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BMJ Health &
Care Informatics

# Sharing data matters: exploring the attitudes of older consumers on an emerging healthy ageing data platform using electronic health records for research

Kim Naude, David A Snowdon, Emily Parker, Roisin McNaney,
Velandai Srikanth, Nadine E Andrew

**To cite:** Naude K, Snowdon DA, Parker E, *et al*. Sharing data matters: exploring the attitudes of older consumers on an emerging healthy ageing data platform using electronic health records for research. *BMJ Health Care Inform* 2025;**32**:e101126. doi:10.1136/bmjhci-2024-101126

► Additional supplemental material is published online only. To view, please visit the journal online (https://doi.org/10.1136/bmjhci-2024-101126).

Received 11 May 2024
Accepted 15 December 2024

Monash University, Melbourne, Victoria, Australia

**Correspondence to**
Dr Kim Naude;
kim.naude@monash.edu

## ABSTRACT

**Background** In Australia, with the recent introduction of electronic health records (EHRs) into hospitals, the use of hospital-based EHRs for research is a relatively new concept. The aim of this study was to explore the attitudes of older healthcare consumers on sharing their health data with an emerging EHR-based Research Data Platform within the National Centre for Healthy Ageing.

**Methods** This was a qualitative study. Two workshops were conducted in March 2022 with consumer representatives across Peninsula Health, Victoria, Australia. The workshops comprised three parts: (1) an ice-breaker (2) an introduction to EHR-based research through the presentation of 'use case' scenarios and (3) focus group discussions. Qualitative data were analysed using reflexive thematic analysis.

**Results** Consumer participants (n=16) were aged between 62 and 83 years and were of mixed gender. The overarching theme was related to trust in the use of EHR data for research; themes included: (1) benefits of sharing data, (2) uncertainty around data collection processes and (3) data sharing fears. The three themes within the overarching theme all reflect participants' levels of trust.

**Conclusion** Our study identified fundamental issues related to trust in the use of EHR data for research, with both healthcare and broader societal factors contributing to consumer attitudes. Processes to support transparent and clear communication with consumers are essential to support the responsible use of EHR data for research.

### WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Electronic health records (EHR) have been widely used for epidemiological research across the USA, European Union and the United Kingdom; consequently, there have been several studies exploring healthcare consumer and public views about the acceptability of their medical records being used for research. In Australia, where the use of hospital-based EHRs for research is a fairly new concept; there is a paucity of literature exploring the opinion of healthcare consumers on this growing area of research and none that specifically explore the attitudes of older consumers.

### WHAT THIS STUDY ADDS

⇒ This study provides new information on the attitudes of older Australian consumers on the use of hospital based EHR data for research. Older consumers are frequent users of hospital services and a group that is often neglected in research. Although the study participants could see many benefits of sharing data for healthcare provision and research purposes, there were varying levels of trust related to the use of EHR data for research. Attitudes related to trust started at the initial data collection phase and continued through the dissemination of research findings. Trust was influenced by both health service and broader societal factors.

### HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ To build public confidence and trust in EHR-based research, a partnership needs to exist between research organisations, healthcare providers and healthcare consumers, which focuses on transparent and clear communication.

## INTRODUCTION

The digitalisation of healthcare systems through electronic health records (EHRs) has made a wealth of clinical data available to researchers for observational studies, safety surveillance, biomedical research and regulatory purposes.[1] Although EHRs offer extensive prospects for research, the large amount of accessible personal information and the ways in which it may be linked and used, raise important questions concerning privacy, confidentiality and consumer awareness.[2,3] In 2020, a Community Attitudes to Privacy Survey was administered to 2688 Australians; findings showed that privacy was a major concern for 70% of respondents, with almost 9 in 10 wanting more choice and control over their personal information.[4] In Australia, the *Privacy Act* allows researchers to access medical and personal information, without consent from the individual concerned, if approved by a Human Research Ethics Committee (HREC). A waiver can only be granted under specific conditions including: where it is impractical to obtain consent, involvement in the research carries no more than low risk and the societal benefit of the research clearly outweighs the risk to an individual.[5] Therefore, it is important to understand how the public feel about the sharing of their personal data for research purposes, particularly within the context of EHR data.

