Engaging consumers in their health data journey

A joint report by NPS MedicineWise
and the Consumers Health Forum of Australia

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Contents

Executive summary

Consumer health data – clinical and socio-demographic – is increasingly collected, linked and used, both with and without consumers' knowledge and informed consent. There is increasing focus on 'big data', evidence-informed policy, and the value of data-driven service development and improvement. Recent examples of this include consultations about the secondary use of health data, incentivising the capture of data at the point of care delivery, and the My Health Record.

While discussions will continue on the benefits to be realised by collecting data and using it more effectively, limited attention has been paid to how consumers feel about this new data era and to assessing their data literacy.

In 2017, NPS MedicineWise collaborated with the Consumers Health Forum of Australia (CHF) on a research project about consumers' attitudes to data. The four phases of the project were: a literature review; exploratory interviews with consumers; a survey with a nationally representative sample of consumers; and a jointly hosted thought leadership roundtable bringing together representatives from key organisations involved in digital health and use of data, consumer organisations, and consumers involved in the research.

Key themes to emerge from the research and roundtable were as follows:

1. **Consumers want ownership of and control over their own health data**

   In addition to ownership and control of their own health data, consumers want access to their health data to be granted to themselves, health professionals and people who care about or for them.

   The research found that consumers are in favour of explicitly giving consent to the sharing and use of their health data. Consumers want control over which organisations have access to their data for secondary purposes (eg research). These findings are indicative of support for the roll out of electronic health records, and for these records to be controlled by consumers themselves.

   Consumers want to be asked for consent when organisations want access to their health data. Developing models of consent that are both acceptable to consumers and feasible for research and health communities should be considered a key challenge and priority. Roundtable participants were clear that consent processes need to be consumer-centric, informed by consumers and should increase commensurate with the risk of identification. Consumer involvement in consent design is crucial to ensuring that consent is meaningful and not a barrier to participation or simply a 'tick the box' exercise.

2. **Consumers are highly segmented and not a homogeneous group. Involving consumers is key to building trust and willingness to share their data for benefits realisation**

   Consumers are more willing to share data when it is for public or individual good, and are significantly less likely to share it if it is to be used for commercial gain. The research found that where consumers have a better understanding of what their data is going to be used for and that there are benefits in doing so, they are more likely to share it.

   One key insight from the roundtable was that consumers were more likely to accept the sharing of their health data if there is an element of a *quid pro quo*; their data in exchange for outputs that are meaningful, useful and of value to them as consumers, and that enable them to hold data custodians/users (eg healthcare providers) to account. The roundtable participants commented that secondary data use tends to be driven by what matters to providers rather than recipients of care, and this non-consumer-centric view could be problematic to gaining consumer trust and willingness to share their data. To redress this, consumers need to be involved in defining what outputs they would like to see from use of their data and how they would like to be kept informed about the use of their data.

An important element of this – and a key reason that they should be involved – is that consumers are not and should not be considered a homogeneous group. The research found that there are specific population subgroups with different needs or concerns that should be explicitly dealt with, requiring appropriate consultation, communication and involvement. These include Aboriginal and Torres Strait Islander consumers, particular cultural groups, consumers who have previous experiences that may impact on their levels of trust, and those who are concerned about discrimination due to their health or other circumstances.

3. A high level of transparency on the part of data custodians and data users is required

Consumers value having an understanding of the purposes to which their data is to be put, who is requesting it and how it will be used. The research highlighted that there are varying levels of comfort and understanding among consumers around the use of health data. The challenge identified by roundtable participants is ensuring that clear, concise, relevant and helpful information is used to inform that understanding of the purposes to which the data is being used; complex concepts should be explained simply.

Data linkage is an ill-understood area that requires further clarification and explanation to consumers; as do its benefits. There is also a lack of understanding about ‘de-identification’ and questions have been raised as to the legitimacy and accuracy of this term.

The onus is on organisations that wish to use consumers’ data to put in place clear, transparent, open and two-way communications about the purpose for which the data is to be used, how and by whom it will be used, and the benefits and risks. Again, involving consumers in designing these communications will ensure they meet consumers’ needs, building their trust and willingness to share data.

4. Clear principles to guide data owners

The concept of social licence is an important one and data custodians must ensure they understand and take their responsibilities for appropriate governance and data use seriously. To build consumers’ trust, they must be clear and transparent in communicating those responsibilities and how they fulfil them.

Participants in the roundtable and consumers in the research identified that addressing and taking account of issues of data completeness and quality is critical when linking and drawing insights from health data and in the provision of safe, high quality care. The obligation for this should be on data custodians to ensure that appropriate safeguards exist.

To support data custodians in fulfilling their obligations, clear principles are needed to guide data ownership and use.

A whole of government and whole of sector approach to using health data was identified by roundtable participants as key to increasing the consistency, quality and value of data collection, use and linkage. Involving consumers in designing that approach is essential to building trust and encouraging data sharing to derive individual and population health benefits.

As an outcome of the research and the roundtable, NPS MedicineWise and CHF will further explore what is practical in this space and find effective ways to work with consumers and all organisations involved to define best practice approaches and guiding principles for collection, use and sharing of health data.

Acknowledgement and attribution

The Consumers Health Forum of Australia (CHF) was commissioned by NPS MedicineWise in December 2016 to conduct research about consumers' attitudes to health data. The project and resulting reports were developed collaboratively, with oversight and guidance provided by Bronwyn Walker (External Relations and Policy Manager, NPS MedicineWise), Leanne Wells (CEO, CHF) and Jo Root (Policy Manager, CHF). The project was coordinated by Rebecca Randall (Policy and Research Officer, CHF) who also conducted the CHF-led research component.

The project culminated in a thought leadership roundtable with delegates representing government, regulators, health insurers, consumer groups, data custodians, the research sector and others involved in digital health and use of data. The roundtable was facilitated by Michael Kitts, a PwC partner. Details and outputs of the roundtable are presented in Chapter 1 and Chapter 5.

The literature review (Chapter 2) was conducted by NPS MedicineWise staff, specifically: Lauren Humphreys (Evaluation and Research Graduate) with the support of Liz Kempton (Health Information Coordinator), and reviewed by Kirsten Saur (Program Evaluation Officer) and Julian McAllan (Senior Editor).

Qualitative interviews with health consumers (Chapter 3) were conducted by CHF. NPS MedicineWise staff provided guidance on the interview question design and editorial feedback on the subsequent report.

The third stage of the project, a cross-sectional survey, was conducted by CHF in collaboration with Urbis (Chapter 4). Urbis was contracted by CHF to develop the survey tool and analyse the responses to the survey. Specific members of the Urbis team were: Julian Thomas (Director), Caroline Tomiczek (Associate Director) and Joanna Farmer (Senior Consultant).

The project was approved by the Bellberry Limited Human Research Ethics Committee, approval number 2017-02-156-A-1.

Project overview and summary of findings

1.1 Overview of project

The what, why and how of health data is a subject of increasing interest from all areas of the health sector. Consumers' data – clinical and socio-demographic – is increasingly being collected, linked and used, both with and without their knowledge and informed consent. There is increasing discussion about the 'big data' agenda, evidence-informed policy. A growing premium is being placed on the importance of data-driven service development and improvement.

While the discussion of the benefits to be realised by collecting data and using it more effectively will continue, little attention has been paid to how consumers feel about this new data era and to assessing their data literacy. This is an omission that needs to be rectified to better inform the national debate.

1.1.1. Project objectives

The project consisted of four stages. The first three stages were a literature review, exploratory interviews with consumers and a survey with a nationally representative sample of consumers. The key issues explored in the research were:

- understanding of what constitutes health data
- views on privacy and consent
- views on sharing health data
- views on secure health data storage
- views about the circumstances for accessing health data
- own health status and health conditions
- demographic information.

The project culminated in a thought leadership roundtable. At this roundtable, representatives from key organisations involved in digital health and use of data including government, regulators, health insurers, consumer groups, and consumers involved in the research met to discuss the findings of the research and its implications; and what Australia could be doing better to use health data in meaningful and appropriate ways with due regard for health consumers.

1.2 Summary of research findings

The following section presents a high-level summary of the research findings, comparing the three research stages. Issues that were not examined at all stages are reported within the specific research stage chapters (Chapters 2–5).

Participants in both interviews and survey believe their health data includes information collected about them by doctors or health practitioners (eg pathology results, information on conditions they may have, information from prescriptions and doctors' visits, and information relating to disabilities they may have). These findings provide a valuable contribution, given the limited available literature on consumers' understanding of what health data is. They suggest that consumers understand health data to be everything about them, not just that which is collected by health professionals.

Ownership of health data is a highly contested area, and no clear understanding of ownership of this data has emerged in Australia. Ownership emerged as a key issue in both the interviews and survey, with consumers strongly advocating that they owned their own health data. This presents a clear challenge for the sector to resolve issues of ownership and better communicate these to consumers.

Participants in both research stages were broadly in favour of access to their own health data being granted to themselves, health professionals and people who care about or for them. These findings are indicative of support for the roll out of electronic health records, and for these records to remain controlled by consumers themselves.

Consumers’ desire for a high level of transparency around data exchanges was identified in previous work and this project. The interview and survey findings indicated that consumers would like to have more information about who is requesting and using their data, and prefer to share data with organisations that have a clearly identified point or purpose. It suggests explaining the purpose of data sharing is critical in gaining people’s support for using their data.

Related to this are research findings about the role of the person or organisation requesting the data. Building on previous work, it was found consumers would like to investigate the organisation requesting their data before sharing their data. This theme was also touched on when specific organisations or purposes were discussed, and is examined below.

A balance will need to be found between overwhelming consumers with information and providing the right information. One way this could be done is by empowering consumers to ask questions about how their data is being used and shared, and providing avenues through which to do this. Organisations from universities through to government and private agencies should consider increasing consumers’ abilities to interact with them to ask these specific questions. They should also consider engaging in further research with consumers to understand their specific information needs and desires. In doing this, consideration should be given to particular groups, such as people from a culturally and linguistically diverse background, who may have specific information needs.

An area of diverse thought and challenging perspectives in the research was the notion of data access and consent procedures, a factor also identified in many previous research projects as affecting consumers’ willingness to share data. Findings of previous research were that consumers’ views about consent changed when presented with information about what consent procedures would entail and the additional burden it may place on the groups seeking the consent.

Participants in the interview study discussed that while broadly happy with their data being shared, they would prefer to share it if they were able to give permission for this to occur. In discussing the purposes data could be put to, consensus emerged that they would prefer to give consent, often on a case-by-case basis. This theme also emerged from the survey, to which respondents strongly reported they would like to be asked permission each time organisations want to use their data (86.7% agree), especially private organisations (94.3%).

Specific investigations into the issue of consent in previous work found consumers’ reasons for desiring this consent were varied. Studies where consumers were asked to discuss and reflect on their need for consent processes have found that as the perceived transparency and value of the research increased, views typically shifted from an explicit opt-in consent system to a more flexible opt-out or circumstantial consent model.[1] This nuance shows one of the limitations of the present research, and suggests that further investigation is warranted into the reasons participants give for wanting to provide consent. While it is important their desires to give specific consent are not disregarded, particularly in the cases of data they perceive to be sensitive (which is not necessarily what those collecting or using the data perceive to be sensitive), how this is operationalised should be carefully considered. The work of Teare et al[2] may be a useful starting point for this. Teare's research into models of dynamic consent with consumers is an example of consumer-centric consent procedures.

Low levels of trust were displayed in all the types of organisations investigated in both the interviews and surveys (government, private and research). This finding is interesting as it shows no particular advantage for one group over another. Research organisations, the most trusted of the three groups, were believed to be more likely to store data securely than to ensure anonymity.

Participants were less likely to choose to share their data if it were to be used for commercial gain, which supports the findings from a poll conducted by the Australian Medical Association that fewer Australians would share their data for commercial purposes than other purposes.[3] Additionally, findings from the survey showed that people without chronic health conditions were significantly less likely to agree that private organisations should be able to make a profit from their health data, or that health insurance companies or other government departments should be able to access health data to plan their services.[a]

A specific area of investigation in all research stages was consumers' attitudes toward sharing their health data for research. The findings showed consumers believe strongly in the role research can play in improving healthcare, that they have a natural right to privacy and that they own their personal health data. These findings highlight that organisations and institutions will need to give attention to these beliefs, and treat them as baseline views, from which policy decisions and directions can be examined and created.

Responses to questions about sharing health data with government organisations found mixed levels of concern. This appears to be in line with previous quantitative work which has found only 50% of consumers are supportive of sharing their health data with government.[4]

Of interest, in light of the above discussion of consumers' desires for greater transparency, are results from the survey that respondents were more comfortable with the Department of Health accessing their data to help plan services (59.2%) than other government departments (30.7%). This was also indicated by more positive responses to data sharing when they were provided with more detail on how governments might use health data. This suggests that where consumers have a greater understanding of the purposes for which their data is going to be used, they may be more willing to share it.

Participants at both stages were supportive of their health data being used to support healthcare providers in improving care and to assist public health officials in tracking diseases, disabilities and their causes. However, participants in the interviews placed a number of caveats on this sharing: they would prefer to be asked to provide consent, often on a case-by-case basis. This finding is consistent with their broader views about consent. That consumers are supportive of it is in line with previous research in which 74% of consumers were supportive of health data being used to support healthcare providers in improving patient care and 68% in favour of health data being used to assist public health providers in tracking diseases, disabilities and their causes.[5] However, this previous work has not explored the caveats consumers place on it. The additional detail provided

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[a] Demographic crosstabs were conducted on respondents reporting they did not have a chronic health condition. They were significantly more likely to be younger (18–44).

by the new research suggests it is an area worthy of further investigation and consideration. Consumers' endorsement of health data for such a use may not be as simple or straightforward as has been reported to date.

Literature review

2.1 Summary

Consumer attitudes toward health data sharing preferences are influenced by many different factors. There is a growing body of literature attempting to identify these factors in primary healthcare settings. However, there is still limited literature specifically exploring consumers' preferences for sharing health data for research purposes, particularly for government-funded research.

In this literature review, attitudes toward sharing health data for research purposes were generally positive as long as the requesting organisation(s) sought consent, or was perceived to be trustworthy and transparent, and the outcomes from the research being conducted were perceived to be beneficial.

However, attitudes toward sharing health data with government organisations were predominantly negative. Despite this perception, Australians reported that improving hospitals and the healthcare system (88%), more funding for health and medical research (79%), and increasing funding and programs for preventive health (76%) were the top priorities for the Australian Government.[5]

This literature review discusses consumers' knowledge of health data as it is currently understood, health data sharing preferences and reasons for these preferences, and the circumstances under which these data should become available for research.

2.2 Health data definitions and usage: consumers' current understandings

Health data is a broad term which can be used to refer to any information pertaining to the health and wellbeing of individuals or populations. This includes, but is not limited to, data on:

- incidence and prevalence of illness
- disease and disability
- dietary habits
- weight and blood pressure measurements
- physical activity and sleep.

These data can also be linked with socioeconomic and environmental data to make inferences about the causes of health outcomes in populations.[6] As technology advances, health data are being captured, stored and presented in an increasing variety of formats, including:[6]

- clinical data stored as medical records
- genomic data
- Pharmaceutical Benefits Scheme / Medical Benefits Scheme data
- data input to wearable devices by individuals for self-tracking purposes
- biometric data that can be streamed from social media mobile applications.

Currently, there is a lack of available literature that has sought to assess consumers' understanding of the different types of health data and how it can be collected and stored.

In Australia the electronic health record (EHR) is the most widely used mechanism for collecting and storing data in primary healthcare. The EHR is defined as a secure repository of patient health data in a digital form for the purpose of supporting the continuity and quality of healthcare. From a sample of 105 patients who were surveyed as part of a study examining their preferences for health data sharing in primary care settings, 72% indicated they understood the purpose of an electronic health record.[7]

From 2014 to 2016 there was a 10% increase in the proportion of consumers (from 78% to 88%) who expressed a desire to have access to their own health records.[5] As a result, there has been greater and more widespread advocacy for consumers to have access to and control over their health data, and this has been reflected in the development of personal health records (PHRs).[8]

The definition of the PHR is still being developed and varies greatly between countries.[3] However, in most cases the PHR refers to an 'electronic application through which individuals can access, manage and share their health information in a private, secure and confidential environment'.[9]

From a sample of 117 consumers who participated in a regional health information survey, 76% of respondents were interested in potentially using a PHR.[10] Australia introduced the Personally Controlled Electronic Health Record (PCEHR) on 1 July 2012, a system which was renamed My Health Record in 2016.

Health data can be categorised into three types of data and access:[6]

- personal and proprietary data, which includes data controlled by individuals and non-government organisations, such as commercial bodies and academia
- government-controlled data, which includes census data and personal health records
- open data commons, which may be private, commercial or government-controlled data that are updated, in accessible format and available to all.

There is little evidence to indicate consumers' awareness about current research practices, particularly the frequency and circumstances under which their health data are being collected and used for research purposes.[11] The various methods by which health data are stored, and who it can and should be shared with, have become controversial topics for health professionals and consumers in recent years.[6]

2.3 Reservations about the use of health data for research purposes

Many studies have sought to identify which demographic characteristics are associated with health data sharing preferences. Characteristics associated with affirmative health data sharing include:[7,8,12-20]

- male gender
- Caucasian ethnicity
- people aged younger than 40 or older than 65
- higher levels of education
- higher socioeconomic status
- being employed
- having at least one child living in the household
- having at least one chronic health condition.

Other factors linked with affirmative health data sharing included higher level of internet use and greater trust in large corporations.[13,19,20]

Characteristics associated with the withholding of health data included:[8,12,14-17,19-22]

- female gender
- high school education level or less
- non-white ethnicity
- being healthy
- low level of internet use
- people aged 18–24, due to a lack of understanding of the health system
- people aged over 40 who either have chronic illness or disease, or are carers.

The possibility that researchers working with identifiable data, or programmers involved in anonymisation processes for de-identifying data, may become aware of the health data of someone they know personally, was noted as a key concern.[23]

In 2005, the Australian Medical Association conducted a poll that found 60% of Australians were concerned about the anonymisation process.[3]

Twenty-four per cent of respondents participating in a national consumer health privacy survey in the United States were able to recall specific incidents in which the privacy of personal data had been compromised. Two-thirds of this 24% of consumers also reported having heightened security concerns.[24] However, the likelihood of this scenario occurring was still recognised by consumers to be extremely low.[23]

Common consumer concerns around the exchange of health data beyond the healthcare setting, including with research organisations, were mainly related to either unauthorised sharing or 'hacking' for purposes of profiling, segmentation and discrimination.

The outcome of most concern was the use of aggregate data to a group's disadvantage.[6,23] This included health insurance companies increasing premiums for consumers of particular demographic profiles who had increased risks of certain health problems, or governments making changes to policies such as increasing the pension age in areas with particularly healthy populations.[23]

Other statistically significant factors associated with consumer willingness to provide health data were often categorised in the literature. Several recurring themes were identified across multiple studies as common influences, including:

- perceived balance of benefits and risks
- perceived trustworthiness of individuals or organisations seeking health data
- transparency surrounding health data exchanges
- data access and consent processes

Focus groups conducted in the United Kingdom found consumers were positively inclined toward the notion of their health data being used in research if they felt the research was going to produce benefits for other people.[25]

Another qualitative study from the UK which involved conducting focus groups with patients, found that 98% of participants believed that the benefits of sharing anonymised health data for research purposes outweigh the risks.[26] Health and medical research is valued by Australians, with 61% reporting they had significantly benefited from past research that had involved the use of personal health data.[5]

Focus groups conducted to gauge consumer perspectives on the use of health data for research purposes found consumers were generally supportive of health and medical research, even if data were not always perceived to be 100% safe.[11] Factors associated with this perception included:[20]

- feeling respected by the healthcare team responsible for data collection, as a result of past experiences when the individual was engaged in shared decision making
- feeling supported by government programs aiming to address health needs resulting from research
- previous awareness of improved quality, access and safety of healthcare because of research participation.

