Aged Care Data Strategy Non-Government Stakeholder Consultation

Australian Institute of Health and Welfare

15 December 2022

nous

Nous Group acknowledges Aboriginal and Torres Strait Islander peoples as the First Australians and the Traditional Custodians of country throughout Australia. We pay our respect to Elders past, present, and emerging, who maintain their culture, country and spiritual connection to the land, sea, and community.

This artwork was developed by Marcus Lee Design to reflect Nous Group's Reconciliation Action Plan and our aspirations for respectful and productive engagement with Aboriginal and Torres Strait Islander peoples and communities.

Contents

1 Executive summary

Improved aged care data has been identified as a key enabler necessary for the achievement of the recommendations of the Royal Commission into Aged Care Quality and Safety (the Royal Commission). The Royal Commission identified myriad shortcomings in the collection, consistency, linking and flow of current data that need to be addressed before the data-related recommendations of the Royal Commission can be achieved. The Department of Health and Aged Care (the Department) has taken the lead with several important initiatives. With the support of the Australian Institute of Health and Welfare (AIHW), the Department is progressing several aged care data initiatives. Chief among them is the draft National Aged Care Data Strategy (the Data Strategy).

Nous Group (Nous) partnered with AIHW and the Department to carry out consultation with non-government stakeholders, with the aim of testing and strengthening draft core elements of the Data Strategy. Non-government stakeholders were broadly split into three groups:

- **Consumers** – which includes older people, their families, carers, and support network

- **Providers** – which includes aged care workers, direct providers of services to older people, as well as providers of systems to aid care and administrative processes

- **Researchers** and **academics**.

A variety of consultation methods were used to ensure that individuals and groups had the appropriate methods of contributing to the development of the Data Strategy. Key methods used were webinars, focus groups, one on one interviews and an online survey. In total, 303 stakeholders were consulted as part of this process.

All consultations were transcribed and carefully collated to produce key insights. These key insights were shared with colleagues from AIHW and the Department. From this process, two sets of results were derived and are presented in this report:

- A summary of the key insights and findings from the consultations

- Proposed amendments to the core elements of the Data Strategy, which reflect these insights and findings.

In general terms, stakeholders were supportive of the Data Strategy and appreciated the opportunity to be involved. There is a clear desire to improve data usage and to harness the possibilities of standardised data definitions and processes to be able to link datasets with the overall aim of improving the provision of care. Stakeholders also expressed a strong desire throughout the consultation to see actionable and tangible outputs from the Data Strategy, reflecting their passion for the improvement of the aged care system. Key insights gathered included a desire for the elements of the Data Strategy to be clearer on the intended audiences and to use more specific language to minimise the scope for misinterpretation.

Table 1 shows the original core elements of the Data Strategy alongside key feedback received by non-government stakeholders.

Table 1 | Draft core elements of the Data Strategy and summary of stakeholder comments

Draft elements presented to stakeholders	Summary of findings
Vision An aged care data system that provides robust information to support the better health, ageing and wellbeing of older Australians.	Feedback on the Vision from stakeholders focused on the following: • Lacks clarity for stakeholders as they are hoping to see more direction • Should articulate what the Data Strategy hopes to achieve for the aged care sector.
Purpose The Data Strategy will explain why we are improving the aged care data system, including providing information about aged care that will better support: • People to make informed choices about aged care. • Services and providers to improve their provision of safe, high-quality, and dignified care. • Government to design, administer, evaluate, and improve the aged care system. • Secondary users of data (such as peak bodies and academic researchers) to study and provide insights that can improve the aged care system.	Feedback on the Purpose from stakeholders focused on the following: • Should clarify the roles of stakeholders • Define the clear benefits of the Data Strategy. • Highlighted that transparency and clear purposes will provide guidance and buy-in for the implementation of the Data Strategy.
Guiding Principles The Data Strategy should be guided by a set of agreed principles, for example: • Putting older Australians at the centre of aged care. • Data that meets the needs of participants and stakeholders including consumers, providers (including aged care workers), governments and researchers. • Safeguarding trust, privacy, and security. • Share data once, and use it often. • Data that supports evaluating the performance of the aged care system and supporting future improvements. • Leveraging existing data assets and capabilities. • Data that continually improves.	Feedback on the Guiding Principles from stakeholders focused on the following: • Broad agreement with the spirit of the Guiding Principles, but many stakeholders are seeking more specificity. • General desire to see Guiding Principles adopt more of a future focus and future-proofing improvements. • There was debate around the principle "putting older people at the centre of aged care". Some felt that "putting" removed agency. • Some stakeholders identified that the Guiding Principles missed the opportunity to identify the Workforce as a critical enabler of implementation. • Some instances of confusion regarding the meaning of Guiding Principles. Specifically, there was confusion regarding "Share data once and using often" and "data that continuously improves"
Scope The scope of the Data Strategy and that of the data system are interdependent. The Data Strategy applies to all aspects of the aged care data system: the comprehensive range of data related to aged care in Australia, and the arrangements that support capture, use and sharing of these data. These supporting arrangements include data governance, information standards and infrastructure	Feedback on the Scope from stakeholders focused on the following: • The draft Scope focusing too much on what the Data Strategy is not. • Must acknowledge how the strategy impacts other reform activities. • Must clearly define the aged care data system.

