

Data (In)visibility and (Dis)connection in the Care Economy Ecosystem

SOME CROSS-ECOSYSTEM OBSERVATIONS



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Executive Summary

Understanding the scope and scale of care provided across the care economy depends on good data.

High-quality data can give decision-makers and care funders critical insights into how, when and to whom care is provided, and the societal, health, and economic impacts of these services [1]. Yet the substantial “work of generating, maintaining, and repairing” care data [2] is often invisible.

This research emerged from a practical problem. At the La Trobe University Care Economy Research Institute (CERI), we had begun to identify sources of publicly available care-related data in Australia. In the process, we encountered difficulties in collecting and classifying anonymised data from care organisations. This alerted us to the fact that data collection, metadata structures, data management and cooperative data sharing are all important topics for research in relation to care organisations.

There is a growing recognition of the work involved in producing and maintaining quality care data. This coincides with increasing pressures to apply Artificial Intelligence (AI) to data to produce more powerful operational, strategic, and client-related insights and to reduce the administrative burden of data analysis. The complex task of ensuring the existence, quality, interpretability and interoperability of care data becomes even more vital in a context where automated data analysis could be applied to existing data assets. There are risks to automation in situations where the data is limited, inaccurate, incomplete or incoherent. But there are also potential benefits for care organisations if AI-assisted analysis of substantial data assets “can be used to develop new care economy funding models, offering opportunities for better risk adjustment and fairer funding” [2].

In this report, we give voice to the people who manage the data. We interviewed people in seven diverse care organisations whose roles require direct handling of data or executive responsibility for data. We thank them for their willingness to share with us their deep knowledge, experience,

and expertise, including compelling insights into the data strengths, challenges, opportunities and risks that they and their organisations experience daily.

The extent of the common concerns voiced by participant organisations was striking. The small scale of our research is important to acknowledge. But the cross-sectoral variety and differences of type and scale among these organisations mean that their shared concerns do not simply arise from common organisational factors such as size, type, or sector. The challenges that our research participants raised with us around data infrastructure, data integration and the unavailability of data are highly impactful for their operations. For this reason, these are also the strongest focus of our report. Yet it is important to acknowledge that we also heard from several participants a strong need and desire to balance the strategic imperatives of collecting and managing high-quality data with the service imperatives of prioritising connection with care recipients and carers on a human emotional level.

We hope that the pilot research presented in this report will be expanded in future to deepen these insights. Even on the basis of this sample, the urgency is clear to address the current pressures on legacy data infrastructures and their impacts on the productivity, growth, and sustainability of organisations of all sizes in the care ecosystem. This urgency will only grow as AI data analytics become more integrated with existing data systems. We hope you will find this report a useful reflection on some current shared challenges across the care economy.

A note on formal and informal care data

When we set out to undertake this study, we expected to place a greater emphasis on data gaps related to informal care. Informal care is the vital, but typically unrecorded, support provided by friends and family members, often in collaboration with the formal care workforce [1, 3]. We had hoped to understand whether the data collected by care organisations indicated or noted, even peripherally, the contributions of informal caregivers.

This remains a key area for research attention [1]. However, our study was intended primarily as an exercise in listening and giving voice to the people working with care data. As the study progressed, it became clear that issues related to formal care data were their strongest focus, with substantial impact on daily operations and strategic planning. This shift in our original focus is reflected in the observations summarised in this report. Nonetheless, we wish to acknowledge with Petrillo and Bennett (2023) that the “formal social care system could not function without the contribution of unpaid carers” [4].

“The formal social care system could not function without the contribution of unpaid carers – family friends and neighbours – who provide a huge amount of support alongside the broader community...”

– PETRILLO & BENNETT (2023)