In the last decade or so, EHRs have been widely used for epidemiological and clinical research across the USA, European Union and the United Kingdom[1 6]; consequently, there have been several studies exploring healthcare consumer and public views about the acceptability of their medical records being used for research. A systematic review and thematic synthesis of qualitative studies (n=25) examining public attitudes towards the sharing or linkage of health data for research purposes found there was a widespread general, though conditional, support for the uses of health data. Conditions included: pledge of confidentiality, guarantees of safeguards to protect against misuse or abuse of data, assurances of data security and agreements that data would only be used for legitimate purposes and in 'the public interest'.[7] In Australia, where the use of hospital-based EHRs for research is a fairly new concept; there is a paucity of literature exploring the public's opinion on this growing source of research data and none to our knowledge that specifically explore the attitudes of older consumers, the group most represented in these data.

In 2019, The National Centre for Health Ageing (NCHA), a partnership between Peninsula Health and Monash University, was established via funding from the Australian Federal Government. A major component of the NCHA is the development and implementation of a curated set of research ready EHR-based data known as the Healthy Ageing Data Platform, developed to support epidemiological and health services research specific to ageing within a geographic region.[8] The aim of this study was to explore the attitudes of older healthcare consumers within this region, on sharing their EHR data for research through this emerging EHR-based data platform. The following paper will describe and discuss the methods and results of two workshops conducted with consumer representatives across Peninsula Health, Victoria, Australia.

## MATERIAL AND METHODS

### Study design

We used a 'generic qualitative' approach[9–11] to identify and describe the attitudes of older consumers on sharing their personal data for research. This approach aims to draw out participants' ideas about things that are 'outside themselves' and seeks to understand a phenomenon, a process or the perspectives of participants. A focus group was used as the data collection technique.

### Setting and participants

Peninsula Health is the major public health network serving the metropolitan and regional areas of the Frankston and Mornington Peninsula areas in Victoria, Australia. The local government area has a population of approximately 300 000 people of whom 51% are women and the median age is 44 years with 22% of the population aged ≥65 years. The large majority were born in Australia (75%), with only 1% being Aboriginal and/or Torres Strait Islander. Of the total population, 87% speak only English at home and 0.7% of the population speak English not well or not at all.[12]

To ensure the health needs of the local community are met, Peninsula Health has engaged numerous consumer representatives who share their experiences as users of the health service and become active partners in design, planning and evaluation of the health service; these positions operate on a volunteer basis. Consumer representatives are members of specific Community Advisory Groups (CAGs) (eg, Community Health, Older Persons and Culturally and Linguistically Diverse) and/or Health Network Committees (online supplemental material 1). To facilitate a diversity of views Peninsula Health has 16 different CAGs, the members of which undergo training to ensure that they represent the needs of the community that they are representing. The value of engaging consumer representatives is their ability to consider and provide a broad consumer perspective and not just their own. They have lived experience as a user of the health service (as either a consumer or carer of a consumer receiving care from Peninsula Health) and can advocate for consumers with disability or disadvantage. For our study, a purposeful sampling technique was used. An Expression of Interest letter was emailed to all enlisted consumer representatives over 60 years (n=90) with a view to recruiting at least one representative from each CAG; participants who agreed to participate provided written informed consent.

### Data collection

Two separate one and a half hour workshops were conducted in March 2022 at Mount Martha Community House, Victoria; a venue that was external to the health network and therefore provided a neutral environment for participants. The workshops were facilitated by two researchers (KN and EP), who both had previous experience running and facilitating workshops and focus groups. Two separate researchers were also present, one to answer any technical questions about the Data Platform and the other to make field notes during the focus group discussions and photograph any written outputs.

