in compute power, storage capacity and the reduced costs of technology by incorporating digital technologies and electronic medical records (EMRs) into their clinical practice. Practitioners now have the capability to collect vast amounts of clinical data points on individual patients to assist them in the assessment and management of patients.

Although patient data collected at point of care is primarily used for managing and treating an individual patient, when integrated across a network of health care providers (3, 4), these health systems can be used to improve clinical processes, care coordination, quality of care, time efficiencies (5, 6), patient safety (7), health outcomes (8) and more recently in pandemic support (9).

The untapped potential within these EMRs has garnered considerable interest from private and public sectors resulting in general practices increasingly being solicited by third parties to share patient data for a variety of purposes with varying degrees of participation. Countries such as Australia, Canada, United Kingdom and New Zealand have invested considerably in the development and implementation in their national health systems to enable data integration to take place. However, apart from New Zealand where all practice data is collected centrally, there has been limited success in attracting general practices to share their data for secondary use.

Although studies have been conducted to gauge patient (10–13) and researcher (14) sentiments on sharing clinical data, there is a limited information on practitioner perception (15–18) to sharing patient information. Understanding practitioner perception is critical, as in most countries, practitioners are the custodians of their patient's data and have ultimate decision as to its use. Using online surveys and in-person interviews, our research builds on previous findings (16) to enable a greater understanding of the associated barriers and facilitators for general practitioners to share their patient data for secondary use.

## Methods

### Study Design

A mixed method approach was used to understand general practitioner's perspectives on sharing health data utilising both an online survey and interviews. The online survey consisted of 21 questions with 7 categories (refer to supplementary material). To overlay context to the survey results, a separate cohort of practitioners were recruited to examine these findings through face-to-face consultations. Data collection for both surveys and interviews extended into the COVID-19 pandemic requiring careful planning to capture general practitioner responses, a cohort known for poor participation rates (19).

The survey and interviews consisted of six sections which explored a) **previous participation** in research; b) **willingness** to share practice data for secondary use including health research; c) **type of data** that

could be shared; d) **concerns** related to sharing data for secondary use; e) **data collection and storage** and f) **understanding** of how the data was collected and stored.

These were subsequently synthesised into three broad areas of discussion of purpose and process of the secondary use request, trust in the organisation collecting and analysing the data, and governance associated with the program. Responses were aligned to assess the barriers and facilitators to data sharing.

## **Survey**

To gather insights from a broad representation of general practitioners and to maximise the responses from the target audience, both on-line (REDCap electronic data capture tool hosted the Curtin University (20)) and printed versions of the survey questionnaire were produced. The survey questionnaire was developed with input from 3 general practitioners and piloted with 6 separate practitioners who were actively engaged with their local Primary Health Network (PHN), one of 31 federally funded organisations responsible for augmenting primary health care based on community need. The survey consisted of 21 questions and was developed to work with the interviews through complementary themed questions around attitudes to data sharing.

Participants were recruited between February and November 2020 using Healthdirect Australia's online Healthmap portal containing a listing of 730 publicly listed general practices (21). The link to the survey including the information pack consisting of a flyer advertising the study containing both the URL and a QR scanning code for smart devices, were sent to primary care organisations including education, training and workforce agencies who engage with general practitioners. In addition, general practices were directly approached, by phone, email and in-person, by the lead author to further promote participation.

## **Interviews**

To further ascertain the perception of general practitioners' acceptance and willingness to share patient data, a cohort of practitioners known to have previously participated in health care intervention programs offered by their local PHN were selected for a follow up interview. Ten general practitioners from WA consented to participate in an audio-recorded semi-structured interview. Eight of the interviews were conducted in person, one by phone and one using video conferencing technologies. The lead author conducted all interviews using an interview run sheet to guide the open-ended discussion ensuring all points were covered.

Interviews were conducted in two batches, pre COVID-19 isolation activities (N=5) and post (N=5). Participants were contacted by phone and email, providing them with participant information sheets, consent forms and an invitation booking.

## **Ethics**

This research project was approved by the Curtin University Human Research and Ethics Committee (HREC) (approval number: HRE2019-0619-02).

## Results

A total of 80 surveys were submitted of which 72 were completed. Sixty-six percent of GPs that completed a survey were over the age of 40 and of these, 54% identified as actively practicing medicine between 11-30 years. Characteristics of the participants are available in Table 1. To provide additional context to the survey, 10 practitioners were interviewed of which 8 identified as either being part owner or sole proprietor of their practices.

