

Private practice

Australian patients harbour serious concerns about how their personal general practice data is collected and shared, according to recent research into community attitudes.

A mixed methods research study supported by the Digital Health Cooperative Research Centre examined the views of a broad cross-section of the Australian population during late 2021 and early 2022.

90 per cent of respondents said they supported sharing their general practice information to directly support their care, but fewer than half felt comfortable with their data being used for secondary purposes like research and health service planning.

Professor Annette Braunack-Mayer from the Centre for Health Engagement, Evidence and Values co-authored the study and says respondents expressed a range of concerns.

'Patients are worried about whether the "data custodians" are trustworthy,' Professor Braunack-Mayer says.

'They're concerned about how they manage the data, who they might release it to and under what conditions. They're concerned about personal harm relating to privacy breaches and discrimination and they're also worried about third parties profiting off their data.'

GP information is increasingly being used for quality assurance, evaluation, health service planning and research.


The study findings suggest that patients are more concerned about sharing general practice data than they are about sharing data collected in other healthcare settings like hospitals.

'My take on this is that general practice relationships of all the healthcare relationships are the most personal ones – they're deeper, often more longstanding and more holistic' Professor Braunack-Mayer says.

'People are telling their GPs things that are more personal and may therefore be more worried about the likelihood that their data is shared.'

Dr Carolyn Adams is a senior lecturer at Sydney's Macquarie University and an expert in privacy law in healthcare settings. She says even though patients view GPs and other healthcare settings differently, the same laws apply when it comes to how data can be shared.

'Some GP data is shared under legislative authority,' Dr Adams says. 'In relation to Medicare for example, doctors



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are required by legislation to send that information to Medicare. They're not breaching confidentiality because the sharing of data is required by law

'Data can also be shared on the basis of express or implied consent. If data is going outside the practice and there is no legislative authority, you would be more inclined to ask for express consent.'

Dr Adams says the other way practices legally share data is through deidentification.

'In the past that has been fine, because if you strip enough of the personal information off each record you could generally say it would not be possible to identify the individuals,' Dr Adams says.

'But as our technical capacity to reidentify information increases, the reliance on deidentification is increasingly coming under the spotlight.'

Both experts agree more must be done to educate patients about how their data is being used.

'What we know based on the research we've done is that many people do not know to what extent their information is being shared outside the practice for purposes that are not related to their clinical care,' Professor Braunack-Mayer says.

'They've told us they want to know how the practice uses their data and they want that information to be accessible. That means it will need to be available in multiple languages and to suit different literacy levels.'

'We need resources for the community, we need resources for GPs and we probably need legislative change.'

Dr Adams agrees regulatory changes are needed and says GPs also have a responsibility to educate their patients better.

'We have to take this really seriously. The reason that obligation of confidentiality exists between a doctor and a patient is because that relationship is based on trust,' she says.

'If that trust is compromised then the therapeutic relationship is compromised, and that's clearly not in the interests of patients, GPs or the community.'