| Draft elements presented to stakeholders	Summary of findings
arrangements associated with capturing, using, and sharing these data. The data system includes, but is not limited to, data in the planned Aged Care National Minimum Data Set (NMDS) and the planned Aged Care Data Asset. The Data Strategy is not: • An information management strategy. • An ICT strategy, although we recognise that technology is fundamental to maximising the value of data. • A people capability or workforce strategy, although we recognise that people are fundamental to implementing the new system.	• Including who the stakeholders are for the Data Strategy.
Strategic priorities / focus areas Strategic priorities / focus areas will be identified through consultation and research. They will articulate shared outcomes for stakeholders that complement existing investments and enable innovation and improved delivery of aged care. Strategic priorities will align with the Vision and Purpose and contribute to the Outcomes. Strategic priorities / focus areas could include: Governance; Culture; Capability (Government and Workforce); Discoverable Data; Data Sharing and Release; and Technology and Innovation.	Feedback on Strategic Priorities from stakeholders focused on the following: • Maximising the use and value of data through data governance, guidelines, and standardisation. • Improving data discovery. • Data reflecting diversity of Australia's population.
Roadmap The Roadmap will be informed by the responses to the Royal Commission, including the NMDS, data asset and stakeholder consultation.	Feedback on Roadmap from stakeholders focused on the following: • The lack of trust with the term "Roadmap". • Stakeholders' strong desire to be continuously engaged and updated throughout implementation.
Outcomes Outcomes will be identified through consultations. An example of an outcome could be 'Users can readily search for, identify and understand our data assets and the information they can provide.'	Feedback on Outcomes from stakeholders focused on the following: • Drive Strategic Priorities and the implementation. • Articulate how it might deliver for different stakeholder groups through tools like personas. • Not be compliance focused and instead future focused.

2 Background and context

Section 2 provides an outline of the background and context behind the development of the Data Strategy. It highlights the recommendations of the Royal Commission, how they relate to aged care data, why the Data Strategy is a necessary initiative, and why non-government stakeholder input is crucial to its success.

2.1 The Royal Commission into Aged Care Quality and Safety recommended transformational changes to aged care

The social and health infrastructure of Australia relies on its aged care system to provide daily assistance and nursing care for over one million older people.[1] As our population ages, this number is expected to grow. In 2019, there were 4.2 working age people (between the ages of 15-64 years). This is expected to drop to 3.1 by 2058.[2] These changing demographics will increasingly impact both demand for, and provision of, aged care.

The Royal Commission detailed the need for transformational change in the aged care sector to achieve the overarching objective of ensuring people receive safe and high-quality aged care according to individual needs. The Royal Commission advocated a fundamental shift for aged care to become centred around older people. Figure 1 summarises the findings of the Royal Commission, which aim to re-focus the sector on offering dignified care to older people that prioritises preference-based care, self-determination, quality of life and caring.

Figure 1 | Summary findings from the Royal Commission[3]