Consumers have also indicated lack of transparency and awareness about the specific uses of their health data was a barrier to securing trust.[26]

Factors associated with a positive trust relationship included healthcare professionals or organisations who engaged in shared decision-making and consent-seeking practices and were perceived as having previously demonstrated responsibility and accountability, and knowledge that healthcare providers were acting in the best interests of their patients when sharing their data.

Transparency and purpose is cited as having a profound impact on consumer participation in health data exchange and on trust in the individual or organisation requesting the health data. Factors identified as having negative impacts on the trust relationship included a lack of confidence in healthcare providers to act in their patients' best interests, and a lack of confidence in security when internet mechanisms are used.

Consumers have indicated they want the same level of transparency offered by bank accounts, specifically the availability of details of when their information was accessed and how it was used.[20]

2.4 Methods and instances when health data could be used

Consumer willingness to provide personal health data for research purposes has been gradually increasing in Australia. A poll conducted by Research Australia in 2016 indicated that overall 91% of Australians were willing to share their health data for research purposes, specifically to:[5]

- advance health and medical research (79%)
- support healthcare providers in improving patient care (74%)
- assist public health officials in tracking diseases, disabilities and their causes (68%).

However, the proportion of consumers in support of sharing health data with government organisations was significantly lower (51%).[4] Many studies supported this finding and have indicated only a small proportion of consumers were concerned about the sharing of health data for research purposes (≤ 10%).

2.5 Who should have access to health data and why

Consumer concerns over data security tend to increase as consumers' control over their health data moves further away from their usual general practice.[11]

From a survey of 200 consumers, findings indicated most respondents were willing to share all their health information with health professionals, health administrators and researchers if they were consulted first. However, consumers were less willing to share their health information with government organisations or private health insurers.

In terms of sharing or withholding their health data specifically with government organisations, consumers reported three important factors influencing their decisions:[6]

- the role of the person requesting the health data
- the nature of the data requested
- the level of anonymisation.

Organisations regarded by consumers as important in deciding whether health data should be provided for research included:

- ethics committees
- independent advisory boards
- consultants in relevant fields, but not individual researchers
- patients and their GPs
- ordinary members of the public.

However, consumers were strongly opposed to government oversight.[11] Health insurance companies and employers were both identified as entities whose access to personal health data was strictly opposed by consumers.

This was mainly due to fears of misuse, for the purpose of creating a ‘risk profile’ as a basis for implementing unfair changes to health insurance policies based on individuals’ data, which may be indicative of current poor health or imminent health complications.[6,23]

Interestingly, although consent was viewed as a necessary procedure to protect consumers’ privacy, it was not perceived to be a solution to the aforementioned security concerns of unauthorised access.

Therefore, there is a need to distinguish privacy from security when discussing the functionality of consent, and how it addresses consumers’ concerns about these aspects of data exchange and storage.[23]

2.6 Consumers’ attitudes toward the need for informed consent

The notion of a ‘natural right to privacy’ was frequently raised in qualitative research examining consumer attitudes to health data sharing and consent.

Surveys conducted by the Office of the Privacy Commissioner in Australia found consumers’ demand for consent has been gradually decreasing – 64% of respondents to surveys conducted in 2001 and 2004 reported that consent should always be sought for the use of de-identified data for research purposes; in 2007 this proportion decreased to 51%.

Research conducted by the Australian Government Department of Health found most consumers were willing to share their de-identified health data for research purposes, as long as the research was purposeful, legitimate and worthwhile.[3]

Consumers generally viewed seeking consent as an act of courtesy, but expressed support for the process to become a legal requirement. Consumers also believed the process of seeking consent could provide an opportunity to learn about how their health data may be used, and to become more involved in their healthcare.[23]

Consumers indicated consent was of greater importance when commercial entities may be involved in research. The poll conducted by the Australian Medical Association found 67% of Australians would consent to their de-identified data being used for research purposes, 45% would consent for government purposes, and only 32% would consent for commercial purposes, as cited in O'Keefe and Connolly.[3]

Other instances in research for which consent was perceived to be important included the use of genetic data, potentially identifiable data, or qualitative data rather than just 'plain statistics'.

In studies where consumers were asked to discuss and reflect on their need for consent processes, as the perceived transparency and value of the research increases, views typically shifted from an explicit opt-in consent system to a more flexible opt-out or circumstantial consent model.[1]

Consumers' support for an opt-out model also seemed to increase as they became more aware of current data exchange processes and potential logistical difficulties associated with introducing more rigorous consent processes.[27]

Consumers tended to recognise that introducing an opt-in system to any healthcare setting might require considerable additional resources. Employing dedicated staff to disseminate relevant information to consumers to ensure an adequate level of understanding about the stipulated health data exchange, and to ensure consent procedures fulfilled any relevant legal requirements, were recognised by consumers as a required support system for implementing an opt-in model.[23]

Consequently, most consumers expressed support for a once-only 'blanket consent' system for each time they attended a new primary care setting. The blanket-consent system enables ongoing consent for specific agreed 'levels' of consent, including the provision of data for research purposes, which allows consumers self-determination without the need for a consent request on a study-by-study basis.[13,25]

The only exception to this system was allowing health professionals to access their data in emergency situations, such as life-threatening instances in which patients are unconscious and unable to provide explicit consent. These exceptional situations were described as 'break the glass' scenarios.[13]

Consent was identified as a key issue in the available literature studying consumer attitudes towards the transfer of health data from primary care health professionals to researchers. Focus groups conducted to gauge consumer attitudes toward sharing their health data for research purposes found a correlation between consumers' lack of trust in large organisations and their increased need for consent.[11]

Despite almost all consumers expressing a willingness to share their health data with third-party organisations for research purposes, the response from consumers to proposed consent processes was polarised.

The main conflicting views emerging from the literature were that some consumers preferred to be asked for consent every time their health data was going to be shared with any organisation external to their usual healthcare provider and, when possible, they should be notified before an upcoming consent procedure. Others believed the potential for health data to be shared with research organisations should be included in the once-only 'blanket consent' model, stipulated within an access agreement during the proposed consent process.

Under the latter model, health professionals would be expected to provide as much information as possible, to the best of their knowledge, regarding current and future data-sharing agreements with specific research organisations.

Consumers generally perceived health research to be highly important in contributing to improved health outcomes. This was accompanied by a general consensus to avoid allowing bureaucracy and the complication of access to health data to have a negative impact on the implementation of research.[23]

2.7 Conclusion

Consumers' preferences for health data sharing are very much linked to their understanding of health data sharing processes, and consumers' understanding of health data exchange is still very limited, which has led to polarised outcomes for many of the issues outlined in this review.

The literature indicated a high proportion of consumers were willing to share their health data for research purposes, due to the perceived importance of health and medical research, and the perception that the benefits of this exchange outweighed any risks posed.

However, the main points of contention about health data sharing are:

- the lack of transparency around health data exchanges
- the implementation of appropriate and efficient consent models
- government oversight and access, and the risk of unauthorised sharing.

Interviews

3.1 Summary

The interviews showed that consumers believed they have an awareness of what health data are, although these views were not particularly nuanced or full. They also varied considerably, to the extent that no consistent definition of health data emerged. The majority of those interviewed had thought about the concepts before and had concerns about the security of how their data are stored. They acknowledged ideas about health data ownership are complex, and are intertwined with ideas of access. They felt they should be the owners of their health data, but many acknowledged this was not currently the case.

With regard to who should have access to their health data and why, consumers believed the health practitioners who treat them should have access, and that groups of people who use the health data to inform health interventions for the broader population should have access to de-identified data. Key to this access, however, was that consumers wanted to have the opportunity to give consent. They would prefer this consent to be on a case-by-case basis, however the practicalities of doing so were not explored in these interviews.

Finally, views about sharing data for research purposes were broadly positive. Key considerations for consumers included the type of organisation requesting the data, the purpose to which it would be put and whether they were able to provide consent for this.

3.2 Design

The paucity of data in this space, particularly with a broad consumer population, warranted a qualitative interview strategy. The results of the interviews directly informed the design of the cross-sectional survey component of the project (Chapter 4).

Participants were selected based on three factors of their experience: gender, self-assessed health status and the number of times they visited a GP in the past 12 months. These categorisations were developed based on data from the Australian Bureau of Statistics Patient Experience Survey (2015–16 Data).[28] The available survey data does not report the proportions of people who had not visited a GP in the past 12 months. In order to not exclude this group, they are combined with those who had visited a GP once.

The sampling frame used in the interviews was as follows:

Number of visits – n = 5 per category	Fair or poor health	Good, very good or excellent health
0–1	1 male	2 male, 2 female
2–3	1 male, 1 female	2 male, 1 female
4+	2 male, 2 female	1 female

Participants were recruited through CHF's networks. Two emails (an initial email and a follow up email) were sent to CHF's members and representatives networks. These emails provided details of the study, including a link to the study information sheet and invited potential participants to fill out a form indicating which of the participant groups they belonged to and their availability for an interview. Participants who completed the interview were given a $50 supermarket gift voucher in return for their time.

The interview questions examined four areas using the questions below. These questions were informed by the literature review. Full text of the interview protocol can be found at Appendix 3B.

- Health data definitions and usage: consumers' current understandings
    - What is health data to you?
    - Where is health data generated?
    - Who is it generated by?
- Who should have access to health data and why
    - If health data is about you, who owns it?
    - Who should have access to your health data?
- Methods and instances that health data could be used for
    - Where is your health data stored?
    - How and where should it be stored?
    - What should your data be used for?
- Reservations regarding the use of health data for research purposes/ Consumer attitudes toward the need for informed consent
    - Thinking now about the use of your health data for research purposes specifically – how do you feel about your health data being used for research purposes?
    - What if there was a possibility that you could be identified from this information?
    - What if there was a possibility that your data could contribute to a particular group being placed at a disadvantage?
    - Are there groups or organisations who you would be more willing to share your data with?

3.3 Findings and discussion

3.3.1 Health data definitions and usage

Work to date, while limited, has categorised health data into three categories:[6] personal and proprietary data, government-controlled data, and open data commons, and has found consumers were largely unaware of how and when their data was being used for research purposes.[11] The wide range of ideas generated by participants in the present study supported this; while consumers seemed to have thought about what health data are, their ideas and views were extremely wide-ranging.

The majority of participants had views about what health data are, with only two commenting they **had not thought about the concepts before.**

> *It doesn't mean anything much to me. I haven't, to be honest, focused on the term* – Participant 10

Participants frequently mentioned they were **concerned about the security of health data** and they **felt they had very little control over how it is stored**. This theme was mentioned predominantly by male participants (6 out of 7 of those who mentioned it), but was not related to either the level of service use or their health status.

> *I hope it's all secure but that is something I have very little control over and very little knowledge about* – Participant 1

A wide range of ideas about what health data specifically are emerged from the interviews. Lists such as these have not been generated in the literature to date and are presented in order of highest to lowest frequency of mentions below.

Those that were mentioned by the majority of the sample were:

That it is **generated and stored in a very broad range of places** – mentioned by 12 participants, from all demographic groups examined

Information about a specific person – mentioned by 12 participants, from all demographic groups examined

Information generated by health professionals and services about a person – mentioned by 11 participants, from all demographic groups examined

Information about the broader population – mentioned by 10 participants, predominantly by males (7/10) and those in good health (7/10)

Information created for and used in research – mentioned by 10 participants, from all demographic groups examined

Ideas about what health data are that were mentioned by a minority of the sample were:

Information created or stored by a person about themselves – mentioned by 5 participants

Information generated by groups of people with a purpose – mentioned by 5 participants, mainly male, all levels of service use, even health status

> *Interested people or people who need to have that kind of information so they take responsibility of organising it and then they and other people build on that* – Participant 12

Information that is stored and transferred electronically – mentioned by 4 participants, mainly male and in bad health

Information created or stored by government about the broader population – mentioned by 3 participants, from all demographic groups examined

Information that is stored and transferred offline – mentioned by 3 participants, all demographic groups

Private health insurance information – mentioned by 3 participants, all female and in bad health, low and mid service use

Financial records and information – mentioned by 2 participants

> *Financial data such as PBS, Medicare and private health insurance* – Participant 9

3.3.2 Perceptions of ownership of health data

As with definitions of health data, consumers' perceptions of who owns their health data have not been widely explored. Findings from the current study suggest this may be in part because the definitions of health data remain broad and wide-ranging. The findings also reveal an elevated level of uncertainty about the idea of ownership of health data more broadly.

Ownership is not a simple idea

A major idea to emerge was **ownership is not a simple or clear-cut idea**. One third of participants commented that **there is not just one owner of health data**, particularly once it has been shared.

> *I don't think you can separate the two, because one person collects it and I'm not sure that they can sell it, I don't think they get paid for selling it to researchers. I think both of them would own it*. – Participant 15

This idea was articulated by one participant who was distrustful of the internet in particular (high service use, male, bad health), who felt **once data is on the internet it becomes public property**.

> *Once it's up on the internet it becomes virtually public properly as far as I can see, open access to people.* – Participant 12

Other participants commented that **some groups, such as doctors and medical specialists, think they own the health data**.

> *In fact it annoys me that GPs or medical specialists reckon they own the data which is produced on you. I don't like that at all. I reckon that's my information and I should own it but that's not the way the law seems to see it.* – Participant 12

Participants contrasted ideas of access and ownership, noting they are separate ideas. For example, **practitioners and third parties who are caring for patients should have access to a person's health data, but should not own it**.

> *It is two different things, to own the data and to use it.* – Participant 4
>
> *If it's a third party, say, his practice nurse or someone else, they have a reasonable right of access or a reasonable excuse to see it if they're treating me or doing something relating to my care or operating under my doctor's instructions.* – Participant 6

Two participants added the idea of 'right of release' to access and ownership through the notion that **while they felt that they do not own their data, they are able to control who accesses it through giving their permission to release it**

> *I would assume, or I would think I have the right, to agree to whether my doctor shares it…. So whoever is sharing it should be with my permission, or using it* – Participant 7

When the data is changed, such as when it is de-identified, then the conditions of who can own it or how it is owned can change. One participant commented that once it's de-identified it can be owned by someone other than the person

> *If it can't be linked to me or it's not directly identifiable, then I guess it can be aggregated and clumped together with other people and then it can be owned by the service provider* – Participant 5

Groups who own health data

Participants were asked a series of prompting questions about who owns their health data. Responses to these questions varied, with the most frequently endorsed option being that **they own the data** (7 participants, even gender, even health status, 4/7 mid service use).

> *I do. The productivity commission report is going to try and change the current status. The current status is that the GP claims copyright over the data; but in reality, it's not about them; it's not about copyright; it's part of who you are and what you are and you've got a right to that data and a right to privacy, and the right to determine how it's going to be used* – Participant 9

Other groups' participants felt owned the health data included: health professionals, organisations like hospitals, the system that establishes the data and whoever has conducted the study or deliberately acquired it. To contrast, some participants were **unsure about who owns the data**, with some participants who mentioned this being worried about it and others not being worried by it.

> *I don't really know the answer to that; it has never really worried me particularly one way or another.* – Participant 10

Groups who do not own health data

Three groups were identified as groups who do not own health data. The major one of these was the person who uses the data, which was because:

> *Use doesn't imply ownership; use implies a right to use it to achieve a particular end. So the doctor can look at the scan and they can use it to make a diagnosis or whatever or if they reckon you're going well or we need to do this that or the other but that doesn't meant that they own it.* – Participant 1

Other groups' participants **did not think owned their health data were themselves and health practitioners**. Some discussed they would like to own their health data, but felt they did not.

> *I doubt I do. I mean, I'm just thinking about whether – no, because the records have got to be maintained for a certain amount of time and I can't change that so I'm assuming I don't own it.* – Participant 14

While most participants discussed that, under current legal arrangements, health practitioners were the legal owners of health data; they felt **health practitioners should not own it**. This was illustrated creatively by one participant who said:

> *It's like the plumber and the plumber came in and he put a video camera up the pipe to see what the problem was, the plumber doesn't say, this video, it belongs to me. Right, he's say well, you know, it's a video of your pipe, you paid for it, you paid me to do it, you wouldn't get all pent up about it, you know, it belongs to me. Or if I employ an accountant or a lawyer, right, and I hand over all the information about my finances to the accountant, the accountant doesn't say that all the information about your finances, that belongs to me because I generated it or this report or whatever. So doctors, for some weird reason, have this completely different view to every other professional group about the data that they generated because apparently, well who knows why, it's because they think people will get confused if they have access to their health data.* – Participant 1

3.3.3 Who should have access to health data and why?

Work to date in the area of who should have access to health data and why has broadly found that consumer concerns over data security tended to increase as the data use moved further away from their general practice.[11] This finding was echoed in the current study, with consumers consistently in favour of their health data being used by health professionals, but not clearly supportive of the government using their health data.

Three key areas of concern were reported with regard to consumers sharing their data with or withholding it from government organisations.[6] The present study found the first of these considerations, ‘the role of the person requesting the data’, to be of concern irrespective of the organisation requesting the data.

People or groups who should have access to health data

Participants had a wide range of views about who should have access to their health data, and these preferences were not clearly related to the demographic group they came from. More consistent was the idea that consent needed to be given for other people to have access. Participants expressed this through the ideas that: **access to records should only be with permission,** their sharing of health data **depends on who they want to give it to**, and people who should have access are **people who I have given permission to have it.**

> *I believe that you should have control as you’re supposed to have with the My Health or whatever the scheme is called now and that you can give permission to various people you select to have access to it. I think that’s the way it should be, that you should be in control of who is able to access your information, even though someone else may claim they own it, but you have the right to control its exposure.* – Participant 12

All participants felt **health professionals should have access in some form** (13 participants, even health service use, 8/13 male, even health status). Two caveats to this were imposed by some participants:

- **Only if explicit consent is given** (3 participants, all health service use, 2/3 female, 2/3 bad health)
- **Only if necessary for treatment** (6 participants, 3/6 mid service use, 4/6 male, 4/6 bad health)

People who care for and or about the person whom the health data is about

Consumers broadly agreed that **people who care for or about them should have access to their health data**; however, they placed a range of caveats around this agreement. In line with the above general comment, the most predominant caveat was that access should be only with their consent (9 participants, no clear demographic trends).

> *If that person who cares about me is not making decisions on my behalf because I am not able to or actually being a carer for me, then they don’t need to have any of my health data. That’s up to me to share it with them. They shouldn’t just have access to it without my consent, I suppose, or my choosing to share it with them*. – Participant 5

The other main caveat articulated by participants was that **the permission granted would depend on their relationship**, particularly how they perceived that relationship as opposed to the way other people perceived that relationship.