The workshops consisted of three distinct components: (1) an introductory ice-breaker activity, (2) presentation of 'use case' scenario videos and (3) focus group discussions. The ice-breaker activity involved the participants brainstorming as a group the meaning of the term 'healthy ageing'. In addition to providing participants with an opportunity to get to know each other, this activity set the scene for the key objective of the NCHA Data Platform: using research to inform healthy ageing. Two 'use case' videos were then presented to the participants; these were developed from interviews with researchers (n=2) involved in recent NCHA research projects, which utilised EHR data from the NCHA Data Platform. The objective of these videos was to communicate and display a tangible understanding of what types of personal health data can be used for research and the underlying process of providing researchers with deidentified, research-grade data.

The ice-breaker activity and 'use case' videos primed participants for the third component of the workshops—the focus group discussions; these were directed at understanding participants' attitudes towards sharing their health data for research. Participants were separated into two groups. Group 1 was asked to consider the question, 'why would someone be willing to share health data?'; group 2 was asked, 'why would someone be hesitant to share health data?'. A facilitator was positioned in each group to enable and direct conversations. During each focus group, participants were asked to summarise their main points of discussion on a piece of paper; this written output was then presented verbally to the other members of that workshop by one spokesperson, which encouraged facilitated deep discussion between the whole group in that workshop only (online supplemental material 2 presents prompt questions that were used in the focus groups to stimulate further discussion).

### Data analysis

Focus groups were audio-recorded and transcribed verbatim by a professional transcribing service. Transcripts were analysed using NVivo V.11,[13] a qualitative data management software. Data were initially analysed by the main investigator (KN) using a reflexive thematic analysis approach; this method facilitates the identification and analysis of patterns or themes in a given data set and highlights the researcher's active role in knowledge production.[14] The results were continually discussed and validated with two other investigators (DAS and NA). The main investigator is a female healthcare professional (pharmacist) and Post-Doctoral researcher with expertise in consumer engagement with disadvantaged communities. This life experience and knowledge shaped interpretation of the data.

To immerse themselves in the data and become familiar with it, the researcher followed a number of steps. She actively read and reread the transcripts, while making notes on initial ideas; this was supported by actively listening to the audio recordings of the focus groups. The researcher then manually coded data relating to the research question: what are the attitudes of older healthcare consumers on sharing their health data with an emerging EHR-based Research Data Platform. The photographs of written outputs from the focus group discussions were used alongside the transcripts to support the generation of codes. This initial list of codes (with raw quotes) was then reflected on and grouped into potential subthemes; these were then further reviewed and refined into the three main themes (online supplemental material 3).

## RESULTS

Both workshops ran for around 2.5 hours, with the focus groups taking up 1.5 hours of this time. A total of 16 consumers (18% of those invited) participated in the workshops (workshop 1=7 participants; workshop 2=9 participants). Participants were aged between 62 and 83 years, with an equal mix of genders (8 women and 8 men), and the majority were born in Australia (n=12; 75%). All participants resided in the Frankston/Mornington Peninsula region of Victoria, Australia, and spoke English. Each CAG (online supplemental material 1) was represented by at least one participant.

### Overarching theme: varying levels of trust in the use of EHR data for research

The overarching theme was that participants conveyed varying levels of trust in the use of EHR data for research. Despite most participants reporting many *benefits of sharing data* for research purposes, a few questioned the trustworthiness of the findings of research studies. Some participants expressed *uncertainty around data collection processes,* especially how and why their data are collected within the healthcare system and whether or not the accuracy of their data was sufficient for research purposes. Many participants reported *data sharing fears,* which led to them feeling cautious about sharing their data. Despite this, some participants were still willing to share their data, whereas others wanted additional actions to be taken to address their fears, such as research organisations actively publicising how secure their IT systems are. The three themes within the overarching theme all reflect participants' levels of trust.