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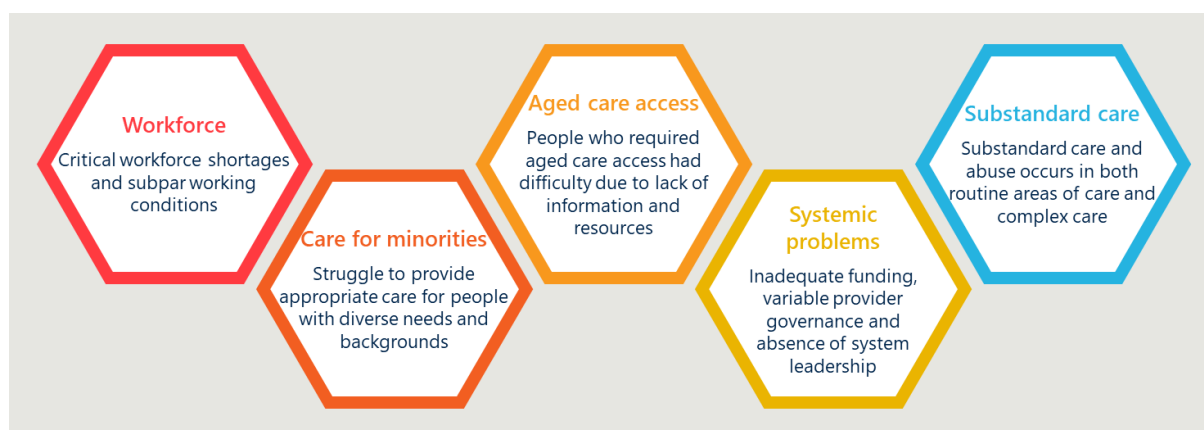
[1] Gen Aged Care Data (2022) 'Aged care use in Australia' Available at: https://www.gen-agedcaredata.gov.au/Topics/People-using-aged-care#Aged%20care%20use%20in%20Australia

[2] Royal Commission into Aged Care Quality and Safety (2021) 'A Summary of the Final Report: Changing demographics' Available at: https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-executive-summary.pdf

[3] Royal Commission into Aged Care Quality and Safety (2021) 'Final Report: care, Dignity and Respect' Volume 2, Available at: https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-2_0.pdf

2.2 The Department and AIHW partnered to deliver a key element in this reform, the National Aged Care Data Strategy

Among the 148 recommendations made by the Royal Commission, there were numerous data-specific[i] and data-related[ii] recommendations to resolve the fragmented nature of data in the system. These recommendations, when implemented, will help stakeholders to understand how the system works, evaluate its performance, and inform research into how improved models of care can be delivered in the future. Addressing these recommendations will assist the Australian Government to effectively regulate and develop responsive policy options to improve outcomes for older people, their families, and carers.

The ability to properly gather, manage, and analyse data is critical to implementing the recommendations of the Royal Commission and improving the quality-of-care older people receive. Of the final recommendations, number 108 targeted improved data governance for aged care, and the development of a National Aged Care Data Asset (the Data Asset). In response to the Royal Commission's recommendations to improve aged care data, the Department and AIHW are partnering to develop the Data Strategy.

The Data Strategy provides an overarching strategy to guide improvement initiatives across the whole aged care data system. The aged care data system is a comprehensive range of data and arrangements that support capture, use and sharing of aged care related data. It includes data such as information collected by services and reported to the Department and other data relevant to care such as hospital data. The data system also includes the governance, ICT, and infrastructure arrangements. Figure 2, created by AIHW, displays the different elements in the data system.

Figure 2 | The aged care data system
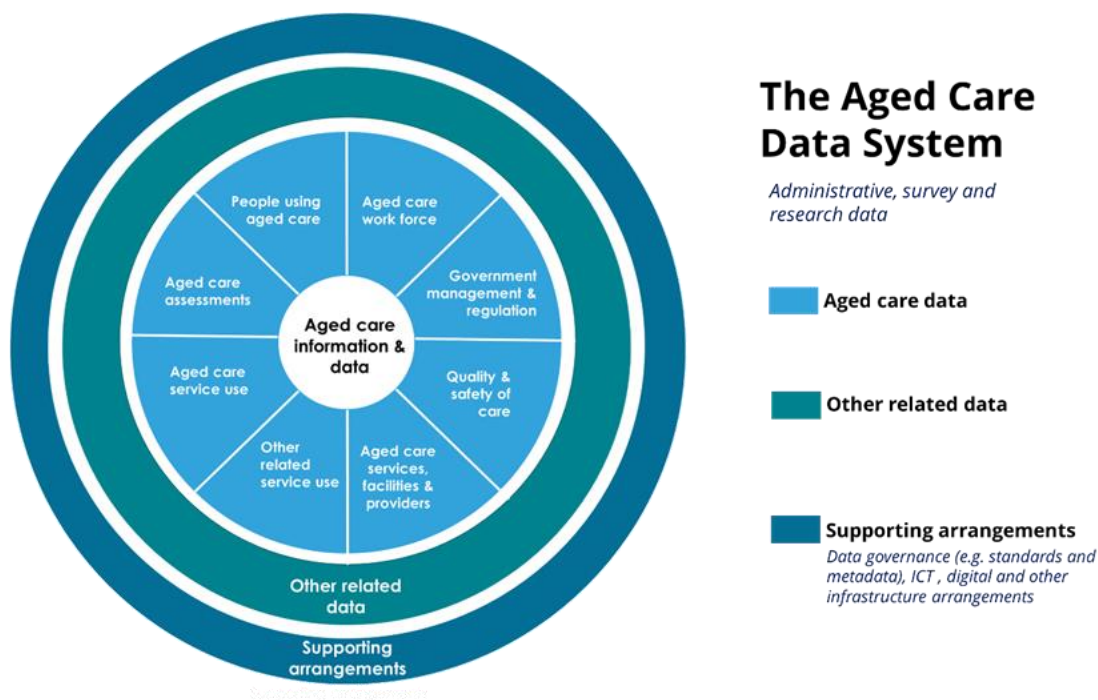
Along with the Data Strategy, two other key assets will be developed – the National Minimum Data Set (NMDS) and the Data Asset. These three aged care data improvement activities are fundamental to all aged care reform activities.