The government

Participants did not feel strongly about whether or not the government should have access to their health data. Some participants felt that the government should have access, while others were opposed. The main reason given for government access was that it **‘would help them get an accurate view on the current situation’**:

> *In order to gain a proper understanding of how Australia is going, I wouldn't mind my data being given because otherwise they might have misconstrued… but they might not have the most appropriate or best data available to make decisions which wouldn't benefit anyone*. – Participant 3

Where participants felt that the government should have access, restrictions they placed on this access included that they would like to give explicit consent to their data being shared and this access should be only under strong restrictive guidelines.

> *I think they're the same as any other Joe Blow. I don't think they should have access to it without my permission. I mean government's a pretty big thing and the health side of government might want it for research purposes but it needs to be sections of my data which I have provided for that purpose or given permission for use for that purpose.* – Participant 13

> *I think a fair amount of access by government can be justified under very strong guidelines, restrictive guidelines so that it can't be used for ruin but I certainly can see the value of amassing information over a large population so that useful and valuable information can come from that.* – Participant 12

How consumers think their health data should be stored

Consumers were asked directly how they thought their health data should be stored. The most frequent response was that it should be **stored securely,** which was mentioned by eight of the 15 participants.

> *Well I hope it will be stored safely that is with some security key to access it but I have absolutely no power on it.* – Participant 11

Other places that consumers felt the data should be stored were:

- **Electronically** – mentioned by 5 participants, from all levels of service use, even gender and even health stats
- **On My Health Record** – mentioned by 5 participants, from all levels of service use, even gender and even health stats

> *Currently we have My Health Record that are starting to be implemented so I think that if it was working it would be the best because the current problem is that there is no good place where all your information is stored in the same place and so it would be best if everything was stored in the right place, like My Health Record if it was working.* – Participant 4

- **Online** – 1 participant, low service use, male, good health

3.3.4 Methods and instances for using health data

The options used were based on a poll conducted by Research Australia in 2016 which found 91% of Australians were willing to share their health data for research purposes, specifically to advance health and medical research (79%), support healthcare providers in improving patient care (74%) and assist public health providers in tracking diseases, disabilities and their causes (68%).[5]

The most strongly endorsed of the options was research (13 of 15 participants), to support public health officials in making decisions (10 participants) and for an individual's treatment and care (10 participants). No patterns among the demographic groups were evident within these.

Participants who generated other purposes they felt their data should be used for were mainly in good health and had a range of levels of health service use. This may suggest that participants who felt less reliant on the health system or felt more positively about their health were more likely to feel their data should be shared for other purposes. These other uses included:

> **Anything without individual attribution and to aggregate into metadata** – mentioned by 2 participants, low and high service use, both male, both in good health
>
> > *I think to aggregate the data into metadata and then it can be used without individual attribution* – Participant 2
>
> **For public good** – mentioned by 3 participants, low and high service use, male, good health
>
> > *I'm perfectly happy for my data to be used for any public good if national statistics are being collected or research done.* – Participant 10

Two other uses data could be put to were generated by participants, some of whom were in good health and some of whom were in bad health. These were:

> **For the patient's best interest** – mentioned by 6 participants, 3/6 high service use, even gender, even health status
>
> > *Well for your best interests but that's a broad answer I guess so yeah, it should just be used in any way that is in your best interest. And that's why, when I say so long as it's with your permission, it's not always – I'm certainly not giving very good answers because I know that patients don't always know what is in their best interests.* – Participant 7
>
> **For the purposes for which it's collected** – mentioned by 2 participants, low and high service use, male, good and bad health
>
> > *There will also be information that's collected as part of research and so that information should be used for the purposes for which it was collected. So at the moment I'm participating in the Australian Breakthrough Cancer Study so all the information that I provided in that study and the saliva samples that I've given to the genetic tests and the bloods that I've given for that, that should be used just for that study and basically within the walls of that study.* – Participant 1

Caveats placed on research use

While participants were strongly supportive of their health data being used for research, a number placed caveats on this. These caveats provide a basis for future work which should investigate how widely held these beliefs are among the broader population, and if the trends found in this small study are apparent in the broader population. The most frequently suggested of these caveats was **if permission was granted**, showing that even when consumers were supportive of their data being used for a purpose they would still like to be asked for, and provide, consent for their data to be used.

> *If I had a serious illness which was of interest to a medical researcher, if I consented to consult or be in contact with that researcher then that would be okay, I would share whatever information I felt useful to that researcher. But the researcher should not have access to my data without permission certainly*. – Participant 2

The need for **adequate safeguards to be in place** and for the **data to be aggregated and anonymised** was mentioned by a similar group of all male participants. No detail was provided as to what they meant by 'adequate', which may suggest either they do not know enough to state specifics or they felt it was self-evident.

> *I believe so as long as adequate safeguards are taken so that it doesn't open up a wide area of people being able to access it but appropriate people should be able to – but that's probably a matter for you to give permission. As things arise you can agree that certain people can have access and use it providing adequate safeguards for its security and confidentiality are put in place.* – Participant 12

The idea of **ethical review** being used to protect consumers' health data in research was only mentioned by two participants. This low frequency was surprising, as human research ethics committee approvals are viewed in the research community as a basic standard and ethics committees have been previously identified as important by consumers. This may suggest either that consumers expect ethical protection as such a basic standard, or they are unaware of it.

> *I guess there probably is but quite strong ethics around how your health data is used but I suppose at the moment my health data might be used for that stuff but I don't know about it and I guess I would probably prefer that there was some sort of layman information or something that I could look at so I could feel confident that if my health data is being used, then these are the basic ethical parameters that surround that.* – Participant 5

Caveats placed on supporting healthcare providers in improving patient care

The caveats placed on the use of health data to support healthcare providers in improving patient care were similar to those placed on the use for research purposes. Consumers were okay with this use, but **only if they were asked to provide consent**, often on a **case-by-case basis**. This view emerged across participant groups.

Caveats placed on supporting public health officials in making decisions

The proportion of the sample who **explicitly remarked that they wanted to provide consent** for this purpose was lower than for the above two purposes (5 of 15 participants). The additional caveat placed on this purpose that was not as evident for the above two purposes, **was that this use should only be if patients were not identified**. This additional caveat may have been due to consumers' concerns about data security increasing as their health data moves away from their general practice location, as has been suggested by previous work.[11]

3.3.5 Things that health data should not be used for

The two purposes consumers mentioned their data should not be used for – to **promote products to someone** (2 participants) and to **stigmatise groups of people** (2 participants) – relate to a fear of the data being misused, an area which has emerged in previous work as a key area of concern.[6]

> *I guess I think my health data shouldn't be used for promoting stuff to me. If it's a product that I have to buy, maybe if it was being used to target me for … like I'm asthmatic, so I guess it makes sense that my health data would be used maybe by a service to say, "You*

> *need an asthma management plan review or something", and target me in that way, that kind of makes sense to me, but not to market …not for commercial use, I guess. I don't think my health data should be used in that way.* – Participant 5

> *If it's used to stigmatise a particular group in the community – let's say, because you live in this location – you know what I mean? "You are mentally deficient because there's a lot of lead in that area." That's not good enough.* – Participant 9

Only one participant said they would not share data with the government, because they felt **some parts of the government have a history of misusing data,** which replicates previous focus group findings.[23] Other participants would **share their data with the government, as long as it was not identifiable** (4 participants across all service use levels, even health status, mostly male).

> *Well I suppose government would be potentially at a de-identified level. I mean, clearly, My Health Record is managed by a government agency but there's protocols around who can access that data and how. So can government see my individual health record? Well, probably I'm not keen on that happening but I'm happy for it to be de-identified.* – Participant 4

3.3.6 Reservations about the use of health data for research purposes

As discussed above, participants were broadly fine with the idea of their health data being used for research. When asked about a number of specific scenarios and how these would influence their willingness to share health data, their views varied.

Participants were asked explicitly **if they would share their data if it could contribute to a specific group being discriminated against** as this had been identified in previous work as an area of concern to consumers.[6,23] The example given as a prompting question, 'a health insurance company raising premiums of people from a disadvantaged group' was drawn from the work of Simon et al.[23] The present work expands on these previous findings considerably by unpacking this issue. Six of 15 respondents spread evenly across the participant groups **expressed scepticism about this occurring**.

> *I would think that's pretty remote. I would hope that I'd be bright enough to detect the chances or the opportunity if it appears to be developing to say no to the access that would be required for that. But I guess, that overall, I can only see that most information gathered would benefit the majority and that that's an unfortunate fact of life that sometimes the benefit to the majority is not to the benefit of a minority.* – Participant 12

A majority of participants (10 participants) felt they would have **very little power to stop this occurring or change their data being used to discriminate against a specific group.**

> *I suppose it can be used for good and not so good so I suppose you can't necessarily pick and choose. I mean if your data is being made available at a population level then it's going to be used for various purposes. I'm not sure how you would protect against that for that purpose.* – Participant 8

However, others expressed that this **would only happen if people should be at a disadvantage.**

> *The only thing I can think of there is a group that may be placed at disadvantage would be a group that should be disadvantaged. I can't see that my records might put anyone at disadvantage that shouldn't be disadvantaged* – Participant 13

Participants were also asked explicitly about **sharing their data with the government**. The mixed levels of concerns identified in this study appear to be in line with previous quantitative work which has found that only 50% of consumers are supportive of sharing their health data with government.[4] Specific concerns they expressed about this included that they **feel like they already share it with the government** (2 participants).

> *I feel like I already share my data with the government now and for good reason have no choice about it, but, yes, I don't have any problem with the idea.* – Participant 10

Others felt that the **government would use it for good**.

> *A government has to plan things, to analyse things with probabilities and statistics to plan for the future so I think that any data that can help the Government to plan for the future is useful.* – Participant 4

Considerations consumers related to sharing their health data

The three major concerns identified by participants that would influence their likelihood of sharing their data are novel when compared to previous work. Participants were interested in knowing more about the group requesting their data, with some remarking that they would **take the time to investigate the organisation before they chose to share data.** This suggests that transparency and willingness to provide information may be a good way for companies to increase consumers' willingness to share their data.

> *I would have to be satisfied that the purpose for which they desire my information would be of benefit to a lot of people and certainly not just good for their bank accounts because they don't need any help with that, they're pretty good at getting it anyhow.* – Participant 12

With regard to the organisation, **participants were less likely to share their data if it were used for commercial gain,** which supports the findings from a poll conducted by the Australian Medical Association that fewer Australians would share their data for commercial purposes than other purposes, as cited in O'Keefe and Connolly.[3] Pharmaceutical companies were mentioned explicitly by participants as a group who are more likely to exploit data given to them for their own profit.

> *I would be thinking a little bit about sharing it with pharmaceutical companies because I don't think they're always as ethical as they should be. That would cause me some issues…. I don't think pharmaceutical companies are as ethical as they could be, and that would cause me some concern.* – Participant 15

Participants were more likely to **share their health data if it would benefit the country and the health industry**, which also supports the findings of the AMA poll mentioned above, as cited in O'Keefe and Connolly.[3] This group of eight participants were drawn from all levels of service use and health status and were mainly male (6/8 participants).

Concerns about being identified

Participants were asked explicitly if their willingness to share their health data would change if there was a possibility they could be identified from the sharing of their data. The majority of participants (8 participants) expressed the view that they would **prefer not to be identified.**

> *I think people like to remain anonymous* – Participant 3

Continuing the theme of consent that emerged throughout the interviews, participants were okay with being identified **if they had given explicit consent for this** or if they were able to give consent **on a case-by-case basis.**

> *I don't have a problem with that as long as I was aware that my information was being used. I think permission still needs to be sought so that you're aware of what your information was being used for. But I don't have a problem with it being used if I give permission, or I'm aware of it anyway*. – Participant 7

> *I'd have to deal with that on a case-by-case basis. Where if it was going to benefit me personally then that would be something I'd have to make a decision on at the time but not blanket coverage.* – Participant 8

However, other participants **were unconcerned with the prospect of being identified**. This lack of concern was mentioned by four participants, three of whom were in bad health.

> *In most cases it [the prospect of being identified] wouldn't worry me personally because I think the risk is pretty slight but there's always a chance, as I said before, no system is perfect.* – Participant 12

3.4 Limitations

CHF's networks, from which the sample was drawn, are generally more highly engaged with health and healthcare issues than the broader population. While attempts were made to stratify the sample through the number of times participants had visited a GP in the last year, this may not have negated the impact of the higher level of engagement with the health system. Future work, including the survey, should attempt to access a broader sample.

The Australian Bureau of Statistics Patient Experience Survey, which the sampling frame was drawn from, does not publicly report the gender and age distribution of the proportion of the population who have seen a GP zero times in the last year. Consequently, the proportions examined in the current survey may not be representative of the Australian population.

Survey

The following chapter reports and discusses the results of the final research stage of the project, an online cross sectional survey with Australian consumers. The survey findings are set out in Appendix 4A *Electronic health data: community survey findings.*

4.1 Design

4.1.1 Survey instrument

An online cross-sectional survey was prepared by Urbis, in consultation with CHF. The survey instrument can be found at Appendix 4A.5. It contained questions relating to respondents':

- understanding of what constitutes health data
- views on privacy and consent
- views on sharing health data
- views on secure health data storage
- views about the circumstances for accessing health data
- own health status and health conditions
- media use
- demographic information.

4.1.2 Participants

Participants were recruited through ResearchNow, an external company that provides online research samples to researchers. ResearchNow collects basic demographic information (age, gender, region, household demographics) about their panel participants at the time their participants register. For each project participants are asked to participate in, they are provided a basic link and information that is non-leading. Panellists are rewarded for taking part in surveys according to a structured incentive scheme, with the incentive amount offered for a survey determined by the length of the survey and the nature of the sample.

There were 1,013 responses to the survey.

4.2 Discussion of findings

4.2.1 Understanding of the concept of health data

Participants believed their health data included information collected about them by doctors or health practitioners (eg pathology results, information to conditions they may have, information from prescriptions and doctors' visits and information relating to disabilities they may have). These findings provide a valuable contribution given the limited available literature on consumers' understanding of what health data is. It suggests consumers understand health data to be everything about them, not just that collected by health professionals.

4.2.2 Beliefs around the benefits of health data

The survey finding showed consumers believed strongly in the role research can play in improving healthcare, that they have a natural right to privacy and that they own their personal health data. These findings highlight that organisations and institutions will need to give attention to these beliefs, and treat them as baseline views, from which policy decisions and directions can be examined and created.

Research is understood as being important and of interest to consumers, a finding previously highlighted by Research Australia.[5] This suggests that where agencies – including government, non-government and insurers – can focus on the research or public benefit nature of their work, it may improve acceptability and the likelihood consumers will choose to participate.

Health practitioners are generally trusted by consumers to keep their information confidential. However, once this information is passed onto third party organisations, trust decreases. Low levels of trust were displayed in all the groups of organisations asked about (government, private and research) which is interesting and shows no particular advantage of one group over another. Research organisations, the most trusted of the three groups, were believed to be more likely to store data securely than to ensure anonymity.

The survey does not tell us why levels of trust are low, which makes this an area for future investigation. No specific organisational names were identified, nor were the industries of these groups. Being more specific and dealing with known quantities may change responses and beliefs, as is suggested by the findings below that MyHealth Record is more likely to be perceived as secure compared to other forms of 'electronic' and 'online' data storage.

4.2.3 Views about My Health Record

The finding that younger people, particularly those in the 18–24 age group, were more likely to agree that all three forms of data storage (online, electronic and MyHealth Record) were more secure than others is in line with broad current thought about how young people perceive online health data. Positive views about security decreased with age, suggesting more attention should be given to conveying to older groups how information about them is governed and protected.

The majority of people of all ages agreed MyHealth Record is more secure than other forms of data storage. This finding, and similar findings described below, suggests consumers are more supportive of health data storage and sharing health data when they have a clear understanding of the purpose it is being used for and the organisation/person they are dealing with. It shows that messaging about how data is stored should be clear and specific, rather than using general or non-specific terms.

Participants were considerably more comfortable with their data being shared if it did not identify them than if they could be identified, confirming a finding from Stage 2 of this project (interviews with consumers). This finding is of interest in light of ongoing discussions around the nature of data and the interest in the potentially identifiable data collected in the 2016 Australian Census. It underscores the importance of ensuring consumers understand what type of data will be shared, and how identifiable or unidentifiable they will be from it. If messaging or communications are able to clearly show that the data being shared are aggregate, or are modified in such a way to ensure that consumers will be unidentifiable then the likelihood consumers will consider sharing it is greatly improved.

4.2.4 The use of health data

One of the areas of strongest difference among consumers was the use of health data.

It is clear from these findings that consumers objected to organisations making a profit from their data regardless of the type of organisation. However, these beliefs did vary according to age. Younger people were significantly more likely to agree they were comfortable with organisations making a profit from their data compared to consumers over the age of 64. This suggests groups who are more familiar with such practices (eg social media data being sold as a commonly accepted practice) are more likely to generalise these experiences to their health data. The age group expressing the highest level of disagreement with data being shared without their consent were those in the 35–44 and 45–54 age ranges.

Consumers' disagreement with statements about organisations of all kinds having access to data to plan services, and about research organisations having access for research purposes, are of particular note.

With the exception of the Department of Health, which 59.2% of consumers agreed should have access to their health data to plan services, consumers on average disagreed with organisations having access to their data to help plan services. The proportion of this disagreement ranged from 64.9% (private companies) to 49.0% (other government departments). These findings have systemic implications for not just the health sector, but for other organisations such as local government, local hospital and Primary Health Networks. These results suggest that while in public policy the sharing of data is perceived as a social good, consumers do not necessarily agree. Greater awareness and communication efforts are needed to increase consumer support for data being used for this purpose, to improve levels of social licence and to avoid a potential backlash if this level of disagreement was given a voice through the media or other consumer channels.

The higher levels of agreement (59.2%) expressed for the Department of Health than other organisations is of interest. It shows that consumers are more comfortable with some organisations than others – primarily those which use the title or concept of 'health' in their title. For example, consumers were more comfortable with the health department (jurisdiction not specified) accessing their health data to plan services than other government departments, and health insurers more so than other private organisations. These findings show that consumers are more likely to respond positively if they have a clearer understanding of the intended purpose or the organisation wanting to use their data. This is reinforced by the detailed findings that consumers' levels of comfort increased with greater levels of information about how governments would use their data.

4.2.5 Consent and access

One of the key themes arising from the interviews was that consumers would prefer to provide case-by-case consent to the use of their data. The survey findings supported this. This finding may present a challenge to organisations, as opt-out models of consent are increasingly favoured. Future work could consider presenting different models of consent to consumers to see what type of case-by-case consent is favoured. This consideration would need to involve both data governance committees and human research ethics committees.

The issue of consent also arose in the findings on personal uses of health data. While broadly consumers agreed that their primary treating team should have access to their health data, there was a large proportion of the sample who believed no one should be able to access their data in an emergency (58%)[b]. This presents a major concern for both digital health advocates and health

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[b] The survey question pertaining to this finding was: If I was in an emergency and unable to consent to share my data, no-one should be able to access my health information without my permission.

professional groups. It is a view that requires higher levels of consideration, particularly in light of the increased use of digital health records, the policy objectives of MyHealth Record and the implementation of the National Digital Health Strategy.

