Submission to the Productivity Commission

in regard to the

Inquiry into Data Availability and Use

on behalf of:
Health Informatics Society of Australia

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August 2016

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Executive Summary

The professional society of HISA is pleased to be able to provide the Productivity Commission with this submission into its inquiry into data availability and use. Our submission constitutes a report on a national survey, summarising the views of professionals across the health sector who have interest and expertise in health data and who are closely associated with e-health development, delivery and application.

HISA members have a strong interest in the sharing and use of health data as a means to improve the care of patients, health outcomes and the management of healthcare services. HISA has organised 8 national conferences over the past 10 years related to data use comprising Health Privacy Futures, Health Data Governance, Health Big Data and Health Data Analytics. The following submission has been derived from a detailed survey that asks for levels of agreement and comment for proposed options provided to questions raised in the Productivity Commission's Inquiry into Data Availability and Use Issues Paper.

The survey attracted 101 respondents, most of whom have detailed knowledge of health data, including issues pertaining to its primary collection and use in clinical care and in the provision of health services and systems management, biomedical and clinical research, technical applications development and implementation, and related ethical issues and legislative regulations.

Overall this survey shows accessibility and use of health information is sub-optimal in Australia and that all stakeholders have a part to play in improving appropriate access and use. There is a general sense of a lack of coordination of data access and use practice with siloed and non-standardised data, fragmented governing legislation across jurisdictions, and consumers unaware of how to obtain meaningful access to their data. Many options to address known barriers are already feasible and available, but data standardisation, culture, education, training and resources to improve data sharing and use need to be addressed. The survey also reveals that health information and data blocking may be a newly identified barrier in Australia.

Nevertheless, the actual and potential benefit of data access and use is strong and should be better promoted. The Federal government, followed by State governments and Health Departments, are seen to be the key agents responsible for setting the direction for improving the state of health data accessibility and use.

We trust this submission and the quantitative and qualitative responses reported herein provide value to the work of the Commission.

About HISA

With a 20+ year history, the Health Informatics Society of Australia Ltd (HISA) is **the peak body for health informatics and e-health in Australia**. We have a vested interest in growing workforce capacity and capability in digital health and are passionate advocates for the e-health enabled transformation of healthcare.

HISA is a not-for-profit, member organisation with a broad and diverse stakeholder community with over 1000 active members and a database of over 13,000 committed participants in digital health, e-health and health informatics. We have access to the best minds in e-health nationally and globally including: IMIA (which links HISA to WHO & over 60 specialist health informatics organisations across the planet), APAMI (Asia Pacific Association for Medical Informatics) and HINZ (Health Informatics New Zealand).

HISA membership is open to individuals and organisations. The majority of HISA members are senior players and leaders in their fields. Together, our membership represents thousands of years of combined experience in health and in health-IT.

Survey Methodology

The survey was developed to address the many questions raised in the 'Issue Paper' developed by the Productivity Commission on the topic of 'Data Availability and Use' with a particular focus on their applicability to health information. HISA's survey approach has proved valuable and insightful for previous government submissions, enabling participants to share their views and contribute to the inquiry more quickly and more easily than writing their own submission. It also provides quantitative and qualitative data rather than just opinions and policy statements to the Commission.

The survey was presented in two parts. Part I covered 24 key questions on health data. Part II included a further 34 additional questions that probed deeper and addressed the more detailed parts of the Commission's Issues Paper. Participants could choose to answer as many or as few of the questions as they liked.

Within the survey, options that facilitate aggregation and analysis of participant views were included, together with 'don't know' or 'not-applicable' responses. A Likert scale was employed to enable both positive and negative views and free text options to capture individual's comments.

Please note that throughout the survey the generic term 'consumer' was used to capture all potential health system users including, e.g. practitioners, carers, health service managers, administrators and technical staff, patients, clients, information system vendors and developers, private health system stakeholders, etc.

As far as possible, the survey attempted to provide a comprehensive and unbiased list of potential responses. Not all the questions raised in the Productivity Commission's issues paper were addressed, especially where they were overly complex or had limited relevance to health. Participants who felt that any particular issue would benefit from more detailed comment were invited make their own submission directly to the Productivity Commission. Furthermore, several questions were included that fall outside the scope of the issues posed by the Productivity Commission, but which are believe to be relevant to health data sharing specifically or to highlight emerging issues in health data sharing.

The survey was conducted using an online application (SurveyMonkey) and distributed as a web link to potential respondents. The survey was open for two weeks and was distributed to HISA's mailing list and through members' networks and further publicised at HISA's HIC 2016, Australia's largest national health informatics and e-health conference.

About the Survey Respondents

A total of 101 respondents contributed to the survey and of these, 64 completed the survey. HISA members made up 37% of the group and the median age was in the 40-50 year age bracket, with an even gender split. The group comprised 55% public sector, 24% both public and private sector and approximately 10% each in the private sector alone and Not for profit/Non-government organisations. There was a broad cross-section of professions represented amongst the respondents, with a tendency to more senior roles. Thirteen respondents indicated they did not have a role directly related to Health Informatics, while the remainder (87%) had an average of 13 years experience in a Health Informatics related field of work.

Findings

HISA have obtained feedback from the Health Informatics professional community on the questions posed in the Productivity Commission's Issues Paper for its Inquiry into Data Availability and Use.

A total of 101 respondents contributed to the survey and of these 64 completed the entire questionnaire. The survey was designed by a team of health industry professionals with expertise in aspects of health data sharing and use to encompass as many useful suggestions in answer to the Commission's questions as feasible. Respondents have provided detailed responses to the questions and offered propositions, each of which were subject to strong agreement, agreement, neutral opinion, disagreement or strong disagreement (where relevant). This gauged the wider acceptance and applicability of the survey propositions. The results of the survey have been detailed below while supplementary anecdotes and comments submitted by respondents for each question are presented in the Appendix.

The Productivity Commission's Issues Paper indicates that previous government Inquiries pointed to a deficit in optimal data availability and use; **this survey confirms strong agreement that health data accessibility and use is seen to be a problem and this impinges on the ability of the health sector to perform its function and create benefit for the Australian community.**

Benefits and High Value Data Repositories

Identified benefits from improved health data accessibility and use include increased efficiency and effectiveness of services, better potential for innovation, research, evidence-informed policy making and even financial gains, although this was not a priority. Patient or consumer convenience and increased trust and transparency in services were also thought useful benefits. Respondents commented that **there should be more focus on demonstrating the delivered benefits of data sharing to encourage access and use**.

Numerous health data repositories were identified as being of high value to users, however many of these are not considered to be used effectively. In particular clinical data including EMR, EHR, Clinical Information Systems, Health Outcomes data and My Health Record/PCEHR data were considered ineffectively used by over 70% of respondents. Publicly Funded Research data, Insurance data,

Pathology and Diagnostic services data and Pharmaceutical/Device data were also thought to be poorly used.

For health consumers, data that provide high value by informing decisions are marked by facilitating service outcomes benchmarking, and providing ways to assess cost, quality, safety or efficiency of care delivery. However, caution is required in these analytical processes to ensure appropriate risk adjustment and interpretation of data for consumers.

Barriers and Solutions to Data Access and Use

Key barriers that contribute to this ineffective use of valuable data resources include data locked in siloed proprietary/vendor systems, non-standardised or poorly formatted data, lack of resources including qualified staff and tools, burdensome regulatory processes, poor data governance and culture and lack of access.

Conversely, while respondents acknowledged organisations may have some reasonable concerns, such as the risk of Privacy Act and security breaches, and the increased workload, these were considered 'last century' and solvable. Many proposed measures to facilitate more efficient and effective use were strongly supported including standardisation of datasets and collection, storage and access processes, increased visibility of the data repositories and education/training in health informatics, privacy management and data science.

A coded/standardised vocabulary and structured data were also considered highly important characteristics of high value datasets and further questions revealed strong agreement for the standardisation of collection, sharing and release of health data. While associated costs are likely, as pointed out by one respondent: "There are already many standards that are fit for this purpose. Implementing them rather than developing new standards should be the focus. International standards use should be the default."

Health Data Privacy, Security and Ethics

The privacy and security of personal data is of significant concern to individuals; health information is especially sensitive and requires extra consideration. While legislation for criminal or civil penalties saw moderate support, more favoured strategies to address Privacy and Security concerns included vendor agreed protocols, Health data sharing Principles or Code of Practice and the NHMRC open access information policy. Management of Health Data breaches was thought best addressed by improved education in this area, but legislative changes introducing compulsory reporting and/or fines and Privacy Impact Assessment were also considered useful.

Lack of coordination across the various jurisdictions is a known barrier to wider health data sharing. Few disagreed that Federal laws should be overarching or that Federal laws should intervene where no State laws exist, and agreement was moderate. Research into legislative improvements was also considered useful, however the favoured option was to establish coordinated legislation for health data across Federal, State and Territory jurisdictions.

Confidentialisation of health data such as anonymisation, de-identification, encryption and privacy preserving technologies are important processes in data sharing, however only half of the survey respondents considered existing approaches to be satisfactory. Commentary raised concerns

regarding re-identification risks in small samples and perhaps that the ability to apply the existing approaches and other technologies in the workplace was suboptimal.

Health data requires an additional level of consideration compared to other personal information due to its sensitive nature. This is substantiated by the results that respondents agreed that the greatest concerns for privacy protection are posed by particular subsets of sensitive health information (e.g. relating to competence for work, mental health, sexuality) and Hospital health and medical records. We included questions on Ethics in the survey as an important layer of regulation for Health data. Amongst our group 73% agreed that the NHMRC/ Australian Health Ethics Council has a role to play in guiding health data sharing practice, although less than half were aware of the NHMRC statement on data sharing.

Health Data Ownership and Costs

Our Health Informatics community clearly recognises that the lack of clarity about the ownership of health data inhibits its availability and use. Ownership rights for the individuals about whom the data pertains are most strongly supported, however the health organisations that collect the data, paying governments, and the community that provides the funding for the governments are all seen to have a stake in ownership. The broadest agreement for ownership rights went to a shared ownership model.

This is an important issue when considering the potential for monetisation of health data. While 13% of the respondents do not consider it appropriate to commoditise health data, around a third see the potential to recover costs associated with access management and use and that it should form part of the business model for healthcare funding. Commentary suggested that this is an inevitable eventuality, but the framework to guide this is still unclear and will need further work and consultation.

While monetisation may have future utility in funding data accessibility and use, currently few of our responders consider funding for data related work to be sufficient. Furthermore, the estimated average proportion of resourcing is considered to be skewed towards Management & Access which could suggest a potential imbalance of resourcing for Analysis & Use activities. Federal and State governments, organisations that provide health services, individuals or organisations that request information especially those who stand to make a profit from the consequences of the use beyond the public interest, should all bear some of the cost of increasing the accessibility and use of health data. Health IT vendors were thought to need to contribute less and lastly the individual health consumers were mostly considered less appropriate to bear the costs of data sharing. However, as one commentator pointed out "All stakeholders need to understand the benefit of using data and contribute to the cost" and the predominant theme in comments was for a user pay model with government supplementation.

It was agreed there were some differences between public and private health sectors in terms of fewer resources available to manage access and sharing, but respondents firmly agreed there is no less potential benefit from sharing health data in the private sector. The respondents agreed voluntary health data sharing arrangements between private or public healthcare organisations/ healthcare practitioners/ consumers/ third party intermediaries could improve data availability and sharing, but were ambivalent as to whether such voluntary arrangements would be likely to raise competition issues among private healthcare providers. Overall, there was strong consensus that governments

should play a bigger role in promoting the wider availability of private health datasets that have the potential to deliver substantial benefits.

Consumer Access to their Own Data

Due to the difficulty of interpreting health data and its potential impact, access for consumers to their own health data has been limited, however this is gradually changing. The survey respondents identified barriers which restrict access including Lack of clarity about access entitlements and arrangements at 94%, Lack of standardisation of data access processes and Lack of mechanisms to allow access by trusted third party intermediaries. Furthermore, respondents considered a lack of knowledge where to find such data, how to use such data and which data will be relevant to them to be to also be important barriers for consumers.

While respondents strongly agreed that that regulatory solutions for the above impediments would be of value in giving consumers more access to and control over their own data, the foremost theme in commented suggestions for encouraging healthcare providers to accept consumer access was around education and awareness of the benefits for consumers to help them manage and take responsibility for their own health management plan.

Third party intermediaries may be an option to increase consumer access, however respondents indicated such useful services are not generally available in healthcare and that such services are not understood by consumers or healthcare providers nor well know, if indeed available.

Health Information and Data Blocking

Health Information and Data Blocking is an emerging issue in health information sharing and system interoperability overseas. This phenomenon has been defined as "when persons or entities *knowingly and unreasonably* interfere with the exchange or use of electronic health information". The US government has dedicated resources and created regulatory guidance to minimise the effects of this issue. We used this survey platform to seek evidence of this in Australia.

We found that a majority of 57% agreed that they had experienced situations where data blocking may have occurred. Most of the suggested reasons for data blocking were confirmed, with Non-standard implementation of Health IT causing technical barriers, Contractual terms or restrictions, and Inappropriate citing of Privacy & Confidentiality regulations being the most agreed with. Technology or policies that are likely to "lock in" users of health data, Inappropriate citing of Ethics restrictions and To influence power or control (eg internal politics) were also considered significant reasons. Business practices to control referrals or exclude competitors was also seen while Opportunistic fees making health data access and exchange cost-prohibitive by custodians or vendors was somewhat less commonly encountered. This indicates that Health Information and Data Blocking may be a new or previously unrecognised issue that Australian governments and Health Services need to address in the interests of better data use.

Survey Limitations

It should be noted that the respondents to this survey may be biased to the public sector and although this is a HISA submission, many of the respondents are not HISA members and the overall demographic is somewhat different to the general Health Informatics professional profile. Further analysis of the

raw data would enable stratification of the sample and more useful information extraction eg how do the opinions of clinicians and vendors or public versus private respondents vary? HISA would welcome the opportunity to do this further analysis should the Department find this useful.

Furthermore, the survey sample is relatively small, however we believe providing aggregate data from a group of experts for the majority of relevant questions asked by the Productivity Commission in its Issues Paper is a powerful tool to help inform future government direction.

While full thematic analysis of the comments was not possible, and Part II was analysed more briefly, we suggest further perusal of the aggregated results of Part II and the full listing of comments provided in the appendix, is also warranted as many useful comments and ideas were made by the respondents to this survey.

Conclusion

Overall this survey informs us that the accessibility and use of Health Information is sub-optimal in Australia and that all stakeholders have a part to play in improving appropriate access and use. Many options to address known barriers are already feasible and available, but data standardisation, culture, education and training and resources to improve data sharing and use need to be addressed. However, it is the Federal government, followed by State governments and Health Departments, that are seen to be the key agents responsible for setting the direction for better accessibility and use.

Survey Respondent Data

Q1 Age
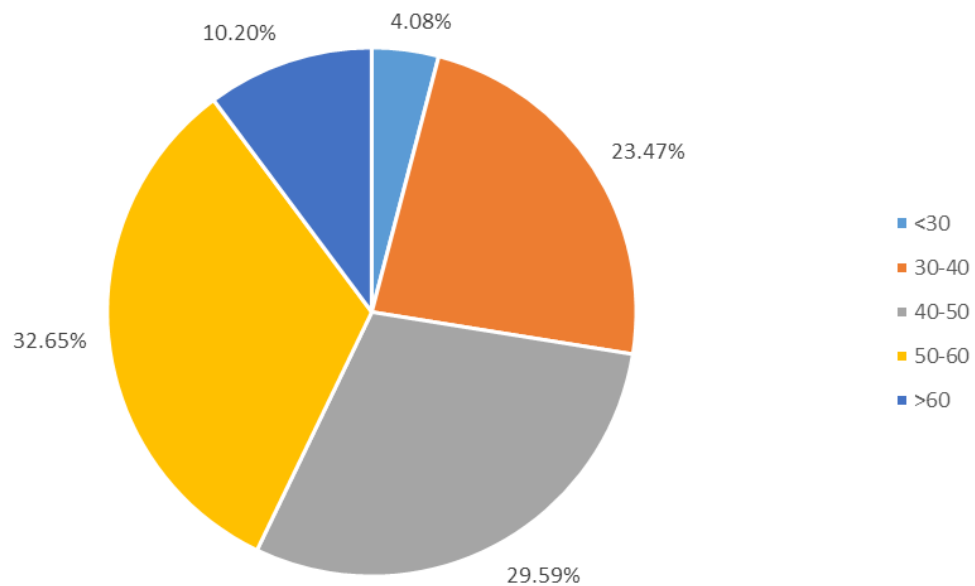
Age

Answer Options	Response Percent	Response Count
<30	4.08%	4
30-40	23.47%	23
40-50	29.59%	29
50-60	32.65%	32
>60	10.20%	10
	answered question	98
	skipped question	3

Of the 101 respondents who provided their age group, the majority were aged between 30 and 60, with a slight skewing to the older age groups. Just over 23% were in the 30-40 age group and just under 30% aged 40-50 and just over 32% between 50 and 60. Just over 10% were aged above 60 and less than 5% were aged below 30. 3 respondents declined to disclose their age.

Q2 Gender

Gender

Answer Options	Response Percent	Response Count
Female	49.98%	48
Male	51.02%	50
	answered question	98
	skipped question	3
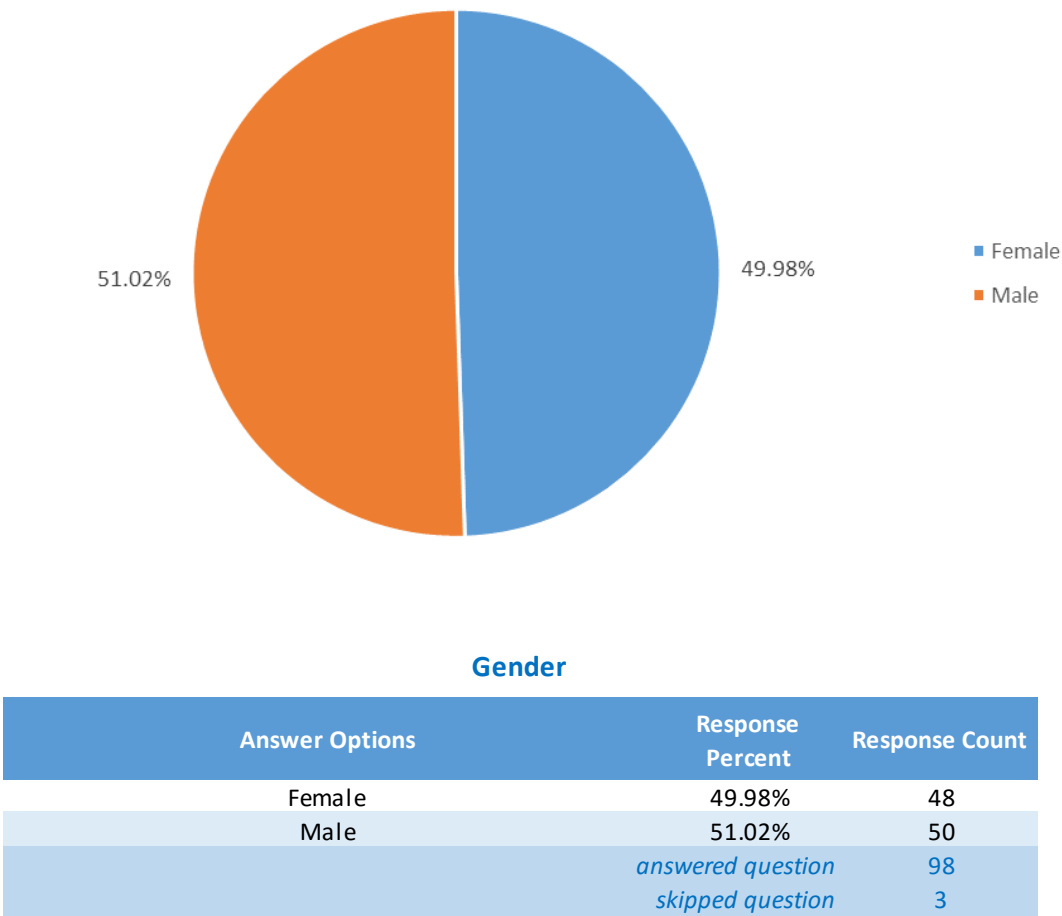
The respondents were evenly split across gender with 51.02% (50) male and 49.98% (48) female respondents and 3 who declined to disclose their gender.

Q3 Years of experience of working in the health informatics field

**Years of experience of working in the health informatics field
(if no direct experience = enter 0)**

answered question	97
skipped question	4

The survey respondents were asked about the years working in the health informatics field. Of 97 responders, 13 reported '0' indicating they did not work directly in a Health Informatics related field. The average number of years' experience working in the field was 13.3 (std dev +/- 10), while the median was 10 (IQR 5-20), ranging from 1 to 43 years.

Q4 HISA member
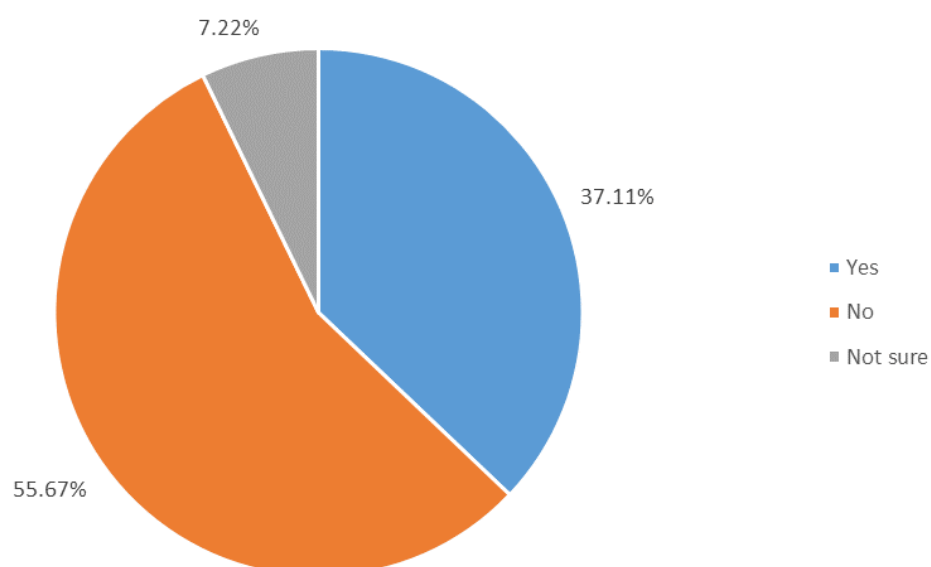
HISA member

Answer Options	Response Percent	Response Count
Yes	37.11%	36
No	55.67%	54
Not sure	7.22%	7
	answered question	97
	skipped question	4

The respondents were asked whether they were HISA members and more than half indicated that they were not (55.67%) with just over 37% stating that they were members. Seven respondents (7.22%) were unsure of their membership status and 4 declined to answer.

Q5 Sector
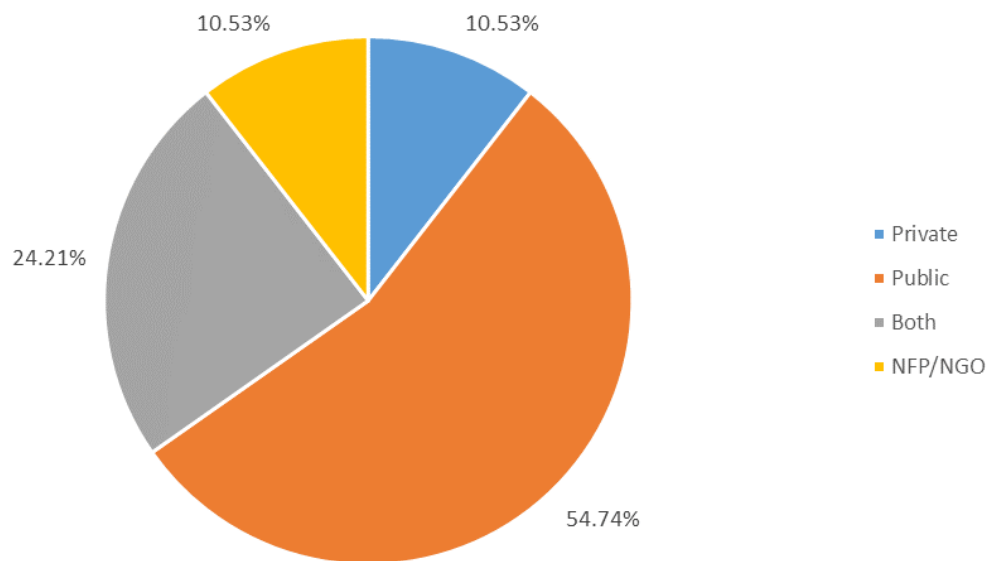
Sector

Answer Options	Response Percent	Response Count
Private	10.53%	10
Public	54.74%	52
Both	24.21%	23
NFP/NGO	10.53%	10
	answered question	95
	skipped question	6

At approximately 55% of the respondents, the majority were employed in the public sector, with another 24% having a joint employment in both the public and private sector. Just over 10% of respondents were employed in the private sector alone and the remaining 10% had roles in non-governmental and not-for-profit organisations. This shows the responders to be heavily skewed towards the public sector.

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Q6 Professional group - please select which one best describes your current role or predominant experience
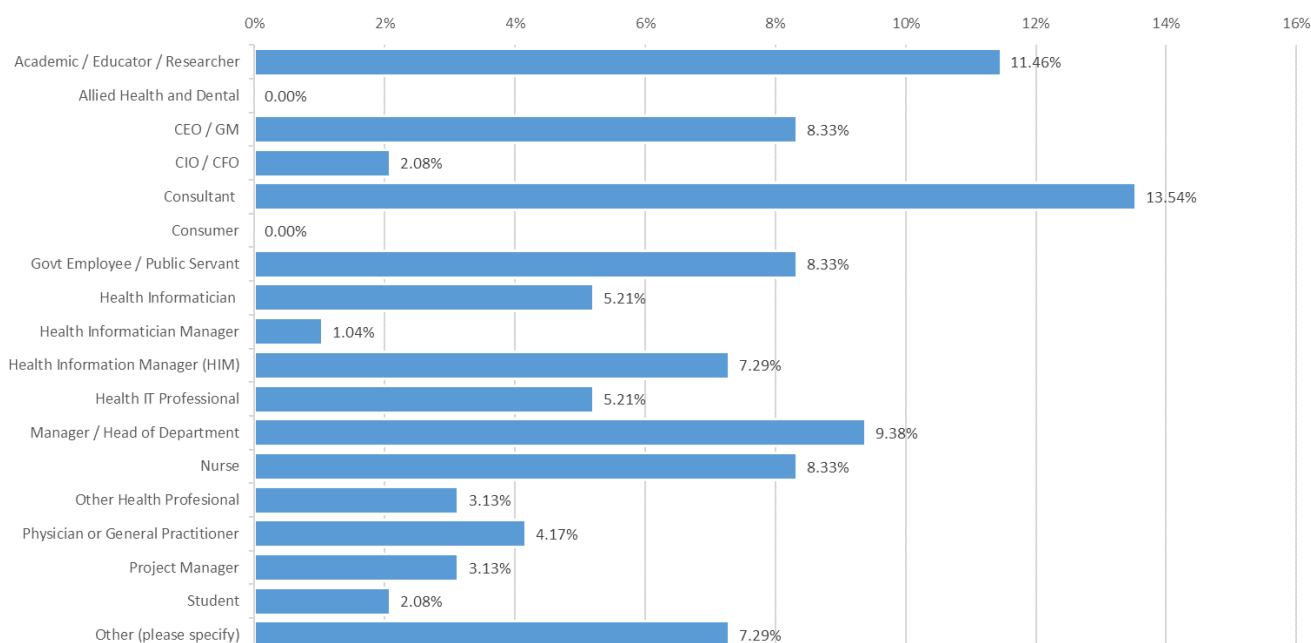
Professional group - please select which one best describes your current role or predominant experience

Answer Options	Response Percent	Response Count
Academic / Educator / Researcher	11.46%	11
Allied Health and Dental	0.00%	0
CEO / GM	8.33%	8
CIO / CFO	2.08%	2
Consultant	13.54%	13
Consumer	0.00%	0
Govt Employee / Public Servant	8.33%	8
Health Informatician	5.21%	5
Health Informatician Manager	1.04%	1
Health Information Manager (HIM)	7.29%	7
Health IT Professional	5.21%	5
Manager / Head of Department	9.38%	9
Nurse	8.33%	8
Other Health Profesional	3.13%	3
Physician or General Practitioner	4.17%	4
Project Manager	3.13%	3
Student	2.08%	2
Other (please specify)	7.29%	7
	answered question	96
	skipped question	5

There was a broad cross-section of professions represented amongst the respondents. The largest group identified as Consultants (14%), followed by Academic/Educator/Researchers (11%), and then

Manager/Head of department (9%). CEO/General Manager, Government employee/public servant and Nurse (all on 8%) and Health Information Managers (7%) made up the other larger groups. The clinical representation in the group stood at 16%, comprising Physician/GP, Nurses and Other Health Practitioners together, however there were none that identified primarily as health consumers.

Note: Question 7 provided optional addition of contact details by respondents, should the Productivity Commission wish to conduct further targeted consultation through HISA.

Analysis

The following pages present the results of the survey, with graphs, tabulated data and brief analysis, including the most pertinent comments contributed by the respondents.

Please note that the term 'survey respondents' is used in the description of results, but as the table for each question shows, the number of individuals who responded to each question varies. In each case we report the data from the number of responses to that question.

The survey was separated into 2 parts with 26 selected key questions in the first part giving respondents the option to answer an abridged cross-section of questions if preferred. Part II includes 33 further questions, comprising the remainder of the health-relevant questions from the Productivity Commission's Issues Paper. Questions from Part II are analysed more briefly than those key questions from Part I. The following analysis follows the design of the survey.

SURVEY PART I:

Q8 Indicate what access and use of health data primarily means to you

- Sharing of health data and information between health practitioners, healthcare organisations and systems during the management of patient care
- Sharing and use of information for secondary purposes (administration, research, quality assurance, disease surveillance, etc.)
- Both
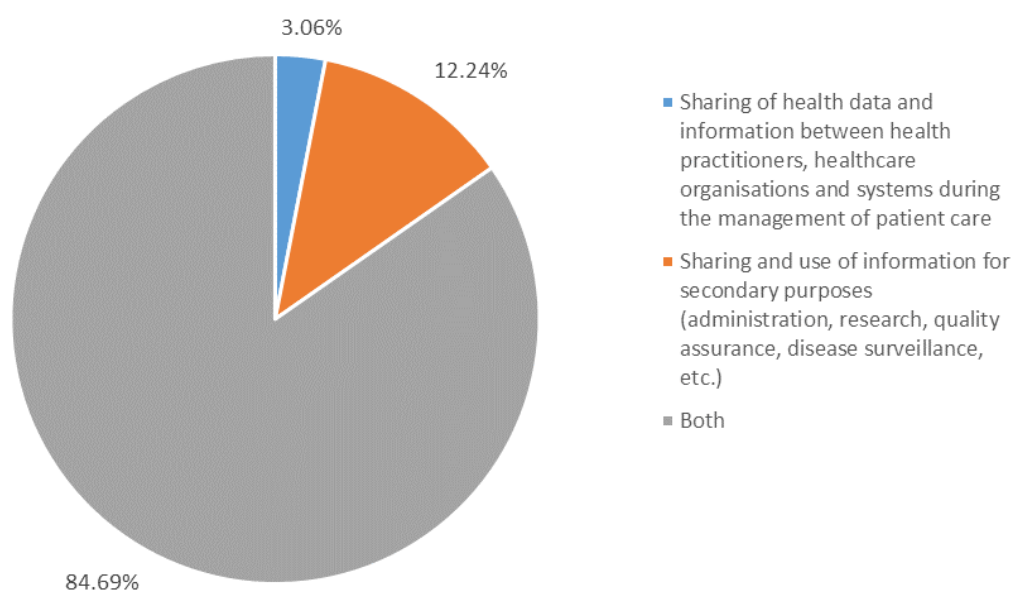
Indicate what access and use of health data primarily means to you

Answer Options	Response Percent	Response Count
Sharing of health data and information between health practitioners, healthcare organisations and systems during the management of patient care	3.06%	3
Sharing and use of information for secondary purposes (administration, research, quality assurance, disease surveillance, etc.)	12.24%	12
Both	84.69%	83
	answered question	98
	skipped question	3

Most respondents (85%) considered access and use of health data to encompass both use for primary purposes related to direct patient care and management and secondary purposes including administrative/operational purposes, research and public health. Quite importantly, only 3% considered data access and use to only concern management of patient care and just over 12% favouring the use of data for secondary purposes only. 3 participants declined to answer.