The NMDS will be a set of standardised data elements for mandatory collection and reporting at a national level related to aged care. The purpose of the NMDS is to improve data quality, comparability, and usefulness by establishing standards and developing supporting metadata across aged care.

The Data Asset will be a multisource enduring linked data set that integrates people-centred data (including the NMDS). The purpose of the Data Asset is to enable integration of a range of people-centred data to support policy and research over time. By integrating a range of data sets through the creation of an aged care 'link map' the Data Asset will be interoperable with other health and welfare related data sets.

The key purpose and intention behind improvements to the aged care data system is to support the key stakeholders in aged care – older people in Australia, providers, researchers, and government. To develop the Data Strategy, it is important to incorporate the views of the non-government stakeholders.

In the aged care system, non-government stakeholders play a key role in driving and shaping the services and development of care for older people in Australia. The Department and AIHW recognise the importance of consulting with non-government stakeholders as they will be most impacted by the reform activities.

3 Methodology

Section 3 describes the approach Nous took to consult with non-government stakeholders. This section outlines the rationale for the consultation approach and describes the stakeholder groups.

3.1 AIHW engaged Nous to lead consultations with non-government stakeholders

AIHW engaged Nous to consult non-government stakeholders to support the development of the Data Strategy. Nous and AIHW identified stakeholders and categorised them into three perspectives that must be captured through the consultation. Those of older people, providers, and researchers (see Figure 3). Nous then mapped and prioritised identified stakeholders based on two factors:

- The degree to which a stakeholder is likely to be **impacted** by the Data Strategy, and

- The degree to which a stakeholder is able to **influence** the development of the Data Strategy.

Nous tested the results of this prioritisation with AIHW, and the Department, to ensure it aligned with their understanding of the stakeholder environment.

Figure 3 | Non-government stakeholder groups

CONSUMERS
- Associations representing older people and aged care service users
- Organisations representing families, carers and support network

PROVIDERS
- Aged care service providers
- Workforce associations
- Aged care peak bodies
- Service delivery partners such as IT, finance and HR services

RESEARCHERS & ACADEMICS
- Universities
- Research organisations
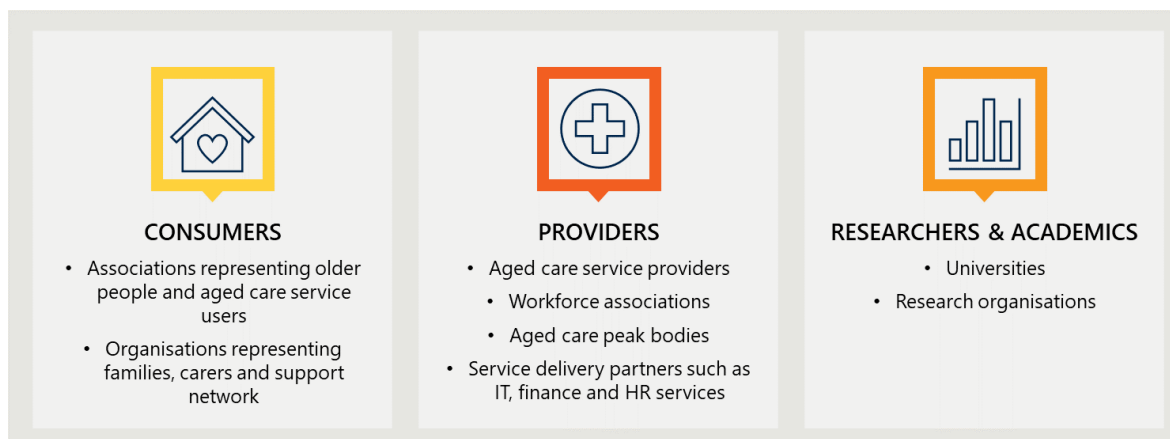
Nous then developed a rigorous consultation plan to engage with a range of stakeholders that represented these perspectives. The consultation was conducted using four methods. These methods are outlined in Figure 4. Nous developed a consultation guide material based on material provided by AIHW.