**Table 1**  
**Interview Participant Characteristics**

<b>Characteristic</b>	<b>Surveys</b>	<b>Interview</b>
	<b>N (%)</b>	<b>N (%)</b>
	<b>Total = 72</b>	
<b>Age Group (Years)</b>		
<40	24 (33.3%)	1 (10.0%)
40-55	19 (26.6%)	4 (40.0%)
>55	29 (40.2%)	5 (50.0%)
<b>Years Practicing</b>		
0-10	35 (48.6%)	4 (40.0%)
11-30	26 (36.1%)	5 (50.0%)
>31	11 (15.2%)	1 (10.0%)
<b>Practice Size</b>		
Solo	2 (2.7%)	-
2-5 GPs	9 (12.5%)	1 (10.0%)
6+ GPs	61 (84.7%)	9 (90.0%)
<b>Location (PHN)</b>		
Perth North [Urban]	32 (44.4%)	4 (40.0%)
Perth South [Urban]	22 (30.6%)	4 (40.0%)
Country WA [Rural and Remote]*	4 (5.6%)	2 (20.0%)
Not Disclosed	14 (19%)	-

\*As defined by the Modified Mixed Monash model (22)

The survey and interview responses were collected across six themed sections to gather information on the practitioner's experience and willingness to participate in research, their understanding of the data sharing requirements and the concerns that they had.

## Previous Participation in Research

A majority of those surveyed (76%) had participated in research on more than one occasion, with ninety-five percent of practitioners stating research to be either important (25%) or very important (70%) to

Australia's future. Given the opportunity of participating in future research projects, 67% of participants considered it very likely (39%) or likely (28%) of being involved, with 30% feeling uncertain.

When specifically asked about sharing data for research purposes the majority of practitioners interviewed (N=6, 60%) indicated that a lack of knowledge about research requirements as a barrier, with one practitioner stating:

"It's not that we're not interested or don't want to be involved in research, it's just that we've never done it and don't know where to start. G1".

Another highlighted regulations imposed within the health system as being the main impediment to sharing data for broader consideration:

**The system is more regulated than it used to be, to the point that it is ridiculous how careful we have to be. I suppose it's this that prevents us from sharing data outright. Even though the technology makes it easier to share data the bureaucracy and the amount of associated regulation is slowing things down. B1**

When asked what factors would prohibit participation in research projects, respondents identified **time** required to thoroughly understanding the purpose of request and obtaining **consent** as the main challenges.

Practice owners (N=8, 80%) who had been asked to participate in previous data sharing projects were expected to expertly review each request and familiarise themselves with all aspects of the project. This includes understanding and agreeing to the purpose of the data request; assessment of clinical and legal risks to both the patient and the practice; impact to the business associated with the time required to collect, prepare and securely transfer the data; ascertain the liability, accountability and extent of coverage specified in the related data sharing agreement; as well as placing trust in the organisation requesting the data.

...most of the time we don't have a good understanding of what the data is being collected for and the data has the potential to be used out of context and even though it may be telling you something it may not be representative of what is actually happening in the practice. To get to that level of understanding I would need to put in dedicated amount of time to match my level of understanding to what is being asked for. It's a fear of not knowing. Sometimes you just have to blindly trust what they are telling you what the data will be used for. B1

Additionally, these concerns led some practitioners question their role in primary care.

....from a collection stand point ... is that going to take away valuable time I have with the patient? Am I now going to be a collector of data rather than a listener of a story to a patient? Will I be taken away from my primary purpose for which I am there? C1

Patient recruitment and obtaining consent requires an investment of valuable time outside the therapeutic relationship between practitioners and their patients.

Consent is cumbersome and time consuming however there is a lot of value in that because you're building a relationship with the patient. You're building an understanding of the project and the natural progression from that is whether they're happy and if all their questions have been answered before they consent. G1

Depending on the data request purpose, practices may be required to obtain consent from both patients and the practice GPs, adding an additional level of complexity and time.