Q9 Do you agree that there is a problem with the accessibility and use of health related data in Australia?

Legend: ■ Strongly disagree ■ Disagree ■ Neither agree nor disagree ■ Agree ■ Strongly agree ■ Don't know / NA
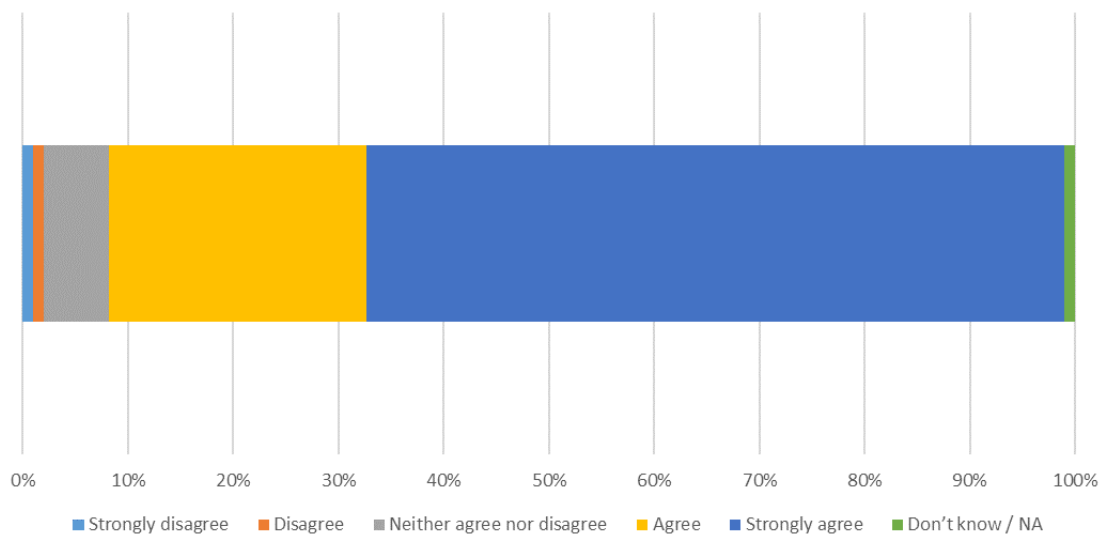
Do you agree that there is a problem with the accessibility and use of health related data in Australia?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
1	1	6	24	65	1	98
1.02%	1.02%	6.12%	24.49%	66.33%	1.02%	
					answered question	98
					skipped question	3

There is broad agreement from the respondents that health-related data is not ideally accessible and used in Australia. Over 66% strongly agree and just over 25% agree while the total disagreement is below 3%. This indicates that there is a strong case for the accessibility and use of health data to be improved.

Q10 Do you agree that the lack of accessibility and use of health related data affect healthcare, or the way healthcare professionals work, or disadvantage the community?
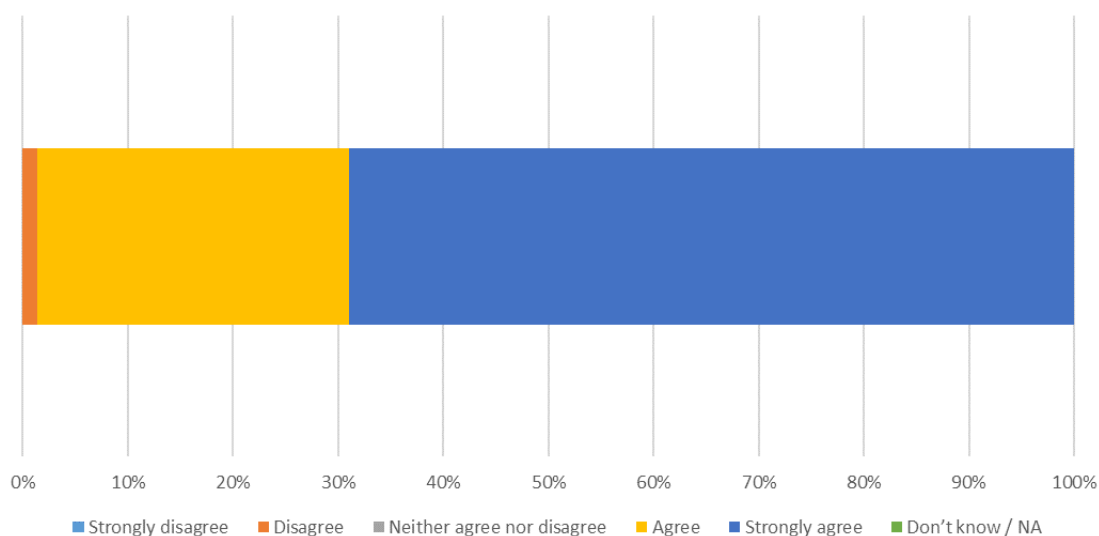
Do you agree that the lack of accessibility and use of health related data affect healthcare, or the way healthcare professionals work, or disadvantage the community?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
0	1	0	22	51	0	74
0.00%	1.35%	0.00%	29.73%	68.92%	0.00%	
					Optional comment:	21
					answered question	74
					skipped question	27

There is very strong agreement that the lack of accessibility of health-related data affects the delivery of care with around 99% of those who responded either strongly agreeing or agreeing to this question. However, 27 respondents chose to skip this question.

The comments received highlighted the issues raised in this question with many respondents pointing to the difficulties of accessing data and the lack of a "point of contact" to ascertain what is available. The presence of "health care silos" that prohibit the cross-referencing of health care data was another common theme from several respondents. Interestingly one respondent highlighted the burden imposed upon patients to manage their own documentation when suffering comorbidity or chronic disease. Other respondents pointed at the lack of opportunity to link care data at a population level in Victoria and noted access restrictions to large scale data in Queensland.

Q11 Do you agree that the community (including yourself) would derive the following benefits from increasing or improving the availability and use of health data?
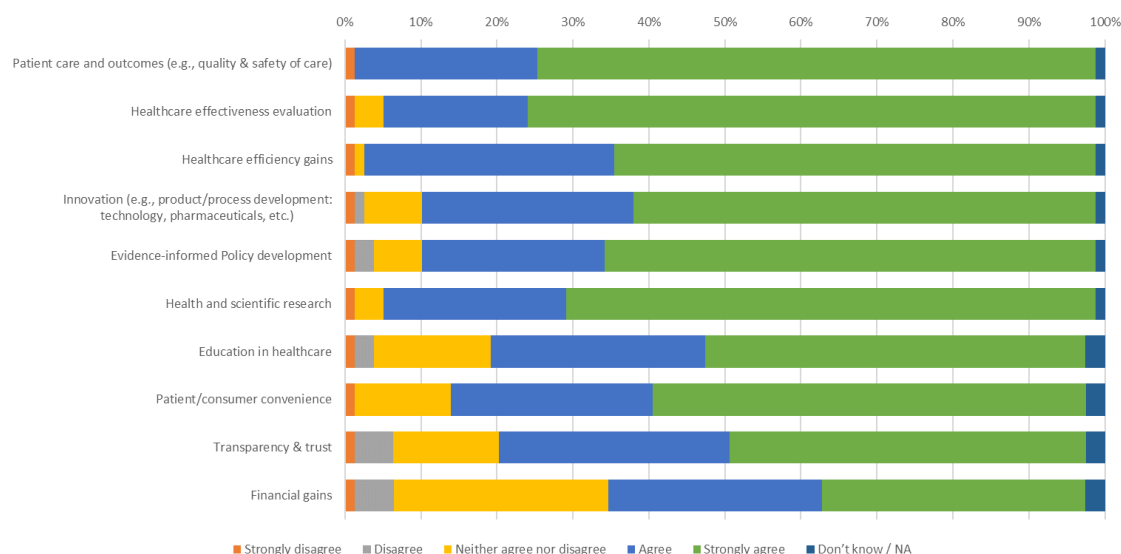
Do you agree that the community (including yourself) would derive the following benefits from increasing or improving the availability and use of health data?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Patient care and outcomes (e.g., quality & safety of care)	1 1.27%	0 0.00%	0 0.00%	19 24.05%	58 73.42%	1 1.27%	79
Healthcare effectiveness evaluation	1 1.27%	0 0.00%	3 3.80%	15 18.99%	59 74.68%	1 1.27%	79
Healthcare efficiency gains	1 1.27%	0 0.00%	1 1.27%	26 32.91%	50 63.29%	1 1.27%	79
Innovation (e.g., product/process development: technology, pharmaceuticals, etc.)	1 1.27%	1 1.27%	6 7.59%	22 27.85%	48 60.76%	1 1.27%	79
Evidence-informed Policy development	1 1.27%	2 2.53%	5 6.33%	19 24.05%	51 64.56%	1 1.27%	79
Health and scientific research	1 1.27%	0 0.00%	3 3.80%	19 24.05%	55 69.62%	1 1.27%	79
Education in healthcare	1 1.28%	2 2.56%	12 15.38%	22 28.21%	39 50.00%	2 2.56%	78
Patient/consumer convenience	1 1.27%	0 0.00%	10 12.66%	21 26.58%	45 56.96%	2 2.53%	79
Transparency & trust	1 1.27%	4 5.06%	11 13.92%	24 30.38%	37 46.84%	2 2.53%	79
Financial gains	1 1.28%	4 5.13%	22 28.21%	22 28.21%	27 34.62%	2 2.56%	78
					Comments, other benefits to consider:		10
					answered question		79
					skipped question		22

There is broad agreement among the respondents to improve the availability and use of health data in the community. The majority, between 80% and 95% agree or strongly agree that the community will derive benefits from improved availability of health data for most of the options provided. Patient care and outcomes, healthcare efficiency, effectiveness and health and scientific research were most favoured as likely benefits, while financial gains was least thought to be a likely benefit (63% agreement).

This is summed up by the comment "Improving decision making requires improved access to high quality, reliable data. The object is not to make financial gains but to minimise ineffective care."

Further commentary on this question suggested there should be a greater focus on understanding the benefits as compared to restricting data use due to potential risks which should be overcome eg:

> "Data is the new currency, we're working in a data economy, but currently the access to data is focussing on the potential risks, without a similar focus on the benefits."

> "The trust issue is a tricky one due to data privacy concerns. But if we can get past that, the availability of health data will surely lead to innovations in health care, reduced errors due to cross-checking of e.g. prescriptions with diagnoses or allergies, etc."

> "Our data is fundamental to gaining robust insight into our business. Innovation comes by leveraging the power of the wider group of data specialists in the health community, not by restricting access to a limited few. We're implementing an EMR with extremely limited flexibility to extract data in real time and report. It's incredibly frustrating and disappointing."

However, one warned "Key benefit of data is better understanding of disease progression. Data itself will not make any of these improvements unless the health system is redesigned to promote integrated care. The current health system is the problem, not the lack of data."

Q12 Do you agree that the following health data repositories should be considered 'high-value' to health data users, stakeholders or the broader community?
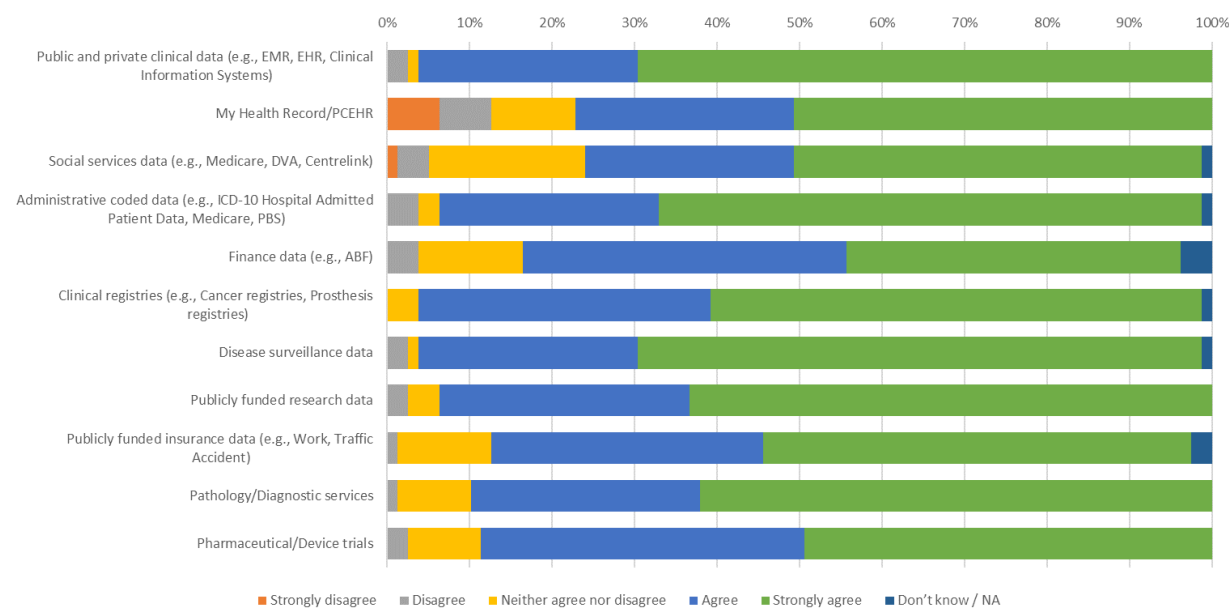
	Do you agree that the following health data repositories should be considered 'high-value' to health data users, stakeholders or the broader community?						
Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Public and private clinical data (e.g., EMR, EHR, Clinical Information Systems)	0 0.00%	2 2.53%	1 1.27%	21 26.58%	55 69.62%	0 0.00%	79
My Health Record/PCEHR	5 6.33%	5 6.33%	8 10.13%	21 26.58%	40 50.63%	0 0.00%	79
Social services data (e.g., Medicare, DVA, Centrelink)	1 1.27%	3 3.80%	15 18.99%	20 25.32%	39 49.37%	1 1.27%	79
Administrative coded data (e.g., ICD-10 Hospital Admitted Patient Data, Medicare, PBS)	0 0.00%	3 3.80%	2 2.53%	21 26.58%	52 65.82%	1 1.27%	79
Finance data (e.g., ABF)	0 0.00%	3 3.80%	10 12.66%	31 39.24%	32 40.51%	3 3.80%	79
Clinical registries (e.g., Cancer registries, Prosthesis registries)	0 0.00%	0 0.00%	3 3.80%	28 35.44%	47 59.49%	1 1.27%	79
Disease surveillance data	0 0.00%	2 2.53%	1 1.27%	21 26.58%	54 68.35%	1 1.27%	79
Publicly funded research data	0 0.00%	2 2.53%	3 3.80%	24 30.38%	50 63.29%	0 0.00%	79
Publicly funded insurance data (e.g., Work, Traffic Accident)	0 0.00%	1 1.27%	9 11.39%	26 32.91%	41 51.90%	2 2.53%	79
Pathology/Diagnostic services	0 0.00%	1 1.27%	7 8.86%	22 27.85%	49 62.03%	0 0.00%	79
Pharmaceutical/Device trials	0 0.00%	2 2.53%	7 8.86%	31 39.24%	39 49.37%	0 0.00%	79
				Comments, other high-value public sector health datasets to consider:			13
						answered question	79
						skipped question	22

There is general agreement from the respondents, with over 78% agreeing or strongly agreeing that all the health data repositories suggested should be considered of high-value. Of the suggested options, the respondents strongly agreed 'Public and private clinical data', 'Administrative coded data' and 'Disease surveillance data', in particular, to be highly valuable resources. In comparison, 'Social services data', 'My Health Record/PCEHR' and 'Finance data' were considered somewhat less valuable. More importantly, the level of disagreement was very low at less than 5% of respondents in all cases except 'My Health Record/PCEHR'.

One respondent confirmed "The above list is a great example of the breadth of what could be available, many of us have access to small parts of the whole. But consistent awareness, policy and access would repay the investment of time required to create it". Several respondents provided

further suggestions for high value data repositories and the potential benefit of linkage, including: Patient Administration Systems (PAS); Doctors Payments/hours of work/performance data; ABS SEIFA (for social deprivation data); education data, crime data; geocoding data.

Another commenter pointed out that "it's not the 'type' of data repository, but the meaningfulness and completeness of the data contained within the repository whatever it is wherever it comes from, however it is encoded... more is not better if it only gives us more junk".

Q13 For health consumers, do you agree that the following criteria could identify 'high value' datasets that would help them make informed decisions? i.e. datasets which:
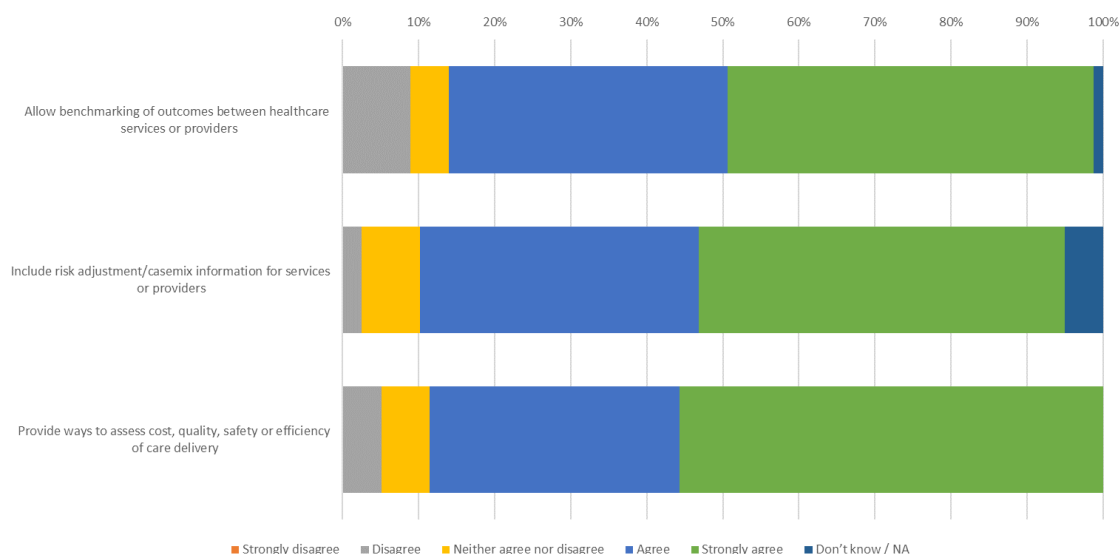
For health consumers, do you agree that the following criteria could identify 'high value' datasets that would help them make informed decisions? i.e. datasets which:							
Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Allow benchmarking of outcomes between healthcare services or providers	0 0.00%	7 8.86%	4 5.06%	29 36.71%	38 48.10%	1 1.27%	79
Include risk adjustment/casemix information for services or providers	0 0.00%	2 2.53%	6 7.59%	29 36.71%	38 48.10%	4 5.06%	79
Provide ways to assess cost, quality, safety or efficiency of care delivery	0 0.00%	4 5.06%	5 6.33%	26 32.91%	44 55.70%	0 0.00%	79
					Comments, other criteria to consider:		10
					answered question		79
					skipped question		22

Most respondents agreed or strongly agreed (more than 85%) that the proposed three criteria would facilitate better decision processes for consumers. More importantly, very few respondents disagreed or were unsure of how to answer the question, although 22 did skip the question.

There were varied comments, although a theme of "realtime" data as beneficial and several warnings about the difficulties of providing meaningful and appropriately risk-adjusted benchmarking data were evident. The difficulties consumers encounter in making decisions based on complex health data was recognised and for rural consumers, choice is not available regardless.

Q14 Which health data repositories would provide 'high value' to consumers in helping them make informed decisions?
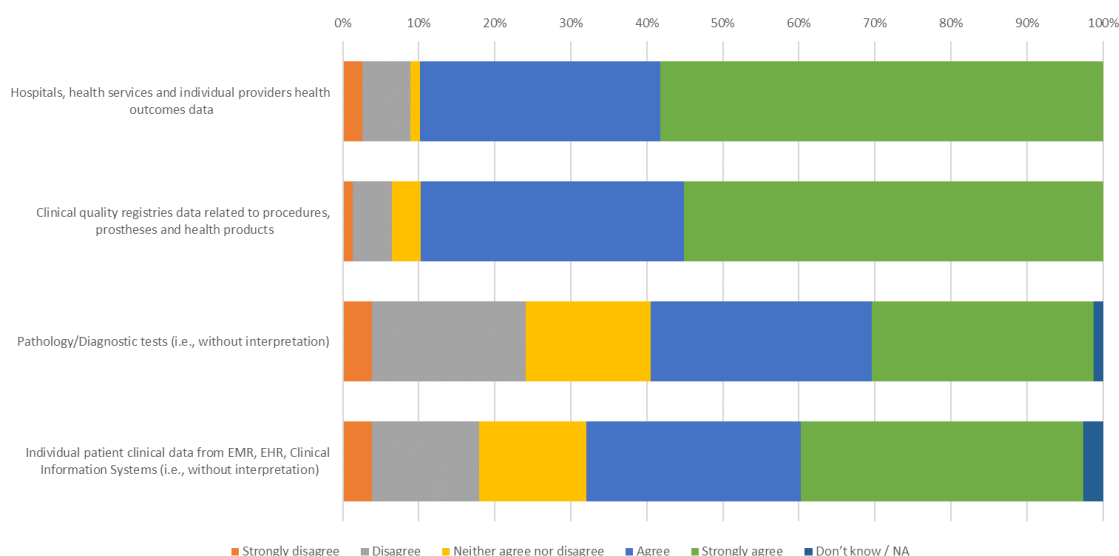
Which health data repositories would provide 'high value' to consumers in helping them make informed decisions?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Hospitals, health services and individual providers health outcomes data	2 2.53%	5 6.33%	1 1.27%	25 31.65%	46 58.23%	0 0.00%	79
Clinical quality registries data related to procedures, prostheses and health products	1 1.28%	4 5.13%	3 3.85%	27 34.62%	43 55.13%	0 0.00%	78
Pathology/Diagnostic tests (i.e., without interpretation)	3 3.80%	16 20.25%	13 16.46%	23 29.11%	23 29.11%	1 1.27%	79
Individual patient clinical data from EMR, EHR, Clinical Information Systems (i.e., without interpretation)	3 3.85%	11 14.10%	11 14.10%	22 28.21%	29 37.18%	2 2.56%	78
					Comments, other datasets to consider:		14
						answered question	79
						skipped question	22

Responses to this question varied with the first two repositories ('Hospitals, health services and individual providers health outcomes data' and 'Clinical quality registries data related to procedures, prostheses and health products') strongly supported by the respondents (both approximately 90%), but the last two ('Pathology/Diagnostic tests (i.e., without interpretation)' and 'Individual patient clinical data from EMR, EHR, Clinical Information Systems (i.e., without interpretation)') showing less support (58% and 65%). One probable contributing factor to this variation in responses is the addition of "without interpretation" to the description of the latter data repositories, again indicating the need for the data to be meaningful to the consumer, as further evidenced in submitted comments.

Comments relating to "interpretation is crucial" included "Interpretation is important and obviously would assist consumers, but even without this I believe access to information is valuable" and "The data repositories are high value themselves, but appropriate analysis & interpretation is always key to realising their benefit".

The imperative for providing information to health consumers was summarised by "Patients as consumers are the new health workforce. They need access to the same data that clinicians have in order to make the right decisions for their own care and the care of their dependants."

Q15 How much do you agree that data in the following 'high-value' health related data repositories are currently being used effectively?
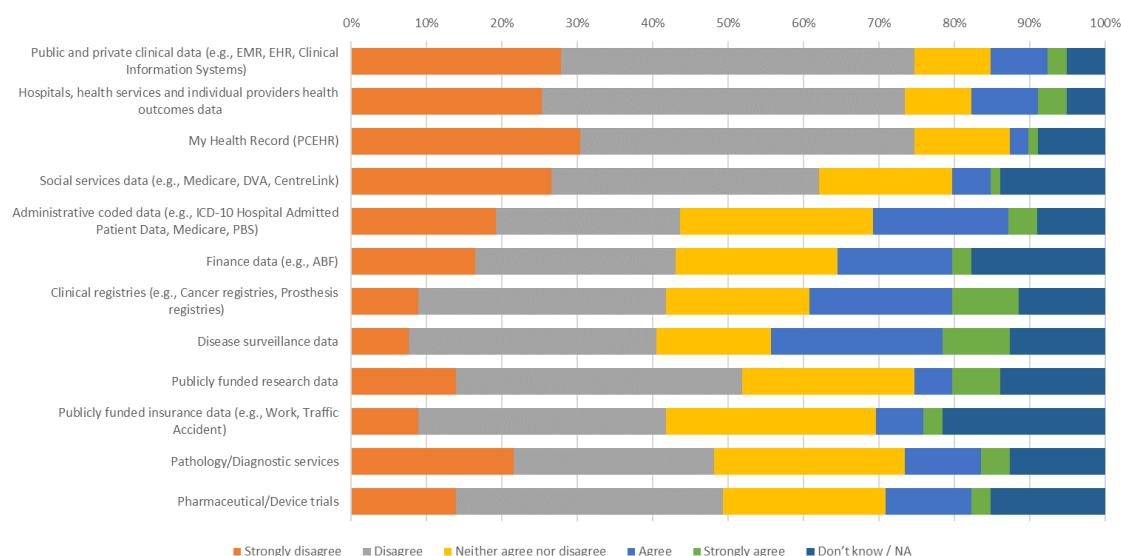
How much do you agree that data in the following 'high-value' health related data repositories are currently being used effectively?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Public and private clinical data (e.g., EMR, EHR, Clinical Information Systems)	22 27.85%	37 46.84%	8 10.13%	6 7.59%	2 2.53%	4 5.06%	79
Hospitals, health services and individual providers health outcomes data	20 25.32%	38 48.10%	7 8.86%	7 8.86%	3 3.80%	4 5.06%	79
My Health Record (PCEHR)	24 30.38%	35 44.30%	10 12.66%	2 2.53%	1 1.27%	7 8.86%	79
Social services data (e.g., Medicare, DVA, CentreLink)	21 26.58%	28 35.44%	14 17.72%	4 5.06%	1 1.27%	11 13.92%	79
Administrative coded data (e.g., ICD-10 Hospital Admitted Patient Data, Medicare, PBS)	15 19.23%	19 24.36%	20 25.64%	14 17.95%	3 3.85%	7 8.97%	78
Finance data (e.g., ABF)	13 16.46%	21 26.58%	17 21.52%	12 15.19%	2 2.53%	14 17.72%	79
Clinical registries (e.g., Cancer registries, Prosthesis registries)	7 8.86%	26 32.91%	15 18.99%	15 18.99%	7 8.86%	9 11.39%	79
Disease surveillance data	6 7.59%	26 32.91%	12 15.19%	18 22.78%	7 8.86%	10 12.66%	79
Publicly funded research data	11 13.92%	30 37.97%	18 22.78%	4 5.06%	5 6.33%	11 13.92%	79
Publicly funded insurance data (e.g., Work, Traffic Accident)	7 8.86%	26 32.91%	22 27.85%	5 6.33%	2 2.53%	17 21.52%	79
Pathology/Diagnostic services	17 21.52%	21 26.58%	20 25.32%	8 10.13%	3 3.80%	10 12.66%	79
Pharmaceutical/Device trials	11 13.92%	28 35.44%	17 21.52%	9 11.39%	2 2.53%	12 15.19%	79
Comments, other high-value public sector health datasets to consider:							12
answered question							79
skipped question							22

Overall there was more disagreement than agreement with the idea that data from these high value data repositories is being used well. Only 3-30% of respondents felt any of these repositories were being used effectively.

In particular, the majority of respondents (73-75% disagreement with effective use) felt that 'Public and private clinical data', 'Health outcomes data', 'My Health Record data' and to a lesser extent (52-62% disagreement with effective use) 'Social services data' and 'Publicly funded research data' were NOT used effectively.

In contrast, the responses were less critical, but still more disagreeing for effective use of 'Administrative coded data', 'Finance data', 'Clinical registries', 'Disease surveillance data', 'Publicly funded insurance data', 'Pathology/Diagnostic services' and 'Pharmaceutical/Device trials' (41-50% agreement with effective use).

There was also a relatively large number of respondents who answered 'Don't know' (5-18%) for this question.

Some respondents commented on the need for linkage of these datasets with examples such as "social determinants of health and linking this to health outcomes data, health service access etc" or "Adverse drug reports Provider data including Medicare provider numbers and prescriber numbers linked to AHPRA number and HPI-I ". Some respondents pointed to the lack of consistency across jurisdictions "without doubt some data is of high value but it is fragmented and not consistent across jurisdictions, i.e. not all ICD 10 coding is adequate, not everyone uses PCEHR". The lack of adequacy of the data for required purposes was also a theme along with "Lack of disclosure and availability" as being contributing factors to the ineffective use of these data repositories.

Q16 What are the main barriers that restrict the accessibility and use of health related data? – including accessibility and use by healthcare providers/ consumers/ researchers/ businesses.
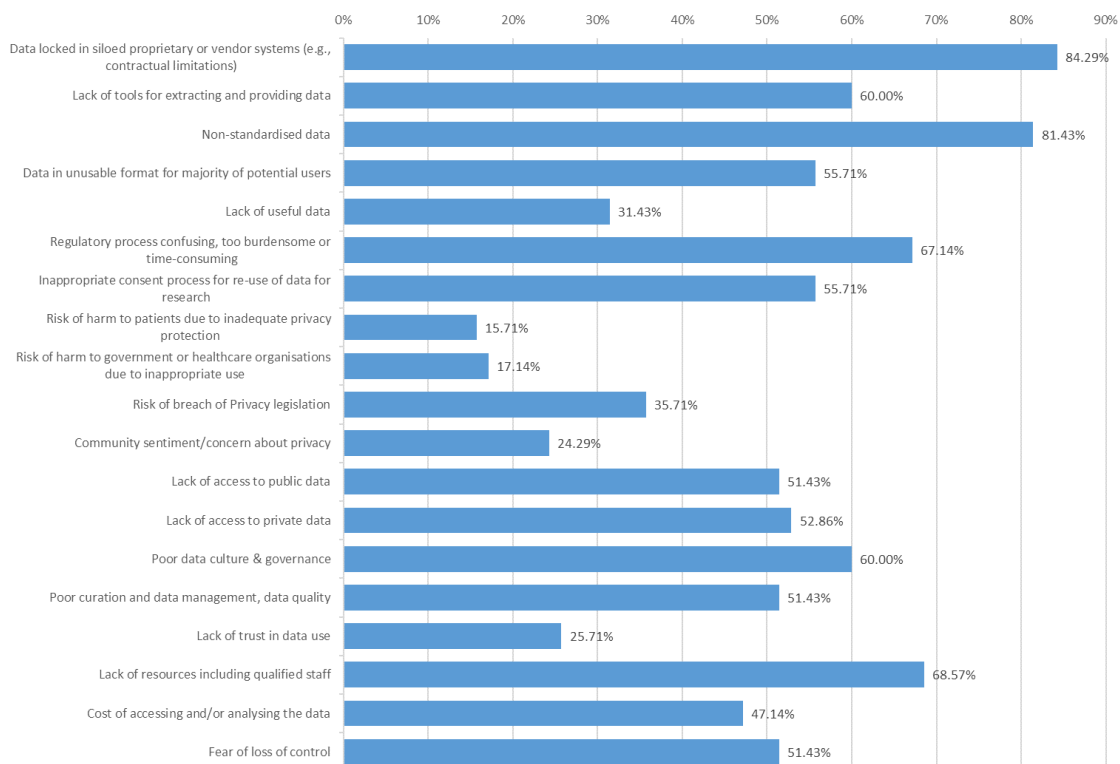
What are the main barriers that restrict the accessibility and use of health related data? – including accessibility and use by healthcare providers/ consumers/ researchers/ businesses.