Higher users of the health system (eg carers, consumers with chronic conditions and those who take prescription medicines) were significantly more likely to agree that doctors should have access to data in emergency situations. This suggests it may be possible to change attitudes of the broader population by showing case scenarios of these higher use groups or attempting or explicitly suggesting to these groups that situations may arise in their lives in the future where they, or others in their lives, would benefit from health professionals being able to access their health data.

Health professionals perceived their health data to be more secure, however they were less likely to believe their health data is confidential. This contrast suggests that the issue for health professionals may not be directly related to electronic health data, but rather intra-professional relationships. In this way, it ties into current discussions around mandatory reporting and levels of trust within health organisations.

A relationship was found between better health status and the comfort of respondents with government using their data, except for those with ‘excellent’ self-reported health status. Poor self-rated health and excellent health were both related to a low level of comfort with governments using health data. For the ‘poor’ health status group, this may be related to this group’s greater use of health services, or higher levels of perceived stigma about their health conditions.

Of the purposes for which health data can be used, cost-effectiveness emerged as an area of consumer concern, particularly when compared to altruistic or more general public good uses (55% agreement, compared to 62.5% for assisting healthcare providers in tracking diseases, disabilities and their causes and 57.6% for health and medical research). Respondents with less confidence accessing health services were significantly less likely to agree with statements relating to the security, privacy and use of their health data. This shows efforts to increase health literacy and improve access to health services may have flow-on effects on trust in health data. The inverse may also be true – by improving trust in health services and perceptions of security and privacy, consumers will become more confident in accessing health services.

4.2.6 Specific population groups

Aboriginal and Torres Strait Islander people displayed significantly different views to the broader sample on a range of measures. As discussed in detail in Appendix 4A, these findings suggested that this population may need significantly more or different attention and consideration in relation to health data. The findings suggested that the involvement of local communities in the health care of some Aboriginal and Torres Strait Islander people may be related to their lower levels of confidence in the security of their data.

When considered in conjunction with the findings that consumers from culturally and linguistically diverse backgrounds were also less likely to be comfortable with data being shared or used, these suggest that consumers who have diverse cultural backgrounds have different understandings from the broader population. More broadly, these findings may be of concern for the wider roll out of Health Care Homes, or other forms of value-based health care. If low levels of trust are related to the type of care received by these groups, rather than specific characteristics of the groups, caution may be needed in the roll out of this type of care.

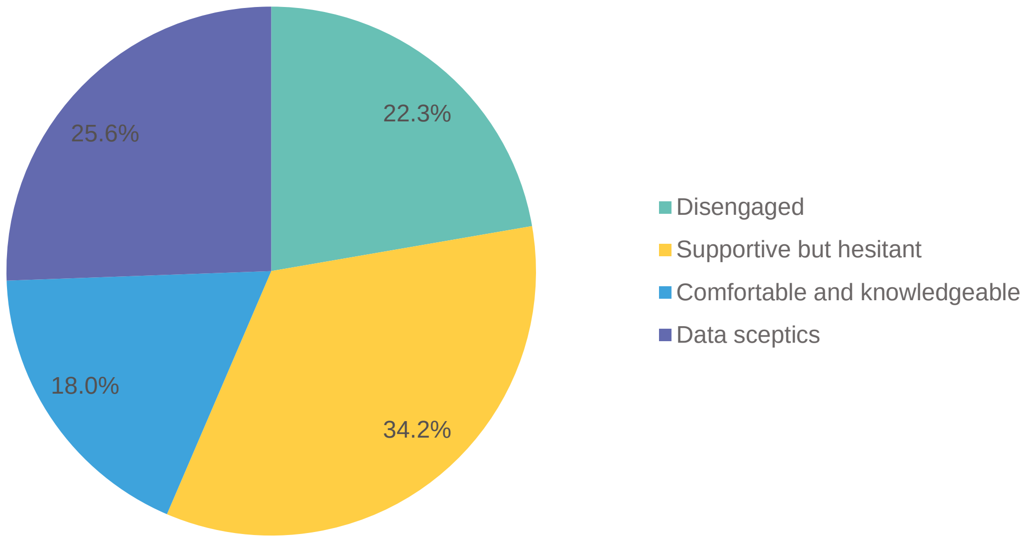
4.3 Market segmentation

Market segmentation techniques were used to develop four distinct categories of participants, representing attitudes toward privacy and sharing of their health data. This segmentation revealed consumers were far from homogeneous with regard to these issues, and provided a range of practical ways to communicate with these distinct groups. Key predictors of the market segmentation were attitudes toward:

- being asked for permission when a research organisation would like to use their data
- being comfortable with government using their data to improve the cost-effectiveness of services
- whether a natural right to privacy exists
- whether private companies should be able to access their health data to plan services.

Of interest when considering the market segmentation were variables on which the groups did not differ, specifically: if they had a My Health Record, if they worked in a health profession, their age and their gender. These non-significant results suggest that where differences exist, they are not always on the dimensions that may be intuitively anticipated.

The four categories were:



4.3.1 Disengaged

The *disengaged* group, which comprised 22.3% of the sample, were most likely to be from a regional area. They were low users of online news or current affairs websites, and had poor self-rated health use and low levels of health service use.

This group was less confident about the use of their data and their ownership of it. They would like the convenience of health professionals being able to access their health data. However, as they were less likely to see health professionals, having a complete health record may be difficult.

This group did not use the internet to access news or current affairs websites, meaning that further engagement would need to be through print media or TV, or through more direct means, such as face-to-face or community-based mechanisms.

The disengaged group were concerned about the idea of a profit being made, but did not believe in a natural right to privacy. This suggests that their concern is about the profit, not because they think the data are theirs or should not be collected. They are disengaged, so may just go along with changes. They are an ambivalent group.

The variance between consumers based on their location is interesting here. It suggests that consumers from smaller communities may feel less connected with policy or projects which appear to be imposed from larger organisations or government agencies.

4.3.2 Supportive but hesitant

The *supportive but hesitant* group, which comprised 34.2% of the sample, were most likely to have completed a TAFE qualification or apprenticeship, and were more likely to be from a regional area. They were broadly in good health, being the most likely of the groups to have very good or excellent self-reported health status, and less likely to have a chronic health condition.

This group was the most likely to want to be asked explicitly for permission before organisations used their data, which makes them noteworthy. However, they would be potentially easy to access to change these attitudes or ask for consent as they were frequent users of news or current affairs sites. Targeting this group through traditional health-related venues would not be practical because of their good/excellent health status and lower likelihood of having a chronic illness. Their lower levels of education, compared to the other groups, would also impact on approaches to engage this group.

4.3.3 Comfortable and knowledgeable

The *comfortable and knowledgeable* group, which comprised 18% of the sample, were most likely to have a postgraduate degree and to be from a metropolitan area. They were high users of online media, being the least likely of the groups to never visit news or current affairs sites, and the least likely to never stream music online. They were more likely than other groups to have very good or excellent self-reported health status, and were the least likely of the groups to feel ‘not at all confident’ accessing health services.

This group were perhaps most similar to many who work in health organisations and many health advocates. This profile is interesting, as it explains many of the biases that people who work in the sector bring to it. However, despite the profile of this group being closest to the overarching views that professionals and advocates hold about consumers, this group was the smallest of the four groups. For the purposes of future work, this highly educated group is not likely to be of concern to organisations who want to share data, as they seem likely to go along with many innovations.

This group shows the importance of broad and wide consultation on this and related issues. They are trusting and comfortable, including with having identified data shared. This may be related to their good or excellent health status.

4.3.4 Data sceptics

The data sceptics were the most heterogeneous of the four groups. Their education levels were varied. They were low and unconfident users of the health system, being the most likely of the groups to have not visited a GP, nurse practitioner or practice nurse in the past year and being most likely to feel ‘not at all confident’ accessing health services. This variance is important, as it suggests that simple strategies to target or change the opinions of this group will not be adequate.

Data sceptics represent the group of most concern for future work. This group, which represents more than one-quarter of the surveyed group, were highly sceptical about their data being shared and used by a wide variety of organisations. They were strong believers in a natural right to privacy and that they, not the person who uses the data, own data which is about them. They were the least likely of the four groups to be comfortable with their data being shared, regardless of level of identification and with whom the data is being shared. They did not trust organisations, as shown by their low levels of belief that organisations will store their data securely.

An important area for future work is research within this group. The heterogeneity present within it makes drawing firm conclusions difficult, yet its presence in the survey is worthwhile to examine further.

4.4 Conclusions

The results of this nationally representative survey show consumers have strong opinions about the use of health data. They consider the ability to give consent to be important and have reservations about sharing their health data with organisations, in particular for planning purposes, when they are given limited information about what it will be used for. The market segmentation shows that when planning how to change these attitudes, organisations should not consider consumers to be a homogeneous group. Key areas of difference exist, and approaches should be developed in light of these. The varied levels of education, health status and media use of these groups provide suggestions for how these strategies could be developed.

This study has developed two of the project objectives: to ascertain which of a range of demographic and health system use measures affect consumers’ preferences for the sharing and use of their health data; and to identify factors or mechanisms which may increase consumers’ likelihood to share their health data. It provides a clear contribution to and starting point for further discussions about how to maximise the use of existing and future health data sets while keeping consumers at the centre.

Thought leadership roundtable

5.1 Overview

On 28 November 2017, consumers and representatives from key organisations attended a ‘roundtable’ to discuss findings from the NPS MedicineWise and CHF research project into consumer attitudes to health data, and examine the implications for data custodians and other groups engaged in collecting and using consumer health data. Delegates represented government, regulators, health insurers, consumer groups, data custodians, the research sector and others involved in digital health and use of data.

The roundtable was jointly hosted by NPS MedicineWise and the Consumers Health Forum of Australia (CHF), and facilitated by Michael Kitts, a PwC Partner.

The roundtable provided an opportunity to:

- hear participants’ views on the findings of this new research for policy and practice, and explore this with consumers
- share activities, research and experiences in this area to identify best practice, opportunities and barriers to implementation
- support networking opportunities, connecting those working in this space
- inform the development of a tool or resource to support organisations to embed best practice principles when collecting, using and sharing health data.

Presentations included an introduction to the purpose and objectives of the research project by NPS MedicineWise CEO, Dr Lynn Weekes; an overview of what is happening in Australia and internationally to better understand and influence consumers’ attitudes to health data by CHF CEO Leanne Wells; and a presentation of the research by Rebecca Randall from CHF and Lauren Humphries, NPS MedicineWise. These were followed by group discussions and a small group case study-based exercise exploring the implications of, and insights from the research: gaps, challenges and opportunities; and potential principles to guide best practice. For roundtable participants, see Appendix 5B.

This chapter summarises the roundtable discussions, including:

- Australian and international examples of data use and consumer research
- The outcomes of the NPS MedicineWise and CHF research on consumer attitudes and their implications for how consumers should, and could, be involved in their health data journeys
- Best practice principles derived from the group via an interactive case-study.

5.1.1 Key themes

A range of key themes emerged from the roundtable.

- **Everyone’s data matters, but there are some consumers who will have different needs or concerns** that should be explicitly dealt with through appropriate consultation, communication and involvement. These include, for example, Aboriginal and Torres Strait Islander consumers, culturally and linguistically diverse consumers, other cultural groups, consumers who have previous experiences that may impact on their levels of trust and those who are concerned about discrimination due to their health or other circumstances.
- **Consumer ‘education’ is not the only solution** or approach: the onus needs to be on increasing transparency, openness and clarity on the part of data custodians and providing consumers with the opportunity to inform and be involved in co-designing the why, what and how of data collection and use.
- **A consumer-centric approach** must be taken to the design of consumer consent processes to ensure consent is meaningful and not a barrier or 'tick the box' exercise to participation.
- **Consumers are more likely to provide their data in exchange for outputs that are meaningful**, useful and of value to them as consumers and which enable them to hold data custodians/users to account. They need to be involved in defining what those outputs should be and how they would like to be kept informed.
- Addressing and taking account of issues of **data completeness and quality** is critical when linking and drawing insights from health data and in the provision of safe, high quality care. This is, and should remain, the responsibility of health providers and data custodians.
- **Data custodians** must take responsibility for appropriate governance and data use seriously, and be clear and transparent in communicating those responsibilities to consumers.
- **Data linkage** is not fully understood by consumers and the concept, processes, benefits and risks involved need to be clearly explained to consumers. There is also a lack of understanding about ‘de-identification’ and questions as to the legitimacy and accuracy of this term.
- There is a need for a **whole-of-sector approach** to build strong connections between Commonwealth and State and Territory governments and with the private sector to increase the quality and value of data collection, use and linkage.
- **Clear principles are needed to guide data ownership and use**. These principles should be co-designed with consumers, data custodians and organisations who wish to use data.
- **Further work is needed to fully understand the characteristics of consumers identified in the research** and market segmentation as ‘data sceptics’ given the heterogeneity of this group. Further segmentation is needed to better understand their concerns and the best approach to addressing these.

5.2 Setting the scene: Australian and international examples of data use and consumer research

5.2.1 International and Australian examples of data linkage and use

Within Australia and internationally a wide range of organisations are using health data in innovative ways. Examples discussed included:

- **Central Coast Local Health District (LHD) and the then Medicare Local in NSW** – the two bodies linked GP data with hospital data relating to elderly people in Wyong, NSW, to gain a better perspective of the end-to-end patient journey; all with the objective of using regression analysis and predictive analytics to understand factors that lead to hospitalisation in elderly people. The power of predictive analytics can then be used to intervene sooner and keep people out of hospital.
- **Victorian State Government** is using similar predictive analytics techniques for its HealthLinks: Chronic Care initiative that aims to keep people with multiple chronic conditions out of the hospital system (in five pilot areas) and look after them more effectively in their homes and communities.
- **South West Sydney PHN and LHD** are using the DB Motion software to share real time GP data with the LHD.
- **New Zealand Integrated Data Infrastructure (IDI)** is a large research database that holds microdata about people and households in New Zealand. The data are about life events, like education, income, benefits, migration, justice, and health. Researchers use the IDI to gain insight into NZ society and economy.
- **UK NHS open access arrangements** - The NHS has set up open access arrangements. Benefits cited were increasing patient choice, patient outcomes, academic growth, accountability (such as around outcomes and success rates), openness and transparency. The NHS's approach to openness and transparency in return for data access and use is an interesting example of the quid pro quo that was discussed later in the roundtable.
- The **Rare UK bone, joint and blood vessel disease study (RUDY)**, a study headed up by a research team at the University of Oxford, in the United Kingdom. RUDY is an internet-based platform with online registration, online capture of patient-reported outcome measures and events within a dynamic consent framework. This framework enables ongoing two-way dialogue between participants and researchers with the ability to view and change consent options online at any time within their secure web-space. The results of the study have shown significant participant retention, as they feel value from being a part of the study (see: https://research.ndorms.ox.ac.uk/rudy/)

In addition to these, work to understand and influence consumers' attitudes to health data is ongoing. Examples discussed included:

- **Australian Digital Health Agency consultation findings** that there is a general lack of understanding as to what data linkage is, or means; and a need for appropriate consent procedures and for consumers to be given the opportunity to better understand the purposes data are being used for.

- **Outcomes from the 2017 Productivity Commission** report that opportunities will be driven by working with consumers to build a genuine understanding of data sources and improve trust. It was noted that without appropriate regard being given to consumer rights over data, the ‘social licence’ to make greater use of growing future data availability will be very challenging.

5.2.2 NPS MedicineWise’s experiences

Lynn Weekes, NPS MedicineWise CEO, provided an overview of NPS MedicineWise’s experiences as a data custodian and reflected on the value of the foundational principles of quality use of medicines – that consumers are involved in every part of the process. Lynn touched on the two health data sets that NPS MedicineWise manages, and the challenges of data completeness, quality, validation, interpretation and security as well as having due regard for community expectations on issues such as the potential to link with non-health data.

- MedicineInsight. MedicineInsight extracts all-of-practice clinical data from consenting practices, applies data algorithms to assess and report on conformance to best practice and enables targeted follow-up for individual patients or groups of patients. Data is de-identified, and encrypted before leaving the practice and is subject to strict data governance processes. MedicineInsight allows GPs to reflect on their own patterns of prescribing and patient care, and compare these with other GPs in their practice. These can be benchmarked at local, regional and national levels. Participating practices are offered customised quality improvement activities that support alignment with best practice and identify key areas for improvement.

  Insights from primary care are drawn from the aggregated clinical data of all participating general practices. These insights can be used by policymakers, health systems and health professionals to identify evidence gaps in primary health care and improve clinical practice and health outcomes in Australia. For more information see https://www.nps.org.au/medicine-insight.

- The MedicineWise App, relaunched in 2017 (previously named 'MedicineList+'), enables consumers to build, edit and share their medicine list, set dose and appointment alerts, track tests and results, record important health information and view relevant medicines information. More features, including a link to My Health Record will be introduced in 2018. For more information see https://www.nps.org.au/medical-info/consumer-info/medicinewise-app.

5.3 Consumers' attitudes to health data: NPS MedicineWise and CHF research findings and their implications

Rebecca Randall from CHF and Lauren Humphries, NPS MedicineWise presented a summary of the research findings.

This presentation was followed by a discussion of the implications and insights of the research. This included defining best practice; gaps and opportunities; what has the potential to become 'derailed' and possible mitigation.

Key discussion points included:

- **Replacing 'consumer education' with transparency, clarity, consumer involvement and co-design:** Consumer 'education' is not the right word or approach as it conveys a sense of a lack of 'education' on the part of the consumer. Rather the onus should be on greater transparency, openness and clarity on the part of data custodians and users in communicating with consumers, and on the principles of consumer involvement and co-design. The conversation needs to become two-way, providing greater opportunity for consumers to be involved in informing and co-designing how health data is used and for what purposes. As a minimum, outcomes need to be shared with consumers. It was noted that too often research commissioned by government only goes back to government and this does not improve consumers' desire to trust or participate.
- **Quid pro quo: data in exchange for accountability and outcomes that are meaningful and useful for consumers:** Global health and care systems too often focus on what matters to providers rather than recipients of care. Increasing the focus on outcomes that are meaningful and useful to consumers – and having consumers inform what those outputs should be and how they should be shared with consumers – has the potential to increase consumers' understanding of the benefits of data sharing and their willingness to be involved.

  The strong sense of quid pro quo and accountability expressed by roundtable participants was illustrated by the following comments: *"If I am happy to give/share my data with you, you need to be more open and accountable for the general performance of the system and the benefit to me"*, *"My health data should also be used to hold data users and providers to account"* and *"I want to better understand variations in things like safety and quality".*

  It was noted that some progress was already being made in this area. Examples included:

  - International Consortium for Health Outcomes Measurement (ICHOM): a non-profit organisation founded by individuals from three institutions with the purpose to transform health care systems worldwide by measuring and reporting patient outcomes in a standardised way – see http://www.ichom.org/. ICHOM has prepared standard health outcome sets of measures that relate to outcomes that matter to both consumers and providers. A good example is for elderly people, http://www.ichom.org/medical-conditions/older-person/.
  - US State of Virginia: a good example of openness, transparency, the quid pro quo, and a greater focus on reporting outcomes. It has established a web site called 'Virginia Performs' that reports to consumers how the state government is doing – in terms and measures that matter to consumers. See http://vaperforms.virginia.gov/ and the scorecard at http://vaperforms.virginia.gov/Scorecard/ScorecardatGlance.php

- The Australian Commission on Safety and Quality in Healthcare (ACSQHC) Atlas of Clinical Variation (see https://www.safetyandquality.gov.au/atlas/)

There was discussion on the question of whether government should mandate the public reporting of measures such as patient outcomes in Australia and the role of consumers in demanding that type of reporting.