My reluctance in going to everybody [in the practice] and getting permission. There is a perception that the data belongs to them [GPs], and that's a bit of a grey area. Because the data doesn't belong to them, it belongs to the practice and that could confuse things. E1

## **Willingness**

Willingness to share data for secondary use was ascertained by the practitioner's perceived risk to their patient, other health providers involved in the patient's care, or their general practice. The majority of respondents (N=48-58, 67%-81%) felt there was very low or low risk with sharing de-identified patient information with other general practitioners (N=48, 67%) other health providers (N=53, 73%) or with the patient themselves (N=58, 81%). This was supported by the interviewed practitioners all of whom had little concern with sharing de-identified patient information across the health care system:

"Look, we already share quite a bit of patient information – as part of their care plans with other GPs including path labs and radiology clinics...so I'm comfortable with this from that approach. E1"

To be honest, whether I give you the data for research or to the federal government, I'd have the same concerns ... what will you be doing with data, what are you going to do with the data, is my data safe, who's benefitting and how ... and can I trust you? H2

When asked to identify the potential consequences to sharing data for secondary use, surveyed practitioners, revealed that litigation (N=19, 27%), misinterpretation of data leading to wrong conclusions for the practitioner (N=14, 20%) and loss of business (N=13, 18%) as the top three concerns. Data breaches (N=11, 15%), information used for outcome payments (N=9, 13%) and wrong conclusions associated with the practice (N=5, 7%) featured less as concerns. Eight survey respondents offered additional consequences which largely reflected their concerns with sharing patient data. These included a lack of clarity with regards to consent (N=2, 2.8%), extra time required in an already busy practice (N=2, 2.8%), data entry errors resulting in unreliable, non-uniform data leading to wrong conclusions (N=3, 4%), and a threat to funding and revenue streams for general practice (N=1, 1%).

## **Types of data**

Depending on the type of data being requested, surveyed practitioners were comfortable in sharing demographic information (N=66, 92%), medical information (N=62, 86%), location information (as postcode) (N=56, 78%), family history (N=50, 69%), hospital information and community care information (N=40, 56%). However, personally identifiable information such as name, birthdate, phone number) was recognised as being sensitive, with high (N=54, 75%) levels of discomfort and concern around secondary research use.

Sharing of non-threatening aggregate data was found to be more acceptable for most of the interviewed practitioners, with many participating in the federal government's Practice Incentives Program for Quality Improvement (PIP QI), a financially incentivised program supporting quality improvement activities (23, 24). However, some concerns still existed where it is perceived that the data will expose practices business intelligence:

Even if you're sharing high level aggregate data like number of active patients or number of patients with a chronic disease for example, you are potentially encroaching on the practices business intelligence and may give insights to our competitive edge and could be used in inappropriate ways. After all we're all in the market competing for the same patients. At the end of day, we are all private business and are operating competitively. E1

I'm happy to share data that's aggregated and nothing else. We already do this to claim the PIP payment. We reviewed this within the practice and found that it was of low risk to both our patients and the practice ... for the moment ... because we don't know what else will it be used for. D1

## Data sharing concerns

When asked what would prevent practitioners from sharing their data, data breaches (N=65, 90%), data being used to tie general practice funding to outcome payments (N=51, 71%) and litigation (N=42, 58%) ranked as the three main concerns (Figure 1). Interviews confirmed that trust in an organisation's ability to collect, store and be responsible for the shared data in a secure manner can influence a practitioner willingness to share their data for research and secondary use (15).

If there is a data breach ... is the practice indemnified? If the patient decides to sue, whom could they go after? F1

## Data Collection and Storage

Surveyed practitioners were asked about the perceived trustworthiness of Australian organisations collecting various forms of health data. Government agencies were generally perceived as having higher levels of trust. The Royal Australian College of General Practice (RACGP) (N=34 47%), the largest organisation representing general practitioners, was also considered to be a trusted entity for data collection and storage. Universities (N=30, 41%) were perceived as having a moderate level of trust; while corporate organisations (N=66, 91%) such as commercial tracking companies, software companies and extraction vendors were perceived to have the lowest trust.

Sharing data with a university provided reassurances that data would only be used for a specific purpose with no potential of over-reaching or scope creep. This is in part attributed to the ethical guidelines and principles universities are required to follow when working with health-related data. As one practitioner noted:

I'm reassured with university research as I know if the project has ethics approval, it can only be used for a specific purpose and nothing else. I'd be happy for the university to have control of the data from an academic perspective because universities tend to have a lot of respect across the clinical and research community... B1

## **Understanding**

When practitioners were asked about their level of understanding of how shared data would be managed across different organisations, most of the respondents had little to no familiarity with the processes (even though many had a medium to high level perception of trust).

Interview participants noted considerable concerns relating to lack of transparency, autonomy and sovereignty around shared data, including a loss of control over what happens to the data. Relinquishing control of the data places some practices in a vulnerable position with many of them being both cautious and sceptical.