Answer Options	Response Percent	Response Count
Data locked in siloed proprietary or vendor systems (e.g., contractual limitations)	84.29%	59
Lack of tools for extracting and providing data	60.00%	42
Non-standardised data	81.43%	57
Data in unusable format for majority of potential users	55.71%	39
Lack of useful data	31.43%	22
Regulatory process confusing, too burdensome or time-consuming	67.14%	47
Inappropriate consent process for re-use of data for research	55.71%	39
Risk of harm to patients due to inadequate privacy protection	15.71%	11
Risk of harm to government or healthcare organisations due to inappropriate use	17.14%	12
Risk of breach of Privacy legislation	35.71%	25
Community sentiment/concern about privacy	24.29%	17
Lack of access to public data	51.43%	36
Lack of access to private data	52.86%	37
Poor data culture & governance	60.00%	42
Poor curation and data management, data quality	51.43%	36
Lack of trust in data use	25.71%	18
Lack of resources including qualified staff	68.57%	48
Cost of accessing and/or analysing the data	47.14%	33
Fear of loss of control	51.43%	36
Comments, other factors:		18
answered question		70
skipped question		31

This question offered respondents a wide variety of suggestions as potential barriers to data accessibility and use. The most frequently chosen reasons were 'Data locked in siloed proprietary or vendor systems (e.g., contractual limitations)' (84%), 'Non-standardised data' (81%), followed by 'Lack of Resources' and difficult 'Regulatory processes' (69%, 67%). 'Lack of tools for extracting data' and 'Poor data culture & governance' were also selected as important by 60%.

The options considered least important as barriers included 'Risk of harm to patients due to inadequate privacy protection' (15%) and 'Risk of harm to government or organisations due to inappropriate use' (17%). Community sentiment/concern about privacy' (25%) and 'Lack of trust in data use' (26%) were also considered less important barriers.

Comments from the respondents reiterated under-resourcing and lack of training in data related competencies including data management, governance and analytics skills. Culture was also a strong theme as a barrier "Health care culture is one of inertia and in providing access to data there is a fear of something going wrong that vastly outweighs the actual risk of something going wrong and maintains the inertia." One further mentioned an inherent difficulty with much health data "80% of data is in text and there are few technologies available to manipulate this".

Q17 What are the reasonable concerns that organisations may have about increasing the availability of health data in their control?
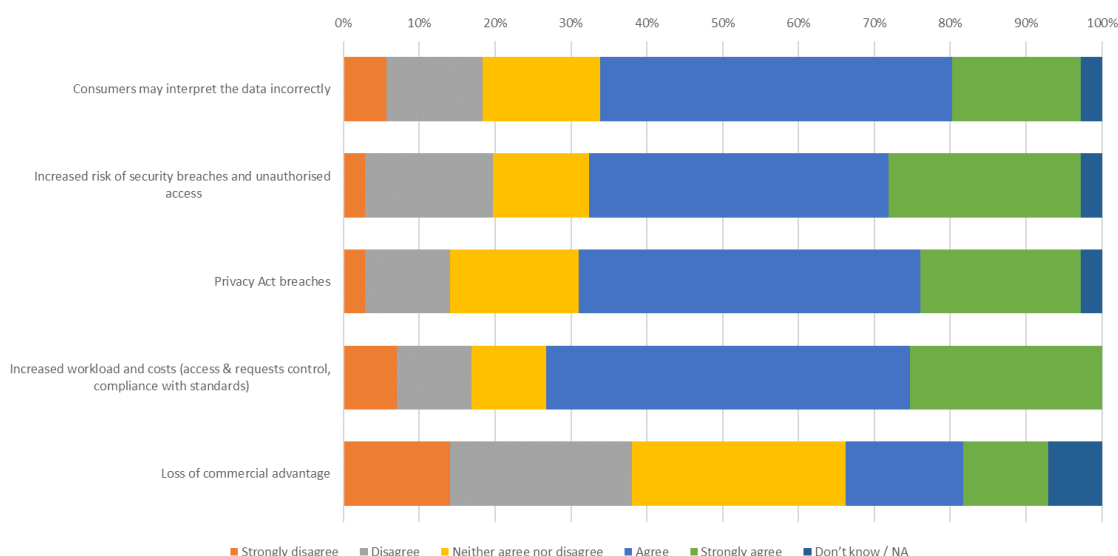
Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Consumers may interpret the data incorrectly	4 5.63%	9 12.68%	11 15.49%	33 46.48%	12 16.90%	2 2.82%	71
Increased risk of security breaches and unauthorised access	2 2.82%	12 16.90%	9 12.68%	28 39.44%	18 25.35%	2 2.82%	71
Privacy Act breaches	2 2.82%	8 11.27%	12 16.90%	32 45.07%	15 21.13%	2 2.82%	71
Increased workload and costs (access & requests control, compliance with standards)	5 7.04%	7 9.86%	7 9.86%	34 47.89%	18 25.35%	0 0.00%	71
Loss of commercial advantage	10 14.08%	17 23.94%	20 28.17%	11 15.49%	8 11.27%	5 7.04%	71
Comments, other concerns to consider:							8
answered question							71
skipped question							30

There was moderate agreement that most of the suggested options might be reasonable concerns for organisations when sharing data. The most well supported (73% agreement) was 'Increased workload and costs (access & requests control, compliance with standards)'. Misinterpretation of data by consumers and risk of security or privacy breaches were agreed to by approximately 65% of respondents. The least well supported option as a reasonable concern was 'Loss of commercial advantage' with only 27% agreeing and close to 38% disagreeing with this being a reasonable concern.

Comments suggested that the concerns presented were "last century" and solvable, with practical solutions readily available. One summarised the sentiment with: "Our only concern should be to mitigate risk from external security/privacy breaches. As with existing front end information systems all Health employees agree to use information appropriately. All other issues are surmountable".

The disregard for concerns regarding commercial advantage was summed up with "Loss of commercial advantage is not a reasonable concern in relation to health data sharing. Commercial and financially sustainable models must be developed that do not commoditise health data"

Q18 Do you agree that the following measures could facilitate more efficient and effective use of health data collections?
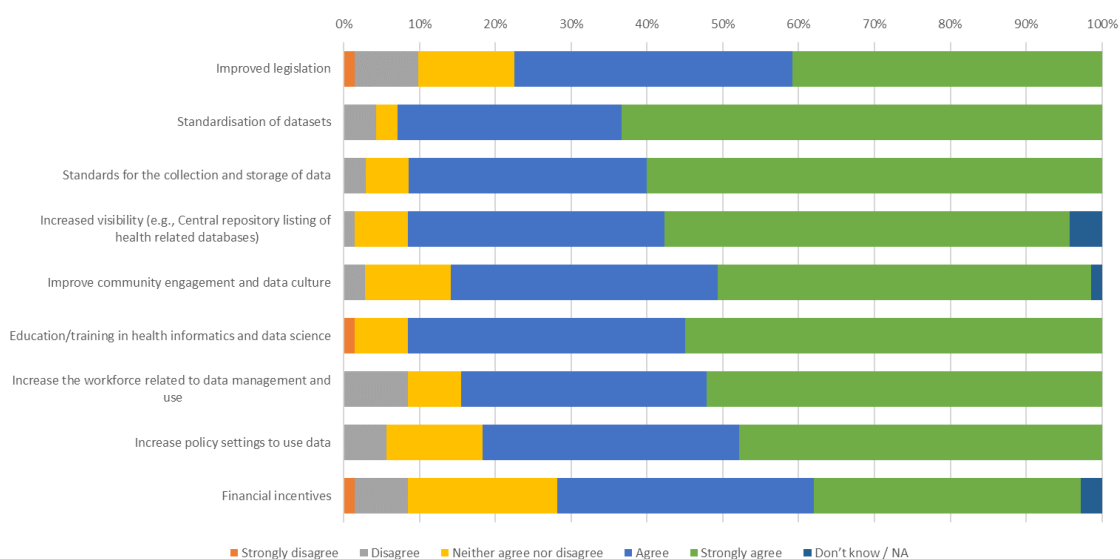
Do you agree that the following measures could facilitate more efficient and effective use of health data collections?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Improved legislation	1 / 1.41%	6 / 8.45%	9 / 12.68%	26 / 36.62%	29 / 40.85%	0 / 0.00%	71
Standardisation of datasets	0 / 0.00%	3 / 4.23%	2 / 2.82%	21 / 29.58%	45 / 63.38%	0 / 0.00%	71
Standards for the collection and storage of data	0 / 0.00%	2 / 2.86%	4 / 5.71%	22 / 31.43%	42 / 60.00%	0 / 0.00%	70
Increased visibility (e.g., Central repository listing of health related databases)	0 / 0.00%	1 / 1.41%	5 / 7.04%	24 / 33.80%	38 / 53.52%	3 / 4.23%	71
Improve community engagement and data culture	0 / 0.00%	2 / 2.82%	8 / 11.27%	25 / 35.21%	35 / 49.30%	1 / 1.41%	71
Education/training in health informatics and data science	1 / 1.41%	0 / 0.00%	5 / 7.04%	26 / 36.62%	39 / 54.93%	0 / 0.00%	71
Increase the workforce related to data management and use	0 / 0.00%	6 / 8.45%	5 / 7.04%	23 / 32.39%	37 / 52.11%	0 / 0.00%	71
Increase policy settings to use data	0 / 0.00%	4 / 5.63%	9 / 12.68%	24 / 33.80%	34 / 47.89%	0 / 0.00%	71
Financial incentives	1 / 1.41%	5 / 7.04%	14 / 19.72%	24 / 33.80%	25 / 35.21%	2 / 2.82%	71
						answered question	71
						skipped question	30

There was strong general agreement (over 70-90%) that the suggested measures could facilitate more efficient and effective use of health data collections. The most well supported were 'Standardisation of datasets', 'Standards for the collection and storage of data', 'Increased visibility' and 'Education/training in health informatics and data science' (all over 87%).

The least most effective measures, although still seen as potentially useful, were considered to be 'Financial incentives ' (69% agreement) and 'Improved legislation' (77% agreement). However, there was little opposition to any of the options provided, the highest being a total of 10% to the 'Improved Legislation' option.

There were no comments for this question.

Q19 Do you agree that the following would most likely address Privacy and Security concerns for sharing the data?
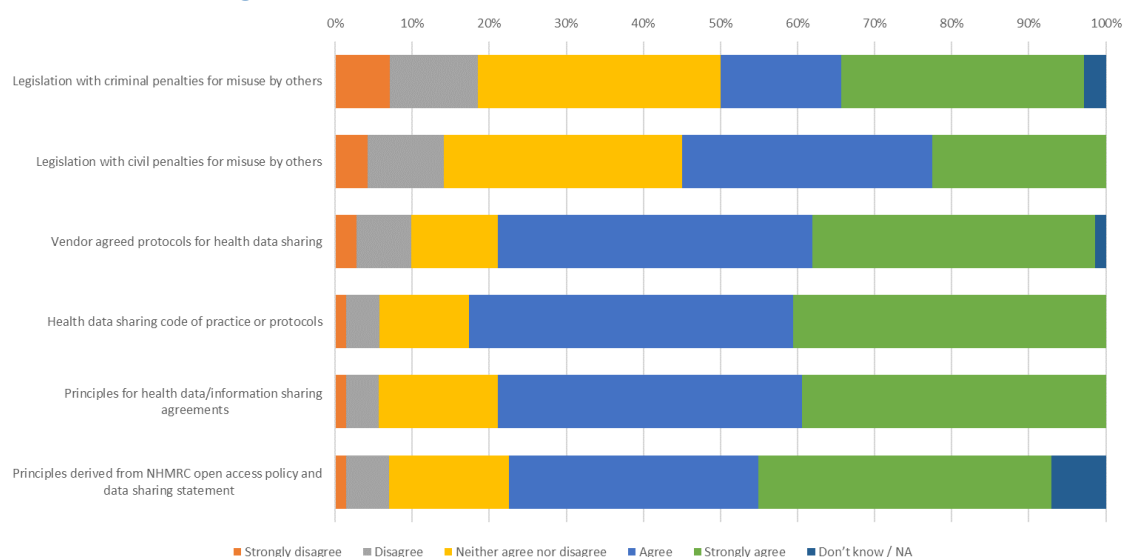
Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Legislation with criminal penalties for misuse by others	5 7.14%	8 11.43%	22 31.43%	11 15.71%	22 31.43%	2 2.86%	70
Legislation with civil penalties for misuse by others	3 4.23%	7 9.86%	22 30.99%	23 32.39%	16 22.54%	0 0.00%	71
Vendor agreed protocols for health data sharing	2 2.82%	5 7.04%	8 11.27%	29 40.85%	26 36.62%	1 1.41%	71
Health data sharing code of practice or protocols	1 1.45%	3 4.35%	8 11.59%	29 42.03%	28 40.58%	0 0.00%	69
Principles for health data/information sharing agreements	1 1.41%	3 4.23%	11 15.49%	28 39.44%	28 39.44%	0 0.00%	71
Principles derived from NHMRC open access policy and data sharing statement	1 1.41%	4 5.63%	11 15.49%	23 32.39%	27 38.03%	5 7.04%	71
			Comments, other principles, protocols or legislative requirements to consider:				8
						answered question	71
						skipped question	30

This question broadly asked what the most appropriate methods would be for addressing privacy and security issues when sharing health data.

Whilst agreed to by close to half of the respondents, the proportions of disagreeing or undecided respondents for legal solutions were larger than for other suggested solutions. Thus 19% believed that criminal penalties were not the appropriate method for addressing privacy and Security issues. 47% agreed with criminal penalties while 31% did not have an opinion in this matter. A slightly higher number (54%) were in favour of civil penalties which had less objection (14%).

A majority (77%) were in favour of vendor agreed protocols and an even great number (83%) for agreed protocols for data sharing. Principles for health data sharing agreements was popular (79% agreeing) as was NHMRC open access information policy (70% agreeing).

Q20 Do you agree that the best way to manage the risks and consequences of both public and private sector health data breaches is to:
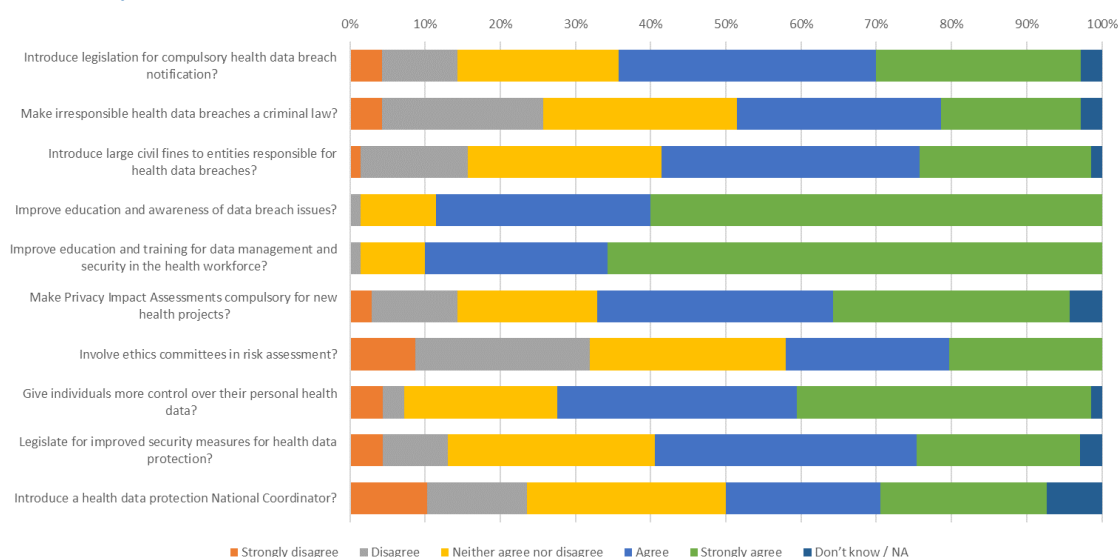
Do you agree that the best way to manage the risks and consequences of both public and private sector health data breaches is to:

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Introduce legislation for compulsory health data breach notification?	3 4.29%	7 10.00%	15 21.43%	24 34.29%	19 27.14%	2 2.86%	70
Make irresponsible health data breaches a criminal law?	3 4.29%	15 21.43%	18 25.71%	19 27.14%	13 18.57%	2 2.86%	70
Introduce large civil fines to entities responsible for health data breaches?	1 1.43%	10 14.29%	18 25.71%	24 34.29%	16 22.86%	1 1.43%	70
Improve education and awareness of data breach issues?	0 0.00%	1 1.43%	7 10.00%	20 28.57%	42 60.00%	0 0.00%	70
Improve education and training for data management and security in the health workforce?	0 0.00%	1 1.43%	6 8.57%	17 24.29%	46 65.71%	0 0.00%	70
Make Privacy Impact Assessments compulsory for new health projects?	2 2.86%	8 11.43%	13 18.57%	22 31.43%	22 31.43%	3 4.29%	70
Involve ethics committees in risk assessment?	6 8.70%	16 23.19%	18 26.09%	15 21.74%	14 20.29%	0 0.00%	69
Give individuals more control over their personal health data?	3 4.35%	2 2.90%	14 20.29%	22 31.88%	27 39.13%	1 1.45%	69
Legislate for improved security measures for health data protection?	3 4.35%	6 8.70%	19 27.54%	24 34.78%	15 21.74%	2 2.90%	69
Introduce a health data protection National Coordinator?	7 10.29%	9 13.24%	18 26.47%	14 20.59%	15 22.06%	5 7.35%	68
					Comments, other examples to consider:		9
						answered question	70
						skipped question	31

As a way of managing the risks and consequences of health data breaches, legal options provided moderate support (46-51%), with only 14% disagreeing with the introduction of compulsory breach notification while 26% disagreed that irresponsible breaches should be treated as a criminal act and 16% disagreed with the introduction of large civil fines.

A small majority of respondents (56%) believed that we should legislate to improve security measures for health data protection with only 13% disagreeing with this option. The introduction of a National coordinator for health data protection had a mixed response with 43% agreeing and 24% disagreeing while 26% were neutral on this option.

In the two most favoured options, 90% of the respondents agreed that improvements in education and awareness of data breach issues was important and of those 60% 'strongly' agreed. The figures for improvements in education in the health workforce for data management and security issues had very similar responses (90% agreeing with 65% strongly agreeing).

Also relatively popular, a majority of 63% agreed with the use of Privacy Impact Assessments for all new projects and this was considered of similar utility to individuals having more control over their own personal health data with interestingly very few respondents (7%) disagreeing.

There was a mixed response on the involvement of ethics committees to undertake risk assessment (42% agreeing and 31% disagreeing) and this was least favoured followed with the introduction of a Health Data Protection National Coordinator.

Q21 Do you agree that to improve coordination across jurisdictions in regard to health data privacy protection, this would best be improved by:
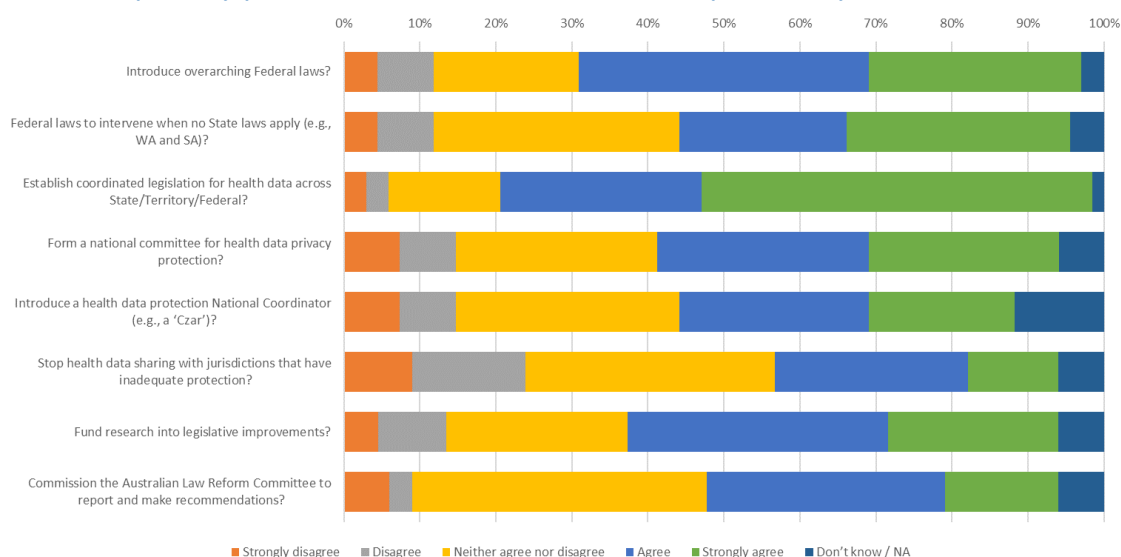
Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Introduce overarching Federal laws?	3 4.41%	5 7.35%	13 19.12%	26 38.24%	19 27.94%	2 2.94%	68
Federal laws to intervene when no State laws apply (e.g., WA and SA)?	3 4.41%	5 7.35%	22 32.35%	15 22.06%	20 29.41%	3 4.41%	68
Establish coordinated legislation for health data across State/Territory/Federal?	2 2.94%	2 2.94%	10 14.71%	18 26.47%	35 51.47%	1 1.47%	68
Form a national committee for health data privacy protection?	5 7.35%	5 7.35%	18 26.47%	19 27.94%	17 25.00%	4 5.88%	68
Introduce a health data protection National Coordinator (e.g., a 'Czar')?	5 7.35%	5 7.35%	20 29.41%	17 25.00%	13 19.12%	8 11.76%	68
Stop health data sharing with jurisdictions that have inadequate protection?	6 8.96%	10 14.93%	22 32.84%	17 25.37%	8 11.94%	4 5.97%	67
Fund research into legislative improvements?	3 4.48%	6 8.96%	16 23.88%	23 34.33%	15 22.39%	4 5.97%	67
Commission the Australian Law Reform Committee to report and make recommendations?	4 5.97%	2 2.99%	26 38.81%	21 31.34%	10 14.93%	4 5.97%	67
					Comments, other options to consider:		6
					answered question		68
					skipped question		33

This question looked at the best ways that coordination across the various jurisdictions could be improved when sharing health data. In particular the gaps in the laws and how national committees or representatives could provide support.

The Federal Laws are not necessarily overarching, e.g. the Commonwealth Privacy Act 1988. 66% of the respondents agreed that Federal laws should be overarching while 51% agreed that Federal laws should intervene where no State laws exist, with few disagreeing (12%).

The majority clearly agreed (77%) with over half of the respondents 'strongly' agreeing (51%) to the need for coordinated legislation for health data across state/federal/territory.

A national committee for health data protection was generally supported (53%) while 26% were undecided. Less agreed with the introduction of a National Coordinator (44%) although few disagreed (15%).

The more radical step of stopping data sharing with jurisdiction that have inadequate protections was not greatly supported (37%) with 24% disagreeing with this approach. Research funding into legislative improvements was supported (57% agreeing) with less agreeing (46%) that the Australian Law Reform Committee should report legislative recommendations.

Q22 Do you agree that the existing approaches to confidentialisation, such as de-identification, are effective in facilitating data sharing while protecting privacy?

■ Strongly disagree ■ Disagree ■ Neither agree nor disagree ■ Agree ■ Strongly agree ■ Don't know / NA
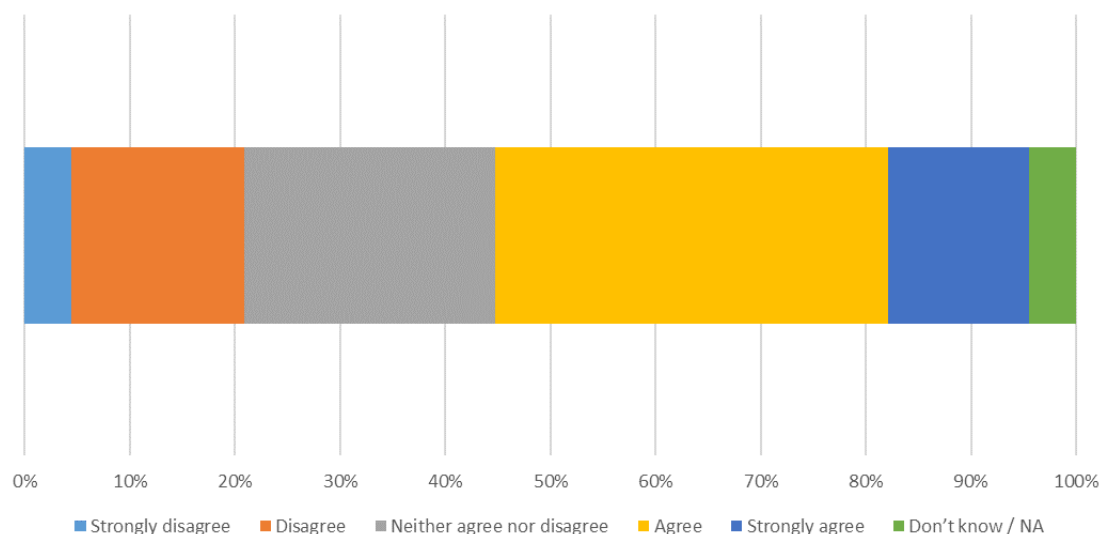
Do you agree that the existing approaches to confidentialisation, such as de-identification, are effective in facilitating data sharing while protecting privacy?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
3	11	16	25	9	3	67
4.48%	16.42%	23.88%	37.31%	13.43%	4.48%	
					Other (please specify)	7
					answered question	67
					skipped question	34

Around half of the respondents (51%) agreed that existing approaches to confidentialised data are effective in facilitating data sharing while protecting privacy, however most of this (37%) was not strong agreement, which was only indicated by 13%. Notably more were neutral (24%) than disagreed (21%) and only 4% felt they did not know.

This reservation in strong support of current approaches to confidentialisation without strong disagreement was reflected in comments which indicated there is room for improvement. Concerns regarding re-identification especially for small subgroups in populations were raised e.g. "De-identification is misleading in the context of data linkage across multiple, large, national datasets. Re-identification through big data triangulation techniques means that the data is not really de-identified, so privacy is not protected. Identifiable data could improve data quality and health outcomes while still protecting privacy." Concern regarding the ability to apply the existing approaches and other technology was also raised e.g. "The current approaches might be effective where they are used properly, but the problem is that there are insufficient people in the workplace that understand how to do this and provide enough support for this".

Q23 How much do you agree that the following levels should bear the responsibility for determining and directing changes in the accessibility and use of health related data?
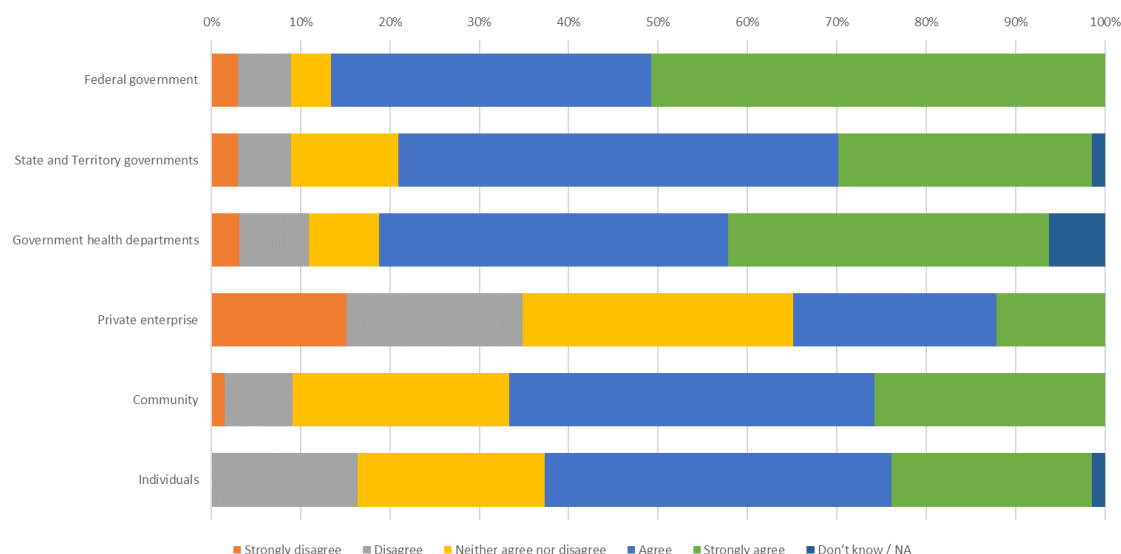
How much do you agree that the following levels should bear the responsibility for determining and directing changes in the accessibility and use of health related data?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Federal government	2 2.99%	4 5.97%	3 4.48%	24 35.82%	34 50.75%	0 0.00%	67
State and Territory governments	2 2.99%	4 5.97%	8 11.94%	33 49.25%	19 28.36%	1 1.49%	67
Government health departments	2 3.13%	5 7.81%	5 7.81%	25 39.06%	23 35.94%	4 6.25%	64
Private enterprise	10 15.15%	13 19.70%	20 30.30%	15 22.73%	8 12.12%	0 0.00%	66
Community	1 1.52%	5 7.58%	16 24.24%	27 40.91%	17 25.76%	0 0.00%	66
Individuals	0 0.00%	11 16.42%	14 20.90%	26 38.81%	15 22.39%	1 1.49%	67
						Comments, other:	5
						answered question	68
						skipped question	33

With 87% agreement (51% strong agreement) the Federal government was seen to be the best option to be responsible for and direct changes for the access and use of health related data. State/Territory Governments and Government Health Departments were also nominated nearly as strongly (77-78% agreement), all with only 9% disagreement.

Individuals and the community both gained moderate support (51-67%), but respondents were ambivalent about Private Enterprise playing a role with 35% agreement, 35% disagreement and 30% neither agree or disagree.