- **Data completeness and quality implications**
  - **For data insights**: The completeness and representativeness of data needs to be borne in mind when drawing insights from health data, as not everyone may be consenting to data collection or accessing health services (either due to good health or a lack of health services and/or health professional they trust), nor are records necessarily complete or accurate.
  - **For safety and quality in healthcare**: Quality of care and patient experience is impeded by consumers having to repeat their story and medical history to multiple providers. In many cases, retelling is a painful process for the consumer and does not necessarily result in greater accuracy of what is recorded. Having data we can trust is critical and there needs to be a more accurate process for collecting and verifying information once (rather than multiple times).

    However, it was noted that attitudes and human error are barriers to safety even where quality data exists, and health professional curricula and training need to support health professionals to utilise the data available. One roundtable participant provided the example of something as obvious as their anaphylaxis bracelet not being taken into account in treatment decisions on admission to ED.

- **Consumer choice and consent:** There is a need to step away from the ‘all or nothing’ approach to consent and also to look at alternatives to the case-by-case approach to consent. There may be value in looking at the merits and feasibility of having universal principles that guide and pertain to all data usage which could be used as an overarching framework. Any such model should be co-created with consumers directly and consumer representatives.

  Participants noted that Harriet Teare and her colleagues at the Centre for Health, Law and Emerging Technologies (HeLEX), University of Melbourne, are working with consumers on dynamic models of consent. This is an example of consumer-centric-consent procedures, in the Australian context.

- **Data in exchange for convenience and the responsibilities of data custodians**: As consumers we release a lot of our data in exchange for convenience without fully understanding the implications of doing so, and are often surprised when we become aware of those implications. Data custodians and users need to be more open about what they are doing with the data (including where it is stored, and what it is linked with) and for what purpose. It was noted that in making consumers read dense and complex terms and conditions, data custodians are arguably abrogating their responsibilities and making consumers do their work for them. They are making it much harder for consumers to understand or give informed consent.

- **The need for a whole-of-sector perspective and whole-person perspectives:** International leading practice suggests that for care to be integrated requires a number of characteristics, not least a holistic and linked data perspective. (See https://www.kingsfund.org.uk/publications/population-health-systems for research into the characteristics of the best global population health systems, that calls out ‘population-level data to understand need across populations and track health’.)

The disconnectedness in federal and state governments’ approaches to and interoperability of health and non-health data and of private health data (including providers, hospitals and private health insurers) exacerbates the challenges with data linkage. This makes it harder to get a full picture, first of what data are being held, used and stored, and second of the consumer as a whole person. It also means a lack of consistency in the legislative and governance frameworks, making it harder for consumers to understand.

It was noted the ADHA has made ‘interoperability’ (sharing between systems) a major strategic priority in recognition of this disconnectedness, but this was about availability and sharing of data, as opposed to linking data sets. There was some discussion about the governance systems required to underpin more joined-up thinking between federal and state governments with reference made to the Council of Australian Governments (COAG) and the Australian Health Ministers' Advisory Council (AHMAC).

It was also noted government agencies and private sector data holders would need to continue to make stronger connections with private sector data holders to get a truly holistic perspective.

- **Building trust with Aboriginal and Torres Strait Islander consumers:** While there were only a small number of Aboriginal and Torres Strait Islander consumers involved in the research, the findings indicating they have lower levels of trust in government, and in the outputs of research, were consistent with other roundtable participants’ experiences and research. It was noted that being clear what data is to be used and communicating this in a culturally appropriate way will be critical to building trust.
- **Culture, religion and previous experience as influencers of participation:** It was noted that culturally and linguistically diverse (CALD) consumers constituted 7% of the survey sample (compared with 21% of the population in the last census) and the research had not found any statistically significant differences. Roundtable participants felt culture, religion and previous experiences (eg with overseas governments) are likely to be more important factors than language in determining attitudes to data.
- **Discrimination concerns as a barrier to participation**: Similar to Aboriginal and Torres Strait Islander consumers, other groups share concerns about the potential for discrimination as a result of sharing their data, for example people with health conditions that come with social stigma, such as mental health issues, hepatitis C and HIV, drug users or those in prison. Research to date has been at very aggregate level so it is important data custodians and users hear about real experiences to understand the community view.

  It was noted another emerging area of concern that has received little attention to date is appropriate ethics and governance frameworks for collection and use of genetic data.
- **Better understanding the ‘data sceptics’ group**: Phase 3 research project included a market segmentation exercise to develop four distinct categories of survey participants based on their attitudes to privacy and sharing of their health data: disengaged; supportive but hesitant; comfortable and knowledgeable; and data sceptics. Participants noted that given the extent of heterogeneity in the data sceptics group, further segmentation is needed to better understand their concerns and the best approaches to addressing these.

5.3 Interactive case study: How do we engage consumers in the health data journey?

Roundtable participants divided into small groups to undertake a case study-based exercise exploring the implications of, and insights from the research: gaps, challenges and opportunities; and potential principles to guide best practice.

The case study (see Appendix 5A) was based around a fictional mobile app to support consumers who are at risk of being diagnosed with type 2 diabetes by giving them tailored exercise, meal and lifestyle programs to help them manage their risk factors; with the owners of the app considering offering the data in a de-identified way to researchers, including linking to other data sets.

The following principles were identified throughout the discussions of the case study, and throughout the course of the day.

- The purpose of collection, use and sharing of the data must be for public or individual good.
- Clear principles are needed to guide data ownership and use.
- Consumers need to be involved in informing and co-designing what and how health data is used, for what purposes and how they would like to be kept informed of the outputs of that data usage.
- There is clear, transparent and open information for and communication with consumers about who will be using their data, why and how.
- Consent processes are consumer-centric, informed by consumers, and increase commensurate with the risk of identification. Where possible, there should be choice within that consent.
- Appropriate governance (privacy, data security and ethics) processes are in place and are clearly communicated.

The participants were split into groups to discuss three themes.

Theme 1: Transparency and consent

Two groups looked at the adequacy of the terms and conditions of the app, what would be needed for consumers to make an informed choice on whether to use the app and what would be the right level of content to share with consumers about how their data is being collected, used and shared.

It was noted that confidentiality, security and trust are significant issues: trust can take years to build and seconds to lose.

Key factor	**Ways to build consumers' trust**
Who, what, why and how	▷ Being explicit about purpose / reason for collection, why the information is helpful and the benefits and risks to the consumer. ▷ Being transparent about the business model behind the app to increase understanding of what is happening with the data and who it is being shared with and why. ▷ Disclosing who the data users are. ▷ Disclosing what data is to be collected, shared and linked (and what is not) and levels of re-identification. ▷ Summarising how the data will be used, with graphics to increase understanding. It was suggested a pictorial diagram or template with visual data may be beneficial in illustrating to consumers in a consistent way how their data is being collected, used and shared.
Clear, transparent communication	▷ Using simple, plain language. ▷ Appropriate location of terms and conditions within the app. Due to their length, consumers often swipe through terms and conditions so might appreciate the opportunity to have them emailed. ▷ Having a readily available and responsive mechanism for dealing with questions so that it is easy for the consumer to get in contact with the data custodian.
Choice	▷ Providing the option of different levels of consent.
Governance	▷ Being transparent about whether the organisation is required to comply and complies with protective legislative frameworks such as the Privacy Act. ▷ Providing a clear statement from the owner about being a responsible data custodian and steps taken to fulfil these obligations. ▷ An easily recognisable consumer 'standard' for apps and other data collection mechanisms such as the Consumer Cancer Voices tick.
Consumer involvement and co-design	▷ Co-designing the app and data uses with consumers and consumer testing of the terms and conditions and their placement in the app. It was suggested that CHF and NPS MedicineWise could partner with app developers to facilitate this. ▷ A further suggestion was a consumer panel(s) to help inform ethics committees.

Theme 2: Data linkage and data users

Two groups looked at whether consumers understand, and if they understand, whether they care what data linkage means; which data sets it would be acceptable to link with (eg health and non-health); and the types of organisations that it would be acceptable to share the de-identified linked data with.

Data linkage and de-identification are not well understood

The groups' observations were:

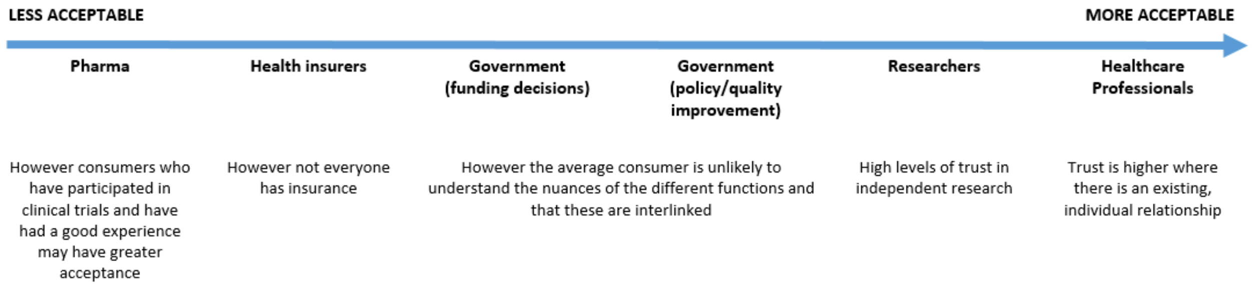
- Consumers do care about use of identifiable data, although views were more mixed about de-identified data.
- While some consumers may understand the concept of data linkage, they may not understand what actually happens or the nuances of re-identification and are looking for greater transparency, particularly around re-identification. Indeed, use of the term 'de-identified' may be inappropriate or misleading.
- There may also be two ends of a spectrum of understanding of data linkage: those consumers who assume data is more linked up than it is and that more insights can be attained than are actually possible; and those who do not understand the extent to which their data is already linked eg linkage of supermarket reward card and banking data.
- Consumers may understand the primary use of their health data for the purpose of care but not the secondary uses. There is also skepticism about data security and concerns with data being used inappropriately later on. As previously discussed, consumers may have concerns about discrimination arising from use of their data.
- Regardless of the data being collected, there is more acceptance if it is being used by the organisation to which it was originally provided and in line with consumers' understanding of the organisation's business. However, often consumers do not have a good understanding of the multiple facets of an organisation's business so their data may be being used in ways they do not expect.

Building acceptance of linked data

The groups considered that consumers are **not** accepting of data being used for others' commercial gain.

The consensus was that consumers are likely to be more accepting of their data being linked in the following circumstances.

Key factor	**Ways to build acceptance of linked data**
Benefits exist	▷ Public good is to be derived from the data usage, eg whole population health/ sub-population health including used to better plan access to different health services or to improve health system efficiently (better use of tax dollars). ▷ Individual good is to be derived from the data usage, eg there is a quid pro quo/benefits statement – 'what's in it for me?' ▷ Personal potential gains exist (health/lifestyle/financial etc) ▷ The data informs consumer choice, eg enables them to select a service based on performance data or to hold a service provider to account.
Clear, transparent, ongoing two-way communication	▷ The intended use is transparent and clearly communicated. ▷ There is feedback to the consumer about how the data is being used and outcomes/insights derived from the data are shared with the consumer.
The risk of re-identification is low	▷ There is a low chance of re-identification, although consumers' risk tolerance is greater when the potential benefit and consent requirements are greater.
There is consent, and choice within that consent	▷ Consent is granted at a higher or more individual level, before or at the time of data capture. ▷ Data consent and use takes into account that some fields may not be considered sensitive to the 'average person' but could be very sensitive to others.
Strong governance framework exists	▷ Appropriate privacy, data security, ethics and compliance frameworks and processes are in place.
Level of trust in the data custodian and users	▷ There was discussion on consumers' levels of trust in different data users and therefore their likelihood of consenting to those organisations using their data which is summarised in the diagram below.



However consumers who have participated in clinical trials and have had a good experience may have greater acceptance

However not everyone has insurance

However the average consumer is unlikely to understand the nuances of the different functions and that these are interlinked

High levels of trust in independent research

Trust is higher where there is an existing, individual relationship

Theme 3: Informing to empowering consumers

The last two groups looked at methods to improve consumers' involvement in their health data journeys; the expectations that should be placed on data custodians to feedback to consumers how their data is contributing to research and policy; and the value in co-designing with consumers.

Responsibilities of data custodians/users to feedback to consumers

The groups' views were that data custodians and users do have a responsibility to feed back to consumers how their data is contributing to research and policy in a simple, easily understandable way but that consumers should be able to decide the level of feedback they would like to receive. Feedback should also include the number of individuals contributing data.

However, it was flagged this may be a disincentive to app creation and consumers would need to be comfortable with fewer products being available.

Involving and co-designing with consumers

In discussing whether there is value in consumers co-designing the app functionality and strategy for use of the data, the groups' views included the following points:

- A first step would be to ask users what type of feedback would promote trust.
- Co-design is particularly important for products that target niche groups with low commercial viability.
- There needs to be clear articulation of the (commercial) benefits of co-design to incentivise organisations to do this as well as incentives to support their marketing such as a consumer tick.

Some participants felt that it should be mandatory to have consumers involved in co-designing the app.

Appendices

3B: Interview question protocol

Area	Key question/interviewer text	Prompting question
Health data definitions and usage: consumers' current understandings	What is health data to you?	When we say health data what do you think we mean?
	Where is health data generated?	
	Who is it generated by?	
Who should have access to health data and why	If health data is about you, who owns it?	Eg you, the health practitioner who created it, the person who uses it
	Who should have access to your health data?	Health professionals? People who care for you? People who care about you? Government?
Methods and instances that health data could be used for	Where is your health data stored?	How is it transferred between the places where it's stored?
	How and where should it be stored?	
	What should your data be used for?	What about areas like, advancing health and medical research? Or supporting healthcare providers in improving patient care? Or to assist public health officials in tracking diseases, disabilities and their causes?
Reservations regarding the use of health data for research purposes/ Consumer attitudes toward the need for informed consent	Thinking now about the use of your health data for research purposes specifically – how do you feel about your health data being used for research purposes?	
	What if there was a possibility that you could be identified from this information?	
	What if there was a possibility that your data could contribute to a particular group being placed at a disadvantage?	For example – if your data contributed to health insurance premiums being raised for people from a particular demographic group
	Are there groups or organizations who you would be more willing to share your data with?	Eg government? For profit companies?

4A: Electronic health data: community survey findings

URBIS STAFF RESPONSIBLE FOR THIS REPORT WERE:

Director	Julian Thomas
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Project Code	ESA22017

The Consumers Health Forum of Australia (CHF) commissioned Urbis to develop a survey instrument to understand and explore the community's attitudes to electronic health data in Australia. This report presents the findings of an online survey of over 1013 community members, including a factor and market segmentation analysis.

4A.1 Methodology

Urbis developed a survey instrument, in consultation with CHF. The questionnaire was informed by previous research undertaken by CHF and NPS MedicineWise into the factors affecting people's understanding of, and willingness to share, health data.

The questionnaire is provided at Appendix 4A.5. It contains questions relating to respondents:

- understanding of what constitutes health data
- views on privacy and consent
- views on sharing health data
- views on secure health data storage
- views about the circumstances for accessing health data
- own health status and health conditions
- media use
- demographic information.

There were 1,013 responses to the survey. Initial frequency analysis was conducted across all questions. Descriptive statistics of the sample are provided at Appendix 4A.5.

Cross tabulations were conducted by collapsing the eleven point scale, later used for the factor analysis and market segmentation, into a simple three point scale of agreement, disagreement and neutral (ie, 6 represented 'neutral' across all analyses, with scores above 6 indicating agreement on the question asked, and scores below 6 indicating disagreement.)[c]

4A.1.1 Market segmentation

Basic approaches to analysing survey data often do not fully reveal patterns in responses. There are a range of analytical techniques, however, that allow for a more detailed exploration of these patterns. One of these techniques is segmentation, a form of analysis that examines relationships between several variables. Put simply, segmentation divides a population into segments based on

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[c] Respondents were asked to rate from zero to ten, with five representing a neutral response. For the sake of this analysis, the responses are coded 1-11.

shared characteristics (eg geographic, demographic, attitudinal, or behavioural factors). Segmentation has been widely accepted as one of the key requirements for successful marketing since the early 1960s. It is assumed that by dividing a market into relatively homogenous submarkets, both strategy formulation and tactical decision-making (eg choice of media for advertising) can be simplified. The basic concept of segmentation (see for example Frank et al., 1972) has not altered greatly over time, and many of the fundamental approaches to segmentation research – including the approach adopted for this project – remain valid today, albeit implemented with greater volumes of data and some increased sophistication in the modelling methods.

A summary of the analytical approach taken for this project is outlined below.

Step one: Data reduction

Markets can be segmented using a wide variety of variables, and these are consistently described in marketing texts (although the number of categories can vary as they are either collapsed or expanded by authors). Most commonly, segmenting variables fit within one (or more) of the following categories: geographic, demographic, attitudinal, and behavioural. The segmentation undertaken for this research project utilised a series of attitudinal items relating to privacy, consent and health data.

As noted above, segmentation divides a population into segments based on shared characteristics, including: geographic, demographic, attitudinal, and behavioural factors. The analytical techniques available for segmenting a population are numerous and vary in complexity. Most commonly, a traditional clustering approach is adopted when segmenting based on a series of behavioural and/ or attitudinal variables. Alternatively, Latent Class Analysis (LCA) is sometimes adopted, especially when categorical variables are included in the model (note: LCA makes no assumptions about levels of measurement). A traditional clustering approach was adopted for this segmentation. The motivation for this choice was twofold: all variables included in the models are at least ordinal (limiting the usefulness of LCA), and a strong model was obtained using a traditional clustering approach.

Traditional clustering approaches, which generally use factor or cluster analysis (or both) begin by amassing a set of available (and ideally relevant) variables (eg a set of attitudinal or behavioural items) on a population sample. Depending on the number of variables, attempts are then generally made to reduce variables to a series of key factors. That is, variables that appear to be measuring the same thing (or close to the same thing) are grouped together using a statistical technique called Factor Analysis.

For this research project, Factor Analysis was undertaken, reducing the attitudinal battery of items to between 11 factors. The reduced number of variables, which consisted of factor scores, were then put into a clustering algorithm (Quick Cluster). We did not specify a priori the number of clusters, instead a series of optimal solutions were identified by the statistical software. The output from this phase is the segment bases (ie the segment membership for each respondent).

Step two: Profiling the segments

After finalisation of the initial segment solution (in this case, four segments), the clusters were compared/profiled using the variables used to form them. The clusters were then compared to other variables, with a focus on (a) demographic factors and (b) health status. These variables were chosen for the segmentation as they were the most meaningful to CHF. The output from this phase is profile of each cluster, including how respondents in the cluster responded to each attitudinal item, and their demographic/health profile.

A simple **chi square test** was used for comparisons between clusters and demographic characteristics/ health status. Most significant results in the report are based on tests of this type.

All statistical testing was conducted at the 95% confidence level.

As outlined below, the relationship between attitudinal/behavioural variables was assessed using Discriminant Analysis.