Figure 4 | Consultation methods

INTERVIEWS
Sessions for those who are impacted most by the implementation and will **drive** the new Data Strategy.

FOCUS GROUPS
Small group sessions for those who want to be **engaged** and provide insights about aged care and its data system.

WEBINARS
Broad sessions for those who want to **understand** the development of the Data Strategy and aged care reform activities.

SURVEYS
A general survey for **all** non-governmental stakeholders, so we ensure all perspectives and voices are heard.

3.2 Nous engaged with 303 stakeholders representing the views of researchers, providers, and older people

In total Nous engaged with 303 stakeholders throughout the consultation process. 271 stakeholders were engaged through webinars, focus groups and interviews. A further 32 unidentified stakeholders completed the survey through AIHW's GEN Aged Care Data website.

Of those, 271 stakeholders, **65** represented the views of **older people**. These stakeholders represent the views of older people when their organisation advocates on behalf of older people, their families, and support network. This stakeholder group was important to capture because they provided valuable insights into the needs and expectations of older people, which will support the Data Strategy to support older person-centred aged care.

Nous consulted **143** stakeholders that represented the views of **providers**. These stakeholders provide services and care for older people, represent the aged care workforce, or deliver enabling services (for example digital and IT services) to the aged care sector. This stakeholder group was identified as important as they are able to speak to the frontline experience of implementing the Data Strategy, and stakeholders in this group are most likely to be directly impacted by the Data Strategy and other data improvement activities.

Nous consulted **63** stakeholders that represented the views of **researchers**. These stakeholders are primarily engaged with the analysis of data and information to conduct research into and inform the provision of aged care and development of health policies. This stakeholder group was identified as important because of the key role they play in improving the aged care data system and the frequency with which they utilise the data.

Each stakeholder group provided unique perspectives and valuable insights into aged care data which will be further explored in Sections 4. Figure 3 outlines the types of organisations categorised under each stakeholder group.

4 Key themes from the consultation

Section 4 outlines the key themes heard across the consultation. The insights in this section apply across multiple elements of the Data Strategy, or to the process for further development.

4.1 Stakeholders welcome the opportunity presented through the development of the Data Strategy to build trust

Stakeholders across all groups consistently acknowledged the importance of the Data Strategy and the opportunities presented in its development, they highlighted the key opportunity for the Data Strategy to build trust across all stakeholder groups. However, each group adopted a slightly different emphasis, where some stakeholders highlighted the opportunity to build trust among the public in the aged care systems, while others outlined the importance of building trust between government and providers. Discussions on these opportunities often included caveats about safety and privacy to protect vulnerable people's sensitive data. As part of gaining trust in the aged care system, all stakeholder groups identified the importance of having information and transparency on quality of care. It was thought that information on the quality of care would increase trust in the aged care system by giving older people agency to make informed choices about care and increase accountability by allowing broader system performance assessments.

> "Privacy and data management has to be the foundation and is the most important aspect of the strategy." – Survey participant

Stakeholders representing the views of older people highlighted the opportunity for the Data Strategy to support greater insight into the experience of people receiving aged care. This includes a more nuanced understanding of the demographic make-up of recipients, their health and care needs, the types of specialised care received, and the cost of care. Stakeholders identified this as a key component to empowering older people and their support network to make informed choices about the quality and cost of their own care.

Stakeholders representing the views of providers were particularly interested in how the strategy could provide more guidance to them on their data collection and reporting requirements. They expressed a keenness for the Data Strategy to standardise data collection and believed this will minimise the burden on providers. Providers also highlighted the opportunity for the Data Strategy to facilitate improvements in the quality of care provided. For example, through benchmarking systems that would allow for better informed service and workforce planning.