Submitted comments gave various opinions that patients and custodians should have control, but that patients also wanted their data to be used and allowing use of de-identified data might be a consideration for services using taxpayers funds. A comment which might summarise this sentiment would be "All parties need to be involved, but national leadership representative of community views is required"

Q24 Who should have the ownership rights to health data that is generated by individuals but collected by healthcare organisations or businesses?
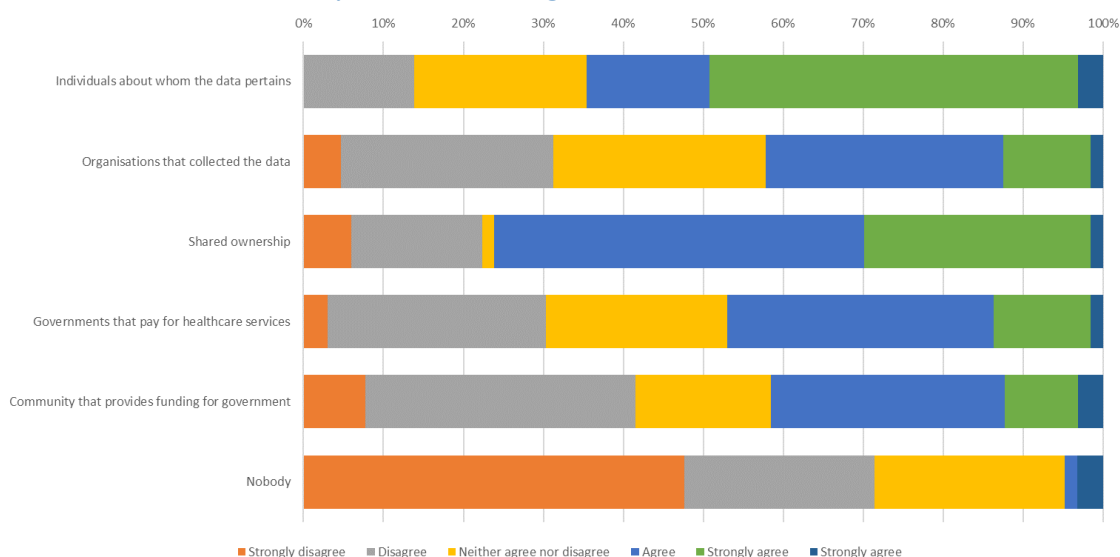
Who should have the ownership rights to health data that is generated by individuals but collected by healthcare organisations or businesses?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Strongly agree	Response Count
Individuals about whom the data pertains	0 0.00%	9 13.85%	14 21.54%	10 15.38%	30 46.15%	2 3.08%	65
Organisations that collected the data	3 4.69%	17 26.56%	17 26.56%	19 29.69%	7 10.94%	1 1.56%	64
Shared ownership	4 5.97%	11 16.42%	1 1.49%	31 46.27%	19 28.36%	1 1.49%	67
Governments that pay for healthcare services	2 3.03%	18 27.27%	15 22.73%	22 33.33%	8 12.12%	1 1.52%	66
Community that provides funding for government	5 7.69%	22 33.85%	11 16.92%	19 29.23%	6 9.23%	2 3.08%	65
Nobody	30 47.62%	15 23.81%	15 23.81%	1 1.59%	0 0.00%	2 3.17%	63
				Comments, other ownership to consider:			5
						answered question	68
						skipped question	33

Ownership of health data is a pertinent issue that can determine the successful sharing for the common good. A majority (61%) agree that the individual to whom the data pertains should have the ownership rights. Less so for the organisations that collect this information (40% agree). A shared ownership arrangement has the agreement of 75% of respondents while government ownership where they paid for the health service only had 45% support with 30% disagreeing. More disagree (41%) that the community that provides funding should have ownership compared with 38% who agreed. Where nobody should own it, then there was strong disagreement (48%) and with 72% disagreeing with this option overall.

Q25 Do you agree that unclear health data ownership inhibits its availability and use?
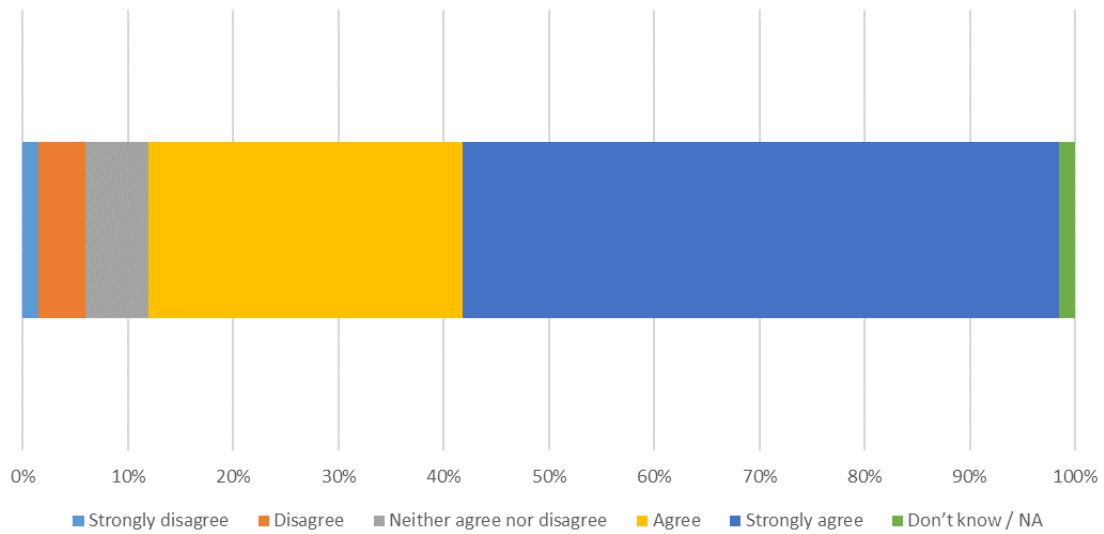
Do you agree that unclear health data ownership inhibits its availability and use?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
1	3	4	20	38	1	67
1.49%	4.48%	5.97%	29.85%	56.72%	1.49%	
					answered question	67
					skipped question	34

The vast majority (87%) agree that the unclear situation with health data ownership is inhibiting its availability and use. In fact there is a majority overall in 'strong' agreement (57%) with this statement and only 6% disagreeing.

Q26 Do you agree there are circumstances where health related data could be commoditised or monetised for financial gain?
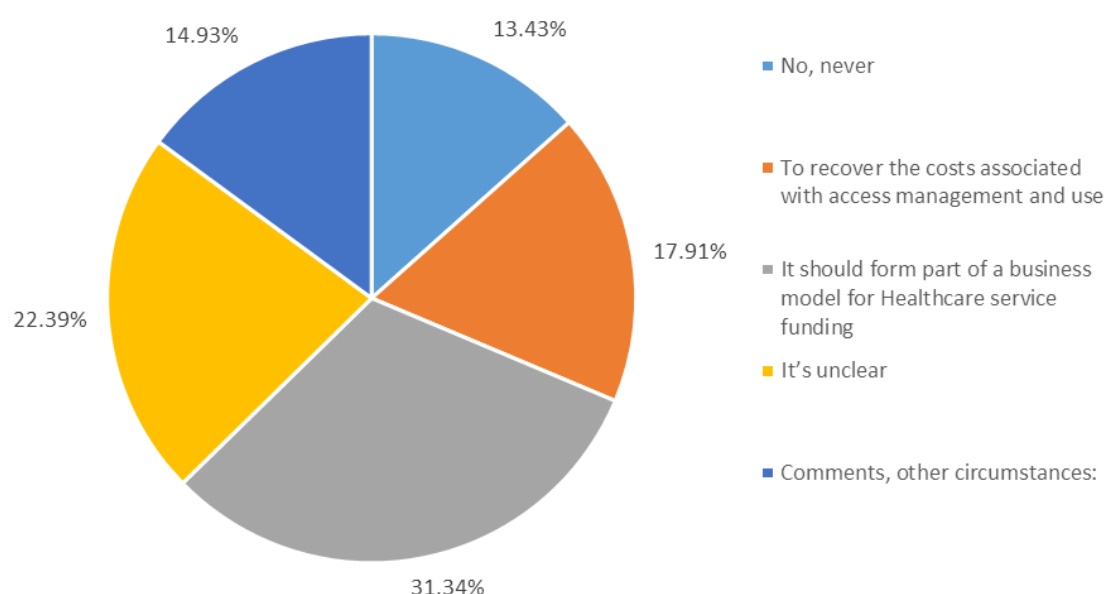
Do you agree there are circumstances where health related data could be commoditised or monetised for financial gain?

Answer Options	Response Percent	Response Count
No, never	13.43%	9
To recover the costs associated with access management and use	17.91%	12
It should form part of a business model for Healthcare service funding	31.34%	21
It's unclear	22.39%	15
Comments, other circumstances:	14.93%	10
	answered question	67
	skipped question	34

The monetisation of health data is growing and is probably more prevalent in overseas societies than in Australia. Only 13% of 67 respondents considered that there are never circumstances where health related data could be commoditised or monetised for financial gain, while 18% agreed this could occur to recover the costs associated with access management and use and 31% considered it should form part of a business model for health care service funding. Nevertheless 22% agreed this situation is unclear, suggesting further community discussion and consultation is required in this area.

Several comments evidenced a belief that monetisation is already occurring and is inevitable with discussion regarding how those resulting funds should be disbursed: "This is already happening - and has huge potential to assist personalised medicine in the future. But we need a framework to consider the issues and determine community views on what is acceptable."

There were some strong sentiments against putting public data in the 'for profit' sector domain eg Telstra's movement into the health data space, but also suggestion that this may be beneficial in the long run "The focus should be on maximising the public good benefits which will become available from opening up data and also on monitoring the productivity and improved healthcare outcomes that are generated as a result".

Q27 In the context of overall healthcare expenditure, do you agree a sufficient proportion of funding is directed to data-related resources?

■ Strongly disagree   ■ Disagree   ■ Neither agree nor disagree   ■ Agree   ■ Strongly agree   ■ Don't know / NA
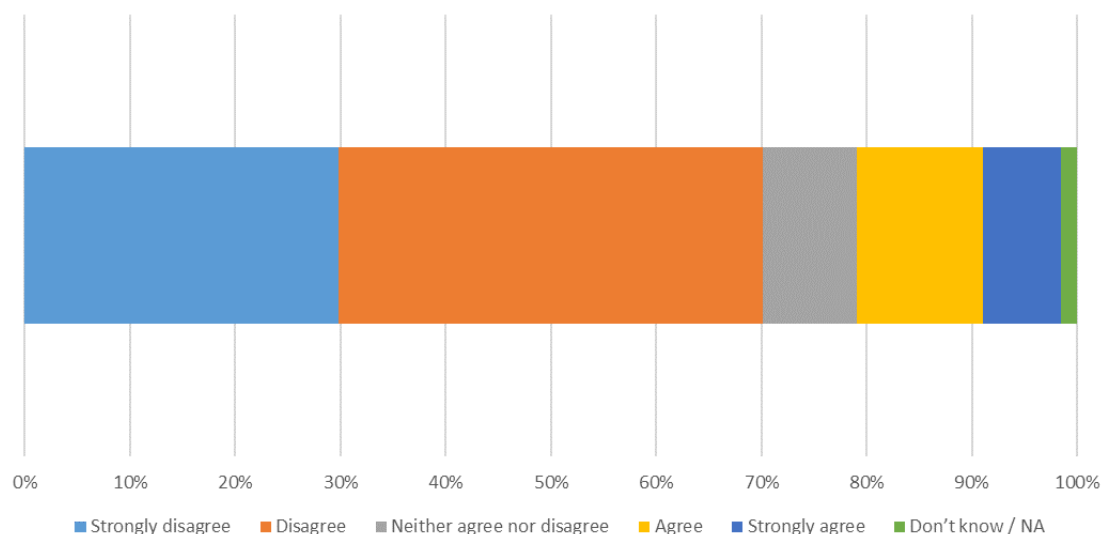
In the context of overall healthcare expenditure, do you agree a sufficient proportion of funding is directed to data-related resources?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
20	27	6	8	5	1	67
29.85%	40.30%	8.96%	11.94%	7.46%	1.49%	
					answered question	67
					skipped question	34

Seventy percent of responders disagreed that there is a sufficient proportion of funding directed to data related resources and 30% disagreed strongly. This is a large proportion of the group which might be within expectations for a group of professionals with a high level of experience in informatics related work. Only 19% agreed that there was sufficient funding and this overall demonstrates a significant level of dissatisfaction with funding prioritisation for data related resources in healthcare.

Q28 To what extent are health data-related resources in organisations being directed towards dealing with data management and access issues versus data analysis and use?
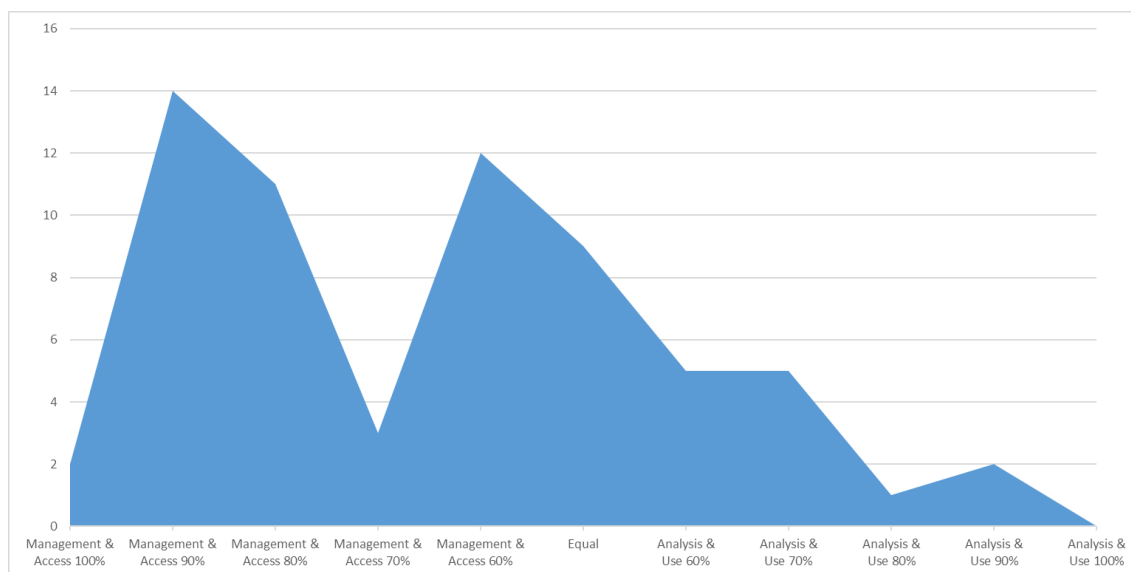
To what extent are health data-related resources in organisations being directed towards dealing with data management and access issues versus data analysis and use?

Management & Access 100%	Management & Access 90%	Management & Access 80%	Management & Access 70%	Management & Access 60%	Equal	Analysis & Use 60%	Analysis & Use 70%	Analysis & Use 80%	Analysis & Use 90%	Analysis & Use 100%	Response Count
2	14	11	3	12	9	5	5	1	2	0	64
3.13%	21.88%	17.19%	4.69%	18.75%	14.06%	7.81%	7.81%	1.56%	3.13%	0.00%	
										answered question	64
										skipped question	37

This question sought to understand the apportioning of the available data-related resources to Management and Access issues as opposed to supporting the Analysis and Use of data. Respondents indicated the proportion of resourcing they observed from 100% Management & Access to 100% Analysis and Use. A skew can be seen towards the Management & Access end with 66% of respondents indicating that 60% or more resources are distributed to Management and Access activities. This results in an estimated overall median for the group sentiment of 60% resourcing towards Management & Access. While it is not clear what the optimal ratio of resources spent on Management and Access versus Analysis and Use should be, the overall picture could suggest a potential imbalance in resourcing of Analysis & Use activities.

Q29 How much do you agree the following should bear the cost of increasing the accessibility and use of health related data?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Individuals (consumer of health services)	18 / 29.03%	22 / 35.48%	10 / 16.13%	10 / 16.13%	2 / 3.23%	0 / 0.00%	62
Organisations that provide health services (public or private)	2 / 3.08%	10 / 15.38%	7 / 10.77%	34 / 52.31%	10 / 15.38%	2 / 3.08%	65
Vendor that provide the software/database	6 / 9.23%	15 / 23.08%	18 / 27.69%	15 / 23.08%	10 / 15.38%	1 / 1.54%	65
Any Individual/organisation that requests or uses the data	4 / 6.15%	7 / 10.77%	10 / 15.38%	35 / 53.85%	8 / 12.31%	1 / 1.54%	65
Individual/organisation that requests or uses the data and may stand to make a profit from the use of the data, beyond the general public interest	0 / 0.00%	4 / 6.06%	3 / 4.55%	20 / 30.30%	39 / 59.09%	0 / 0.00%	66
Federal government (through general taxation)	0 / 0.00%	9 / 13.43%	9 / 13.43%	29 / 43.28%	19 / 28.36%	1 / 1.49%	67
State/Territory government	0 / 0.00%	8 / 12.31%	10 / 15.38%	34 / 52.31%	11 / 16.92%	2 / 3.08%	65
					Comments, other funding models to consider:		6
						answered question	67
						skipped question	34

A majority of respondents disagreed (64%), including 29% strongly, with 'Individuals (consumer of health services)' bearing the cost of increased access and use of health data, only 19% considered this a useful option with only 3% agreeing strongly. The 'Vendor that provide the software/database' produced a more ambivalent response with 38% agreeing and 32% disagreeing, with quite a large 27% remaining undecided either way.

'Organisations that provide health services (public or private)' and 'Any Individual/organisation that requests or uses the data' both received similar favourable support as targets for cost bearing with around 67% agreeing and only approximately 18% disagreeing.

Governments at State and Federal level were considered a good option for bearing the cost of increased data access and use with 68-71% agreeing and only approximately 13% disagreeing. The Federal government seemed to be slightly favoured with a higher stronger agreement level.

The strongest agreement (89%, including 59% strongly) however, was reserved for 'Individual/organisation that requests or uses the data and may stand to make a profit from the use of the data, beyond the general public interest' to contribute to covering increased access and use costs.

Comments were generally supportive of user pays models e.g. "User pays model is reasonable for individuals and organisations, supplemented by a government pays model for public health and population health management purposes". The theme of the resulting value derived through data use balancing initial cost was important: "By enabling access to the data and providing analytical education you will free up resources hence the overall cost to health will decrease", but as one commentator pointed out: "All stakeholders need to understand the benefit of using data and contribute to the cost".

The next two questions have been added in response to emerging issues in health information sharing and system interoperability overseas. While in most instances data blocking is likely to have complex, but innocent causes, there is a new recognition that unreasonable purposeful blocking of electronic health information does occur. This question sought to establish evidence as to whether this may also be a problem in Australia.

Q30 Health information and data blocking have been defined as "when persons or entities knowingly and unreasonably interfere with the exchange or use of electronic health information". Do you agree you have experienced situations where health data or information blocking seems to have occurred?

Legend: Strongly disagree ■ Disagree ■ Neither agree nor disagree ■ Agree ■ Strongly agree ■ Don't know / NA
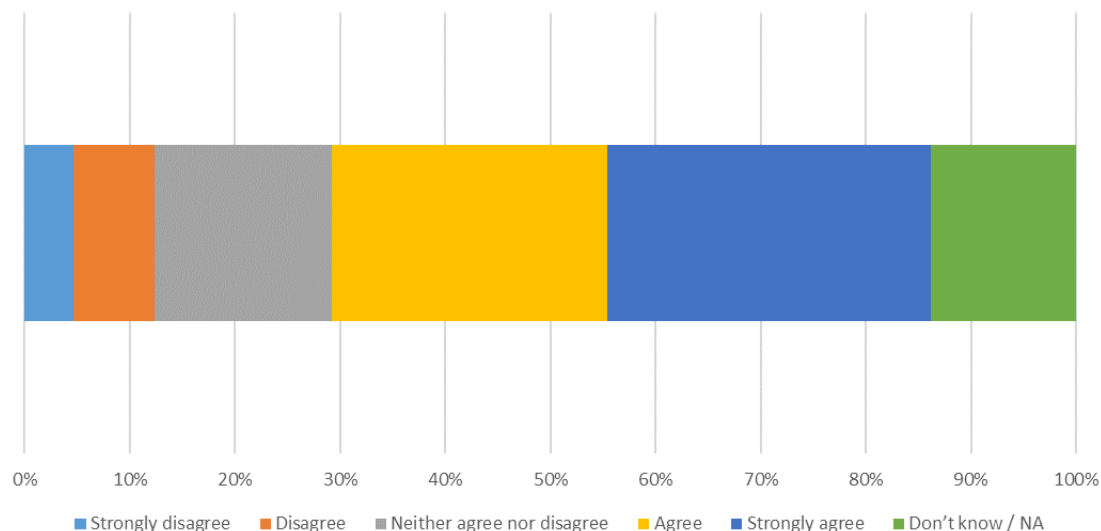
Health information and data blocking have been defined as "when persons or entities knowingly and unreasonably interfere with the exchange or use of electronic health information". Do you agree you have experienced situations where health data or information blocking seems to have occurred?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
3	5	11	17	20	9	65
4.62%	7.69%	16.92%	26.15%	30.77%	13.85%	
					answered question	65
					skipped question	36

For 65 respondents, a majority of 57% agreed that they had experienced situations where data blocking may have occurred whilst only 12% disagreed and 17% were undecided. This indicates that health information and data blocking may be a significant existing issue that Australian governments and Health Services need to address in the interests of better data use.

Q31 Do you agree to the following as the probable reason for the health data or information blocking?
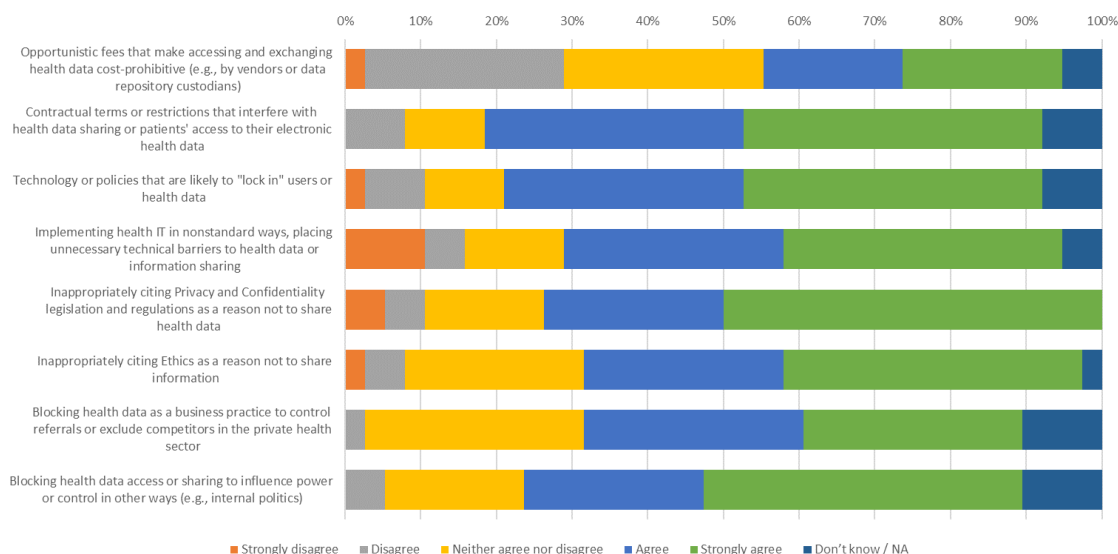
Do you agree to the following as the probable reason for the health data or information blocking?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Opportunistic fees that make accessing and exchanging health data cost-prohibitive (e.g., by vendors or data repository custodians)	1	10	10	7	8	2	38
	2.63%	26.32%	26.32%	18.42%	21.05%	5.26%	
Contractual terms or restrictions that interfere with health data sharing or patients' access to their electronic health data	0	3	4	13	15	3	38
	0.00%	7.89%	10.53%	34.21%	39.47%	7.89%	
Technology or policies that are likely to "lock in" users or health data	1	3	4	12	15	3	38
	2.63%	7.89%	10.53%	31.58%	39.47%	7.89%	
Implementing health IT in nonstandard ways, placing unnecessary technical barriers to health data or information sharing	4	2	5	11	14	2	38
	10.53%	5.26%	13.16%	28.95%	36.84%	5.26%	
Inappropriately citing Privacy and Confidentiality legislation and regulations as a reason not to share health data	2	2	6	9	19	0	38
	5.26%	5.26%	15.79%	23.68%	50.00%	0.00%	
Inappropriately citing Ethics as a reason not to share information	1	2	9	10	15	1	38
	2.63%	5.26%	23.68%	26.32%	39.47%	2.63%	
Blocking health data as a business practice to control referrals or exclude competitors in the private health sector	0	1	11	11	11	4	38
	0.00%	2.63%	28.95%	28.95%	28.95%	10.53%	
Blocking health data access or sharing to influence power or control in other ways (e.g., internal politics)	0	2	7	9	16	4	38
	0.00%	5.26%	18.42%	23.68%	42.11%	10.53%	
					Comments, other examples to consider:		4
						answered question	38
						skipped question	63

This question offered possible reasons for the data blocking experienced. The responders agreed with most of the suggestions, but the suggestions leading most agreement were non-standard implementation of Health IT causing technical barriers, contractual terms or restrictions, and inappropriate citing of Privacy & Confidentiality regulations, all at around 75% agreement.

Technology or policies that are likely to "lock in" users or health data, inappropriate citing of Ethics restrictions and influence power or control (e.g. internal politics) were also considered significant reasons with 66-71% agreement. Business practices to control referrals or exclude competitors was also seen as a reason by 58% of the responders while opportunistic fees making health data access and exchange cost-prohibitive by custodians or vendors was less commonly encountered at 39% agreement.

A few comments primarily expressed frustration with such situations e.g. "Why is the policy to have Homer not accept HL7 messages? (control, politics, not technical)" and "It is like a virus - in one organisation it took 18 months to the date of birth field added to a flat file - 2 minutes work - not uncommon"

SURVEY PART II - More Detailed Questions on Health Data and Use

Question 32 is not included as it was a survey navigation question.

The following questions explore aspects of health data use in further detail. As in the previous section, they provide a range of suggestions for which respondents have indicated their level of agreement. However, the responses to questions in this section are not analysed in as great a detail as the key questions selected for Part I.

SURVEY PART II - More Detailed Questions on Health Data and Use

Q33 Do you agree that the following characteristics define high value datasets in healthcare?
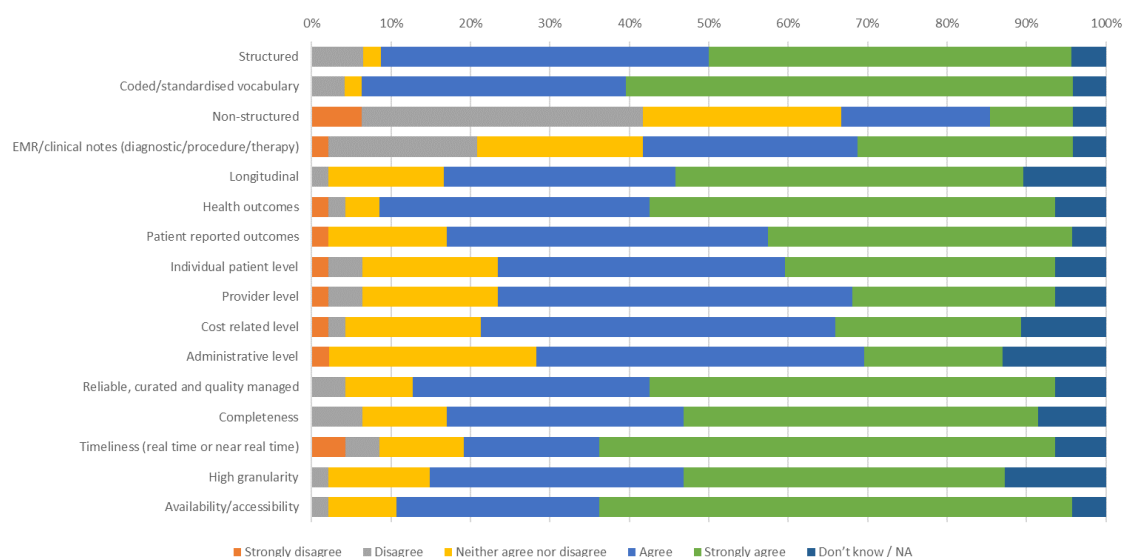
Do you agree that the following characteristics define high value datasets in healthcare?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Structured	0 0.00%	3 6.52%	1 2.17%	19 41.30%	21 45.65%	2 4.35%	46
Coded/standardised vocabulary	0 0.00%	2 4.17%	1 2.08%	16 33.33%	27 56.25%	2 4.17%	48
Non-structured	3 6.25%	17 35.42%	12 25.00%	9 18.75%	5 10.42%	2 4.17%	48
EMR/clinical notes (diagnostic/procedure/therapy)	1 2.08%	9 18.75%	10 20.83%	13 27.08%	13 27.08%	2 4.17%	48
Longitudinal	0 0.00%	1 2.08%	7 14.58%	14 29.17%	21 43.75%	5 10.42%	48
Health outcomes	1 2.13%	1 2.13%	2 4.26%	16 34.04%	24 51.06%	3 6.38%	47
Patient reported outcomes	1 2.13%	0 0.00%	7 14.89%	19 40.43%	18 38.30%	2 4.26%	47
Individual patient level	1 2.13%	2 4.26%	8 17.02%	17 36.17%	16 34.04%	3 6.38%	47
Provider level	1 2.13%	2 4.26%	8 17.02%	21 44.68%	12 25.53%	3 6.38%	47
Cost related level	1 2.13%	1 2.13%	8 17.02%	21 44.68%	11 23.40%	5 10.64%	47
Administrative level	1 2.17%	0 0.00%	12 26.09%	19 41.30%	8 17.39%	6 13.04%	46
Reliable, curated and quality managed	0 0.00%	2 4.26%	4 8.51%	14 29.79%	24 51.06%	3 6.38%	47
Completeness	0 0.00%	3 6.38%	5 10.64%	14 29.79%	21 44.68%	4 8.51%	47
Timeliness (real time or near real time)	2 4.26%	2 4.26%	5 10.64%	8 17.02%	27 57.45%	3 6.38%	47
High granularity	0 0.00%	1 2.13%	6 12.77%	15 31.91%	19 40.43%	6 12.77%	47
Availability/accessibility	0 0.00%	1 2.13%	4 8.51%	12 25.53%	28 59.57%	2 4.26%	47
			Comments, other characteristics to consider:				4
						answered question	48
						skipped question	53

The following characteristics were considered the most important in defining high value health datasets: 'Structured', 'Coded/standardised vocabulary', 'Health outcomes', 'Availability/accessibility' and 'Reliable, curated and quality managed', all with over 80% agreement and less than 10% disagreement.

'Non-structured' and 'EMR/clinical notes (diagnostic/procedure/therapy)' and 'Administrative level' data afforded the least positive support as criteria to identify valuable health data sets. 'Non-structured' data in particular only received 29% agreement and 32% disagreement.

Q34 Do you agree the collection, sharing and release of health data should be standardised?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
2	1	4	14	29	0	50
4.00%	2.00%	8.00%	28.00%	58.00%	0.00%	
					answered question	50
					skipped question	51

Following on from the endorsement of structured data as more high value in Question 33, there was good agreement (86%) that health data collection, sharing and release activities should also be standardised.