Step three: Evaluating the initial segmentation

A statistical technique referred to as Discriminant Analysis was used to assess the extent to which the initial segment solution explains patterns in the attitudinal/ behavioural variables used to segment respondents. The main purpose of Discriminant Analysis is to predict group membership based on a linear combination of interval variables. The procedure begins with a set of observations where both group membership and the values of the interval variables are known. The result of the procedure is a model that allows prediction of group membership when only the interval variables are known. In the case of evaluating a segmentation, a preferred solution (at least per this criterion in isolation) will be characterised by strong predictive relationship between the attitudinal variables and segment membership.

Step four: Developing and testing alternative models

Once the initial segmentation has been evaluated, alternative models will typically be developed and evaluated until a satisfactory model is reached. Alternative models will vary in terms of the attitudinal variables included in the data reduction phase. For example, it may be the case that a model created using only certain attitudes results in more robust segments with increased explanatory power (ie, to explain the variance in the sample). It will also be possible to set the number of segments desired in the final solution, a process that may result in a more robust final segment solution. It is possible for demographic variables to be included in alternative segment solutions, if required.

For the current research project, minimal time was spent exploring alternative models, as strong, meaningful four segment solutions. Reducing or altering the number of items included in the model would only service to reduce utility, and having a consistent number of segments across respondent groups aided in interpretation of findings.

Step five: Applying the model

Once a satisfactory final solution has been developed, Discriminant Analysis is typically undertaken to ascertain the top five and top ten predictors (ie, attitudinal/behavioural items) of segment membership. This analysis allows for future survey respondents to be classified into segments (with some degree of certainty) using a reduced number of items. It should be noted that the capacity for correct classification will be impacted by the extent to which the sampling approach, and resulting sample, adopted for future surveys matches that adopted for the current study.

4A.2 Limitations

The main limitation to consider is the representativeness of the samples. It should be noted that representation from Aboriginal and Torres Strait Islander people (0.9 per cent of the sample) and people from a culturally and linguistically diverse background (7.0 per cent of the sample) are both lower than proportions in the 2016 census (2.8 per cent and 21 per cent respectively[30]). Despite these low proportions, some of the results across these demographics were extremely statistically significant (p <0.000) – where this is the case, these have been reported.

The recruitment method, an online recruitment panel, may have also limited the generalisability of the findings as participants were proficient enough with internet usage to complete an online survey.

4A.3 Summary findings

This section presents a summary of findings from overall analysis of the survey responses, including mean responses to questionnaire items, and cross-tabulations with key demographic indicators. The proportion of the sample who agreed to each item are presented below. Section 4A.6 reports the proportion of the sample who reported agreeing, disagreeing and neutral and mean responses to each item.

There are three key issues explored in the survey: respondents' understanding of the concept of health data; their beliefs around the benefits of health data; and, an examination of the perceived risks of the collection and storage of health data, such as privacy and anonymity.

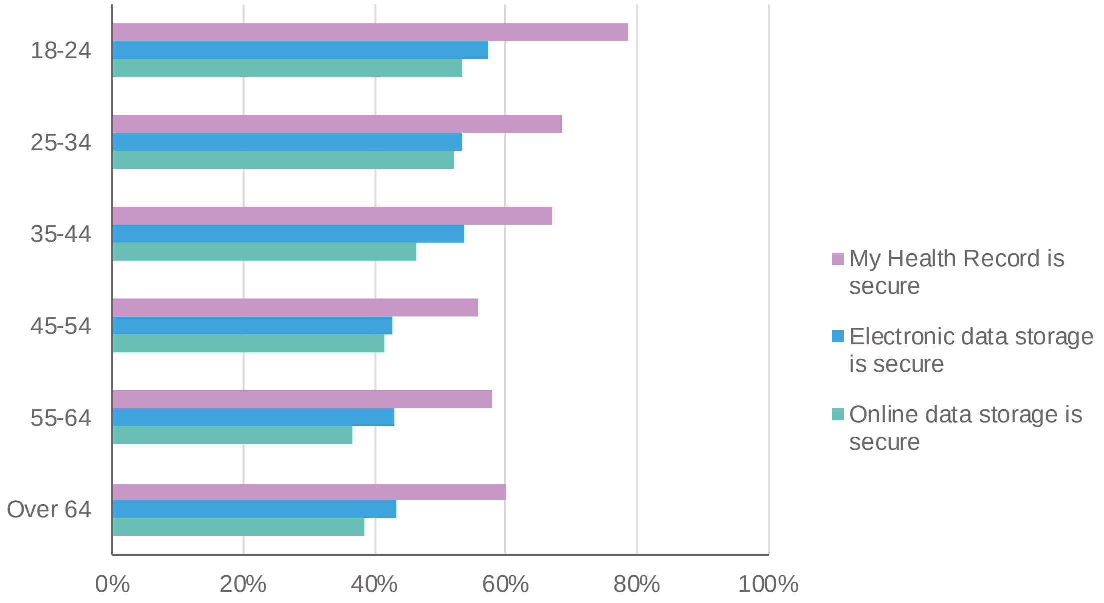
On the first issue, on average, respondents reported the majority of the elements they were asked about constituted health data. The clearest elements of health data were pathology results (agree= 93.7%), information to conditions they may have (90.5%), information from prescriptions and doctors' visits (89.6%) and information relating to disabilities they may have (88.4%). The elements with least agreement were wearable fitness tracker data (46.8%) and information relating to habits and lifestyle (57.2%).

Respondents reported strong agreement to the statement that research can improve the delivery of healthcare (95.2%). They also strongly agreed that people have a natural right to privacy (94.2%) and that people own their own health data (66.6%).

While respondents strongly believed that the information they tell their health practitioners is confidential (89.9%), they were concerned about the ability for organisations (government, private and research) to store their data securely and ensure their anonymity. The majority of participants disagreed with all items in this section with private organisations least trusted (30.9% agree "will store my data securely"; 28.5% "will ensure my anonymity"), and research organisations more trusted (39.3%"will store my data securely"; 41.7% "will ensure my anonymity"); governments scored in between (40.5% "will store my data securely"; 37.7% "will ensure my anonymity").

While respondents disagreed that online and electronic data storage were secure, they were more likely to believe My Health Record was secure (43.2%, compared to 25.8% and 30.9% for online and electronic respectively). Younger people were significantly more likely to agree that electronic data storage, online data storage and My Health Record were secure Figure 1. Perhaps unsurprisingly, respondents who already hold a My Health Record electronic health record were significantly more likely to agree that online data storage was secure than those who do not (52.2 per cent, compared to 41.6 per cent). However, there were no statistically significant differences in the extent to which the groups who do and do not have a record reported that they think My Health Record is secure. Respondents were considerably more comfortable sharing data if they were not identified (64.8% agreed) than if they were identified (21.8% agreed).

Figure 1 – Proportion of respondents who agree with data security statements, by age



Most disagreement in the survey lay in how organisations could use health data relating to individuals. Respondents strongly disagreed with organisations making a profit from their data, including research organisations (23.2% agreed), non-government organisations (13.7%) and private entities (12.8%). Younger people were significantly more likely to agree that they were comfortable with organisations making a profit from their data, for example 42.6 per cent of 18-24-year olds agreed they were comfortable with non-government organisations making a profit from data about them, compared to 24.2 per cent of those aged over 64.

However, the least agreement came in those in 'middle age' (ie, those in the 35-44 and 45-54 year old age brackets). In general, these age groups were least likely to agree with statements relating to the free sharing of data. For example, these age groups were significantly more likely to want to be asked for their permission for a research organisation to use their data, but were also least likely to support their doctors' access to their data in an emergency situation where they were unable to consent. Table 1 shows the proportion of each age group who agreed with the each of the following statements.

Table 1 – Proportion of respondents who agree with sharing statements, by age

	18-24	25-34	35-44	45-54	55-64	Over 64	Prefer not to say
I am comfortable with non-government organisations making a profit from data about me	46.2%	29.9%	27.1%	19.3%	26.5%	24.2%	22.2%
I am comfortable with research organisations making a profit from data about me	48.4%	41.3%	35.6%	33.7%	49.7%	41.2%	44.4%
I am comfortable with private organisations making a profit from data about me	40.2%	24.5%	23.4%	18.8%	23.1%	22.5%	24.6%
I would like to be asked for my permission when a research organisation wants to use my data	92.6%	95.1%	99.5%	98.9%	94.6%	97.3%	100%
If I was in an emergency and unable to consent to share my data, all doctors and clinicians in my treating team should be able to access my health information	86.1%	92.9%	95.7%	91.2%	94.6%	98.4%	88.9%

On average, respondents disagreed with organisations having access to data to plan health services in their region (43.8% agreed); for health insurance and other private companies to plan their services (30.6% and 17.5% respectively); and, for research organisations to have access for research purposes (39.1%). Respondents were more comfortable with the Department of Health accessing their data to help plan services (59.2%) than other government departments (30.7%).

However, when provided with greater detail on how governments might use their data, respondents indicated more agreement with the survey items:

- I would be comfortable with government using my data to support healthcare providers to improve my care (65.9% agree)
- I would be comfortable with the government using my data to assist public health officials in tracking diseases, disabilities and their causes (62.5% agree)
- I would be comfortable with the government using my data for health and medical research (57.6% agree)
- I would be comfortable with government using my data to improve the cost-effectiveness of services (55.5% agree)

- I would be comfortable with government using my data to support healthcare providers to improve the care of others in the community (55.9% agree)

This suggests that explaining the purpose of data sharing is critical in gaining people's support in using their data. Additionally, respondents strongly reported that they would like to know which organisations have access to their data (94.6% agree), and be asked permission each time organisations would like to use their data (86.7% agree), especially private organisations (94.3%).

When it came to personal use, respondents strongly agreed that they should have access to their data (96.2%). Participants were asked how they believed their data should be used in an emergency[d]. However, to the slightly different proposition that no-one should be able to have access to their data in an emergency situation where consent was not possible, a large proportion of respondents (29.9 per cent of respondents) selected the highest agreement response. Regional respondents were significantly more likely to agree that, in emergency and non-emergency situations, their health practitioners should have access to their data; indeed, over 99 per cent of regional respondents agreed with the statement that "in an emergency situation, health practitioners who treat me should have access to my data" (compared to 95.8 per cent of metropolitan respondents).

In general, people with better self-reported health status were significantly more likely to agree with statements relating to the ability of organisations to securely store their data and ensure their anonymity. Additionally, there was a relationship between better health status and the comfort of respondents with government using their data, except for those with 'excellent' self-reported health status (Figure 2).[e] The reasons for this are not able to be ascertained from the survey responses. It is an issue which could be explored further through qualitative studies.

Additionally, people without chronic health conditions were significantly less likely to agree that private organisations should be able to make a profit from their health data, or that health insurance companies or other government departments should be able to access health data to plan their services.[f] Similarly to the above, further reasons for this finding are unable to be ascertained from the present quantitative analysis. Those with chronic conditions, and those taking prescription medications were significantly more likely to agree that in emergency situations, doctors should have access to their health data.

The small percentage of those who worked in a health profession were significantly more likely to report that data storage was secure. However, they were less likely to report that they believe the information they tell their health practitioners is confidential, and less likely to agree that they owned information about their health.

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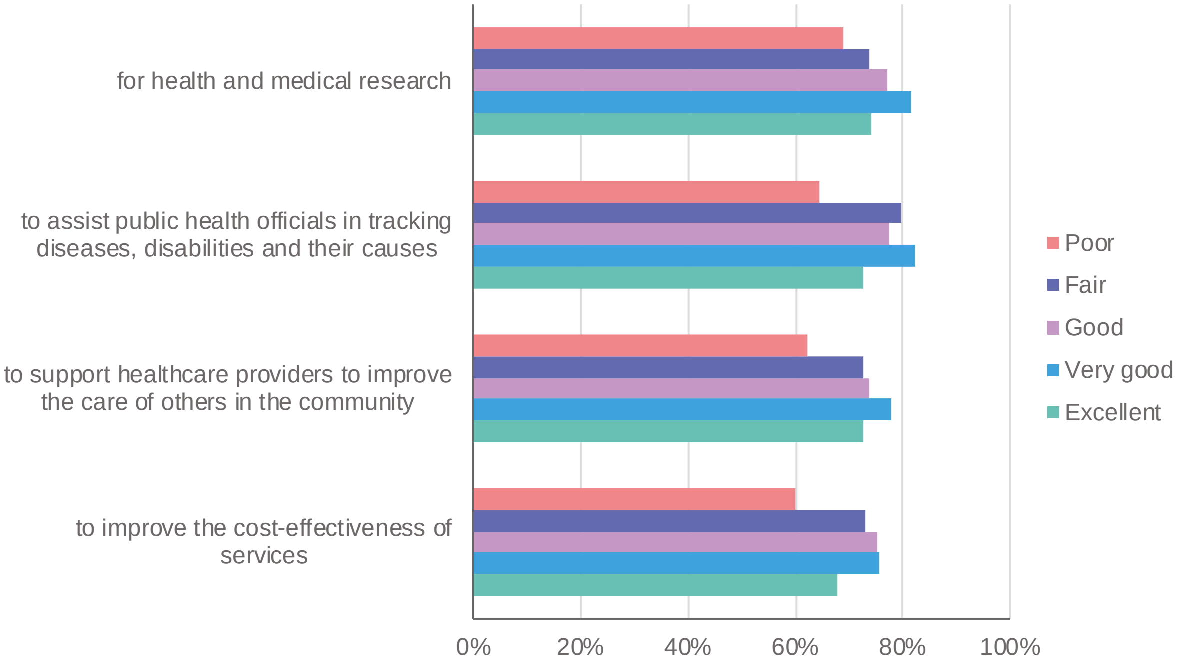
[d] Participants could select more than one response, hence the high level of agreement across all categories.

[e] Demographic crosstabs were conducted on respondents reporting 'excellent' health status. They were significantly more likely to be female and younger (18-34).

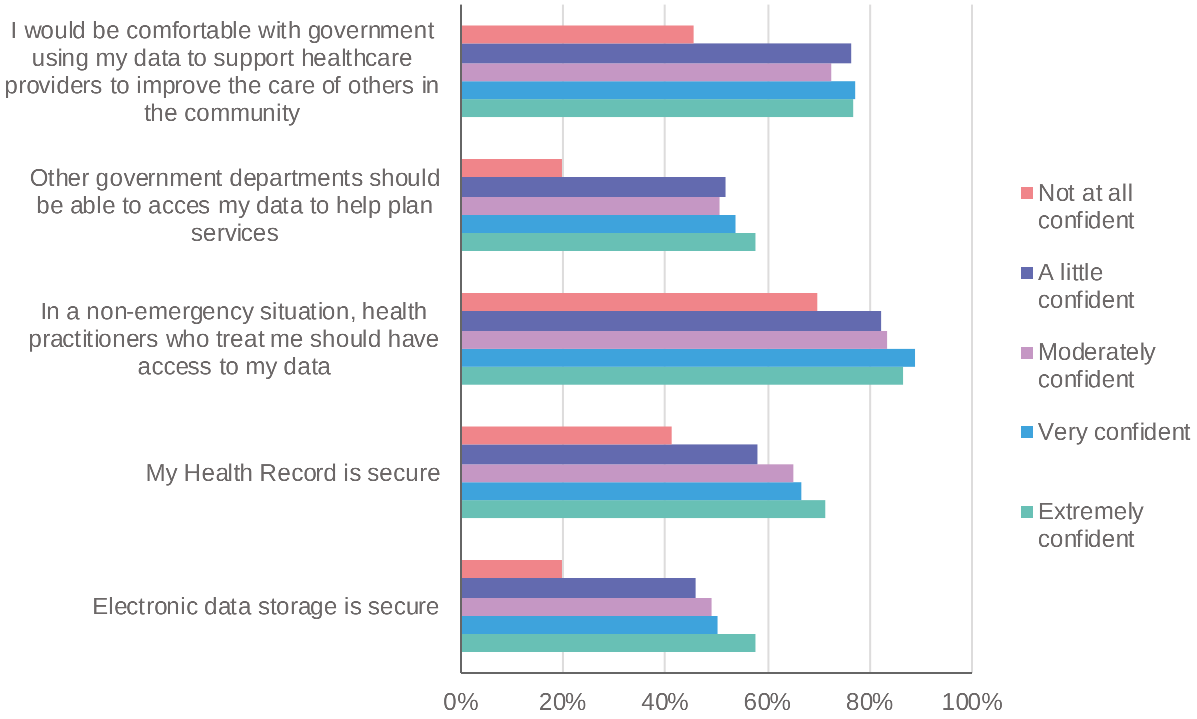
[f] Demographic crosstabs were conducted on respondents reporting they did not have a chronic health condition. They were significantly more likely to be younger (18-44).

Figure 2 – “I would be comfortable with government using my data…” by self-reported health status



Across the majority of survey items, respondents with less confidence accessing health services were significantly less likely to agree with statements relating to the security, privacy and use of their data. This was especially the case for the small group who described themselves as ‘not at all confident’ (n=46). A selection of these indicators are shown in Figure 3.

Figure 3 – Selection of indicators by confidence accessing health services



Aboriginal and Torres Strait Islander respondents were significantly less likely to report that “People have a natural right to privacy” (88.9 per cent compared to 97.9 per cent)[g]. They were significantly less likely to believe that the information that they tell health practitioners is confidential (66.7 per cent compared to 96.5 per cent) and that they owned health data about themselves (44.4 per cent compared to 90.2 per cent).

These findings are important to remember in a context where many Aboriginal people may be accessing health services through community-controlled organisations where perceptions of confidentiality may be changed by the involvement of the local community in the delivery of their health care.

Additionally, Aboriginal people were significantly less likely to report that research can improve the delivery of healthcare (88.9 per cent compared to 98.3 per cent) and significantly less comfortable with people using health data to plan services in their region (44.4 per cent compared to 66.1 per cent).

4A.4 Market segmentation

This section presents the results of the market segmentation analysis, which identified four clusters of respondents. Table 2 below shows the top five ‘predictor’ statements for the segmentation, ie, these are the statements that responses are most indicative of cluster membership. The table also includes an evaluation of the segmentation solution, ie, its capacity to accurately classify respondents into one of the clusters on the basis of their survey responses. In this case, the segmentation is moderate to strong.

Table 1 – Key segmentation statistics

Factors	Final solution	Cluster sizes	Evaluation of final solution	Top five predictors
11	4	1 – 22.3% 2 – 34.2% 3 – 18.0% 4 – 25.6%	Moderate to strong – 80.2% of original grouped cases correctly classified into a segment	I would like to be asked for my permission when a research organisation wants to use my data. I would be comfortable with government using my data to improve the cost-effectiveness of services. People have a natural right to privacy. I would like to be asked for my permission when a private organisation wants to use my data. Private companies should be able to access my health data to plan their services.

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[g] Due to the low sample size, the threshold for significance for these findings was set at p=<0.000 (see limitations section).

Our segmentation identifies four clusters of respondents, which are characterised in Figure 4. Table 3 outlines the description of each segment – only significant differences are indicated in the demographic characteristics and health status, ie, if a characteristic is not included in these columns it indicates there was no significant difference between clusters.

For the sake of clarity and brevity, not all attitude statements are mapped to the segments in this section, but they have been selected where responses were clearly differentiated between clusters to give an indicative guide to their attitudes.