4.2 More clarity on the intended audience for the Data Strategy will support stakeholders to understand their role

Stakeholders across all groups are seeking clarity around the intended audience for the Data Strategy. They outlined that certain elements seemed to speak to industry, while others spoke to the role of government. This led to many stakeholders indicating that they would like more clarity on what role they are expected to play under the Data Strategy. The elements covering Scope, Strategic Priorities, Roadmap and Outcomes were seen as more related to government while other elements spoke more clearly to industry.

> "The order is right but what about for the audience?" – Provider

4.3 High potential for impact through increased system connectivity

All stakeholder groups highlighted gaps on the quantity, quality and interrogatability of current data systems and outlined that the Data Strategy has potential to drive dramatic impact through increased connectivity and interoperability. Through this, all stakeholders highlighted the importance of the Data Strategy in supporting a" joined up" and systemic approach. They believed that the development of the Data Strategy could support:

"At the moment, the data is too disjointed between bodies and makes planning services difficult. [I would like to] get a holistic picture of the ageing population with a defined geographic area."
– Survey participant

- Aged care data to be used and shared more, and

- The aged care data system to be better integrated with other health and social data systems.

Stakeholders identified that a system approach to aged care data will support better use of existing data to fill critical data gaps. Furthermore, stakeholders encouraged the use of data standards and associated governance to reduce collection burden and accelerate analytics at all levels of the system. For example, some stakeholders spoke of the impact understanding a person's flow across the primary health, hospitals, and aged care sectors could have. Additionally, stakeholders highlighted that aligning to non-health data systems such as Centrelink would help broaden understanding of issues around wellbeing.

In summary, increasing system connectivity was seen to achieve two primary aims:

- Reducing burden on older people and providers by only requiring stakeholders to share information once and allow a connected aged care data system to automate information sharing and storing. This reduces the burden of the data system on both older people and providers. It may also help to ensure older people do not feel lost in the system, and support providers to spend more time focused on providing high-quality care.

- Providing access to more longitudinal data on a person's health-care journey. The development of the Department of Health and Aged Care Data Strategy is an opportunity to increase this connectivity across primary and acute health care, NDIS, housing, and income support.

Finally, **Stakeholders representing the view of providers** similarly expressed that having data and information connected between the health and aged care data system would be beneficial, outlining its value to improvement of aged care planning capability. For instance, aged care providers do not always have access to current, consistently captured information about the health and care needs of older people particularly as they transfer to and from health and aged care settings.

4.4 Strong accountability measures should be embedded into the Data Strategy

Broadly, stakeholders welcomed the development of the Data Strategy. However, many indicated a degree of scepticism about the outcomes it might achieve. In particular, they expressed a desire to ensure there are strong accountability measures incorporated in the strategy. This included measures for delivering strategic priorities, embedding review and evaluation points, and providing adequate data to assess the extent to which government is delivering on their objectives.

"Accountability is missing in this strategy – especially with the department." *– Provider*

4.5 The Data Strategy is a key opportunity to increase data capability

Stakeholders across all groups highlighted the importance of building data capability and the capacity of individual stakeholders to the success of the Data Strategy. They identified that a key prerequisite for the success of the Data Strategy would be that individuals understand and are able to use the data system.

"The Data Strategy needs to address that not all providers are of the same size, capability, and resources – the Data Strategy needs to make sure that this is recognised and there is sufficient time for providers to collect and use data as planned." – Peak body

Stakeholders representing the views of older people, their families and support network to know what data they are providing and how it is being used. Additionally, information from data analysis and research needs to be digestible and useful for older people to make informed choices about their care. In several consultations, stakeholders representing older people suggested increasing data and digital capability could support the changing landscape of aged care from traditional residential care to home care. For example, by promoting wearables and digital devices as a method of future-proofing and automating data collection.

Like other stakeholder groups, **stakeholders representing providers** identified the need to build data and digital capability at both organisational and individual levels. In building that capability, the Data Strategy needs to recognise the different levels of capability across the industry. Many stakeholders highlighted that providers will require different levels of support from the government to uplift data capability. For example, data literacy can vary based on an organisation's size, regionality, and whether they provide residential or at home care.

"We need to ensure people with sufficient skills are entering the information from the outset. [Because] once data starts being shared and used, a single mistake can be multiplied and made worse." –Survey participant

i Such as *Recommendation 22: Quality indicators, Recommendation 67: Improving data on the interaction between the health and aged care systems*, and *Recommendation 108: Data governance and a National Aged Care Data Asset,* amongst others

ii Such as *Recommendation 30: Designing for diversity, difference, complexity and individuality* and *Recommendation 41: Planning based on need, not rationed*, amongst others.