Q35 Do you agree the following would be benefits of standardisation?
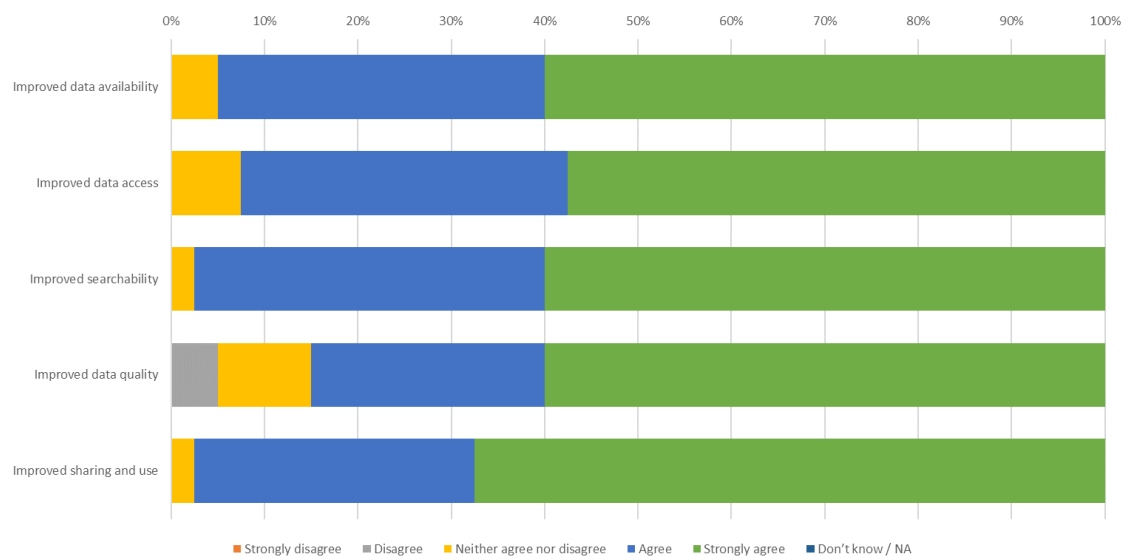
Do you agree the following would be benefits of standardisation?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Improved data availability	0 0.00%	0 0.00%	2 5.00%	14 35.00%	24 60.00%	0 0.00%	40
Improved data access	0 0.00%	0 0.00%	3 7.50%	14 35.00%	23 57.50%	0 0.00%	40
Improved searchability	0 0.00%	0 0.00%	1 2.50%	15 37.50%	24 60.00%	0 0.00%	40
Improved data quality	0 0.00%	2 5.00%	4 10.00%	10 25.00%	24 60.00%	0 0.00%	40
Improved sharing and use	0 0.00%	0 0.00%	1 2.50%	12 30.00%	27 67.50%	0 0.00%	40
					Comments, other:		4
					answered question		40
					skipped question		61

There was overall very good agreement (85-98%) with all options offered as being benefits of standardisation of health data collection, sharing and release, with almost no disagreement, although 'improvement in data quality' was thought to be the least likely benefit (85%).

Q36 Do you agree the following describes significant increased costs associated with standardisation?
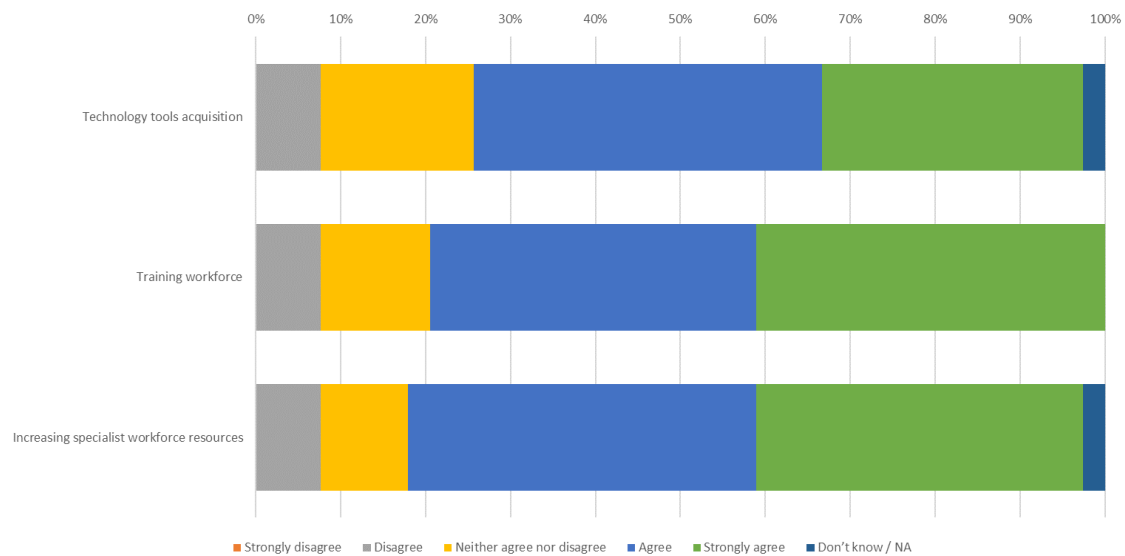
Do you agree the following describes significant increased costs associated with standardisation?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Technology tools acquisition	0	3	7	16	12	1	39
	0.00%	7.69%	17.95%	41.03%	30.77%	2.56%	
Training workforce	0	3	5	15	16	0	39
	0.00%	7.69%	12.82%	38.46%	41.03%	0.00%	
Increasing specialist workforce resources	0	3	4	16	15	1	39
	0.00%	7.69%	10.26%	41.03%	38.46%	2.56%	
						Comments, other:	5
						answered question	39
						skipped question	62

Overall there was agreement (72-80%) that 'Technology tools acquisition', 'Training workforce' and 'Increasing specialist workforce resources' would represent significant increased costs associated with standardisation, however only up to 41% of these respondents agreed strongly with these.

Q37 Do you agree the following would provide standards that are 'fit for purpose'?
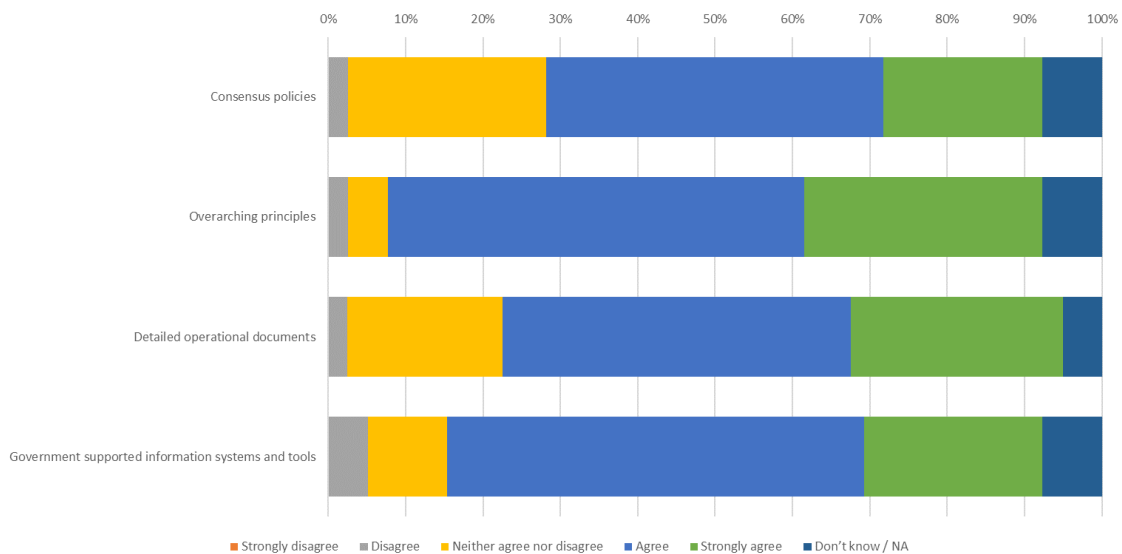
Do you agree the following would provide standards that are 'fit for purpose'?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Consensus policies	0 0.00%	1 2.56%	10 25.64%	17 43.59%	8 20.51%	3 7.69%	39
Overarching principles	0 0.00%	1 2.56%	2 5.13%	21 53.85%	12 30.77%	3 7.69%	39
Detailed operational documents	0 0.00%	1 2.50%	8 20.00%	18 45.00%	11 27.50%	2 5.00%	40
Government supported information systems and tools	0 0.00%	2 5.13%	4 10.26%	21 53.85%	9 23.08%	3 7.69%	39
						Comments, other:	3
						answered question	40
						skipped question	61

Overarching principles and Government supported information systems and tools were considered the most agreeable options (77-81% agreement), however Detailed operational documents and Consensus policies were also broadly agreed to. As pointed out by a commenter: "There are already many standards that are fit for this purpose. Implementing them rather than developing new standards should be the focus. International standards use should be the default."

Q38 Do you agree healthcare organisations use the following criteria and decision-making tools to decide which public sector Health data to make publicly available?
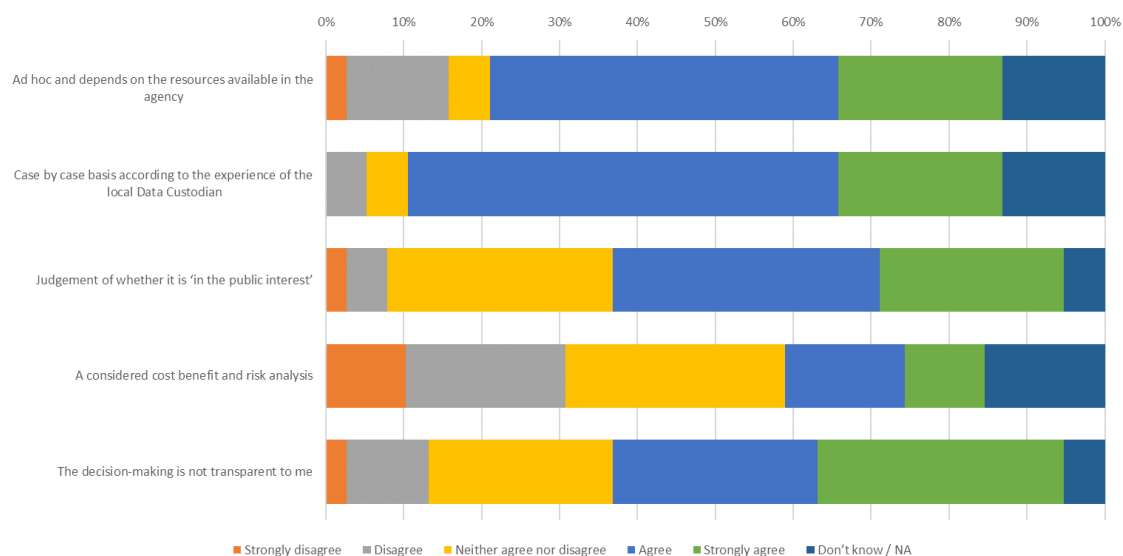
Do you agree healthcare organisations use the following criteria and decision-making tools to decide which public sector Health data to make publicly available?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Ad hoc and depends on the resources available in the agency	1 2.63%	5 13.16%	2 5.26%	17 44.74%	8 21.05%	5 13.16%	38
Case by case basis according to the experience of the local Data Custodian	0 0.00%	2 5.26%	2 5.26%	21 55.26%	8 21.05%	5 13.16%	38
Judgement of whether it is 'in the public interest'	1 2.63%	2 5.26%	11 28.95%	13 34.21%	9 23.68%	2 5.26%	38
A considered cost benefit and risk analysis	4 10.26%	8 20.51%	11 28.21%	6 15.38%	4 10.26%	6 15.38%	39
The decision-making is not transparent to me	1 2.63%	4 10.53%	9 23.68%	10 26.32%	12 31.58%	2 5.26%	38
						Comments, other criteria to consider:	1
						answered question	39
						skipped question	62

Responses to this question were more varied. Notably there was considerable disagreement (31%) and only 26% agreement that 'A considered cost benefit and risk analysis' was a criteria or decision-making tool that described how healthcare organisations decided to make public health sector data publicly available, although there were also a large number of undecided and unsure respondents.

Most respondents agreed that the criteria could be described as 'ad hoc and depends on the resources available in the agency' (66%) and on a 'Case by case basis according to the experience of the local Data Custodian' (76%). Agreement with 'Judgement of whether it is 'in the public interest' was very ambivalent.

Q39 Do you agree that government agencies should undertake the following processing before releasing health data?
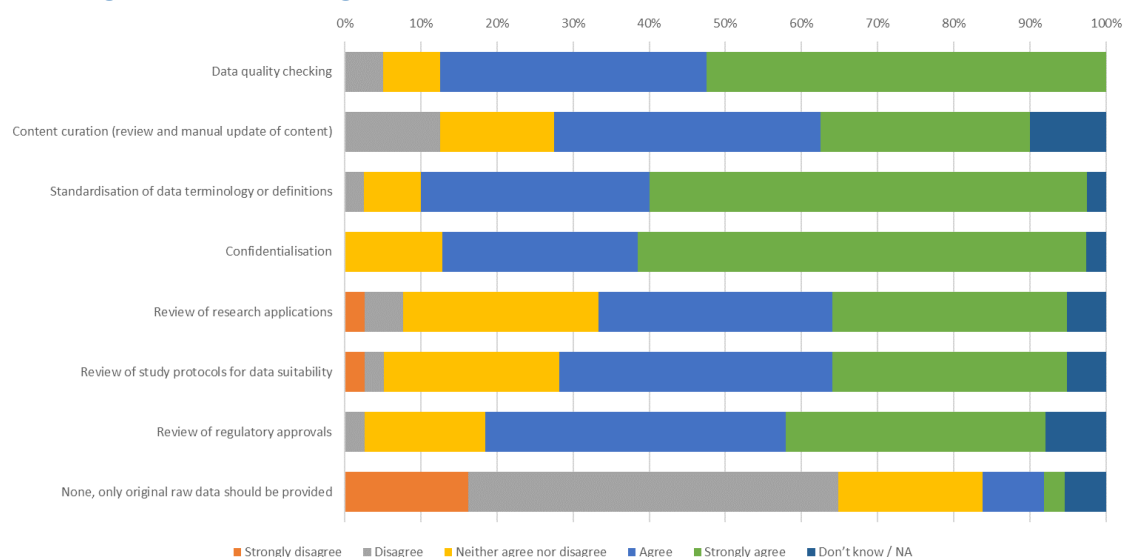
Do you agree that government agencies should undertake the following processing before releasing health data?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Data quality checking	0 0.00%	2 5.00%	3 7.50%	14 35.00%	21 52.50%	0 0.00%	40
Content curation (review and manual update of content)	0 0.00%	5 12.50%	6 15.00%	14 35.00%	11 27.50%	4 10.00%	40
Standardisation of data terminology or definitions	0 0.00%	1 2.50%	3 7.50%	12 30.00%	23 57.50%	1 2.50%	40
Confidentialisation	0 0.00%	0 0.00%	5 12.82%	10 25.64%	23 58.97%	1 2.56%	39
Review of research applications	1 2.56%	2 5.13%	10 25.64%	12 30.77%	12 30.77%	2 5.13%	39
Review of study protocols for data suitability	1 2.56%	1 2.56%	9 23.08%	14 35.90%	12 30.77%	2 5.13%	39
Review of regulatory approvals	0 0.00%	1 2.63%	6 15.79%	15 39.47%	13 34.21%	3 7.89%	38
None, only original raw data should be provided	6 16.22%	18 48.65%	7 18.92%	3 8.11%	1 2.70%	2 5.41%	37
				Comments, other processing steps to consider:			3
				answered question			40
				skipped question			61

Respondents favoured 'Data quality checking', 'Standardisation of data terminology or definition', 'Confidentialisation' and 'Review of regulatory approvals' (74%-88% agreement) as processing activities that government agencies should undertake prior to release of health data. There was firm disagreement (65%) and low agreement (11%) with 'None, only raw data should be provided'.

Q40 Do you agree that the following government initiatives (whether Australian Government, state, territory or local government, or overseas jurisdictions) have been particularly effective in improving health data access and use, including linkage?
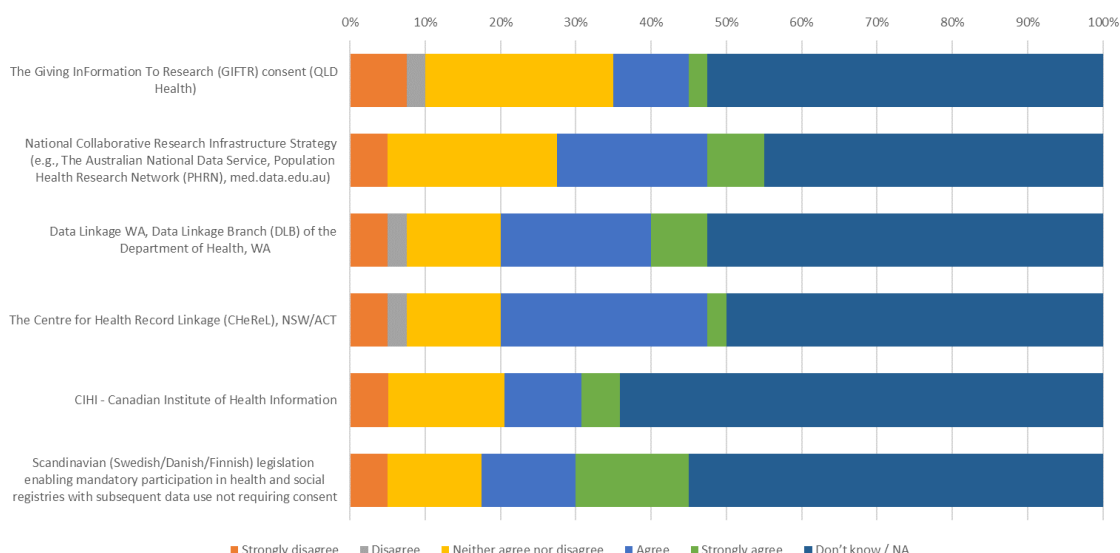
Do you agree that the following government initiatives (whether Australian Government, state, territory or local government, or overseas jurisdictions) have been particularly effective in improving health data access and use, including linkage?							
Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
The Giving InFormation To Research (GIFTR) consent (QLD Health)	3	1	10	4	1	21	40
	7.50%	2.50%	25.00%	10.00%	2.50%	52.50%	
National Collaborative Research Infrastructure Strategy (e.g., The Australian National Data Service, Population Health Research Network (PHRN), med.data.edu.au)	2	0	9	8	3	18	40
	5.00%	0.00%	22.50%	20.00%	7.50%	45.00%	
Data Linkage WA, Data Linkage Branch (DLB) of the Department of Health, WA	2	1	5	8	3	21	40
	5.00%	2.50%	12.50%	20.00%	7.50%	52.50%	
The Centre for Health Record Linkage (CHeReL), NSW/ACT	2	1	5	11	1	20	40
	5.00%	2.50%	12.50%	27.50%	2.50%	50.00%	
CIHI - Canadian Institute of Health Information	2	0	6	4	2	25	39
	5.13%	0.00%	15.38%	10.26%	5.13%	64.10%	
Scandinavian (Swedish/Danish/Finnish) legislation enabling mandatory participation in health and social registries with subsequent data use not requiring consent	2	0	5	5	6	22	40
	5.00%	0.00%	12.50%	12.50%	15.00%	55.00%	
				Comments, other government initiatives to consider:			3
						answered question	40
						skipped question	61

The most notable feature of the responses to this question is the high level of respondents (45-65%) indicating not knowing about the effectiveness of suggested initiatives in improving health data access and use including linkage. Some of these initiatives are relatively new e.g. the Qld 'Giving Information To Research (GIFTR)' initiative and may not be broadly known of, however others have a relatively high profile and large investment, but still do not seem to be well recognised as effective initiatives.

Q41 Which datasets related to health other than those previously listed, if linked or coordinated across public and/or private sector agencies, would be of high value to the community?
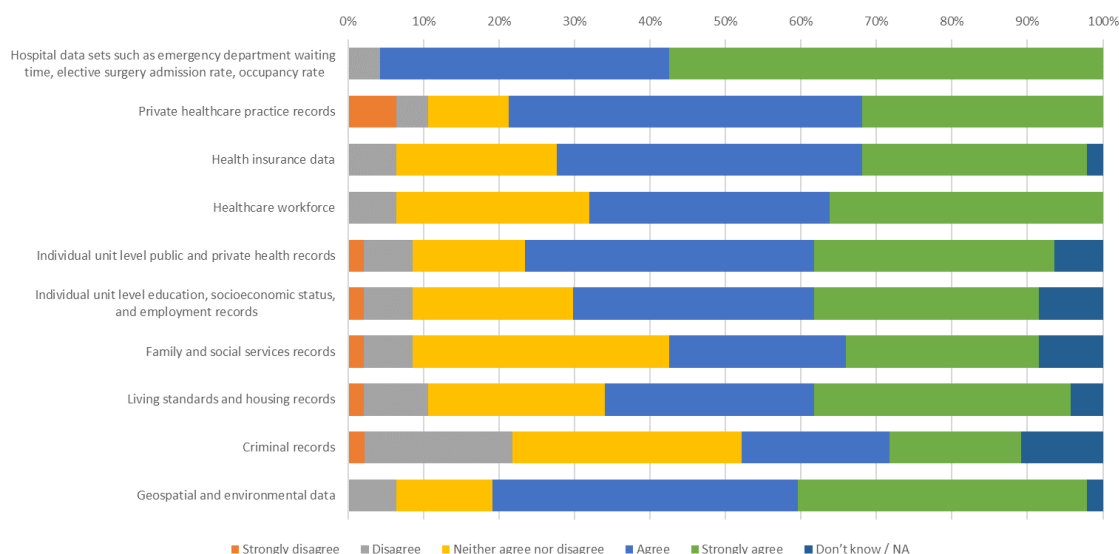
Which datasets related to health other than those previously listed, if linked or coordinated across public and/or private sector agencies, would be of high value to the community?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Hospital data sets such as emergency department waiting time, elective surgery admission rate, occupancy rate	0 0.00%	2 4.26%	0 0.00%	18 38.30%	27 57.45%	0 0.00%	47
Private healthcare practice records	3 6.38%	2 4.26%	5 10.64%	22 46.81%	15 31.91%	0 0.00%	47
Health insurance data	0 0.00%	3 6.38%	10 21.28%	19 40.43%	14 29.79%	1 2.13%	47
Healthcare workforce	0 0.00%	3 6.38%	12 25.53%	15 31.91%	17 36.17%	0 0.00%	47
Individual unit level public and private health records	1 2.13%	3 6.38%	7 14.89%	18 38.30%	15 31.91%	3 6.38%	47
Individual unit level education, socioeconomic status, and employment records	1 2.13%	3 6.38%	10 21.28%	15 31.91%	14 29.79%	4 8.51%	47
Family and social services records	1 2.13%	3 6.38%	16 34.04%	11 23.40%	12 25.53%	4 8.51%	47
Living standards and housing records	1 2.13%	4 8.51%	11 23.40%	13 27.66%	16 34.04%	2 4.26%	47
Criminal records	1 2.17%	9 19.57%	14 30.43%	9 19.57%	8 17.39%	5 10.87%	46
Geospatial and environmental data	0 0.00%	3 6.38%	6 12.77%	19 40.43%	18 38.30%	1 2.13%	47
				Comments, other important dataset for linkage to consider:			5
						answered question	47
						skipped question	54

Most options provided gained at least moderate agreement. Hospital level datasets, Private healthcare practice records, Individual unit level health records and geospatial data were considered the best candidates for linking. Socio-economic demographic data, Health insurance, Health workforce and Living standards data were also endorsed, however Family and Social Services and Criminal records saw a more ambivalent response.

Q42 Do you agree that such linked or coordinated health datasets could be used to investigate or improve the following?
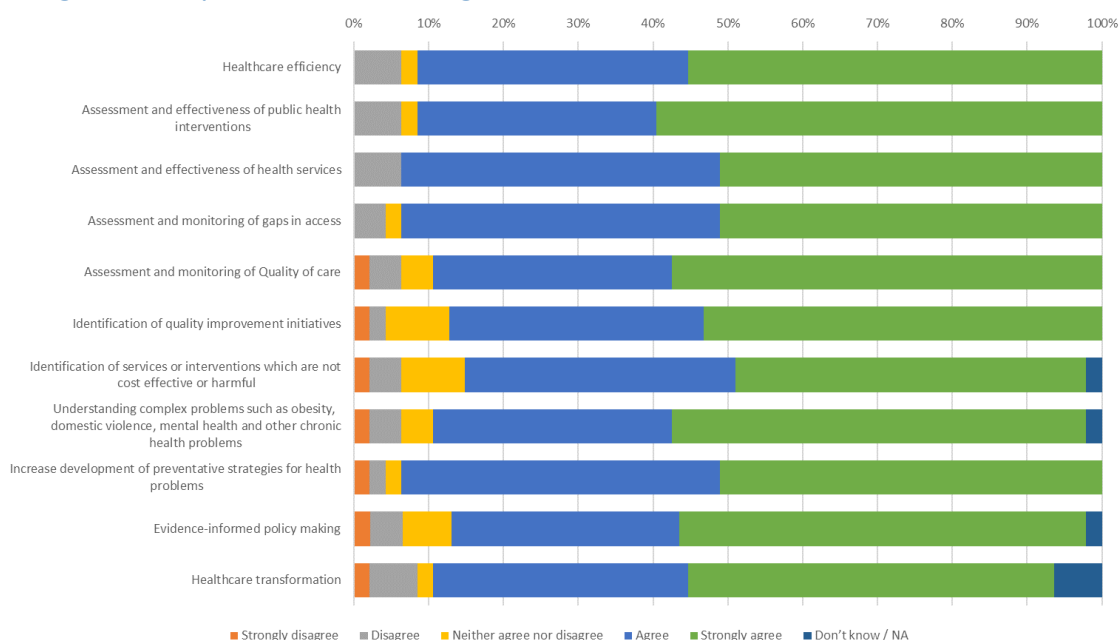
Do you agree that such linked or coordinated health datasets could be used to investigate or improve the following?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Healthcare efficiency	0 0.00%	3 6.38%	1 2.13%	17 36.17%	26 55.32%	0 0.00%	47
Assessment and effectiveness of public health interventions	0 0.00%	3 6.38%	1 2.13%	15 31.91%	28 59.57%	0 0.00%	47
Assessment and effectiveness of health services	0 0.00%	3 6.38%	0 0.00%	20 42.55%	24 51.06%	0 0.00%	47
Assessment and monitoring of gaps in access	0 0.00%	2 4.26%	1 2.13%	20 42.55%	24 51.06%	0 0.00%	47
Assessment and monitoring of Quality of care	1 2.13%	2 4.26%	2 4.26%	15 31.91%	27 57.45%	0 0.00%	47
Identification of quality improvement initiatives	1 2.13%	1 2.13%	4 8.51%	16 34.04%	25 53.19%	0 0.00%	47
Identification of services or interventions which are not cost effective or harmful	1 2.13%	2 4.26%	4 8.51%	17 36.17%	22 46.81%	1 2.13%	47
Understanding complex problems such as obesity, domestic violence, mental health and other chronic health problems	1 2.13%	2 4.26%	2 4.26%	15 31.91%	26 55.32%	1 2.13%	47
Increase development of preventative strategies for health problems	1 2.13%	1 2.13%	1 2.13%	20 42.55%	24 51.06%	0 0.00%	47
Evidence-informed policy making	1 2.17%	2 4.35%	3 6.52%	14 30.43%	25 54.35%	1 2.17%	46
Healthcare transformation	1 2.13%	3 6.38%	1 2.13%	16 34.04%	23 48.94%	3 6.38%	47
					Comments, other uses to consider:		4
					answered question		47
					skipped question		54

While there was more variable support for the suggested data sets in Question 42, there was almost uniform agreement with the suggested potential benefits linkage can provide. Assessment and effectiveness of Public Health interventions, monitoring of care quality and identification of quality improvements opportunities, assessment of health services for efficiency, effectiveness, gaps in access to care, development of preventative healthcare strategies and generally healthcare transformation all won over 80% agreement, with all close to or over 50% strong agreement.

Q43 Are there any legislative or other impediments that may be unnecessarily restricting the availability and use of private sector health data which are different to public sector health data?
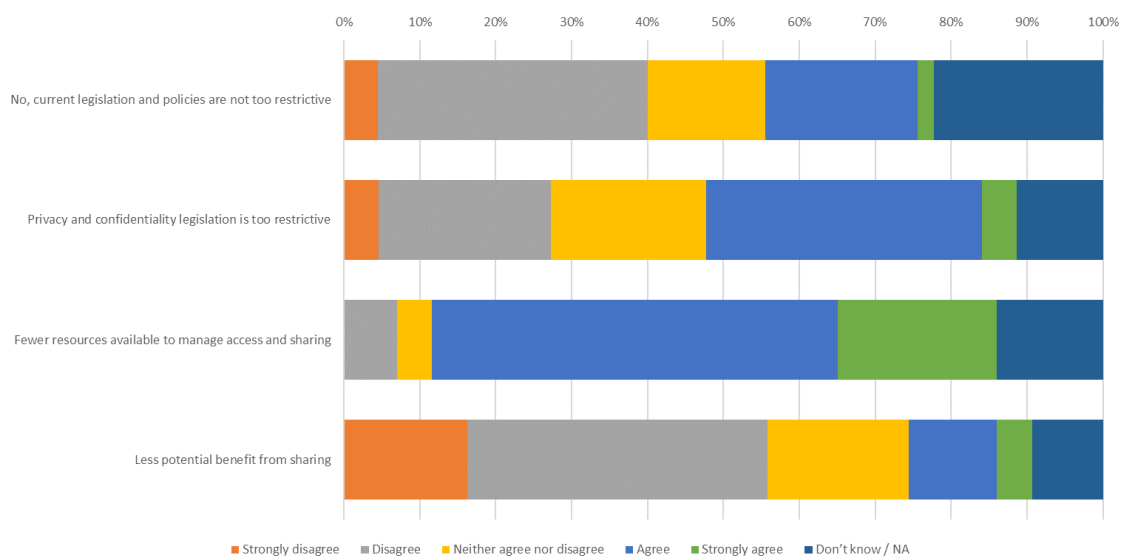
Are there any legislative or other impediments that may be unnecessarily restricting the availability and use of private sector health data which are different to public sector health data?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
No, current legislation and policies are not too restrictive	2 4.44%	16 35.56%	7 15.56%	9 20.00%	1 2.22%	10 22.22%	45
Privacy and confidentiality legislation is too restrictive	2 4.55%	10 22.73%	9 20.45%	16 36.36%	2 4.55%	5 11.36%	44
Fewer resources available to manage access and sharing	0 0.00%	3 6.98%	2 4.65%	23 53.49%	9 20.93%	6 13.95%	43
Less potential benefit from sharing	7 16.28%	17 39.53%	8 18.60%	5 11.63%	2 4.65%	4 9.30%	43
					Comments, other impediments to consider:		5
						answered question	45
						skipped question	56

74% of respondents considered Fewer resources available to be an important barrier for private sector health data use and sharing even more so than for the public sector. Privacy and confidentiality legislation also gained some agreement as an impediment, but the idea that there was less potential benefit for the private sector was rejected (56%).