Figure 4 – Market segmentation solution

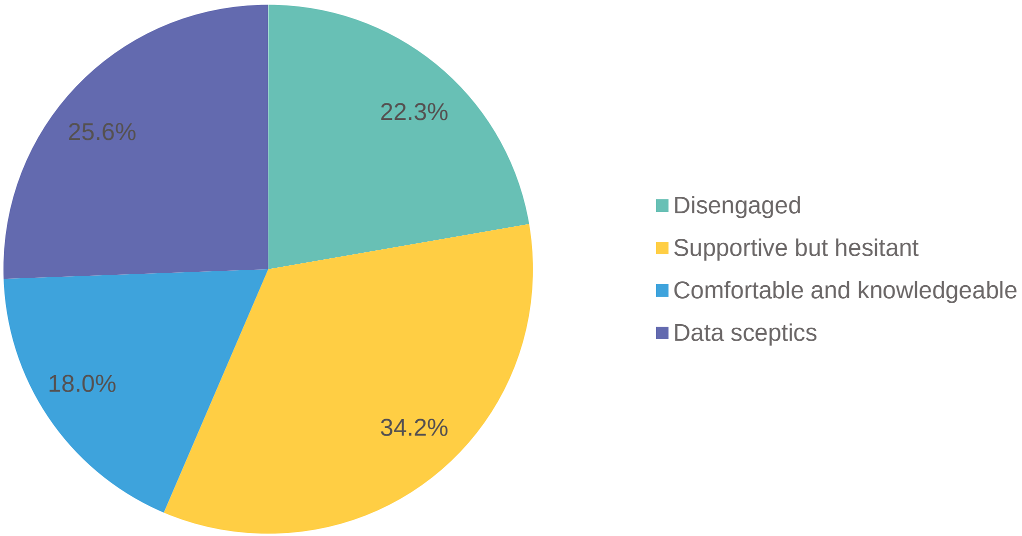


Table 2 – Summary of segments

Segment	Demographic characteristics	Media use	Health status	Attitudes
Segment 1 **Disengaged** **(22.3 %)**	Most likely to be regional	More likely to never visit entertainment, or sports sites More likely to visit news or current affairs sites More likely to never stream music online	Most likely to have poor/fair self-reported health status More likely to have a chronic health condition More likely to have visited the GP, nurse practitioner or practice nurse in the last year	Least likely to believe people have a natural right to privacy Least likely to believe that they own data that is about them Less comfortable with non-government, research and private organisations making a profit from data about them More likely to believe health practitioners should have access to their data in an emergency situation
Segment 2 **Supportive but hesitant** **(34.2 %)**	More likely to be regional Most likely to have completed a TAFE qualification/ apprenticeship	More likely to visit entertainment, or sports sites Less likely to visit news or current affairs sites More likely to stream music online	Most likely to have very good/excellent self-reported health status Less likely to have a chronic health status	More likely to believe people have a natural right to privacy Most likely to believe data can provide valuable insights for improving society More likely to believe government, research organisations and private organisations will store data securely and ensure anonymity Most likely to believe organisations should have access to health data to plan services Most likely to believe governments should have access to data to improve cost-effectiveness of care and health and medical research Most likely to want to be asked for permission before organisations use their data
Segment 3 **Comfortable and knowledgeable** **(18.0 %)**	Most likely to be metropolitan Most likely to have a postgraduate degree	More likely to visit news or current affairs, or entertainment, or sports sites	More likely to have very good/excellent self-reported health status Least likely to have a chronic health condition	Most likely to be comfortable sharing data if identified or unidentified Most comfortable with non-government, research and private organisations making a profit from data about them

		More likely to stream music online	Least likely to feel ‘not at all confident’ accessing health services	Most likely to believe government, research organisations and private organisations will store data securely and ensure anonymity More likely to believe governments should have access to data to improve cost-effectiveness of care and health and medical research Least likely to want to be asked for permission before organisations use their data
Segment 4 **Data sceptics** **(25.6 %)**	More likely to be metropolitan	Most likely to never visit news or current affairs, or entertainment, or sports sites Most likely to never stream music online	More likely to have poor/fair self-reported health status Most likely to have a chronic health condition Most likely to have never visited the GP, nurse practitioner or practice nurse in the last year Most likely to feel ‘not at all confident’ accessing health services	Most likely to believe people have a natural right to privacy Most likely to believe that they own data that is about them Least likely to believe that the person who uses the data owns the data, eg a researcher Least likely to be comfortable sharing data if identified or unidentified Least comfortable with non-government, research and private organisations making a profit from data about them Least likely to believe organisations should have access to health data to plan services Least likely to believe governments should have access to data to improve cost-effectiveness of care and health and medical research Least likely to believe government, research organisations and private organisations will store data securely and ensure anonymity Least likely to believe health practitioners should have access to their data in a non-emergency situation Most likely to want to be asked for permission before organisations use their data

4A.5 Questionnaire

Privacy and consent

P1	**To what extent do you agree or disagree with the following statements? Rate your answers out of 10, with 0 as strongly disagree and 10 as strongly agree. [Randomise]**	**0** **Strongly disagree**	**1**	**2**	**3**	**4**	**5** **Neutral**	**6**	**7**	**8**	**9**	**10** **Strongly agree**
P1.1	People have a natural right to privacy											
P1.2	Governments should only be able to access certain types of data											
P1.3	Data can provide valuable insights for improving society											
P1.4	Research can improve the delivery of healthcare											
P1.5	I think the personal information I tell health practitioners is confidential											
P1.6	I own data that is about me											

Understanding

U1	**To what extent do you think the following things are 'health data'? Rate your answers out of 10, with 0 as definitely is not health data and 10 as definitely is health data. [Randomise]**	**0** **Definitely is not health data**	**1**	**2**	**3**	**4**	**5** **Unsure**	**6**	**7**	**8**	**9**	**10** **Definitely is health data**
U1.1	Information relating to any conditions I have											
U1.2	Information relating to any conditions my family members have											
U1.3	Information relating to any disabilities I have											
U1.4	Information relating to my habits and lifestyle											
U1.5	Wearable fitness tracker data, eg a Fitbit											
U1.6	Genetic data											
U1.7	Information from prescriptions and doctors' visits											
U1.8	Pathology and diagnostic imaging results, eg blood tests											

Owning and storing health data

For the purposes of the following questions, we use this definition of health data:

Health data is information about the health and wellbeing of individuals or populations. This includes: data controlled by individuals, the government and non-government organisations, such as census data and personal health records. It also includes, but is not limited to, the Government's My Health Record system, an electronic health record, which provides a secure online summary of your health information.

O1	**To what extent do you agree or disagree with the following statements? Rate your answers out of 10, with 0 as strongly disagree and 10 as strongly agree. [Randomise]**	**0** **Strongly disagree**	**1**	**2**	**3**	**4**	**5** **Neutral**	**6**	**7**	**8**	**9**	**10** **Strongly agree**
O1.1	The person about that the health data relates to, eg a patient											
O1.2	The person who created the health data, eg a health practitioner											
O1.3	The person who uses the health data, eg a researcher											

O2	**To what extent do you agree or disagree with the following statements? Rate your answers out of 10, with 0 as strongly disagree and 10 as strongly agree.**	**0** **Strongly disagree**	**1**	**2**	**3**	**4**	**5** **Neutral**	**6**	**7**	**8**	**9**	**10** **Strongly agree**
O2.1	I am comfortable with sharing health data about me, <u>if I am not identified</u>											
O2.2	I am comfortable with sharing health data about me, <u>if I am identified</u>											
O2.3	I am comfortable with non-government organisations making income from health data about me											
O2.4	I am comfortable with research organisations making a profit from health data about me											
O2.5	I am comfortable with private organisations making a profit from health data about me											

O3	**To what extent are you confident that…** **Rate your answers out of 10, with 0 as not at all confident and 10 as extremely confident.** **[Randomise]**	**0** **Not at all confident**	**1**	**2**	**3**	**4**	**5** **Neutral**	**6**	**7**	**8**	**9**	**10** **Extremely confident**
O3.1	The government will store my health data securely											
O3.2	Research organisations, eg universities, will store my health data securely											
O3.3	Private organisations will store my health data securely											
O3.4	The government will ensure my anonymity											
O3.5	Research organisations, eg universities, will ensure my anonymity											
O3.6	Private organisations will ensure my anonymity											
O3.7	Electronic data storage is secure											
O3.8	My Health Record is secure											
O3.9	Online data storage is secure											

Accessing and sharing data

A1	**Thinking about who should have access to your health data, to what extent do you agree or disagree with the following statements? Rate your answers out of 10, with 0 as strongly disagree and 10 as strongly agree.** ***De-identified data is information about your health status where identifying indicators such as your name and address have been removed.***	**0** **Strongly disagree**	**1**	**2**	**3**	**4**	**5** **Neutral**	**6**	**7**	**8**	**9**	**10** **Strongly agree**
A1.1	In a non-emergency situation, health practitioners who treat me should have access to information about my health conditions											
A1.2	In an emergency situation, health practitioners who treat me should have access to information about my health conditions											
A1.3	I should have access to my health data											
A1.4	People planning health services in my region should have access to health data											
A1.5	Health insurance companies should be able to access my health data to plan their services											
A1.6	Private companies should be able to access my health data to plan their services											
A1.7	The Department of Health should be able to access my health data to help plan services											
A1.8	Other government departments (not the Department of Health) should be able to access to my health data to help plan services											
A1.9	A research organisation, eg a university, should have access to my health data, for research purposes											

A2	**If I was in an emergency and was unable to consent to share my health data… Rate your answers out of 10, with 0 as strongly disagree and 10 as strongly agree. [Randomise]**	**0** **Strongly disagree**	**1**	**2**	**3**	**4**	**5** **Neutral**	**6**	**7**	**8**	**9**	**10** **Strongly agree**
A2.1	My family should be able to access to my health information											
A2.2	Only a designated family member, carer or friend should be able to access to my health information											
A2.3	My primary treating doctor should be able to access my health information											
A2.4	All doctors and clinicians in my treating team should be able to access my health information											
A2.5	No one should be able to access to my health information without my permission											

A3	**Thinking about how comfortable you would be with government using your health data, to what extent do you agree with the following statements? Rate your answers out of 10, with 0 as strongly disagree and 10 as strongly agree.** ***De-identified data is information about your health status where identifying indicators such as your name and address have been removed.*** **[Randomise]**	**0** **Strongly disagree**	**1**	**2**	**3**	**4**	**5** **Neutral**	**6**	**7**	**8**	**9**	**10** **Strongly agree**
A3.1	I would be comfortable with government using my data to improve the cost-effectiveness of services											
A3.2	I would be comfortable with government using my data to support healthcare providers to improve my care											
A3.3	I would be comfortable with government using my data to support healthcare providers to improve the care of others in the community											
A3.4	I would be comfortable with the government using my data to assist public health officials in tracking diseases, disabilities and their causes											
A3.5	I would be comfortable with the government using my data for health and medical research											

A4	**Thinking about accessing your health data, to what extent do you agree or disagree with the following statements? Rate your answers out of 10, with 0 as strongly disagree and 10 as strongly agree.** **[Randomise]**	**0** **Strongly disagree**	**1**	**2**	**3**	**4**	**5** **Neutral**	**6**	**7**	**8**	**9**	**10** **Strongly agree**
A4.1	I would like to know which organisations have access to my health data											
A4.2	I would like to be asked for my permission each time an organisation wants to use my health data											
A4.3	I would like to be asked for my permission when a research organisation wants to use my health data											
A4.4	I would like to be asked for my permission when a government department wants to use my health data											
A4.5	I would like to be asked for my permission when a private organisation wants to use my health data											

A5	**Thinking about if your health data was shared between medical practitioners, to what extent do you agree or disagree with the following statements? [Randomise]**	**0** **Strongly disagree**	**1**	**2**	**3**	**4**	**5** **Neutral**	**6**	**7**	**8**	**9**	**10** **Strongly agree**
A5.1	My doctor would use a computer to send my medical information electronically to another doctor involved in my healthcare											
A5.2	My doctor would send my health information to me electronically so that I can share it with other health practitioners											
A5.3	My doctor would ask my consent to share it electronically on a shared online platform where all information is stored relating to my care											

About your health

H1	**In general, how would you rate your health?**	**Single response**
	My health is poor	1
	My health is fair	2
	My health is good	3
	My health is very good	4
	My health is excellent	5

H2	**Tick all that apply to you [Randomise]**	**Yes**	**No**
		1	0
H2.1	I have a chronic health condition		
H2.2	I care for someone with a chronic health condition		
H2.3	I take prescribed medication(s)		
H2.4	I have a My Health Record electronic health record		

H2B	**IF YES TO H2.1 or H2.3:**	**Yes**	**No**
	Tick all that apply to you [Randomise]	1	0
H2B.1	I have arthritis		
H2B.2	I have diabetes		
H2B.3	I have heart disease		
H2B.4	I have stroke		
H2B.5	I have cancer		
H2B.6	I have a mental health condition		
H2B.7	I have another health condition		

H3	**In the last year how many times have you visited the following healthcare providers for your own health?**	**None**	**One visit**	**2 or 3 visits**	**3 or more visits**
		0	1	2	3
H3.1	GP, nurse practitioner or practice nurse				
H3.2	Medical specialist (eg gynaecologist, cardiologist)				
H3.3	Emergency department				
H3.4	Hospital – and not stayed overnight				
H3.5	Hospital – and stayed overnight				

H4	How confident do you feel accessing health services, such as those listed above?	Single response
	Not at all confident	1
	A little confident	2
	Moderately confident	3
	Very confident	4
	Extremely confident	5

About your media use

M1	**When online, how often do you… [Randomise]**	**Never**	**Once a month or less**	**A few times a month**	**A few times a week**	**Daily**
		0	1	2	3	4
M1.1	Visit news or current affairs sites					
M1.2	Visit entertainment sites					
M1.3	Visit sports news sites					
M1.4	Shop					
M1.5	Stream music (eg through Soundcloud or Spotify)					
M1.6	Use social media					

About you

D1	**I am aged…**	**Single response**
	18-24 years old	1
	25-34 years old	2
	35-44 years old	3
	45-54 years old	4
	55-64 years old	5
	65 or older	6
	I'd prefer not to say	99

D2	**I am…**	**Single response**
	Male	1
	Female	2
	Other	3
	I'd prefer not to say	99

D3	**My postcode is…**	**Number response**

D4	**What is the furthest level of education you have completed?**	**Single response**
	I did not complete Year 12 (or equivalent)	1
	I completed Year 12 (or equivalent)	2
	I have completed an undergraduate degree	3
	I have completed a postgraduate degree	4
	I have completed TAFE qualification/apprenticeship	5
	Other	6
	I'd prefer not to say	99

D5	**Which of the following best describes you?**	**Single response**
	Working full time	1
	Working part time or on a casual basis	2
	Unemployed, looking for work	3
	Unemployed, not looking for work	4
	Retired	5
	Home duties or a stay-at-home mother/ father/ partner	6
	Carer	7
	A student	8
	Other [Please specify…………..]	9
	I'd prefer not to say	99

D6	Do you work in a health or medical profession?	Single response
	Yes	1
	No	2
	I'd prefer not to say	99

D7	I am…	Single response
	Aboriginal or Torres Strait Islander	1
	Not Aboriginal or Torres Strait Islander	2
	I'd prefer not to say	99

D8	What language do you speak at home?	Single response
	I speak English at home	1
	I speak a language other than English at home [Please specify…]	2
	I'd prefer not to say	99

D9	How many children do you have? If you have no children, please write 0.	Number response matrix
	Number of children aged under 18	
	Number of children aged 18 or over	

4A.6: Questionnaire results descriptive statistics

In total there were 1,013 survey respondents. Any sub-totals that do not add up to 100 per cent are due to rounding errors.

Table 3 – Descriptive statistics

Sample characteristic	Percentage	n
Gender		
Female	50.5%	512
Male	49.3%	499
Other/I'd prefer not to say	0.2%	2
Age		
18-24	12.0%	122
25-34	18.2%	184
35-44	18.6%	188
45-54	17.9%	181
55-64	14.5%	147
Over 64	18.0%	182
I'd prefer not to say	0.9%	9
State		
ACT	2.0%	20
NSW	31.7%	321
NT	1.2%	12
QLD	20.9%	212
SA	8.0%	81
TAS	2.0%	20
VIC	24.1%	244
WA	10.2%	103
Region		
Metropolitan	65.7%	666
Regional	34.3%	347

Sample characteristic	Percentage	n
Aboriginal and Torres Strait Islander		
Aboriginal and/or Torres Strait Islander	0.9%	9
Not Aboriginal and/or Torres Strait Islander	94.6%	958
I'd prefer not to say	4.5%	46
Cultural and linguistic diversity		
I speak English at home	91.2%	924
I speak a language other than English at home	7.0%	71
I'd prefer not to say	1.8%	18
Furthest level of education completed		
I did not complete Year 12 (or equivalent)	9.7%	98
I completed Year 12 (or equivalent)	18.6%	188
I have completed an undergraduate degree	27.3%	277
I have completed a postgraduate degree	16.3%	165
I have completed TAFE qualification/apprenticeship	24.5%	248
Other	2.7%	27
I'd prefer not to say	1.0%	10
Do you work in a health or medical profession?		
Yes	5.3%	54
No	94.1%	953
I'd prefer not to say	0.6%	6
Employment status		
Working full time	37.1%	376
Working part time or on a casual basis	17.2%	174
Unemployed, looking for work	5.1%	52
Unemployed, not looking for work	2.1%	21
Retired	19.3%	196

Sample characteristic	Percentage	n
Home duties or a stay-at-home mother/ father/ partner	9.6%	97
Carer	0.4%	4
A student	6.7%	68
Other	1.7%	17
I'd prefer not to say	0.8%	8

Figure 5 – In general, how would you rate your health?

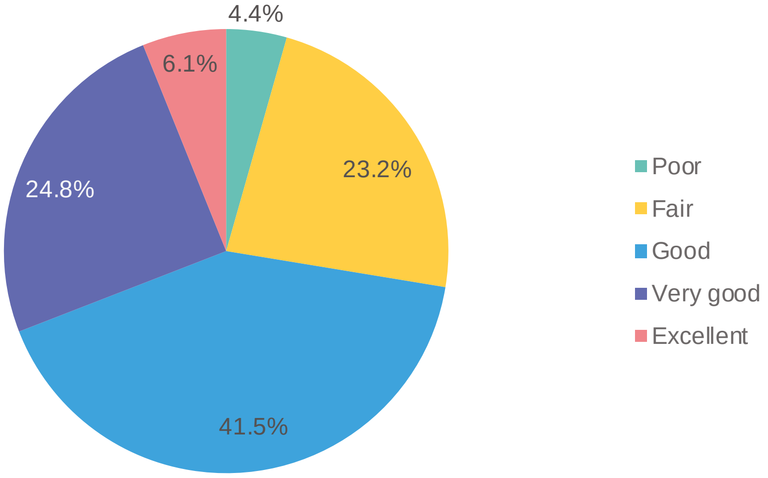


Figure 6 – About your health status

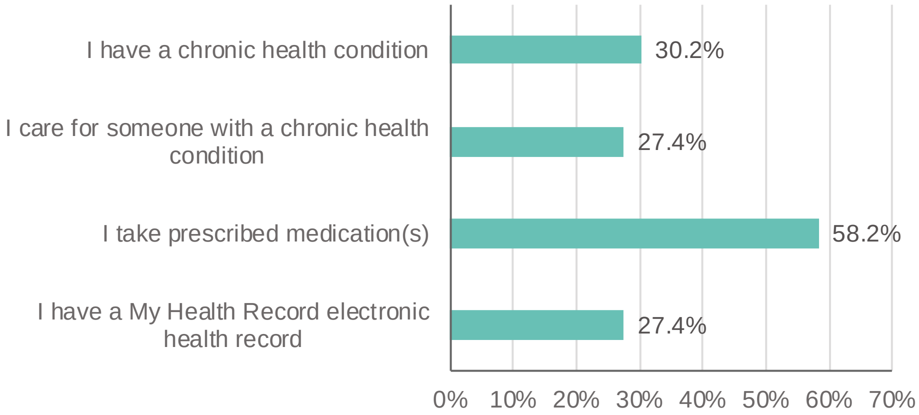


Table 4 – Chronic health conditions

Chronic health conditions	**Percentage**	**n**
I have arthritis	17.3%	175

I have a mental health condition	16.9%	171
I have diabetes	8.0%	81
I have heart disease	5.0%	51
I have cancer	2.2%	22
I have stroke	1.5%	15
I have another health condition	41.7%	422

Figure 7 – How many times in the last year have you visited…?