The themes are described in detail below with illustrative participant quotes. Ellipses have been used where quotes have been abbreviated and square brackets represent additional text inserted to provide context to the quote. Themes, subthemes, codes and raw data (quotes) are presented in online supplemental material 3.

#### Theme 1: benefits of sharing data

Participants reported many benefits to sharing their personal health data for research purposes, including benefits to consumers, to their family and to themselves. Public benefits included improvements to current health practice and the development of new medications and treatment; the latter being illustrated by one participant using COVD-19 as an example:

> The rapidity with which we were able to discover the COVID immunisations, all related initially to the data collection on what was happening to people, where it was hitting, et cetera, et cetera. I also assume that's

> helped them to identify where it's come from. (female participant; workshop 1)

Another benefit to sharing data for research, specifically genetic data, as expressed by one participant, was that the health of future generations can be improved: *Most of my conditions are genetic, therefore me sharing my information will directly help members of my family to come - helping other people, helping family directly. This will directly assist research by sharing our data* (male participant; workshop 1). A few participants agreed that if the findings of research into high priority areas (eg, mental health) were publicised appropriately in the media, government bodies would prioritise funding to this area to either improve current resources or to enable further research:

> I think it will get out there into the media and they'll be saying 'Because of the research into mental health, we now are able to supply better funding, we can train more doctors, because we know the information is out there with more people with mental health issues'… the data can be used for funding, to do more research to help people (female participant; workshop 2)

Sharing data for research could also be in one's own 'self-interest' where one's own health and well-being could benefit from the results of research in the long term: *Hopefully it will come back to help you later on. For me, it's about getting better care across the board* (female participant; workshop 2). A few participants discussed that through gaining knowledge from the findings of different research studies, they felt more empowered to be able to participate in the shared decision-making process with their healthcare team:

> The consumer knowing more about (research), it's terribly important that we know what's happening with ourselves and that we're able to ask questions, because doctors aren't the font of all knowledge. It needs to be that partnership. So, if you're well-informed, you've got the knowledge (female participant; workshop 1)

Although the majority of participants could see the benefits to sharing their data for research, there was a minority who felt that one cannot be entirely trusting of the findings of all research studies. One participant in particular discussed how research can sometimes appear to highlight an issue that perhaps isn't one:

> I'm not at all convinced that we are having more people with mental health issues these days. I can remember back when this question was never sort of raised because it didn't seem to be a problem. Anyone who did have [a] mental health [issue], they used to be put into a mental hospital. Now, how many of those have we got? They're now letting these people into the community. That's why it appears to be more of it, because they're out amongst us, not research (male participant; workshop 1)

### Theme 2: uncertainty around data collection processes

Many participants expressed their frustrations with how their data is collected in the health system. Electronic medical record data are collected for clinical and operational purposes. In Australia, when data are released for research, the project is reviewed by a HREC. In situations where it is not feasible to obtain informed consent, and where the benefits of the research outweigh the potential harms, data may be provided to researchers with a waiver of consent. As such, some participants were concerned that consumers do not always understand how and why their data are collected within the health system. Furthermore, these participants explained that consumers attending a health service may not be aware that their data could be used for research purposes and how these data are managed. They believed that this could be due to several communication barriers; including culture, language and religion.

> A lot of people don't understand how the data is collected and managed. Privacy, culture, language, religion - these things come into it… I think we need to start thinking about data gathering, how do we need to change our messaging from a cultural point of view. That's really for me the key message here (female participant; workshop 1)

Another concern for some participants was the accuracy of data collected in the health system, particularly due to the omission of consumer data: *It's counterproductive. If people are strange, I might shut up because you're not being nice to me, and so I won't tell you about something that's going to help me and help you. Is it [the data] correct?"* (male participant; workshop 2). Some participants felt too embarrassed to share some aspects of their personal health information such as prostate issues or a urinary tract infection, whereas a few others discussed feeling patronised by younger health professionals because of their age and subsequently feeling hesitant to share their health data:

> The attitude of the medicos. In other words, a younger doctor talking down to an older person… quite often you'll get a 50-year-old saying, 'All right dear'… but to us it's important because we've gone to them and the last thing you want is to feel stupid. (female participant; workshop 2)

Negative perceptions towards data collection processes may also stem from how data are perceived to be *insidiously* collected in society through channels such as social media and Artificial Intelligence, without consumers knowing. One participant stated:

> I have been inundated with all these calls at home. I have a private number on my mobile. I don't even answer Peninsula Health anymore because I'm hesitant. Do you want led lights in your house or a new shower? It's just, I don't know where they get all that information? (female participant; workshop 2)

### Theme 3: data sharing fears

Participants conveyed various levels of caution around sharing their data. A few participants discussed being completely open to sharing their data during the receipt of healthcare for research purposes and were indifferent to who had access to their data:

> I shared, and I'll give them everything and I don't care who sees it (female participant; workshop 1)

On the other hand, a large portion of participants discussed the many threats or fears that shaped their concerns in sharing their data; including breaches of confidentiality and potential abuses of their personal health data. It was apparent that these concerns stemmed from an inherent fear of sharing personal data within broader society, particularly the susceptibility of their personal data to hackers or cyber criminals: *Have you taken into account the Russian hackers? People are worried about their medical data, and I say, "What about your bank?" The bank can be hacked too* (male participant; workshop 2).

Some participants feared the negative implications of data leaks, such as family members discovering information they did not want them to know about or having one's career jeopardised as a result of specific data being revealed. One participant spoke about the potential consequences of data being shared externally to the healthcare system and being seen by certain people, such as a health or travel insurer:

> One of the biggest problems we have within - it's not only the hospital, but anywhere with anything is litigation, that we're so worried about giving information out and therefore hesitant to share. The thing that maybe life insurance companies and things like this [might see my data], travel insurance even… (male participant; workshop 2)

Some participants expressed that data sharing can be seen as a 'double-edged sword'. They explained that there are many perceived risks to sharing data; however, also acknowledged that if we do not share our data, we would not get the benefits of research such as new treatments or improved healthcare provision. For example, one participant discussed how people are fearful of pharmaceutical companies, especially due to their bad reputation. However, they acknowledged that we rely on them to *keep us alive with tablets* and it is therefore *essential that they have access to our data*. Another participant explained that we live in an era of increased data misuse, and that we may need to *put up with it*, especially when considering the sharing of personal data for research purposes, where data security is often perceived to be more safe or *controllable*:

> Those [data security] problems will probably go away, but they don't. They're here, and we live with it now. We have to put up with it. What's being suggested here is a minor contrivance. It's easily controllable (male participant, workshop 1)

To create trust, it is apparent that one needs to address and reduce the fears that consumers have in sharing their data. As one participant discussed, although she fears her data being leaked, she is happy to share her information, if the research institution holding her data reduces this fear by actively *publicising how secure their information technology systems are*. Another facilitator of trust mentioned by a few participants was research organisations being accountable for data breaches including penalties or punishment. One participant stated:

> Once we have this system going there has to be accountability, especially if our human rights and our privacy is being taken. It's all good putting all this together, but if research organistaions do use it incorrectly, they must be punished (female participant; workshop 2)

However, even if research organisations are open and transparent with how they handle consumer data, some participants expressed they may still not believe or trust in these processes: *Is my name withheld? That would be the question. Is it really? Is it really withheld? You're telling me it is, but do I believe you? And I think that's a lot of the fear.* (female participant; workshop 1). For some consumers, to develop trust, they may need to have a more active role in the control of their data. One participant expressed a desire to have more knowledge over what data are collected and the opportunity to review the accuracy of that data:

> At an individual level, I'd want to know that I can challenge and/or change information, and every now and then find out what it is that you've got, because otherwise I'm not even going to know what you're keeping… (male participant; workshop 2)

## DISCUSSION

In this study, we explored the attitudes of older Australian consumers on sharing their health data for research with an emerging EHR-based Healthy Ageing Data Platform. Although participants could see many benefits of sharing data for healthcare provision and research purposes, there were varying levels of trust related to the use of EHR data for research. Feelings related to trust started at the initial data collection phase and continued right through to the final dissemination of the research findings.