Q44 Could voluntary health data sharing arrangements between private or public healthcare organisations/healthcare practitioners/consumers/third party intermediaries, improve outcomes for the availability and use of private or public data?
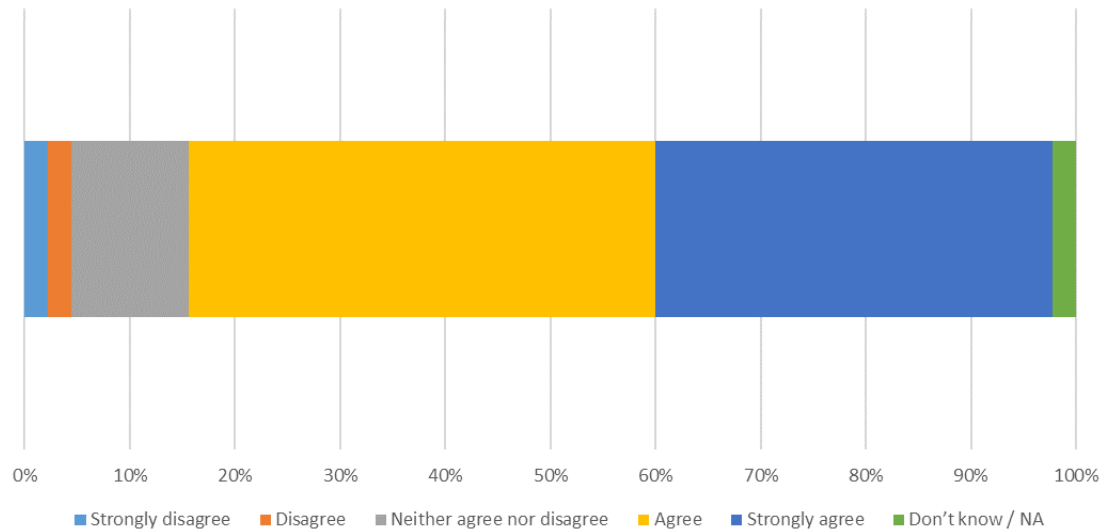
Could voluntary health data sharing arrangements between private or public healthcare organisations/healthcare practitioners/consumers/third party intermediaries, improve outcomes for the availability and use of private or public data?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
1	1	5	20	17	1	45
2.22%	2.22%	11.11%	44.44%	37.78%	2.22%	
					answered question	45
					skipped question	56

There was overall very good agreement (82%) that voluntary data sharing arrangements between sectors and parties could improve data sharing and use.

Q45 Would such voluntary arrangements be likely to raise competition issues among private healthcare providers?
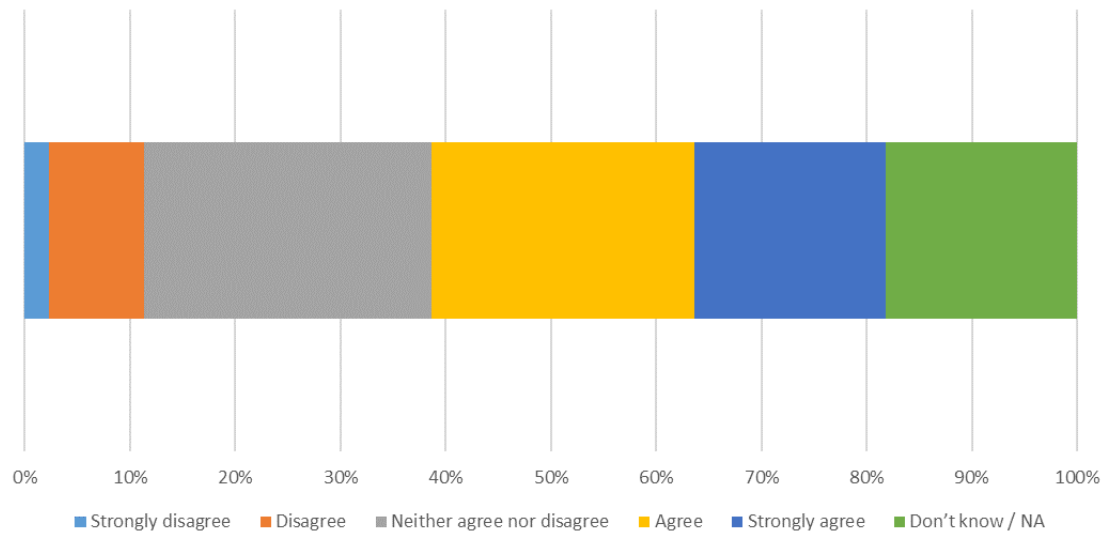
Would such voluntary arrangements be likely to raise competition issues among private healthcare providers?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
1	4	12	11	8	8	44
2.27%	9.09%	27.27%	25.00%	18.18%	18.18%	
					answered question	44
					skipped question	57

Of 44 respondents, 43% thought competition issues might be raised by voluntary arrangements, but there was some disagreement (11%) and many respondents were unsure or didn't know (45%) .

Q46 Would this be likely to change if private sector health information sharing were mandated?

Strongly disagree ▪ Disagree ▪ Neither agree nor disagree ▪ Agree ▪ Strongly agree ▪ Don't know / NA
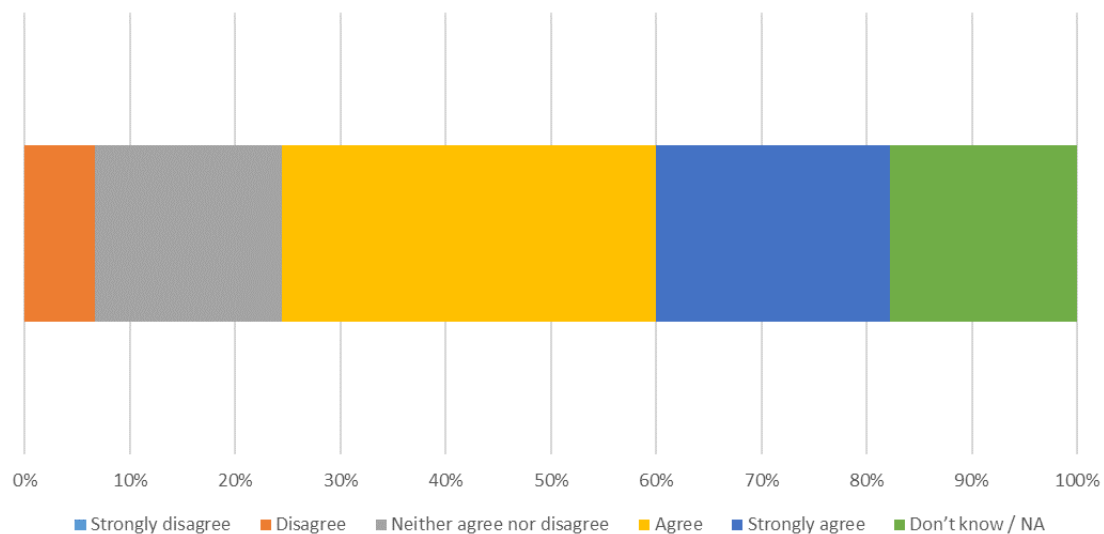
Would this be likely to change if private sector health information sharing were mandated?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
0	3	8	16	10	8	45
0.00%	6.67%	17.78%	35.56%	22.22%	17.78%	
					answered question	45
					skipped question	56

Of 45 respondents, 58% thought mandating information sharing in the private sector would influence competition issues, but many were also unsure or didn't know.

Q47 Should governments play a bigger role in promoting the wider availability of private health datasets that have the potential to deliver substantial benefits?

Strongly disagree ■ **Disagree** ■ **Neither agree nor disagree** ■ **Agree** ■ **Strongly agree** ■ **Don't know / NA**
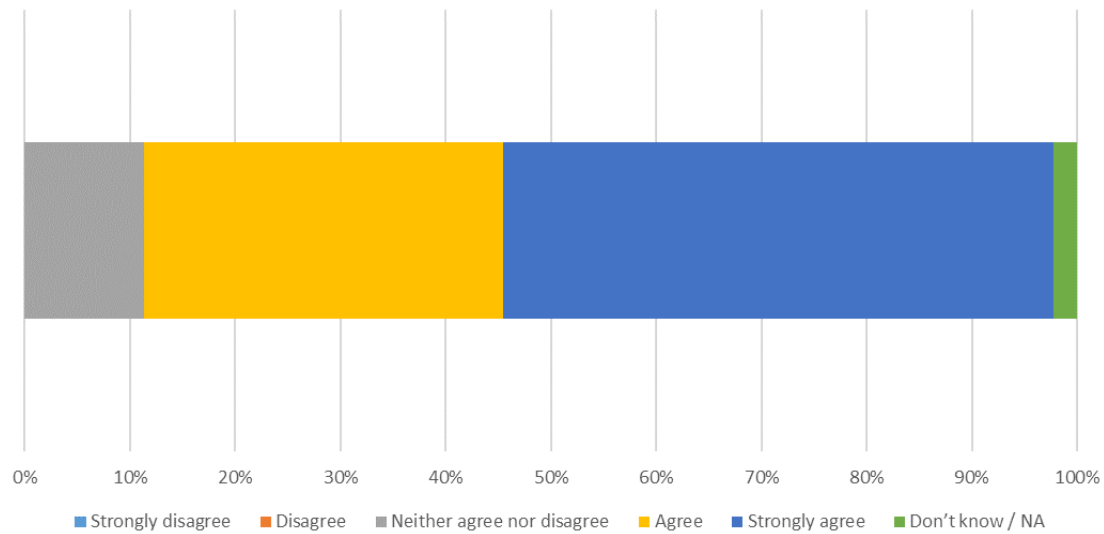
Should governments play a bigger role in promoting the wider availability of private health datasets that have the potential to deliver substantial benefits?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
0	0	5	15	23	1	44
0.00%	0.00%	11.36%	34.09%	52.27%	2.27%	
					answered question	44
					skipped question	57

Over 84% of respondents thought the government should be more forthright in promoting the availability and beneficial use of private health datasets, with no disagreement.

Q48 Are there any mechanisms other than those already listed for the public sector and above that could improve the sharing and linking of private sector health related data?
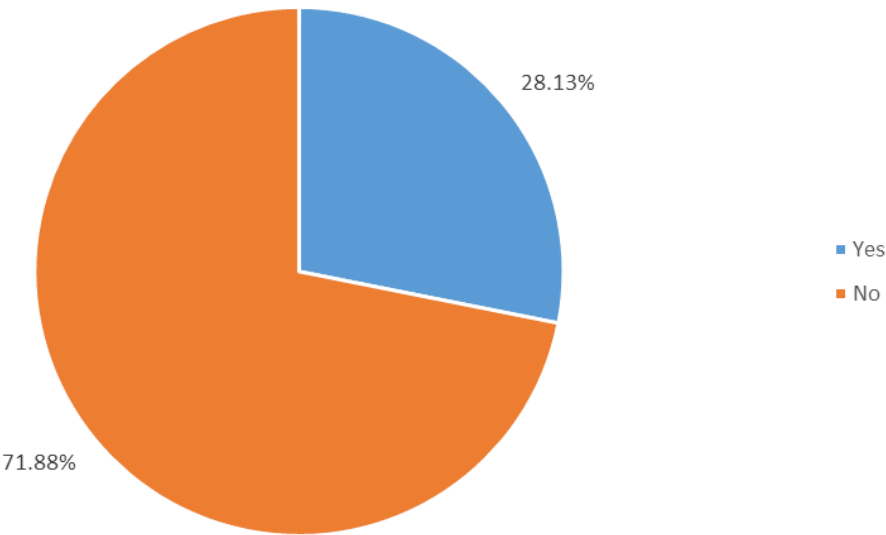
Are there any mechanisms other than those already listed for the public sector and above that could improve the sharing and linking of private sector health related data?

Answer Options	Response Percent	Response Count
Yes	28.13%	9
No	71.88%	23
Comments, other mechanisms to consider:		8
answered question		32
skipped question		69

Most respondents thought there were not many more mechanisms other than those already listed for the public sector which could facilitate data sharing and use, while 28% indicated there were others.

Q49 Do you agree that the following impediments currently restrict consumers' access to and use of public and private sector data about themselves?
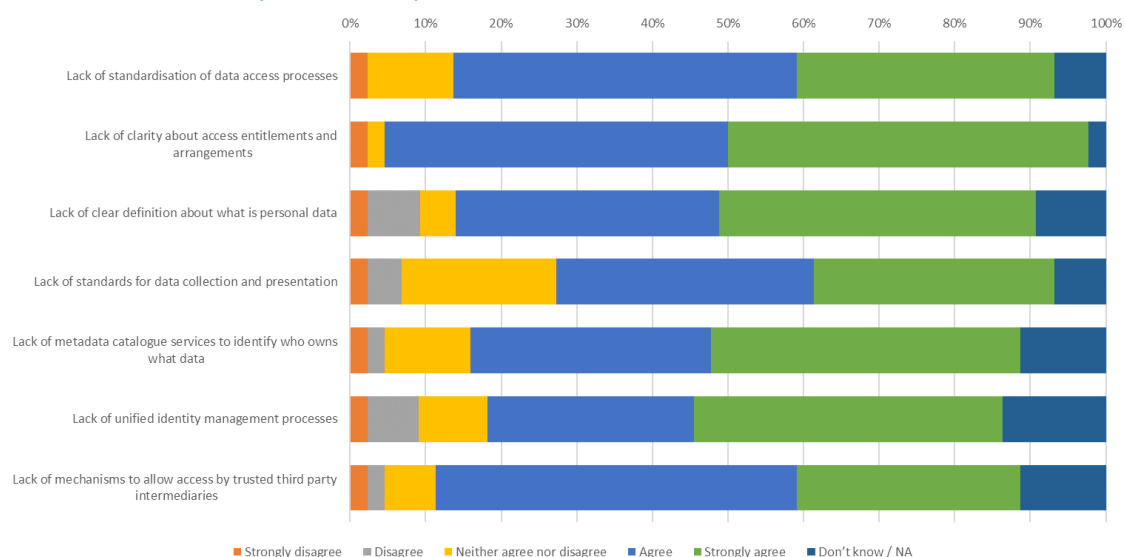
Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Lack of standardisation of data access processes	1 2.27%	0 0.00%	5 11.36%	20 45.45%	15 34.09%	3 6.82%	44
Lack of clarity about access entitlements and arrangements	1 2.27%	0 0.00%	1 2.27%	20 45.45%	21 47.73%	1 2.27%	44
Lack of clear definition about what is personal data	1 2.33%	3 6.98%	2 4.65%	15 34.88%	18 41.86%	4 9.30%	43
Lack of standards for data collection and presentation	1 2.27%	2 4.55%	9 20.45%	15 34.09%	14 31.82%	3 6.82%	44
Lack of metadata catalogue services to identify who owns what data	1 2.27%	1 2.27%	5 11.36%	14 31.82%	18 40.91%	5 11.36%	44
Lack of unified identity management processes	1 2.27%	3 6.82%	4 9.09%	12 27.27%	18 40.91%	6 13.64%	44
Lack of mechanisms to allow access by trusted third party intermediaries	1 2.27%	1 2.27%	3 6.82%	21 47.73%	13 29.55%	5 11.36%	44
			Comments, other impediments to consider for access by individuals or trusted third parties:				4
						answered question	44
						skipped question	57

Respondents showed very good agreement with all options, but 'Lack of clarity about access entitlements and arrangements' was considered the foremost impediment to consumers use of health data about themselves. This is also similar to the lack of metadata catalogue services available for consumers and poor definition about what personal data is. Lack of standards likely leading to further confusion was also supported.

Q50 Do you agree that regulatory solutions for the above impediments would be of value in giving consumers more access to and control over their own data?

■ Strongly disagree ■ Disagree ■ Neither agree nor disagree ■ Agree ■ Strongly agree ■ Don't know / NA
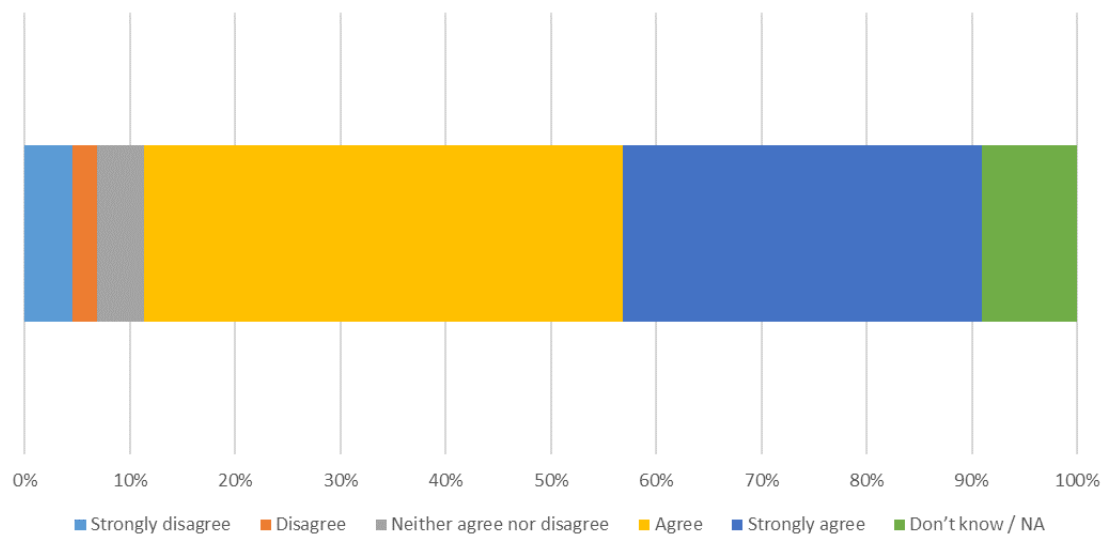
Do you agree that regulatory solutions for the above impediments would be of value in giving consumers more access to and control over their own data?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
2	1	2	20	15	4	44
4.55%	2.27%	4.55%	45.45%	34.09%	9.09%	
					answered question	44
					skipped question	57

There was approximately 80% agreement that regulatory solutions to address the above impediments would be useful for giving consumers more access to their data.

Q51 What other solution(s) would encourage greater cultural acceptance amongst health providers of consumer access to their data?

What other solution(s) would encourage greater cultural acceptance amongst health providers of consumer access to their data?	
answered question	17
skipped question	84

Respondents offered 17 comments with themes including the main idea of education, ranging from embedding data management at higher education and university level to education and awareness campaigns to promote the understanding that consumers should be the owners of their health data. Using technology to allow access and get feedback from patients and involving patients more directly was also mentioned and one respondent recommended mandating automatic provision of data to patients but including a step for explanation and counselling.

Q52 Do you agree that third party intermediaries are currently available to assist consumers to access and use data about themselves by:

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Providing simplified access?	5 11.63%	13 30.23%	10 23.26%	6 13.95%	1 2.33%	8 18.60%	43
Providing mash-up services (linking different datasets)?	5 11.36%	10 22.73%	14 31.82%	5 11.36%	2 4.55%	8 18.18%	44
Providing added value (e.g., clinical interpretation services, access to relevant guidelines)?	8 18.18%	9 20.45%	11 25.00%	6 13.64%	1 2.27%	9 20.45%	44
					Comments, other assistance to consider:		7
						answered question	44
						skipped question	57

This topic caused a higher number of respondents to select 'Don't know' or unsure either way, but overall there was very little agreement that third party intermediaries were available to assist consumers with a variety of services such as simplifying access, linking/mash-up services or other added value services such as clinical interpretation. Overall, 34-42% of respondents concurred that these services were NOT available.

Q53 What barriers impede the availability (and up-take) of services offered by third party intermediaries?
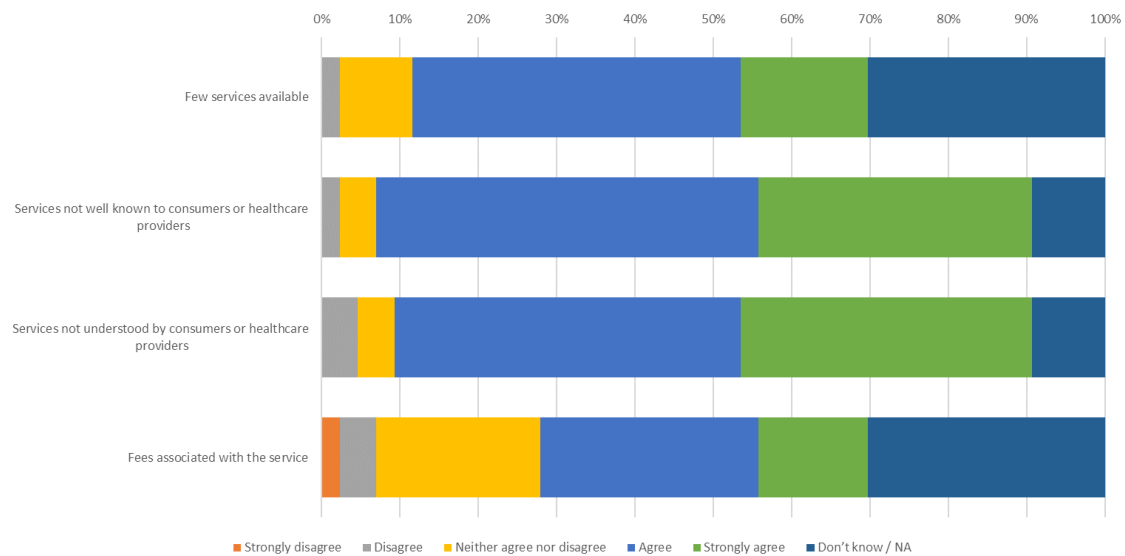
What barriers impede the availability (and up-take) of services offered by third party intermediaries?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Few services available	0 0.00%	1 2.33%	4 9.30%	18 41.86%	7 16.28%	13 30.23%	43
Services not well known to consumers or healthcare providers	0 0.00%	1 2.33%	2 4.65%	21 48.84%	15 34.88%	4 9.30%	43
Services not understood by consumers or healthcare providers	0 0.00%	2 4.65%	2 4.65%	19 44.19%	16 37.21%	4 9.30%	43
Fees associated with the service	1 2.33%	2 4.65%	9 20.93%	12 27.91%	6 13.95%	13 30.23%	43
					Comments, other barriers to consider:		1
						answered question	43
						skipped question	58

We suggested several barriers to the uptake of third party services, which showed moderate to strong agreement, with the most favoured options being Few services available and also that they are not well known or understood. Fewer respondents considered fees to be as important a barrier.

Q54 Do you agree that the following barriers are impeding consumers' access to, and use of, 'high value' data?
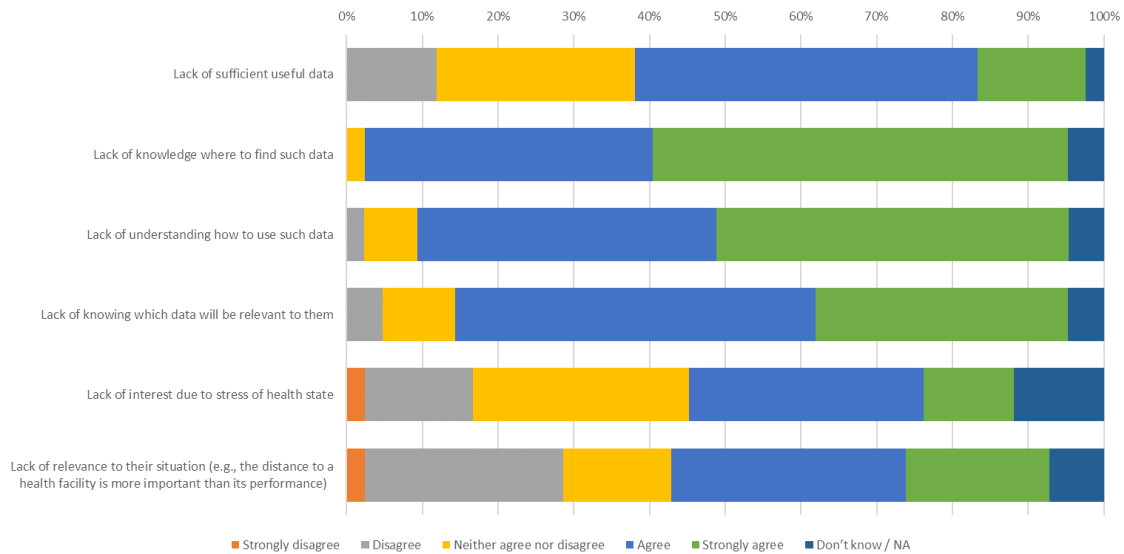
Do you agree that the following barriers are impeding consumers' access to, and use of, 'high value' data?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Lack of sufficient useful data	0 0.00%	5 11.90%	11 26.19%	19 45.24%	6 14.29%	1 2.38%	42
Lack of knowledge where to find such data	0 0.00%	0 0.00%	1 2.38%	16 38.10%	23 54.76%	2 4.76%	42
Lack of understanding how to use such data	0 0.00%	1 2.33%	3 6.98%	17 39.53%	20 46.51%	2 4.65%	43
Lack of knowing which data will be relevant to them	0 0.00%	2 4.76%	4 9.52%	20 47.62%	14 33.33%	2 4.76%	42
Lack of interest due to stress of health state	1 2.38%	6 14.29%	12 28.57%	13 30.95%	5 11.90%	5 11.90%	42
Lack of relevance to their situation (e.g., the distance to a health facility is more important than its performance)	1 2.38%	11 26.19%	6 14.29%	13 30.95%	8 19.05%	3 7.14%	42
					Comments, other barriers to consider:		4
						answered question	43
						skipped question	58

Lack of consumer knowledge about where to find high value health data, how to understand its use and which data would be relevant to them were favoured by the most respondents as the barriers impeding consumer use. There was still moderate agreement, though less, with the lack of relevance to their situation, lack of sufficient useful data or lack of interest due to their stressed unwell state as being impediments to consumer use of high value data.

Q55 Do you agree that availability of skilled labour in the health sector is an issue in areas such as Health Informatics, data science, or other quantitative and data-specific occupations?

■ Strongly disagree ■ Disagree ■ Neither agree nor disagree ■ Agree ■ Strongly agree ■ Don't know / NA
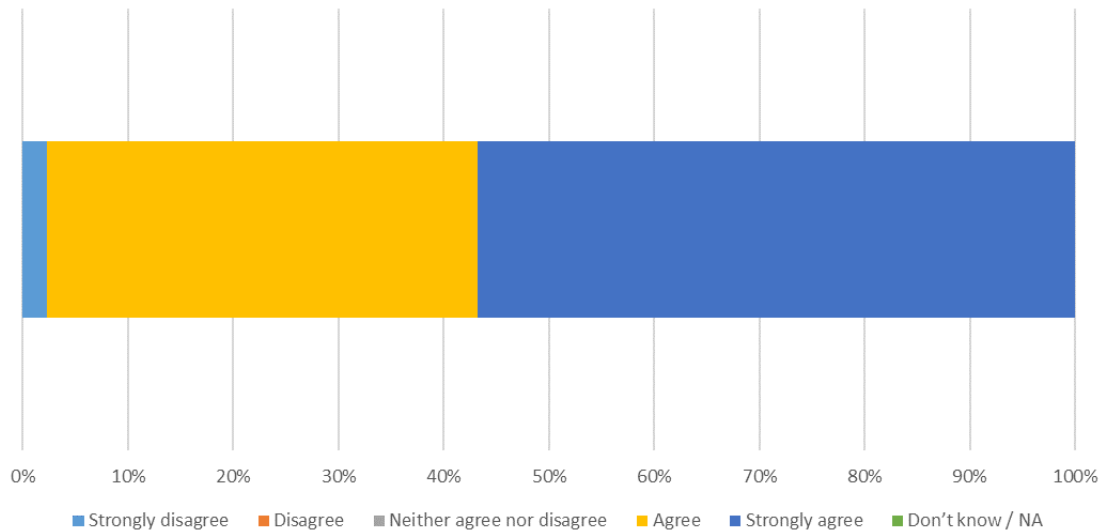
Do you agree that availability of skilled labour in the health sector is an issue in areas such as Health Informatics, data science, or other quantitative and data-specific occupations?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
1	0	0	18	25	0	44
2.27%	0.00%	0.00%	40.91%	56.82%	0.00%	
					answered question	44
					skipped question	57

There was nearly unanimous agreement (98%) by the respondents that the availability of skilled Health Informatics, data sciences and similar occupations is an issue, with 57% agreeing strongly.

Q56 Do you agree the government should have a role in improving the skills base in this area?
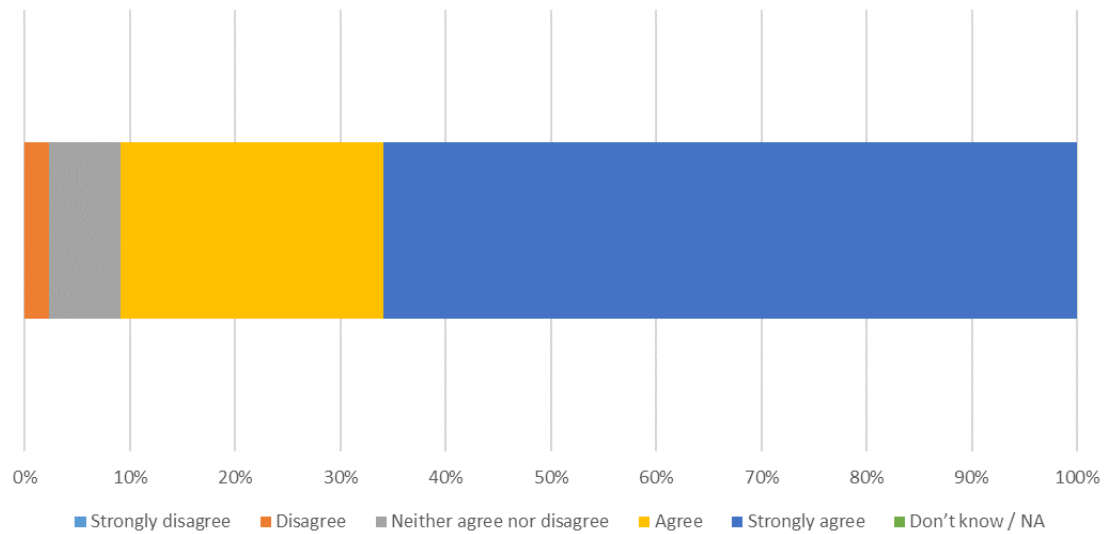
Do you agree the government should have a role in improving the skills base in this area?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
0	1	3	11	29	0	44
0.00%	2.27%	6.82%	25.00%	65.91%	0.00%	
					answered question	44
					skipped question	57

Over 90% of respondents agreed, including 66% strongly agreeing, that the government should have a role in addressing this issue.