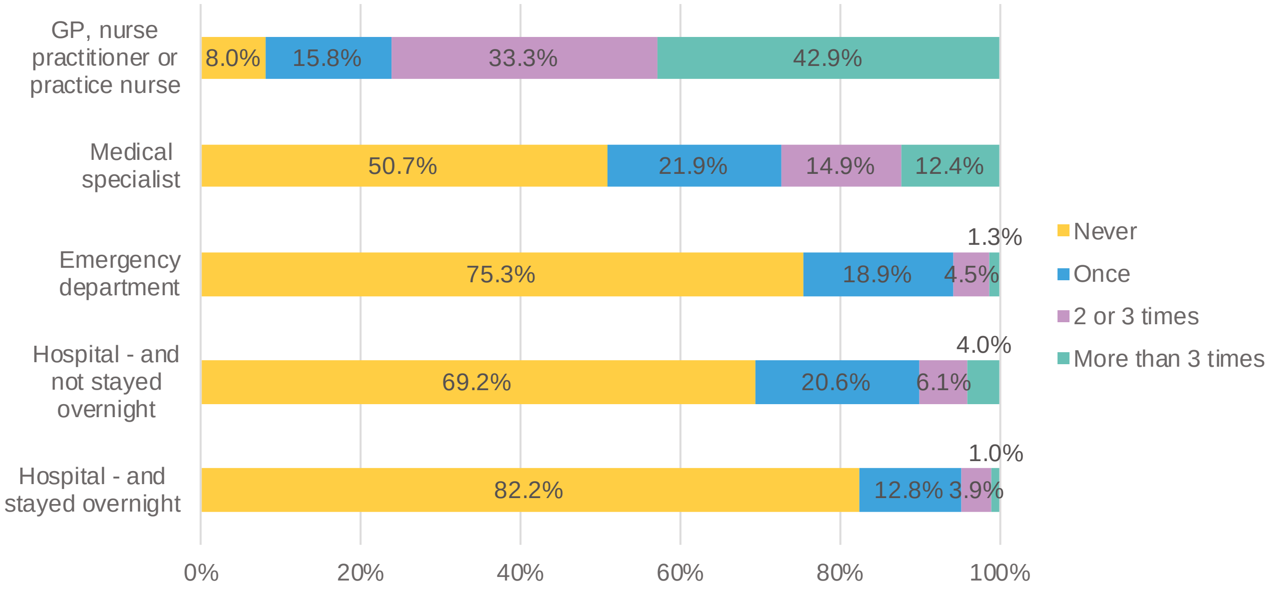
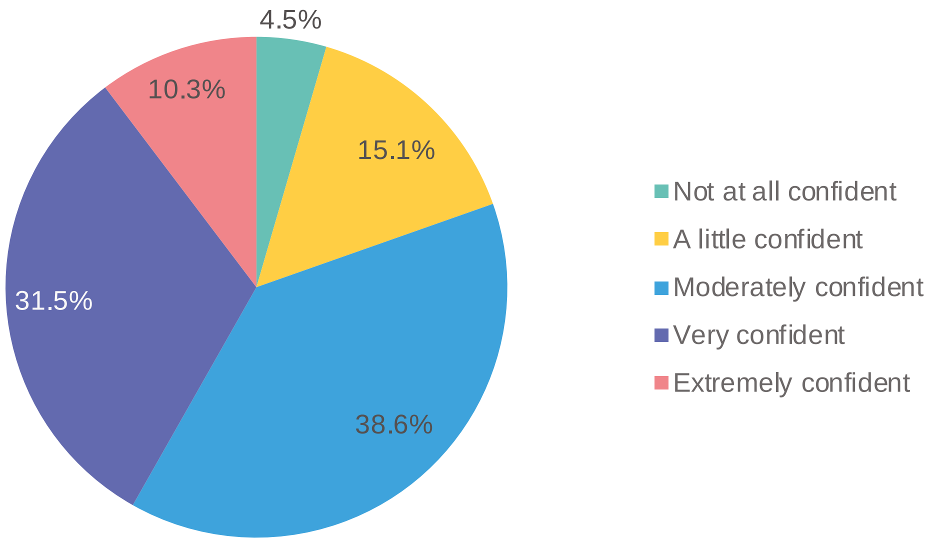


Figure 8 – How confident do you feel accessing health services?



4A.7: Questionnaire results – results using measures of central tendency

Table 5 presents the mean score for each questionnaire item (possible scores 1-11). Items rated above 9.00 have been highlighted green. Items rated below 6.00 (ie, disagreement) have been highlighted red.

Table 5 – Responses to questionnaire items, mean and standard deviation

Questionnaire item	Mean	SD
People have a natural right to privacy	9.96	1.59
Governments should only be able to access certain types of date	8.82	2.30
Data can provide valuable insights for improving society	8.81	1.94
Research can improve the delivery of healthcare	9.66	1.59
I think the information I tell health practitioners is confidential	9.52	1.86
I own data that is about me	8.21	2.61
Information relating to any conditions I have [is health data]	9.56	2.02
Information relating to any conditions my family members have [is health data]	8.93	2.37
Information relating to any disabilities I have [is health data]	9.40	2.04
Information relating to my habits and lifestyle [is health data]	6.94	3.00
Wearable fitness tracker data, eg Fitbit [is health data]	6.23	3.13
Genetic data [is health data]	8.61	2.57
Information from prescriptions and doctor's visits [is health data]	9.44	2.10
Pathology results, eg blood tests [is health data]	9.85	1.82

The person the data relates to, eg a patient [owns the data]	9.43	2.01
The person who created the data, eg a health practitioner [owns the data]	7.10	2.77
The person who uses the data, eg a researcher [owns the data]	6.29	2.92
I am comfortable with sharing data about me, if I am not identified	7.44	2.76
I am comfortable with sharing data about me, if I am identified	4.23	2.96
I am comfortable with non-government organisations making a profit from data about me	3.61	2.67
I am comfortable with research organisations making a profit from data about me	4.42	2.92
I am comfortable with private organisations making a profit from data about me	3.44	2.64
The government will store my data securely	5.68	2.95
Research organisations will store my data securely	5.72	2.76
Private organisations will store my data securely	5.08	2.80
The government will ensure my anonymity	5.51	2.92
Research organisations will ensure my anonymity	5.97	2.75
Private organisations will ensure my anonymity	4.94	2.78
Electronic data storage is secure	5.09	2.79
My Health Record is secure	6.08	2.78
Online data storage is secure	4.81	2.69
In a non-emergency situation, health practitioners who treat me should have access to my data	7.74	2.60
In an emergency situation, health practitioners who treat me should have access to my data	9.58	1.82

I should have access to my health data	10.24	1.39
People planning health services in my region should have access to my data	5.99	2.79
Health insurance companies should be able to access my health data to plan their service	5.02	2.94
Private companies should be able to access my health data to plan their services	4.09	2.62
The Department of Health should be able to access my data to help plan services	6.96	2.71
Other government departments should be able to access my data to help plan services	5.06	2.79
A research organisation should have access to my data, for research purposes	5.70	2.75
If I was in an emergency and unable to consent to share my data, my family should be able to access my health information	7.33	2.94
If I was in an emergency and unable to consent to share my data, only a designated family member, carer or friend should be able to access my health information	7.63	2.81
If I was in an emergency and unable to consent to share my data, my primary treating doctor should be able to access my health information	9.65	1.78
If I was in an emergency and unable to consent to share my data, all doctors and clinicians in my treating team should be able to access my health information	8.81	2.28
If I was in an emergency and unable to consent to share my data, no-one should be able to access my health information without my permission	7.39	3.41
I would be comfortable with government using my data to improve the cost-effectiveness of services	6.68	2.81
I would be comfortable with government using my data to support healthcare providers to improve my care	7.35	2.72
I would be comfortable with government using my data to support healthcare providers to improve the care of others in the community	6.68	2.76
I would be comfortable with the government using my data to assist public health officials in tracking diseases, disabilities and their causes	7.11	2.79

I would be comfortable with the government using my data for health and medical research	6.90	2.72
I would like to know which organisations have access to my data	10.08	1.56
I would like to be asked for my permission each time an organisation wants to use my data	9.46	2.12
I would like to be asked for my permission when a research organisation wants to use my data	9.81	1.81
I would like to be asked for my permission when a government department wants to use my data	9.69	1.93
I would like to be asked for my permission when a private organisation wants to use my data	10.09	1.62
My doctor would use a computer to send my medical information electronically to another doctor involved in my healthcare	8.77	2.17
My doctor would send my health information to me electronically so that I can share it with other health practitioners	8.65	2.39
My doctor would ask my consent to share it electronically on a shared online platform where all information is stored relating to my care	8.94	2.32

Table 6 Proportion of sample who disagreed/neutral/agreed with statements

Questionnaire item	Disagree		Neutral		Agree	
	n	**%**	**n**	**%**	**n**	**%**
People have a natural right to privacy	24	2.4	35	3.5	954	94.2
Governments should only be able to access certain types of date	64	6.3	136	13.4	813	80.3
Data can provide valuable insights for improving society	48	4.7	103	10.2	862	85.1
Research can improve the delivery of healthcare	20	2.0	29	2.9	964	95.2
I think the information I tell health practitioners is confidential	38	3.8	61	6.0	911	89.9
I own data that is about me	107	10.6	231	22.8	675	66.6
Information relating to any conditions I have [is health data]	44	4.3	52	5.1	917	90.5
Information relating to any conditions my family members have [is health data]	73	7.2	92	9.1	848	83.7
Information relating to any disabilities I have [is health data]	46	4.5	72	7.1	895	88.4
Information relating to my habits and lifestyle [is health data]	267	26.4	167	16.5	579	57.2
Wearable fitness tracker data, eg Fitbit [is health data]	344	34.0	195	19.2	474	46.8
Genetic data [is health data]	93	9.2	139	13.7	781	77.1
Information from prescriptions and doctor's visits [is health data]	49	4.8	56	5.5	908	89.6
Pathology results, eg blood tests [is health data]	30	3.0	34	3.4	949	93.7
The person the data relates to, eg a patient [owns the data]	37	3.7	84	8.3	892	88.1
The person who created the data, eg a health practitioner [owns the data]	218	21.5	212	20.9	583	57.6

Questionnaire item	**Disagree**		**Neutral**		**Agree**	
	n	**%**	**n**	**%**	**n**	**%**
The person who uses the data, eg a researcher [owns the data]	315	31.1	225	22.2	473	46.7
I am comfortable with sharing data about me, if I am not identified	183	18.1	174	17.2	656	64.8
I am comfortable with sharing data about me, if I am identified	630	62.2	162	16.0	221	21.8
I am comfortable with non-government organisations making a profit from data about me	735	72.6	139	13.7	139	13.7
I am comfortable with research organisations making a profit from data about me	598	59.0	180	17.8	235	23.2
I am comfortable with private organisations making a profit from data about me	764	75.4	119	11.7	130	12.8
The government will store my data securely	435	42.9	168	16.6	410	40.5
Research organisations will store my data securely	407	40.2	208	20.5	398	39.3
Private organisations will store my data securely	523	51.6	177	17.5	313	30.9
The government will ensure my anonymity	440	43.4	191	18.9	382	37.7
Research organisations will ensure my anonymity	363	35.8	228	22.5	422	41.7
Private organisations will ensure my anonymity	541	53.4	183	18.1	289	28.5
Electronic data storage is secure	522	51.5	178	17.6	313	30.9
My Health Record is secure	365	36.0	210	20.7	438	43.2
Online data storage is secure	562	55.5	190	18.8	261	25.8
In a non-emergency situation, health practitioners who treat me should have access to my data	156	15.4	148	14.6	709	70.0
In an emergency situation, health practitioners who treat me should have access to my data	31	3.1	54	5.3	928	91.6

Questionnaire item	Disagree		Neutral		Agree	
	n	**%**	**n**	**%**	**n**	**%**
I should have access to my health data	13	1.3	25	2.5	975	96.2
People planning health services in my region should have access to my data	348	34.4	221	21.8	444	43.8
Health insurance companies should be able to access my health data to plan their service	510	50.3	193	19.4	310	30.6
Private companies should be able to access my health data to plan their services	657	64.9	179	17.7	177	17.5
The Department of Health should be able to access my data to help plan services	223	22.0	190	18.8	600	59.2
Other government departments should be able to access my data to help plan services	496	49.0	206	20.3	311	30.7
A research organisation should have access to my data, for research purposes	403	39.8	214	21.1	396	39.1
If I was in an emergency and unable to consent to share my data, my family should be able to access my health information	207	20.4	196	19.3	610	60.2
If I was in an emergency and unable to consent to share my data, only a designated family member, carer or friend should be able to access my health information	181	17.9	181	17.9	651	64.3
If I was in an emergency and unable to consent to share my data, my primary treating doctor should be able to access my health information	30	3.0	37	3.7	946	93.4
If I was in an emergency and unable to consent to share my data, all doctors and clinicians in my treating team should be able to access my health information	66	6.5	106	10.5	841	83.0
If I was in an emergency and unable to consent to share my data, no-one should be able to access my health information without my permission	267	26.4	158	15.6	588	58.0
I would be comfortable with government using my data to improve the cost-effectiveness of services	266	26.3	185	18.3	562	55.5

Questionnaire item	Disagree		Neutral		Agree	
	n	%	n	%	n	%
I would be comfortable with government using my data to support healthcare providers to improve my care	191	18.9	154	15.2	668	65.9
I would be comfortable with government using my data to support healthcare providers to improve the care of others in the community	265	26.2	182	18.0	566	55.9
I would be comfortable with the government using my data to assist public health officials in tracking diseases, disabilities and their causes	220	21.7	160	15.8	633	62.5
I would be comfortable with the government using my data for health and medical research	234	23.1	196	19.3	583	57.6
I would like to know which organisations have access to my data	16	1.6	39	3.8	957	94.6
I would like to be asked for my permission each time an organisation wants to use my data	50	4.9	85	8.4	878	86.7
I would like to be asked for my permission when a research organisation wants to use my data	34	3.4	43	4.2	936	92.4
I would like to be asked for my permission when a government department wants to use my data	33	3.3	66	6.5	914	90.2
I would like to be asked for my permission when a private organisation wants to use my data	23	2.3	35	3.5	955	94.3
My doctor would use a computer to send my medical information electronically to another doctor involved in my healthcare	51	5.0	131	12.9	831	82.0
My doctor would send my health information to me electronically so that I can share it with other health practitioners	73	7.2	151	14.9	789	77.9
My doctor would ask my consent to share it electronically on a shared online platform where all information is stored relating to my care	72	7.1	115	11.4	826	81.5

5A: Interactive case study

‘App X’ is one of the most popular health apps on the Google Play Store and the Apple App Store. It supports consumers who are at risk of being diagnosed with type 2 diabetes by giving them tailored exercise, meal and lifestyle programs to help them manage their risk factors.

On setting up a user account, the consumer is asked a set of questions about their age, weight, height, smoking status, alcohol consumption, medical history, family medical history, whether they are Aboriginal or Torres Strait Islander, and lifestyle choices. While there are a lot of questions, they are answered easily by swiping left for ‘no’, and swiping right for ‘yes’.

The information entered by the consumer is analysed using specially designed algorithms, and as a result, a tailored exercise, meal and lifestyle program is developed for the consumer. The consumer self-reports their commitment to these programs, and to ensure the consumer is truthful, App X links the data about the consumer app with information from Woolworths Rewards and FlyBuys card programs which can confirm what is in the consumer’s shopping trolley. The consumer is made aware of this in the Terms and Conditions that they agree to when they first set up a user account.

App X is free to use, however the owners of the app make a profit by showing advertisements in the App from their sponsors, which include a number of health insurers, fitness gyms, and vitamin companies. The owners of the app also recognise that the data can provide powerful insights into proactive, preventative care and would be of benefit to researchers. The owners of App X are thinking about offering the data in a de-identified way to researchers (including linking to other data sets), even though this is not within the current Terms and Conditions.

Group questions

- o <u>Transparency and consent</u>
    - Are terms and conditions enough in this scenario for the consumer to make an informed choice to use the app?
    - Should consent be obtained for sharing de-identified consumer data?
        i. If yes, what model of consent is practical?
        ii. If no, should the consumer still be informed about the use?
    - What is the right level of content to share with consumers about how their data is being collected, used and shared?

- o <u>Data linkage and data users</u>
    - Would the linking of the app data with the Woolworths and FlyBuys data pass the ‘pub test’? Would a consumer understand what this means, and would a consumer care?
    - If App X were to link de-identified app data with other data sets, which data sets would be acceptable? Do they need to be health related data sets (eg hospital data), or could they also be non-health related data sets (eg banking data)?
    - Should de-identified app data be shared with researchers? If yes, does your answer change if:
        i. The researcher is from government?

    ii. The researcher is from a commercial organisation, such as a private health insurer?
    iii. App X makes a profit from selling the data?

- <u>Informing to empowering consumers</u>
    - What ways or methods can be used to improve the consumer's trust, while not impeding on public good and ethical uses of their de-identified data?
    - Is there a responsibility or expectation of the owners of App X to feed back to the consumer how the consumer is contributing to research and policy? If not, why not?
    - Is there value in consumers co-designing App X functionality and strategy for use of the data? If so, what is that value and what needs to happen for this to be successful?

5B: Roundtable participants

Australian Bureau of Statistics

Australian Institute of Health and Welfare (AIHW)

Australian Institute of Health Innovation, Macquarie University

Centre for Big

Data Research in Health, UNSW

Centre for Health, Law and Emerging Technologies (HeLEX), University of Melbourne

Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM)

Consumers Health Forum (CHF)

Department of Health

Department of Social Services

Deeble Institute

National Aboriginal Community Controlled Health Organisation (NACCHO)

National Mental Health Consumer and Carer Forum

NPS MedicineWise

Office of the Australian Information Commissioner (OAIC)

Private Healthcare Australia

South Eastern Melbourne PHN

The Royal Australian College of General Practitioners (RACGP)

Together with consumers involved in the NPS MedicineWise and CHF research on consumer attitudes to data

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