As evidenced by our study findings, there is a limited understanding of the purpose of health data collection within the healthcare system and how it can be applied to research.[15 16] The Privacy Act (1998) asserts that sensitive information may only be collected with consent from the healthcare consumer.[17] However, although consent is required for collection of the data, it can be released for secondary use with a waiver of consent under certain predefined circumstances. Healthcare consumers generally provide health information without full awareness of the potential for its secondary use for research. Another study exploring healthcare consumer perspectives on the secondary use of their personal health data found that a key factor in enabling trust in the healthcare organisation was the need for transparency and communication, including the purpose; intent for use; potential future use (research) and outcomes of past use.[18] To build public trust in the collection of health information, we advocate for consumer education on the sharing of their electronic health data for both healthcare provision and research at the initial healthcare consumer–provider interaction.[16 18 19] Although one cannot disclose all possible future uses of data, in part because these uses may be unknown,[20] as expressed by a few study participants consumers should still be made aware of the potential use of their data for research and how these data are managed. To ensure this message is clear, healthcare providers will need to address potential language, cultural and religious barriers to communication between themselves and the healthcare consumer.

Although having a better understanding of the purpose of data collection within the health system may facilitate trust in the data sharing process; our findings suggest that some consumers may be hesitant to provide sensitive health information based on their interactions with healthcare providers, impacting data quality and completeness. These findings align with those from a previous study exploring the attitudes of healthcare consumers on the sharing of data held in primary care records for research.[21] Findings from this study indicated that consumers may be unwilling to entrust certain types of information, such as details about sexual or mental health, to health professionals. A recent survey (2021) exploring ageism in the healthcare sector in New South Wales, Australia, found that 48.57% (n=100) of the respondents said they had been treated differently by healthcare professionals because of their age, with many being reluctant to seek medical advice in the future as they do not want to be put in a position where their input is not respected.[22] In addition to the impacts on data quality, omission of or lack of recording of information at the clinical interface may also impact on the community's perception of the trustworthiness of research arising from the data. To address data quality issues stemming from the point of data capture; such as missing data, erroneous data or inconsistent data, Bayley *et al* advocate for a partnership between researchers and healthcare providers that focuses on helping providers understand the value of research to the healthcare team and the importance of data quality for 'improvement, innovation and discovery'.[23] Health professionals also need to learn to critically reflect on their practice and regularly evaluate the beliefs that affect their communication with healthcare consumers, especially older consumers in this case.[22]

In alignment with prior research,[24] our study demonstrated that consumers may be happy to share their data for research purposes as long as their fears related to data sharing and data security are addressed. Our results highlighted that fears and attitudes towards the sharing of EHR data are inherently shaped by how data are used and managed within the broader society. An Australian survey exploring community attitudes to privacy found that online services and social media sites are a large societal privacy concern, along with identity theft and fraud, and data security breaches.[25] Within Australia, the handling (collection, use, storage and disclosure) of personal information is governed by the Privacy Act (1988).[17] Although health data fall under *sensitive information*, which attracts further privacy protections compared with other types of personal data, consumers may lack awareness of the nuances between legislation/security requirements pertaining to different types of personal data shared within different contexts. Previous research shows a limited public awareness of regulatory frameworks supporting the use of anonymised health data and a very low knowledge of safeguarding practices.[15 26–28] To build public confidence in the use of EHR data for research, it is vital that research organisations develop and convey clear messages about the governance and security measures assigned to EHR-based data and how these may differ from other contexts such as corporate or social media.