Q57 Do you agree that the greatest concerns for privacy protection are posed by the following types of health data and health data applications (both public sector and private sector)?
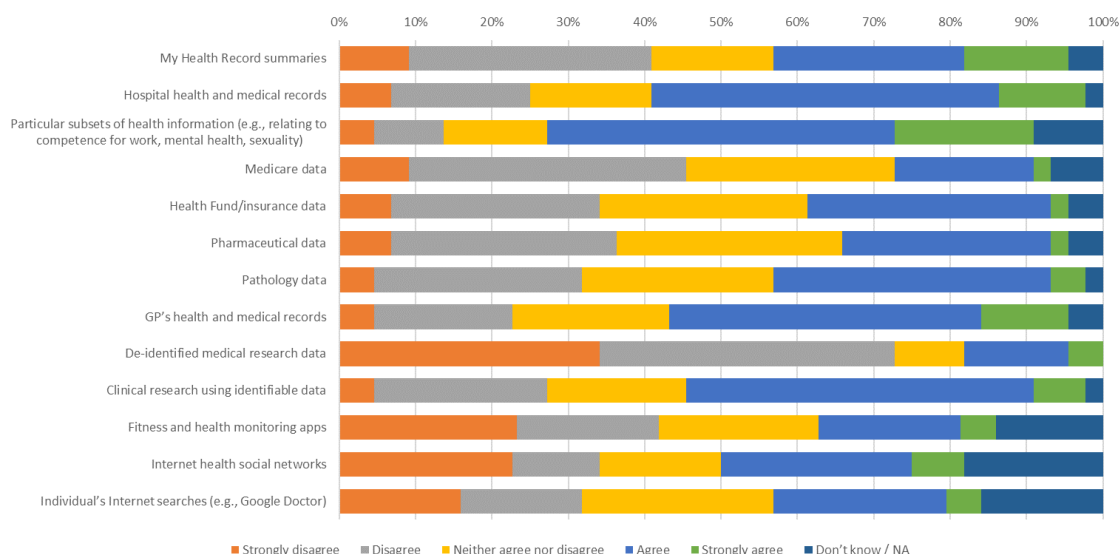
Do you agree that the greatest concerns for privacy protection are posed by the following types of health data and health data applications (both public sector and private sector)?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
My Health Record summaries	4 9.09%	14 31.82%	7 15.91%	11 25.00%	6 13.64%	2 4.55%	44
Hospital health and medical records	3 6.82%	8 18.18%	7 15.91%	20 45.45%	5 11.36%	1 2.27%	44
Particular subsets of health information (e.g., relating to competence for work, mental health, sexuality)	2 4.55%	4 9.09%	6 13.64%	20 45.45%	8 18.18%	4 9.09%	44
Medicare data	4 9.09%	16 36.36%	12 27.27%	8 18.18%	1 2.27%	3 6.82%	44
Health Fund/insurance data	3 6.82%	12 27.27%	12 27.27%	14 31.82%	1 2.27%	2 4.55%	44
Pharmaceutical data	3 6.82%	13 29.55%	13 29.55%	12 27.27%	1 2.27%	2 4.55%	44
Pathology data	2 4.55%	12 27.27%	11 25.00%	16 36.36%	2 4.55%	1 2.27%	44
GP's health and medical records	2 4.55%	8 18.18%	9 20.45%	18 40.91%	5 11.36%	2 4.55%	44
De-identified medical research data	15 34.09%	17 38.64%	4 9.09%	6 13.64%	2 4.55%	0 0.00%	44
Clinical research using identifiable data	2 4.55%	10 22.73%	8 18.18%	20 45.45%	3 6.82%	1 2.27%	44
Fitness and health monitoring apps	10 23.26%	8 18.60%	9 20.93%	8 18.60%	2 4.65%	6 13.95%	43
Internet health social networks	10 22.73%	5 11.36%	7 15.91%	11 25.00%	3 6.82%	8 18.18%	44
Individual's Internet searches (e.g., Google Doctor)	7 15.91%	7 15.91%	11 25.00%	10 22.73%	2 4.55%	7 15.91%	44
					Comments, other options to consider:		2
						answered question	44
						skipped question	57

Respondent sentiment towards the suggested concerns for Privacy Protection were more variable, with more Don't know and Unsure either way responses. Particular subsets of health information, and Hospital health and medical records, rated the most agreement for highest concern for privacy protection. GP's health and medical records, and Clinical research using identifiable data were also considered higher risk datasets or applications.

Conversely, De-identified medical research data was strongly disagreed with as a potential risk for Privacy protection; Medicare data, and Fitness and health monitoring apps were also considered low risk.

Q58 Do you agree that 'confidence' and 'trust', by both individuals and businesses, in the way health data is used will best be maintained and enhanced by:
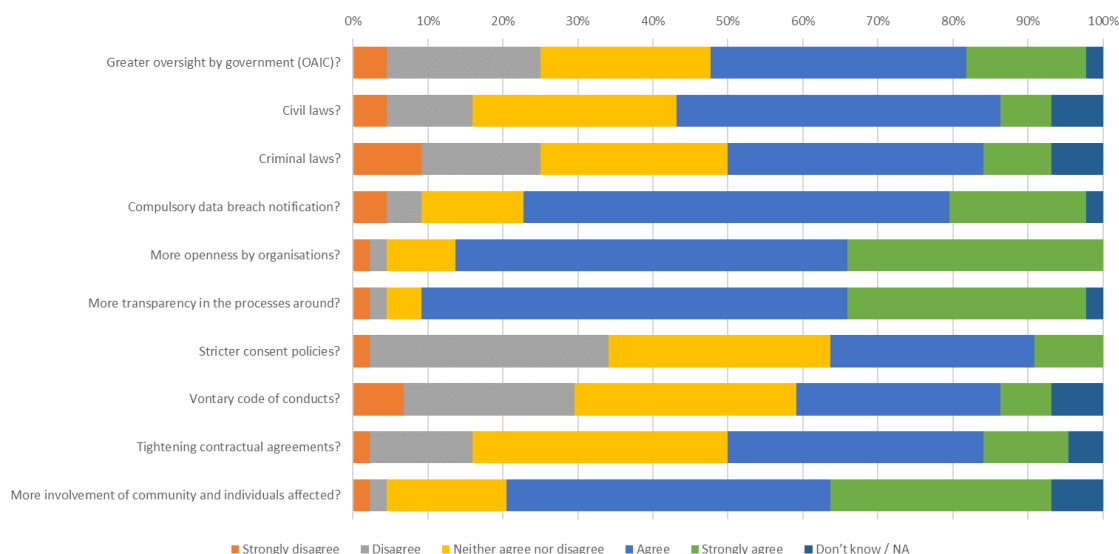
Do you agree that 'confidence' and 'trust', by both individuals and businesses, in the way health data is used will best be maintained and enhanced by:

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
Greater oversight by government (OAIC)?	2 4.55%	9 20.45%	10 22.73%	15 34.09%	7 15.91%	1 2.27%	44
Civil laws?	2 4.55%	5 11.36%	12 27.27%	19 43.18%	3 6.82%	3 6.82%	44
Criminal laws?	4 9.09%	7 15.91%	11 25.00%	15 34.09%	4 9.09%	3 6.82%	44
Compulsory data breach notification?	2 4.55%	2 4.55%	6 13.64%	25 56.82%	8 18.18%	1 2.27%	44
More openness by organisations?	1 2.27%	1 2.27%	4 9.09%	23 52.27%	15 34.09%	0 0.00%	44
More transparency in the processes around?	1 2.27%	1 2.27%	2 4.55%	25 56.82%	14 31.82%	1 2.27%	44
Stricter consent policies?	1 2.27%	14 31.82%	13 29.55%	12 27.27%	4 9.09%	0 0.00%	44
Vontary code of conducts?	3 6.82%	10 22.73%	13 29.55%	12 27.27%	3 6.82%	3 6.82%	44
Tightening contractual agreements?	1 2.27%	6 13.64%	15 34.09%	15 34.09%	5 11.36%	2 4.55%	44
More involvement of community and individuals affected?	1 2.27%	1 2.27%	7 15.91%	19 43.18%	13 29.55%	3 6.82%	44
					Comments, other options to consider:		2
						answered question	44
						skipped question	57

Respondents showed strong agreement (86-89%) for More openness by organisations, More transparency in the processes around the way health data is used as being the best options to maintain and enhance trust and confidence in data use. More involvement of community and individuals affected, and Compulsory data breach notification also gained very good agreement (73-75%). The least popular choices were Stricter consent policies, and Voluntary code of conducts with roughly equal splits between respondents for agree, unsure and disagree.

Q59 Do you agree that Australia could learn from the following who have better protection of personal data, especially sensitive health information?
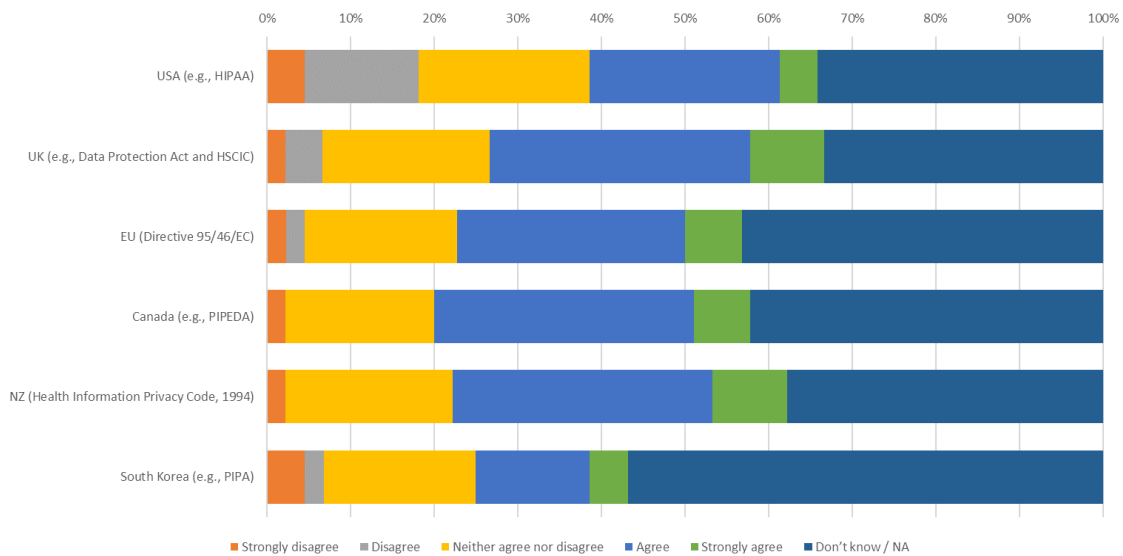
Do you agree that Australia could learn from the following who have better protection of personal data, especially sensitive health information?

Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
USA (e.g., HIPAA)	2 4.55%	6 13.64%	9 20.45%	10 22.73%	2 4.55%	15 34.09%	44
UK (e.g., Data Protection Act and HSCIC)	1 2.22%	2 4.44%	9 20.00%	14 31.11%	4 8.89%	15 33.33%	45
EU (Directive 95/46/EC)	1 2.27%	1 2.27%	8 18.18%	12 27.27%	3 6.82%	19 43.18%	44
Canada (e.g., PIPEDA)	1 2.22%	0 0.00%	8 17.78%	14 31.11%	3 6.67%	19 42.22%	45
NZ (Health Information Privacy Code, 1994)	1 2.22%	0 0.00%	9 20.00%	14 31.11%	4 8.89%	17 37.78%	45
South Korea (e.g., PIPA)	2 4.55%	1 2.27%	8 18.18%	6 13.64%	2 4.55%	25 56.82%	44
					Comments, other examples to consider:		2
						answered question	45
						skipped question	56

There were a larger number of respondents indicating Don't know or Unsure regarding overseas examples of better data privacy protection, however New Zealand, the UK and the EU were favoured over the USA and South Korea.

Q60 Under some circumstances consumers may request deletion of personal information about themselves. When should requests for the deletion of health data be denied?
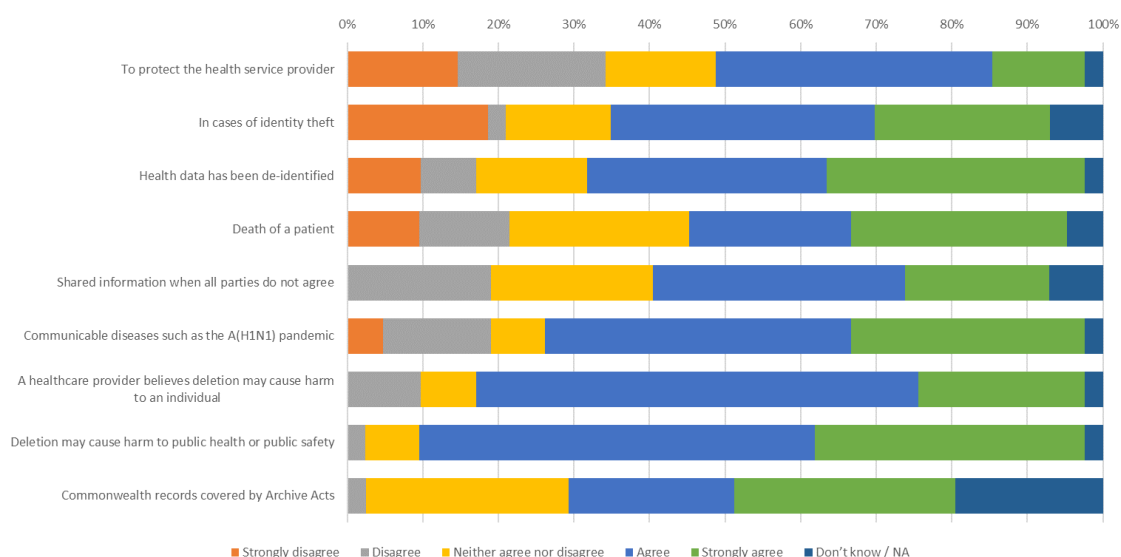
Under some circumstances consumers may request deletion of personal information about themselves. When should requests for the deletion of health data be denied?

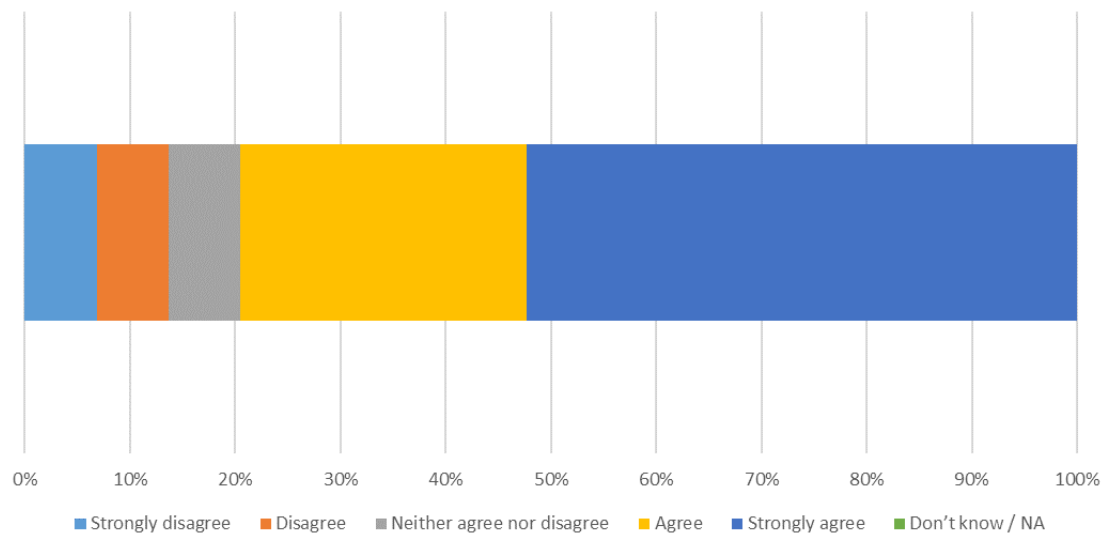| Answer Options	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
To protect the health service provider	6 14.63%	8 19.51%	6 14.63%	15 36.59%	5 12.20%	1 2.44%	41
In cases of identity theft	8 18.60%	1 2.33%	6 13.95%	15 34.88%	10 23.26%	3 6.98%	43
Health data has been de-identified	4 9.76%	3 7.32%	6 14.63%	13 31.71%	14 34.15%	1 2.44%	41
Death of a patient	4 9.52%	5 11.90%	10 23.81%	9 21.43%	12 28.57%	2 4.76%	42
Shared information when all parties do not agree	0 0.00%	8 19.05%	9 21.43%	14 33.33%	8 19.05%	3 7.14%	42
Communicable diseases such as the A(H1N1) pandemic	2 4.76%	6 14.29%	3 7.14%	17 40.48%	13 30.95%	1 2.38%	42
A healthcare provider believes deletion may cause harm to an individual	0 0.00%	4 9.76%	3 7.32%	24 58.54%	9 21.95%	1 2.44%	41
Deletion may cause harm to public health or public safety	0 0.00%	1 2.38%	3 7.14%	22 52.38%	15 35.71%	1 2.38%	42
Commonwealth records covered by Archive Acts	0 0.00%	1 2.44%	11 26.83%	9 21.95%	12 29.27%	8 19.51%	41
					Comments, other examples to consider:		1
					answered question		43
					skipped question		58

There was variable but moderate agreement for most options, however nearly 90% agreed consumers personal data about themselves should not be deleted at their request if it could cause harm to public health or public safety. 56% also agreed for if A healthcare provider believes deletion may cause harm to an individual, although this was much less strong. Other mitigating reasons thought important included in the case of Communicable diseases such as the A(H1N1) pandemic, or if the data was de-identified. While there was still moderate agreement (48%) the strongest negative response against denying deletion of a consumer's personal health data, was given for To protect the health service provider.

Q61 Do you agree with Opt Out consent as a potentially useful ethical mechanism for sharing health data under certain circumstances where sound privacy and security protections are in place?

Do you agree with Opt Out consent as a potentially useful ethical mechanism for sharing health data under certain circumstances where sound privacy and security protections are in place?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
3	3	3	12	23	0	44
6.82%	6.82%	6.82%	27.27%	52.27%	0.00%	
					answered question	44
					skipped question	57

Opt Out consent was considered an ethical mechanism by 80% of respondents, but 14% disagreed.

Q62 Do you agree the NHMRC/Australian Health Ethics Council should have a role in guiding health data sharing practice?
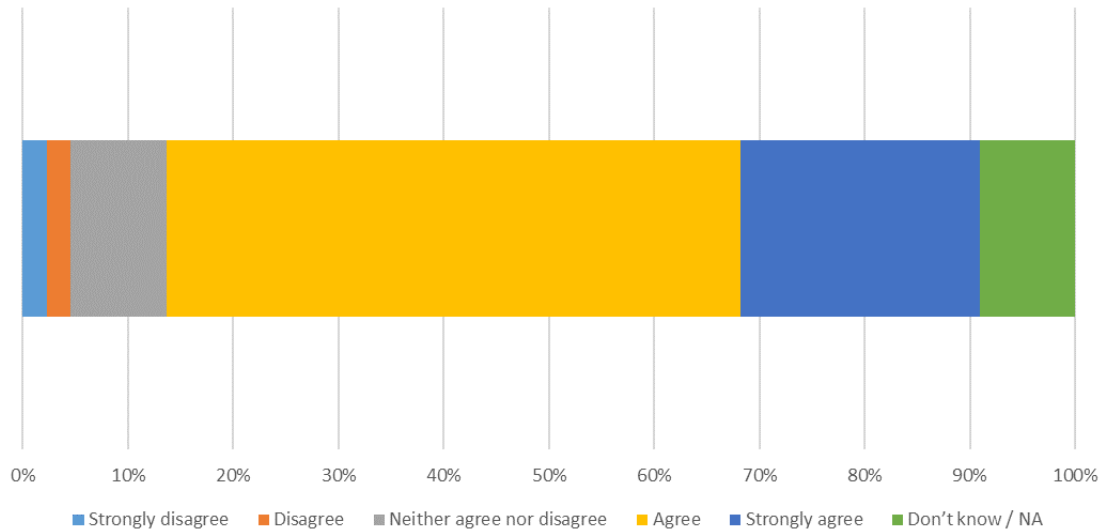
Do you agree the NHMRC/Australian Health Ethics Council should have a role in guiding health data sharing practice?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
1	1	4	24	10	4	44
2.27%	2.27%	9.09%	54.55%	22.73%	9.09%	
					answered question	44
					skipped question	57

Although only 23% agreed strongly, overall 78% of respondents agreed the NHMRC/ Australian Health Ethics Council should have a role in guiding health data sharing practice.

Q63 Are you aware of the NHMRC Statement on data sharing?

43.90%

56.10%

- Yes
- No

Are you aware of the NHMRC Statement on data sharing?

Answer Options	Response Percent	Response Count
Yes	43.90%	18
No	56.10%	23
	answered question	41
	skipped question	60
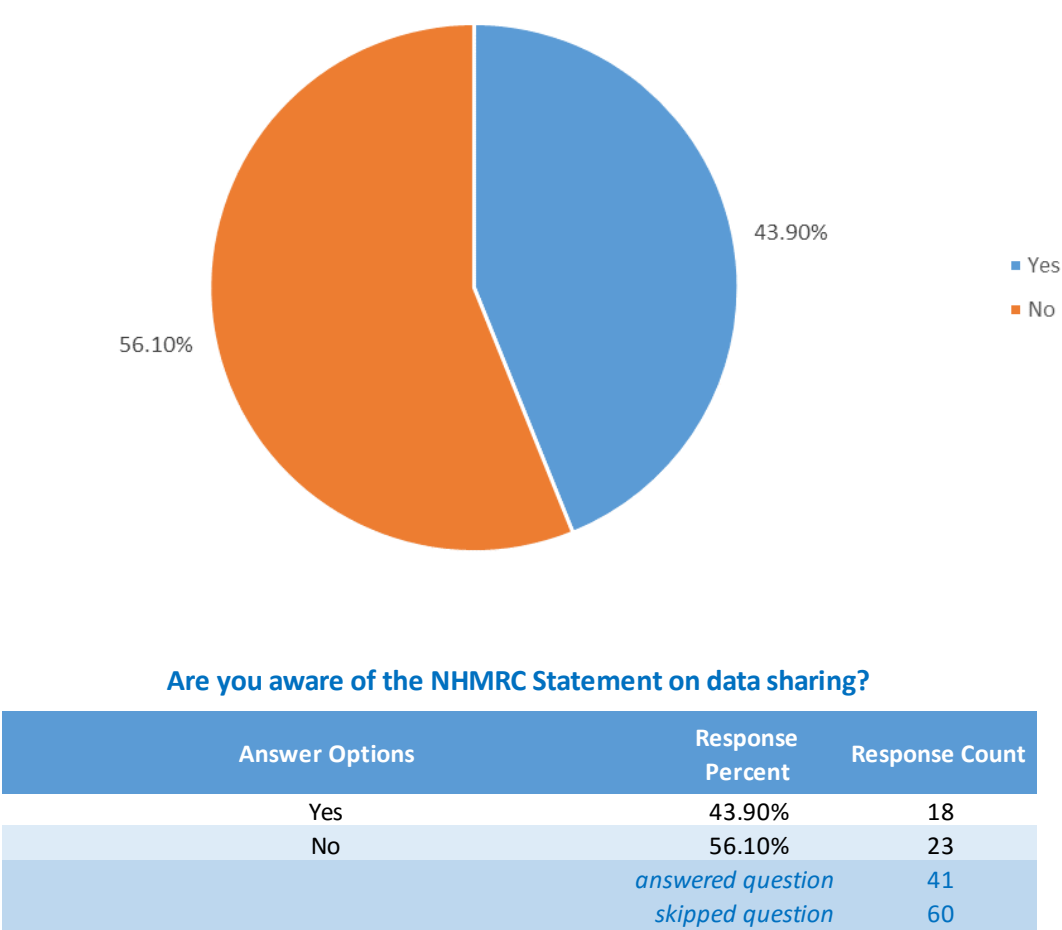
However, 44% of respondents were aware of the NHMRC Statement on Data Sharing.

Q64 Do you agree that the NHMRC Statement on data sharing is useful in practically promoting the ethical sharing of health data?

■ Strongly disagree ■ Disagree ■ Neither agree nor disagree ■ Agree ■ Strongly agree ■ Don't know / NA
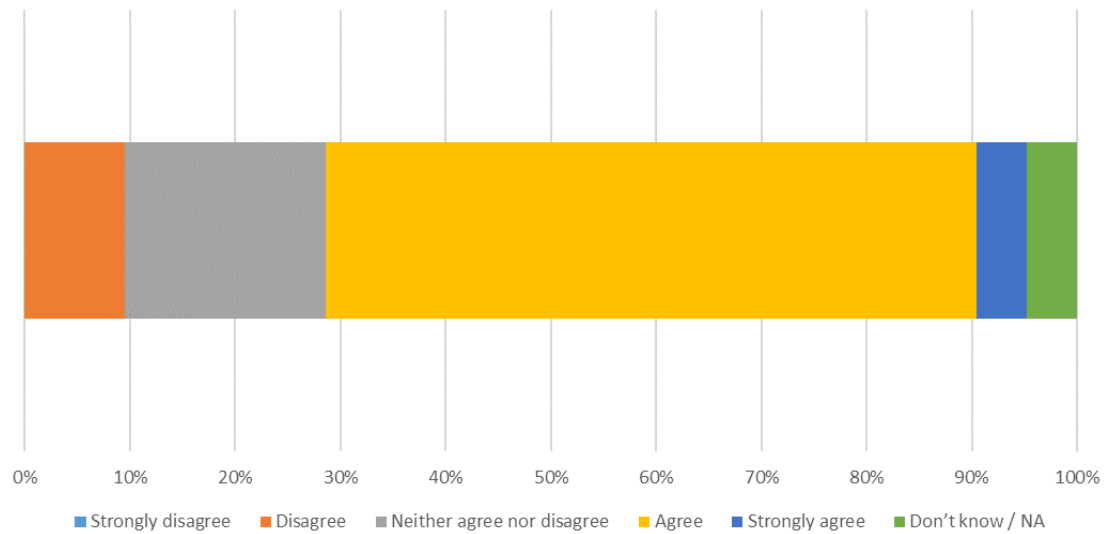
Do you agree that the NHMRC Statement on data sharing is useful in practically promoting the ethical sharing of health data?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
0	2	4	13	1	1	21
0.00%	9.52%	19.05%	61.90%	4.76%	4.76%	
					answered question	21
					skipped question	80

Although 67% of respondents agreed that the NHMRC Statement is useful, only 5% agreed strongly

Q65 Are security measures for public sector health data too prescriptive?
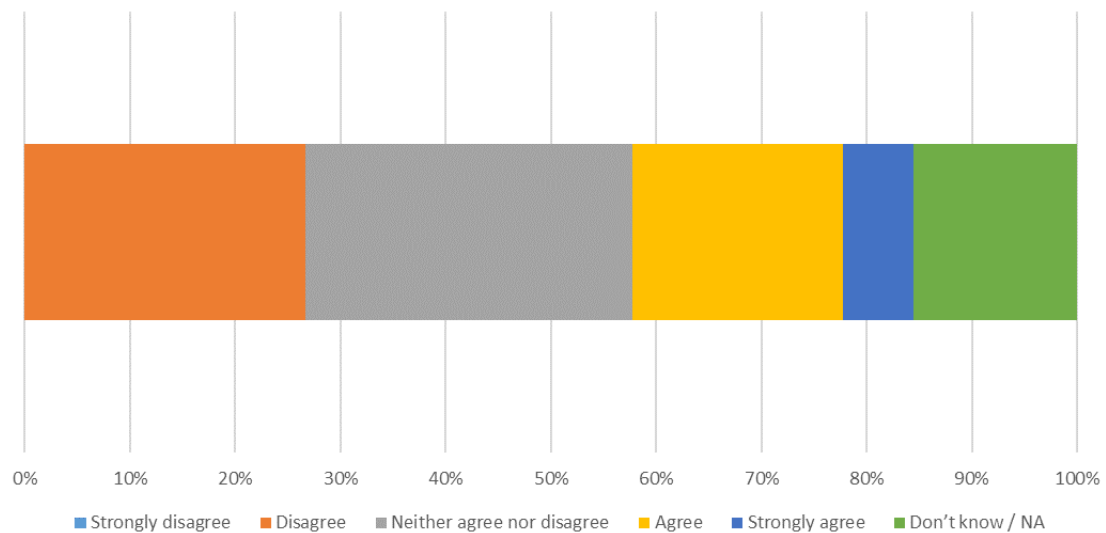
Are security measures for public sector health data too prescriptive?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
0	12	14	9	3	7	45
0.00%	26.67%	31.11%	20.00%	6.67%	15.56%	
					answered question	45
					skipped question	56

A small proportion of respondents (27%) agreed that security measures for public sector health data are too prescriptive.

Q66 Do security measures need to be more flexible to adapt to changing circumstances and technologies?
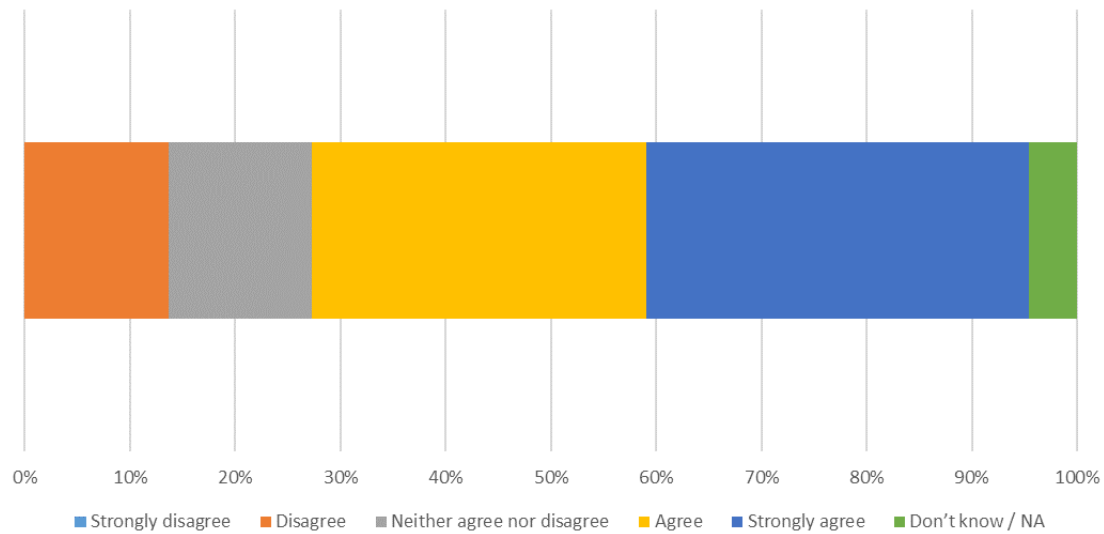
Do security measures need to be more flexible to adapt to changing circumstances and technologies?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Don't know / NA	Response Count
0	6	6	14	16	2	44
0.00%	13.64%	13.64%	31.82%	36.36%	4.55%	
					answered question	44
					skipped question	57

Respondents firmly agreed (68%) that security measures need to be more flexible to adapt to changing circumstances and technologies.

Appendix

List of All Comments Received

Do you agree that the lack of accessibility and use of health related data affect healthcare, or the way healthcare professionals work, or disadvantage the community?

The lack of certain types data makes the health system very difficult to both understand and manage
Clinicians need access to current health Information at point of care to assist with making clinical decisions.
Health professionals collect the data they need when they see that patient. However, the health system is disadvantaged by not having sufficient data at a macro level.
Rich data is held in hospitals, state and federal government vaults, but is difficult to access, there's no point of contact to explain what is available and how it can be used. Small example datasets are non-existent and even that small step would make our analysis journey so much easier.
Regional care coordination is extremely difficult due to no shared electronic medical record.
Data analysis and availability is fundamental in healthcare
Particularly between primary care/general practice and the hospital/institutional sectors
The Australian system requirement for patient self-administration is both a burden to administer and lacks continuity of care increasing the likelihood of errors in care delivery. A patient having to manage their own documentation when suffering co-morbidity or chronic disease lets down the patient
Without large-scale data access, it is impossible to truly monitor the health of the population or the impact of treatment decisions. Our evidence base is limited to randomised controlled trials performed on different populations in different countries.
No opportunity for linking health care data at a population level in Victoria. restricted access to large scale data in QLD
There is a need for much greater evidence based local, regional, state and national planning and policy, resource allocation and research. Opening up health data for access, discovery, use and re-use will also be essential to support new technology enabled health service delivery approaches and to enhance citizen involvement and health outcomes.
If data can not be accessed, then services will find it extremely difficult to determine current demand and future planning to meet demand
We should aim for a streamlined way for patients to facilitate the flow of information between GPs, Hospitals and Specialists. There are so many privacy constraints aimed to protect the patient, but then they / their doctors have to jump through hoops to get the information.
The current lack of data transparency within the silos of our public and private healthcare sectors will be detrimental for Australian patients as we approach a rapidly ageing population with chronic disease that requires clinical and economic evidence-based solutions.
We're only scratching the surface at present. We could vastly improve quality and cost effectiveness for our patients through efficient and appropriate access to data.
Restrictions on both primary and secondary uses of health data adversely affect health outcomes for individuals and populations.
An example is Waiting List Demand for Surgery in Victoria - it is an artificial construct with the bulk of regional Victoria not on a Waiting List - so how can you measure demand - surgeons work in many health institutions - their data is not aggregated to determine performance in both private and public
Too many data silos so sensible compilation of usable health data at the primary care interface is not possible
There is too many independent systems not connected to one another with very inaccurate data collection for rapid diagnosis for health care professionals. There is also no take on alternative medical treatments or tracking of day to day risk factors such as massage for physios
Health care data silos ensure that quality of data (or lack thereof) cannot be identified by cross-referencing
Delays decision making and wastes time / money

Do you agree that the community (including yourself) would derive the following benefits from increasing or improving the availability and use of health data?