"Look, we're a business - just like all the other practices – and we need to take advantage of whatever funding opportunities come our way and you can argue that PIP is one of those opportunities. We wouldn't share otherwise. We upload our data to the PHN who in turn do who knows what with it... I expect that eventually the data will be used in some way to get more out of us. Without context the data could actually be misrepresenting us and that's a concern. It would be nice to have more control as we currently don't really know how are data is being used and for what purpose. D2 "

I'd like more control over my data.... being able to opt in or out. Ensuring that the data would not be used for punitive purposes...it's about not knowing what they will be doing with the data in the future. C1

Overall practitioners were 'fairly confident' (N=33, 45.3%) in their understanding of their obligations and responsibilities of Australia's privacy legislation, although there was a reliance on the RACGP to provide them with guidance. A small group of general practitioners (N=11, 15.6%) identified as being extremely confident by having read the legislation and have a complete understanding of their obligations.

I understand the ethical considerations of the Privacy Act. I've recently had to revisit this for the eHealth application [My Health Record] that was rolled out recently. Where I have to call my patient in and explain to them and give them an explanation statement. I have to make sure they fully understand why I'm sharing their data with this organisation. A1

## **Discussion**

Our paper identified Western Australian general practitioners as having an understanding of the importance of primary care data for secondary use. They were however apprehensive with sharing their data in the absence of an understandable purpose; trust in the organisation collecting and analysing their data. These observations reflect previous studies (15, 16, 25).

Depending on the purpose, practitioners had misgivings to what and how long their data was used for and the potential misrepresentation of. Practitioners who previously participated in research projects were more likely to consider the request because of the associated ethics approval which stipulates the scope and limitations of what the data can be used for, including the consideration of participant consent if required. In lieu of a national privacy policy, health providers must be extra vigilant in their custodianship role by assessing the potential risk to their patients (26). While ethics approvals are essential for research studies they provide a level of surety for both the patient and general practitioner, ensuring that the collected data will be used as stipulated, it can be an impediment to a rapidly evolving data landscape (27). Related concerns have not been reported in New Zealand where a national privacy policy has been developed and implemented (6, 28, 29). An additional facilitator to the New Zealand context is the availability of unique health identifier for each citizen, which when used in the auspicious of the privacy policy, reduces the need to de-identify aggregated patient data which is the mainstay in other jurisdictions when using data for secondary use.

The lack of a clearly defined, nationally approved, data sharing framework (16, 30) has further detracted Australian general practice from investing time to familiarise itself with each data request to confidently share their patient data for secondary use. Hesitation in participating in data sharing activities related to a general lack of understanding that went beyond how the collecting organisation was managing, processing and analysing their data asset. A frustration in the acknowledgement of their inadequate understanding of what was being asked of them as part of the data request, originated from the amount of time necessary to become familiar with the project.

General practices in Australia are independent businesses in competition with one another. Unlike those in the New Zealand and the United Kingdom, Australian general practice required the principal practitioner(s) to be experienced in all aspects of running a business in addition to maintaining clinical accreditation and providing care; all within a limited time frame and tight budgetary constraints (31). Dedicating time to be informed about the project, collect, review and validate the data and potentially collect consent, provides challenges for general practice simultaneously questioning the practitioner's primary role as health provider, becoming more of a health care data administrator.

In Australia, over 72% percent of general practitioners receive a financial reimbursement from the federal government for voluntarily providing their de-identified patient data as part of PIP QI program (23). Through the quarterly submission process orchestrated by the PHNs, practices are further supported through the provision of data extraction software and practice specific data quality reports.

The reports provided by the PHN allow general practices to review and improve their data quality, with some practitioners hesitantly anticipating these payments to ultimately be associated to outcomes as

was implemented in the UK with the Quality Outcomes Framework (QOF). Although the benefits of the QOF are yet to be determined (32, 33), the adoption of a pay for performance program was unpopular with many practitioners at the time, which could be a contributing factor to the low uptake of voluntary secondary use data programs. A similar observation was shared amongst several Australian practitioners that participated in a national study related to the PIP QI implementation (34) generating division and confusion across general practice in participation of the program.

The potential of implementation of an outcome-based funding model together with the uncertainty as to how the collected general practice data will be used, has made Australian practitioners weary and concerned their data will be used against them and disrupt the current business model. Sub-themes of autonomy and data sovereignty were prolific throughout the interviews with practitioners wanting to be able to opt-out of data sharing program in light of the undefined scope of what the data will be used for. Practitioners benefit financially from data sharing for payment incentives; however, some have questioned the administrative time required to complete the claims which would be better spent with their patients. A similar sentiment was seen in the UK with physicians being over burdened with increased administrative workloads resulting in increased work stress (35)

Another area of concern for general practice is with the current funding model of claiming for provided medical services and prescribing medication. In Australia, general practitioners are more prone to being audited than any other healthcare professional, resulting in revenue loss and reputational damage should a claim of inappropriate service provision or prescribing be made. Although a hyper vigilant approach to health care provision may be conducive to optimal care, it is yet another barrier to overcome, as general practitioners feel scrutinized at multiple levels.