As demonstrated by our findings, some participants felt disengaged from the research process and wanted to have more control over how this was done and how their data were used. This message is consistent with previous research where consumers were willing to support and participate in research, however, they wanted to be consulted first on the use of information from their health records and would like more information about how the research is conducted.[26 27 29–31] However, due to the nature of EHR-based research, that is, the quantity, age or accessibility of health records and large number of healthcare consumers represented within an analytic dataset (upward of a thousand), it can be impracticable and nearly impossible to engage with each individual consumer from a time and resource perspective to obtain consent.[6 27] For epidemiological research, it would mean that only a small proportion of the population would be able to be included leading to inherent biases in the research. Therefore, to establish trust in the EHR-based research process, we encourage public awareness on the role of HREC and the significant value placed on the research subject. Establishing processes that allow community members to actively participate in an advisory capacity on how data are managed and used, and providing transparent communication of research outputs resulting from the use of the community's data, may increase public confidence and ensure that the requirements for waiver of consent are met when individual consent is not practical.[6] To this end, the NCHA Healthy Ageing Data Platform has recently implemented consumer review of projects requesting the use of platform data and is actively exploring ways to further engage the local community in how their data are managed and used.

## Strengths and limitations

Our study provides new information on the attitudes of Australian consumers, specifically older consumers, on the use of hospital-based EHR data for research. Given that older consumers are a group that frequently attend hospitals and are often neglected in research, our findings add to the international literature on this population and could be transferred to older consumers in similar settings. However, our study does have limitations. While we engaged with a diverse range of consumers from all of the CAGs, our sample size would be classified as 'small' for thematic analysis and therefore the generalisability of our findings may be limited.[32] A further limitation is that the recruitment of consumers from CAGs may have biased the results in the workshops. CAG members are actively involved in Peninsula Health in a volunteer capacity. As such they may not have been representative of the broader elderly population, especially with regard to socioeconomic status and health literacy. Future research would benefit from targeted recruitment to capture a broader sample of consumers, that is, telephone or mail for elderly consumers who do not use email. Although we may not have captured a sufficiently diverse set of views, our findings are consistent with consumer views from previous research.[7 29–31]

## CONCLUSION

Our study contributes to the growing literature on public trust in the use of routinely collected health data for research, specifically focusing on EHR data and the views of older consumers. We identified core issues related to trust encompassing both support and concern for the sharing of personal health data for research. Processes to support transparent and clear communication with consumers are essential to support the responsible use of EHR data for research and build trust between consumers, healthcare providers and research organisations. Although our study provides new information on the attitudes of older Australian consumers, further research is needed to capture a broader sample of consumers and how best to implement practice change to incorporate the views and concerns of consumers.

**Acknowledgements** The National Centre for Healthy Ageing acknowledges the financial support of the Australian Government Department of Health. We would like to thank the clinicians and consumers at Peninsula Health who participated in this study.

**Contributors** KN: conceptualisation, methodology, formal analysis, investigation, writing—original draft. DAS: formal analysis, writing—review and editing. EP: conceptualisation, methodology, investigation. RM: conceptualisation, methodology, writing—review and editing. VS: conceptualisation, writing—review and editing. NEA: conceptualisation, writing—review and editing, supervision. KN is responsible for the overall content (as guarantor).

**Funding** The National Centre for Healthy Ageing acknowledges the financial support of the Australian Government Department of Health.

**Competing interests** None declared.

**Patient consent for publication** Not applicable.

**Ethics approval** Ethical approval for this study was obtained from the Peninsula Health Human Research Ethics Committee (AM/73610/PH-2021-281834(v1)). Participants gave informed consent to participate in the study before taking part.

**Provenance and peer review** Not commissioned; externally peer-reviewed.

**Data availability statement** All data relevant to the study are included in the article or uploaded as supplementary information.

**ORCID iD**

Kim Naude http://orcid.org/0000-0003-2118-4729

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