Benchmarking,
Key benefit of data is better understanding of disease progression. Data itself will not make any of these improvements unless the health system is redesigned to promote integrated care. The current health system is the problem, not the lack of data.
Data is the new currency, we're working in a data economy, but currently the access to data is focussing on the potential risks, without a similar focus on the benefits. Throughout the conference the message is that data and evidence will strongly leverage our abilities, which has to happen.
Data is essential for a multitude of reasons and all for the benefit of everyone concerned.
The trust issue is a tricky one due to data privacy concerns. But if we can get past that, the availability of health data will surely lead to innovations in health care, reduced errors due to cross-checking of e.g. prescriptions with diagnoses or allergies, etc.
Our data is fundamental to gaining robust insight into our business. Innovation comes by leveraging the power of the wider group of data specialists in the health community, not by restricting access to a limited few. We're implementing an EMR with extremely limited flexibility to extract data in real time and report. It's incredibly frustrating and disappointing.
Improving decision making requires improved access to high quality, reliable data. The object is not to make financial gains but to minimise ineffective care.
I have or am working across 25 Health Services in Victoria - not one of them was extracting Theatre Utilisation Data and using it effectively - 2 were still collecting data manually and keeping it on hand written sheets - it isself evident that providing access to data you will benefit greatly
This is currently being produced and designed privately to force government come to the table for full integration.
Reduced red tape for providers with subsequent gains in efficiency and time spent on clinical care. Improved data quality and ability to identify data quality issues effectively. Improved ability to have outcome focussed government initiatives and test the veracity of the outcome measures.

Do you agree that the following health data repositories should be considered 'high-value' to health data users, stakeholders or the broader community?

General Practice / Primary Care data Unique identifier to allow the tracking of patient journeys across the health system
Personally identifiable data should be protected, but the secondary extracts do not require protection.
The above list is a great example of the breadth of what could be available, many of us have access to small parts of the whole. But consistent awareness, policy and access would repay the investment of time required to create it.
My health record - i hear it is not so easy to work with.
Disagrees have been provided where personal knowledge of the effectiveness of systems reduces the data value based on "known" data
linking data with other features such as geomapping
The value of open health data will be enhanced when it can be very easily brought together with ABS data, crime data, education data, etc. etc. Data needs to be made available in machine readable, standards based formats.
it's not the 'type' of data repository, but the meaningfulness and completeness of the data contained within the repository whatever it is wherever it comes from, however it is encoded... more is not better if it only gives us more junk
PAS data, and for QH, Homer is not the only PAS.
Deprivation is a highly weighted factor in determining health outcomes so ABS SEIFA or similar would be critical.

It was also be useful to look at Doctors Payments to work performance and hours of work - not difficult but informatiive
My Health Record scores low because it is fundamentally flawed in that although attempting to bring together disparate health data there is no one who has both a curating role and a healthcare knowledge role
The LifeSync system is meant to achieve a full management capability of national health records in which a real-time record of someone's health can be updated at the click of a button or monitored in a hospital by the patient's assigned medical practitioner for the day. This system will create the capability for the combining and washing of patient information to unify their medical histories into one solid centralised information piece. The system allows for the streamlining of the health sector processes for medical services with the ability to track information on a national scale but within time be able to track medical records from partnering countries, to ensure complete unification of a person's medical history helping to distinguish an enhanced diagnosis or treatment outcome.   Some of the type of data should be: The patient history will be a full comprehensive record accessible to authorised persons in which they will be able to see such details (Neurological, Neurovascular, Mental Status Questions, [Patient Wellbeing] and the Glasco Coma Scale) (Assesses the patients level of consciousness best score 15, worst 3).   The patient observation component will allow for both clinical checklists and automatic medication calculations. (Oral, Tablet, Capsule, Wafer, Liquid, Sublingual (Under the tongue). (Let dissolve) (GTN) Glyceral Trinitrate. Monitor blood pressure before and after dose - if out of range withhold medication and get doctor. Relieves chest pain. Angina pectoris. Max 3 doses. Spaced within 5 minutes. Pain scale after 5 minutes. (Syncope) (Adverse effects). Buccal - (let medication dissolve in the side of your cheek.) / (IV - Infusion rate (per hr) and drips per minute).   Real time monitoring of Electrocardiograms (ECG), Oxygen Saturations (95-100%), unless COPD - Chronic Obstructive Pulmonary Disease (88-90%), Manual check monitoring against real time a and a full comprehensive history of all medical and alternative treatments.

For health consumers, do you agree that the following criteria could identify 'high value' datasets that would help them make informed decisions? i.e. datasets which:

Benchmarking and analysis take time to complete - and are not timely enough for consumers to make decisions, unless a "tripadvisor" style rating system is used that is accessible to patients seeking elective surgery.
Improving outcomes and experience is an important measure for health which is often cost effective.
Realtime data widely accessible
Benchmarking of services by consumers is tricky, given that populations in different locations may vary and that therefore "baselines" are different for different services. The risk adjustment data is important but may be difficult for consumers to interpret.
the real value of data is NOT ABOUT cost or money (and indeed such a focus will encourage/allow/legitimise gaming or burden shifting or access limitations
In regional/rural locations there is no choice available for health service providers
I agree this would be useful BUT the validity of such comparisons can be a problem. I see a lot of people trying to produce league tables that are not adequately risk adjusted due to the presence of confounders that may not be measured in the data or just a lack of understanding of the data.
All self evident
Consumers require information presented with an intuitive interpretive data overlay that makes it easy to understand and distils complex data into simple messages that assist and motivate consumers to make informed decisions
Health consumers do not always understand the language of medicine so cannot always make informed choices

Which health data repositories would provide 'high value' to consumers in helping them make informed decisions?

Interpretation is important and obviously would assist consumers, but even without this I believe access to information is valuable.
Patient and doctor recommendations are always the key variable in making informed decisions. The doctors may need to rely on these systems, but not the patients.
If the data is made available p, a secondary market of interpretation services will fill the gaps
Not quite sure about the last two. Individual health literacy is important in all of these four points but particularly the last two.
Not sure what last item really meant
(see comments above.) Access to one's own data can allow for deeper understanding and engagement in one's own conditions. Also for error checking.
EHR and CIS have not delivered the much hyped benefits.
Patients as consumers are the new health workforce. They need access to the same data that clinicians have in order to make the right decisions for their own care and the care of their dependants.
Working out the Polypectomy rate for individual colonoscopists would be a very useful community and quality exercise
As above- interpretation is crucial
Data must be interpreted to be useful to consumers
The data repositories are high value themselves, but appropriate analysis & interpretation is always key to realising their benefit
needs interpretation with clinician before consumer can understand some conditions
The key is access to quality information in a format consumers can understand.

How much do you agree that data in the following 'high-value' health related data repositories are currently being used effectively?

Lack of disclosure and availability are contributing factors.
Responses are based on Australia's healthcare digital maturity being low
I haven't looked deeply at many of these data sets. In general the administrative coded data is only used for limited purposes and the PCEHR was not designed with public health or disease surveillance needs in mind.
social determinants of health and linking this to health outcomes data, health service acccess etc
I have no first hand knowledge of how these repositories are being used in the community.
There's a reason it's not used.... it's not useful... what we have is NOT what we need.... more access to stuff that isn't helpful won't help almost all the data listed above (except for the first row) is statistical, financial, population based COUNTS of patients accessing a health service ... and very little interesting data about the actual health (or illness) of the patients
Obtaining IDC-10 coded data in QH is problematic.
GPS and geo-location mapping is indispensable to population health management. Analysis of unstructured big data such as social media and telematics would also help.
Data is so poorly used - it makes me cry - frustrated to see the waste associated with not using it
Adverse drug reports Provider data including Medicare provider numbers and prescriber numbers linked to AHPRA number and HPI-I
without doubt some data is of high value but it is fragmented and not consistent across jurisidications, i.e. not all ICD 10 coding is adequate, not everyone uses PCEHR and in fact it has been a poor implementation with technical challenges
The difficulty is accessing public data sets from AIHW and ABS with adequate area information for analysis makes undertaking research on relevant policy questions difficult. For example, the SDAC unit record file only provides information on state and rural/regional making any analysis of local area variation impossible. While privacy concerns need to be managed, where the applicants are research universities and the research has a strong public benefit there needs to be scope for greater access to meaningful data for research.

What are the main barriers that restrict the accessibility and use of health related data? – including accessibility and use by healthcare providers/ consumers/ researchers/ businesses.

My organisation (Chappell Dean) currently processes over 6 million inpatient episodes per year on behalf of member organisations of The Health Roundtable and the Hospital Benchmarking network. We take data in any format and process it to produce thousands of detailed reports for each of the 150+ hospitals. The key to our process is ownership of the data by the hospitals themselves, with constant feedback and tuning of the reports based on feedback.
As a nurse I found that it was incredibly difficult to access data from many systems and it was expected that you report on KPI's but data acess meant waiting for a team to provide you with Data rather than you being able to run the report yourself. There was a sentiment that "people" were inaccurately reporting on data but the team that was running the reports was under resourced meaning a long turn around time for what was often for data that was required almost immediately. In my mind training is something that would mitigate the issue of innapropriate use of data and if there were adequate policy in terms of use of data then people who break them can be denied access rather than a blanket whole of service approach which is neither necessary or enabling for people to perform day to day tasks.
Patients want us to use their data, and are generally assuming this is already happening. The barriers are more cultural than technical - many organisations are solving the integration issue, but organisations are risk adverse and won't share data.
The biggest problem not mentioned here is that 80% of data is in text and there are few technologies available to manipulate this data source.
there is also a general lack of understanding by consumers (including care providers) on what data is available and where to go to access it
There are successful data federation models in health internationally and in other sectors nationally which could be progressively implemented to deliver health and research sector insights and productivity gains. Regions like South West Victoria are actively progressing plans for increasing the availability of health and other data with the support of the Western Alliance with leadership from Federation University Australia and Deakin University.
Under resourced
There is an absence of a qualified trained workforce in data management and health information management
Access to health-related administrative data for secondary purposes is quite well established. Issues arise because those collecting the data are not aware of the secondary use which impacts on quality and reliability of data.
Poor understanding of privacy regulations and privacy protection technologies - hence playing safe when it is not necessary
QH Homer/HBCIS and ieMR are good examples of the barriers produced. ieMR cannot accept data from non-enterprise systems and HBCIS policy (not technical limitation) is to not accept anything. Each Homer install is a 'source of truth', even on patients not in that system. - A highly flawed approach.
There's an overwhelming fear, not just of loss of control, but "Fear of Risk of breach of Privacy legislation". Health care culture is one of inertia and in providing access to data there is a fear of something going wrong that vastly outweighs the actual risk of something going wrong and maintains the inertia.
Data and business intelligence appear to be an afterthought in any clinical information system implementations. The "old school" approach to controlling access to data and reporting centrally must change. Again, it's incomprehensible to consider the move toward an EMR that locks our data (contractually or otherwise) in proprietary systems and further reduces our flexibility with respect to operational information requirements.
The major barriers are cultural and historical rather than regulatory
All of the above - anaytucal skill deficit and Fear by IT of loss of control
LifeSync system will provide individual health practitioners the ability to access a national system to obtain and update a single record of their client to better treat them, in addition this will allow for many benefits and some social issues to be addressed such issues this will address range from: 1.   Workplace Compensation - This system will bring about the ability for claims to be assessed more fairly, quickly and will help to diminish false workplace compensation claims. 2.   Emergency / Triage – This system will allow

for the tracking of patients in real time from the ambulance to the emergency ward allowing for a doctor to assess the patient in real time while in transit . 3.   Pharmacy – This system will allow for all current functions with added functionality of tracking patient's prescriptions and drug dispense history, as well as basic treatment overview for the pharmacist. This will allow for non-adverse drugs to be prescribed on current drug treatment charts and will allow the stoppage from multiple drug similarities being prescribe and handed out. 4.   Real time patient monitoring – This system will be created with the ability to monitor patient vitals from anywhere in the hospital, using all types of technology but allow for mobility and quick access, to required information, and automation within health checking, to run side by side with doctor and nurse observations.   5. Statistical Analysis – The data collected within this system will have a built in Static analysis frame work created and updated regularly by our static development partners to allow for researchers to access required information to run a majority of analytical research based on national and international information. 6.   Drug Adverse Effect Notification – The system will be connected in with the national register and/or will also be connected to Drug company systems to allow for notification in real time of different drug findings. This will then notify all authorised and required users of drug-to-drug adverse effects, in the hospital it will notify automatically to a patient's record. 7.   Maternity – The system will have a module named Ybirth, this is a full maternity information suit linking together, midwifery, obstetricians, student midwifery, mothers, birthing founders, and health professionals together. This will provide an area for mothers to save their information and a real time ability to contact their birthing professionals via video, and instant messaging. 8.   Disease and Infection Control – This system will allow for real time monitoring of disease geo clusters on a national scale, to show outbreak information, establish trending disease and control patterns, as well as pre-historic ground zero data pattern analysis and isolation.

There is a real lack of data literacy and analytical understanding at the coal face, as well as a sense of keeping data 'safe' or 'hostage' by gatekeepers for various reasons

What are the reasonable concerns that organisations may have about increasing the availability of Health data in their control?

Most organisations are reluctant to provide data to third parties because the analyst (not the consumer) is likely to misinterpret the results. Administrative data only tells 20% of the story of a patient visit, and can only be used as a screening tool for further analysis.

Privacy and security issues are real, but 'simulated patients' and technology that enables the analysis to be delivered to the data (Data61) address those issues. There is cost associated with data access, but it's far outweighed by the real dollar benefits.

Many of these risks of increasing access to health information have long been solved or are reduced through a range of mitigation approaches in other sectors. Health sector organisations will require support, access to new tools, infrastructure and know how if their capacity is to be built to ensure the most up-to-date, reliable and appropriate data is made available to generate new insights, discoveries, evidenced based policy etc.

All of these reasons/arguments are 'last century'...

Our only concern should be to mitigate risk from external security/privacy breaches. As with existing front end information systems all Health employees agree to use information appropriately. All other issues are surmountable.

Organisations are already subject to FOI requests. Improving access should decrease complexity as long as the means and outcomes are clearly defined, stated and agreed with stakeholders.

By placing the data in the hands of user and providing them with analytical tool such as Tableau you will decrease, improve decision making and hence productivity in cases up to 20 - 40%

Loss of commercial advantage is not a reasonable concern in relation to health data sharing. Commercial and financially sustainable models must be developed that do not commoditise health data.

Do you agree that the following would most likely address Privacy and Security concerns for sharing the data?

Frameworks and policies need to sit under a strong and nationally CONSISTENT legislative regime if the public are to have confidence in data sharing mechanisms. Efforts have been made over many years, but the legislation is still a complex patchwork.
Greater regulation and use of larger datasets will only slow down the process of sharing data. Australia is far behind other countries due to bureaucratic red tape.
A balance would be needed between user demand and system capacity.
Criminal penalties for poor/ineffective data security and privacy management
International approaches to open health data frameworks have been effective.
For places that use CardiacCatherisation Laboratories getting data from the commercial vendor is nigh impossible - the outcome of this is that in leads to poor decision making such as organisations purchasing too machines when they need one
Changes in legislation, or a more direct intervention by government to mandate data sharing as a critical foundation of an effective publicly funded health system.
It's more about the training of clinical staff, having data steward roles in place, than specific protocols

Do you agree that the best way to manage the risks and consequences of both public and private sector health data breaches is to:

More regulation and bureaucracy will not improve the process.
This will require funded positions to undertake this work at local levels and signficant legislative changes
There is a risk of introducing bias if a consent-based process is used..
1) Train more staff with a sound knowledge in security and privacy technology protection - 2) educate on pragmatic risk assessment (i.e. striking the right balance rather than advocating an unrealistic 'no-risk' viewpoint). 3) Fund a national campaign to reduce the occurrence of breaches to maintain public confidence
Security - There are already excelent security initiatives in other industry. Health is just a late adopter, no need to reinvent the wheel. Thre are already huge barriers to sharing data, most of them 'policy' and fear based. Don't add to the issues. Make it a penalty to not share.
The punitive approach generates higher cost and complexity by encouraging marginalised people to abuse the system. Education, training and support along side strong data security and data confidentiality policies de-incentivises the abuse of health data.
We need to consider decreasing barriers and provide access to the data and educate in how that data can be analysed presented and used
all suggestions will not solve the universal problems
Ethics committee should weight up the potential benefits against the risks for privacy breaches.

Do you agree that to improve coordination across jurisdictions in regard to health data privacy protection, this would best be improved by:

This has been on the agenda for years. National leadership and consistency is required.
These measures would delay Australia's ability to use health data by 5-10 years!
The regulatory data protection approach promulgated by these questions is philosophically diametrically opposed to the freedom of data approach espoused by open data policies.
Mandatory data sharing should be part of normal care processes and documentation and no publicly funded Medicare or other funding should be able to be billed unless data is shared to support better care outcomes and system effectiveness

National Data Steward might be better than a Data Protection Coordinator so that the emphasis is on good sharing and use practice rather than withholding.
Introducing bad federal laws is not an automatic improvement to the status quo, it depends if the legislators and politicians are competent. We lost so much IT progress when Dutton was Health Minister, it reversed the advancement of data collection, and standardisation!

Do you agree that the existing approaches to confidentialisation, such as de-identification, are effective in facilitating data sharing while protecting privacy?

what is the experience from the uk and elsewhere with reidentification?
Could be better when dealing with small number of de-identified patients
Yes along with other technology methods
Only as long as the data pool is not so small and targetted that individuals could then be identified.
Data remain potentially identifiable in most cases.
De-identification is misleading in the context of data linkage across multiple, large, national datasets. Re-identification through big data triangulation techniques means that the data is not really de-identified, so privacy is not protected. Identifiable data could improve data quality and health outcomes while still protecting privacy.
The current approaches might be effective where they are used properly, but the problem is that there are insufficient people in the work place that understand how to do this and provide enough support for this

How much do you agree that the following levels should bear the responsibility for determining and directing changes in the accessibility and use of health related data?

All parties need to be involved, but national leadership representative of community views is required.
Only the patient should control who has access to their identifiable data. All de-identified data should be available via the funder/provider for research and financial analysis purposes
Patients want their data shared, governments should support that
Data custodians need to maintain control of their own data - they should be able to determine the level of access (e.g fully open, restricted access etc)
Data should be available to researchers where services are subsidised by the taxpayer. And a consider of taking taxpayers money is to make de-identified data available.

Who should have the ownership rights to health data that is generated by individuals but collected by healthcare organisations or businesses?

The patient owns their personal record. The providers obtain informed consent to collect and analyse the data for treatment purposes, but can only use the de-identified data for other purposes.
Not enough information as to the date being identified or de-identified to make a decision. I also assumed that the last column is "Don't know' even though it says strongly agree (and is duplicated)
The concept of custodianship is more useful than ownership. An indivual that receives a health service should be able to access their health information but the service provider is the appropriate custodian for that data. A research or government funder should be able to set out term for data publishing, access and reuse as part of operations or funding agreements.
Individuals should own the data that pertains to them. If health care is subsidised by a payor (e.g. public health service or private insurer), the data are licensed to the payor for the purposes of improving their services. National legislation requires data available for research unless individual opts out.

It has to be shared because all data is multifaceted and has relevance to more than one side, also the cost of collecting is shared between many

Do you agree there are circumstances where health related data could be commoditised or monetised for financial gain?

This is already happening - and has huge potential to assist personalised medicine in the future. But we need a framework to consider the issues and determine community views on what is acceptable.

Companies like 3M already use health data for their commercial products to develop coding systems.

Data should be available for use, and if profitable use is made of that data then a proportion of those profits be payed back to support the data czar

commercial gain shouldn't be awarded to the custodian however this is a problem when funding for health interventions is awarded based on the evidence gleaned from the data.

The focus should be on maximising the public good benefits which will become available from opening up data and also on monitoring the productivity and improved health care outcomes that are generated as a result.

And I used to have a PCEHR/MyHealth Record, but as soon as the Govt allowed Telstra into the data space (yeah..not PCEHR) but into the broader industry by funding cancer registries.... I closed my PCEHR down. We now can't trust a Govt NOT to but public/individual healthd ata into 'for-profit' companies...

Statistical data but never data on individuals

This is a peripheral matter. Australia has a combined public and private health system and attempts to monetise data will happen whether people like it or not. If it is commercialised then whether the money goes to a private entity or back to healthcare is beyond the control of anyone.

Commercial enterprises should pay to use public data - they are likely to gain financially from it

Generally not, but I would never say 'never'.

How much do you agree the following should bear the cost of increasing the accessibility and use of health related data?

While there may be initial costs associated with capability and capacity building for opening up health data - these will be eclipsed rapidly through the productivity and knowledge benefits that follow.

Care should be taken to ensure that each time the data is collected that a clear outcome is defined. There is a lot of non clinical data collection in QH that has no justifiable end goal.

Access to data is a cost of doing business, but large volumes of high quality data a hugely valuable and can be licensed to many organisations so costs can be balanced with new revenue streams.

User pays model is reasonable for individuals and organisations, supplemented by a government pays model for public health and population health management purposes.

By enabling access to the data and providing analytical education you will free up resources hence the overall cost to health will decrease

All stakeholders need to understand the benefit of using data and contribute to the cost

Do you agree to the following as the probable reason for the health data or information blocking?

Confusion over what is allowable - and therefore opting not to share because the it is seen as lowest risk and easiest path.
I have experienced this with federal government agencies.
QH - Why is the policy to have Homer not accept HL7 messages? (control, politics, not technical)
It is like a virus - in one organisation it took 18 months to the date of birth field added to a flat file - 2 minutes work - not uncommon

Do you agree that the following characteristics define high value datasets in healthcare?

Real time data in EMR is only valuable for the patient being treated. Most datasets are incomplete and span only a fraction of the patient's experience. Only when home Apps are routinely capturing data from patient will a more complete picture be available. Simple example: Hospital doctor may write a script for a medication and record this in the patient notes. However, the patient may not actually take the medication properly at home, and have to come back to hospital. The data system won't know this problem.
If you focus on achieving all of the above in one step we'll never get there - sustainable first step in opening up data incentivising priority areas of health - obesity, dementia, cancer, family violence woukd demonstrate what's possible, create heal data champions and build momentum, skills, establish technology frameworks and toolsets for scaling up practice chance across the health sector.
However it comes, it's all extremely valuable particularly when the alternative is nothing at all. We should not wait until it's perfect, that day will never come. Use it as it is with a view to improve the quality at every opportunity.
difficult question to answer like Q 28, it is not always that black and white with data

Do you agree the following would be benefits of standardisation?

Sorry, but standardisation does not equal improved data quality.
When is was in England 8 years ago I got the NHS HRG for Hip Replacement - 70,000 cases and was able to provide useful anlysis on the data - not possible in Australia
QUlity would only be improved if there was a feedback loop from data consumers to data providers that improved resourcing and quality incentives for the data providers.
The only problem with this is medicine is not easy to standardise but the status quo is not effective either

Do you agree the following describes significant increased costs associated with standardisation?

There should be little increase in costs as much of this data is already gathered multiple times. Standardisation should reduce costs, and the scale ability where the EMR vendors will again reduce the load on individual hospitals.
First you need to find a workforce!
When you do not train your staff right and do not get data out to provide feed back what do you expect - in one of the hospitals that I worked in 70% of patient demographics had an error
Costs of learning multiple bespoke systems are far higher than a single standardised system. However these costs are often buried in "training" and on-going development costs. It is the medium to long-term cost reductions that will be most significant

> data managers and business analysts need to understand medicine and the healthcare system, it is not enough to train a workforce of IT boffins!

Do you agree the following would provide standards that are 'fit for purpose'?

> The standards are the most important thing, technical detailed standards will free industry to deliver the solutions. Government needs to provide governance and storage,

> There are already many standards that are fit for this purpose. Implementing them rather than developing new standards should be the focus. International standards use should be the default.

> gaining consensus is a very difficult process

Do you agree healthcare organisations use the following criteria and decision-making tools to decide which public sector Health data to make publicly available?

> The rational as to what data is made available and what data is not is definitely nit transparent at the Federal level

Do you agree that government agencies should undertake the following processing before releasing health data?

> Data quality is best addressed by crowd sourcing, I'd envisage early data which many organisations can use and check, and then curated data once that initial 'early stage' data has been analysed and used. This is scale able and free

> If data is going to be provided then there must be some governance and responsibility taken for it

> Data quality is best addressed at the source. However, it may take external third party review for this to lead to changes that improve data quality.

Do you agree that the following government initiatives (whether Australian Government, state, territory or local government, or overseas jurisdictions) have been particularly effective in improving health data access and use, including linkage?

> GIFTR was only implemented in Queensland in April 2016 so it is soon to tell its effectiveness

> I'm not aware of any of these initiatives which is part of the problem - there is no central clearing house to find out how to access data.

> I am not in a position to know if it is effective, I know that linkage occurs, I am not sure could comment further

Which datasets related to health other than those previously listed, if linked or coordinated across public and/or private sector agencies, would be of high value to the community?

IHPA already collects a lot of data from hospitals, but it is 2 years out of date. Let's get that to happen faster before launching huge new programs.
linking doesn't work
Linkage at individual consumer level is more informative
National and state clinical registries.   Anonymised public and private pathology and radiology data
linkage in health is enough of a challenge I am not sure you want to go to those levels listed for service delivery and planning unless you are doing research or writing papers.

Do you agree that such linked or coordinated health datasets could be used to investigate or improve the following?

Having the data is only 5% of the solution. Aligning the incentives in the health system for individuals to value their health, and for coordination of health provision would be key to a solution. A good first step would be to provide a "patient bill" for every health system encounter to indicate the amount of money the government is paying for care episodes. This would force hospitals to actually count and evaluate what it is doing!
disagree because there is no such thing as evidence based policy (or actions) that rely on health data... those policies and actions rely on the latest opinion polls only
identification of environmental risk factors, unanticipated long-term medication effects and side-effects, Issues with standards based on limited population data e.g. PAP smear abnormality rates, modification of normal values in pathology and radiology to better reflect Australian populations and sub-populations.
patient access to their data and acceptance of their own responsibility for the health maintenance is important for healthcare transformation

Are there any legislative or other impediments that may be unnecessarily restricting the availability and use of private sector health data which are different to public sector health data?

Private providers have no incentives to share their patient results with others. If we switch to a case management system like the National Disability Insurance scheme for health care, there would be more incentive for private providers to evaluate the effectiveness of their interventions.
please do not use double negatives as in question 1
The private sector needs to be incentivised or forced to share, it won't happen unless there's incentive
Private sector has less emphasis on 'the public good' therefore is probably less interested in sharing, even though overall it benefits their private patients
Private pathology and radiology databases for example are a huge untapped research resource

Are there any mechanisms other than those already listed for the public sector and above that could improve the sharing and linking of private sector health related data?

Not sure
Participation in voluntary benchmarking programs.
Private or Public the centre of the data is the patient, although the private hospitals may have a financial imperitive to not share, I feel the greater good argument should outweigh that and the data should be made available
Increased consumer understanding of the benefits of data sharing
Federated authentication and identity management via a Research and Education Federation - using existing international policy, governance and privacy protections (The Australian Access Federation)
training of workforce - specific positions/roles identified
Innovation and learning from other industries
Where services are government funded, mandate that the data is made publicly available with appropriate privacy and confidentiality safeguards

Do you agree that the following impediments currently restrict consumers' access to and use of public and private sector data about themselves?

Consumers already have access to their data through the My Health Record system.
Consumers access is impacted by lack of available data, my hospital and other sites come from government data, as they are the only ones who are able to access the raw. Much better consumer access will naturally follow from better data.
The lack of a unique identifier is not a huge barrier - data linkage processes have been useful to overcome this problem.
Organisation believe and a legislative owners of the data despite the data being given or about patients. A higher priority of risk is assigned to legal action than patient being aware of their own information.

What other solution(s) would encourage greater cultural acceptance amongst health providers of consumer access to their data?

Education around informatics and the benefits of data.
Provide opportunities for providers to benchmark amongst themselves in a confidential high-trust environment, so that they can examine the data and verify its accuracy.
Asking their patients what they would like especially those who are ill.
Education on the benefits of consumer access with demonstrative evidence. Education needs to start at undergraduate level
Data management embedded within all Healthcare University and Higher Education courses to highlight the need for quality data and accountability for all users
education and awareness campaigns which promote that the consumer is the owner of their health data
Understanding how consumers would use the data
financial incentives - so requests are cost neutral to providers
Case studies that show that consumer involvement gets better outcomes
Recognising it's not their data but the patients data.
Improved access through mobile platforms and technology
Feedback from patients e.g. OpenNotes
Developing a conversation and partnership with consumers in the care and management of their data
Mandate automatic provision of all data to patients possibly including a practitioner "filtering" step for explanation/counselling

All specialists rooms invest in IT solutions for data collection and transfer and remove the burden of last century workflows, faxes, dictation, paper!
Exposure to what it looks like (e.g. PCEHR) through a trusted intermediary like their GP.
An increased understanding that consumers need their own data to help them manage and take responsibility for their own health management plan.

Do you agree that third party intermediaries are currently available to assist consumers to access and use data about themselves by:

In England, intermediaries such as Methods Analytics have products such as Steth-o-scope to allow patients to evaluate the performance of hospitals, and for hospitals to evaluate the performance of clinicians across the entire country. My organisation offers a similar service, but there is no incentive to provide this data to consumers in Australia. The only result would be greater pressure on the publicly funded health system to improve performance that the consumer currently gets for free. It is a no-win situation for government.
Are there many examples of this happening?
AURIN (Melbourne University) is a prime example of a very valuable data-linkage mash-up that provides top level data and services across multiple datasets >1200 and in different disciplines
Online data presentation/summary tools could help here. Data are available and linked but most people would struggle to make use of data in its raw state.
Third parties could potentially provide such useful services, but it is not easy or common to obtain their use either due to cost or availability
I'm assuming here that third parties include the patients healthcare providers
do not understand the question

What barriers impede the availability (and up-take) of services offered by third party intermediaries?

AURIN is free to government organisations and should be used to make policy decisions

Do you agree that the following barriers are impeding consumers' access to, and use of, 'high value' data?

Patients want to know if their care will be good or not, but can only rely on the opinion of friends and the GP in making the decision for hospital care. There are huge differences, but people don't know.
last point most important
English data showed the availability of parking was more important that better clinical outcome in inter-hospital comparisons by consumers
many consumers don't know they can access their data.

Do you agree that the greatest concerns for privacy protection are posed by the following types of health data and health data applications (both public sector and private sector)?

Genetic screening data and life insurance are major issues.
We can mitigate the risk, we just need to try harder

Do you agree that 'confidence' and 'trust', by both individuals and businesses, in the way health data is used will best be maintained and enhanced by:

Data needs to be used first by the providers of care to improve its quality.
The millenials have a vastly different perception of privacy, this is a system we're building for them when they reach middle age.

Do you agree that Australia could learn from the following who have better protection of personal data, especially sensitive health information?

I'm not sure whether all of these countries have better protection of personal data but we can always learn from others.
sweden

Under some circumstances consumers may request deletion of personal information about themselves. When should requests for the deletion of health data be denied

Records should be corrected, but original information should not be deleted as it formed a basis for treatment decisions at a point in time.