## **Removing Barriers**

Practitioners' hesitation to participate in secondary use data projects is substantiated through numerous unsolicited data requests from across the health system. Absence of a coordinated system devoid of standards has developed a culture of trepidation and resistance. To engender confidence within primary care and to promote data being used for secondary use, we suggest the establishment of an authoritative clinical council consisting of elected representatives of data owners and custodians, which on behalf of their constituents, would act as a unified voice to review and assess each data request for its purpose, legal and ethical considerations including associated stakeholder impacts, accountabilities, and risks. Subsequent to the project's approval by the clinical council, each health care provider would be provided with reassurances and the confidence to share data without any reservations. Similar governance structures have proven to be effective in jurisdictions such as the UK (36), Canada (37, 38) and New Zealand (26).

In addition to the establishment of a transparent authoritative governance structure, the collection, analysis and storage of the data facilitated by a trusted federal entity further reduces the barrier for data sharing. Trust in this context is associated with national prominence and reassurance that appropriate

compensation (financial and legal) could be obtained should it be required. This is seen in other countries where centralised data collections are managed and funded in part by federal bodies. With the recent implementation of national storage and analytics platform (39), the Australian government has funded the Primary Health Networks to manage and continue to develop their relationships with general practice to share their data for quality improvement activities.

### Coi

nciding with the national data platform implementation, the Australian government restructured the practice incentive payment program by compensating general practice financially for sharing their data through their PHN who in turn provide reports and improvement activities, assisting practices to achieve quality improvement and patient outcomes.

## Strength and Limitations

This study utilised a mixed-methods approach, providing in-depth information from the small number of interviewees complimented by the larger number of survey respondents. Considerable effort was made to promote the survey and recruit across the practitioner network, resulting in 80 survey submissions. This was considered a successful result given general practitioner recruitment for research is acknowledged as a major challenge for researchers (40, 41) which for this study was further compounded by the COVID-19 pandemic which restricted survey promotion. GPs who completed the survey may be more likely to be involved with research and may have different views to the barriers compared to those who did not complete the survey; however, those GPs more involved in research may also have a greater understanding of the current barriers.

## Conclusions

Several benefits have been identified from sharing and integrating routinely collected patient data from general practice. These advantages are contrasted by barriers including trust in what the data will be used for, lack of knowledge of the process, no financial incentive, concerns related to litigation, and data breaches which restrict the efficient use of these data. These barriers can in part be addressed through the establishment of a local clinical governance council, as well as a federal entity to facilitate the collection, storage and analysis of data. Understanding these barriers will have a fundamental contribution to increasing general practitioner participation in secondary-use projects and programs to facilitate these data resources to their fullest potential.

## Abbreviations

COVID-19 - Corona Virus Disease 2019

EMR – Electronic Medical Records

GP – General Practitioners

HREC – Human Research and Ethics Committee

PHN – Primary Health Network

PIP QI – Practice Incentive Program for Quality Improvement

RACGP – Royal Australian College of General Practitioners

UK – United Kingdom

URL – Universal Resource Locator

QOF – Quality Outcomes Framework

QR code – Quick Response code

WA – Western Australia

## **Declarations**

### **Ethics approval and consent to participate**

All methods were carried out in accordance with relevant guidelines and regulations. The research received ethics approval from the Curtin University's Human Research Ethics Committee (Ref approval number: HRE2019-0619-02). All participants provided informed written consent to participate.

### **Consent for Publication**

Not applicable.

### **Availability of data and materials**

The datasets generated and/or analysed during the current study are not publicly available based on ethics committee approval and participants' consent but are available from the corresponding author upon reasonable request (and after obtaining ethics approval).

### **Competing interests**

The main author, RV, is currently working for the WA Primary Health Alliance as an industry embedded researcher. The authors SR, SR and JB declare that they have no competing interests.

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### **Author's Contribution**

RV designed the study, collected the data, analysed the data, and drafted the first manuscript. All authors read and approved the final manuscript.

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## Figures

### Figure 1

Concerns related to data sharing for secondary use.

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