Data Visibility for Care Visibility: Research Context

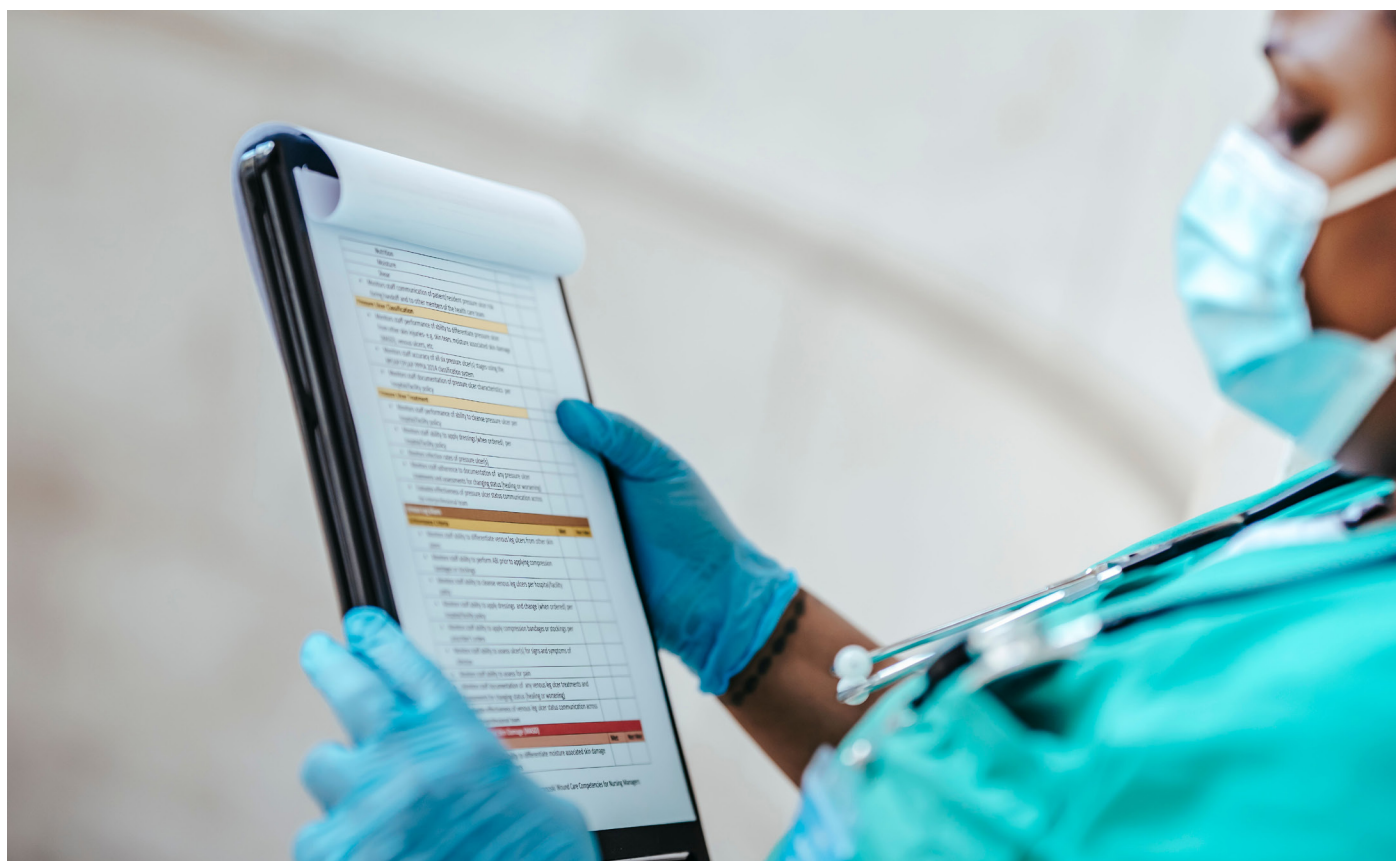
Globally, the care economy is one of the fastest growing sectors. Yet care economy research and research data typically do not consider the sector holistically [1]. Research attention tends to focus on larger, more established sub-sectors such as aged care, leaving smaller organisations and less formalised areas of care work comparatively invisible in the evidence base [5].

Within the care economy, formal care data infrastructure is reported as a key issue [4]. In Australia, data gaps are pervasive across aged care, disability, and community services, compounded by fragmented funding, inconsistent reporting requirements, and limited cross-sector collaboration [5, 6].

A growing body of literature on administrative burden documents how demands for compliance imposed by governments and funders can crowd out the core work of service delivery. This pressure is felt acutely across the care sector [7]. At the infrastructure level, the absence of common metadata standards means that data cannot be easily

transmitted between systems or aggregated for analysis, limiting both service quality and reporting efficiency [8, 9]. Research on clinical information systems in aged care and disability services identifies non-standardised systems, workforce shortages, and poor system design as compounding drivers of poor data quality [11]. The Australian Digital Health Agency's *National Healthcare Interoperability Plan 2023-2028* acknowledges these gaps, but its focus is primarily on the health system, leaving broader care economy organisations comparatively unaddressed [10].

The La Trobe Care Economy Research Institute takes an organisation-level approach to discovering care data and smoothing the path for its use in research. We hypothesise that care economy organisations represent a significant and largely untapped data resource, whose potential contribution to sector-level knowledge and policy development are unrealised due to structural, technical, and resourcing limitations.



Towards a Care Economy Ecosystem

Why an ecosystem perspective?

An ecosystem is a complex system of actors, participants and environments in which the functionality of the whole system is supported by the health of the relationships between the parts. Globally, there is an interest in ecosystem perspectives as a means of making visible the systemic capacities and challenges that are common to ecosystem members, and to encourage whole-of-ecosystem thinking to help address systemic issues. The social care sector has been a leading voice in promoting ecosystem perspectives on shared opportunities and challenges [11].

It is widely recognised that taking an ecosystem perspective may enable the development of a deeper and more actionable understanding of the complex relationships between sectoral organisations and their multiple stakeholders. This perspective has been used by organisations in the care sector globally to highlight the need to reduce problem-solving in isolation from other organisations with shared challenges and needs. As the Camden Coalition observes, a coordinated ecosystem approach is needed to solve complex, deeply rooted problems and inequities [12].

Technologists and data experts have also recognised the value of taking a whole-of-ecosystem approach to understanding shared challenges. For example, Australia's National AI Centre has produced an ecosystem report to identify key issues and barriers to AI and data work in Australia.

“Building and strengthening a coordinated ecosystem of care is a powerful way to advance health equity. No single organisation or sector can solve complex, deeply rooted health inequities alone, but by bringing partners together, we can address inequities at the community level.”

– PETRILLO & BENNETT (2023)

What is Australia's care economy ecosystem?

While definitions and conceptualisations vary, for the purpose of this report, the care economy includes “the paid and unpaid labor, services, and policies supporting human health, well-being, and daily living across all life stages.” [1] We use the phrase ‘care economy ecosystem’ to describe the complex layers of social, relational and organisational ties that underpin the care and support that each of us gives and receives at different points throughout our lives.

In our research, we have sought to describe some key characteristics of organisational members of the care economy ecosystem in Australia. These characteristics include common features used to describe organisations of any kind, such as the organisational size, type, client base, purpose/mission, and the sector(s) served.

These core features, which define an organisation at a particular stage of its development, can help to inform our understanding of the common capacities and challenges that a given care organisation may have, and whether and how these might differ for care organisations of different types, sizes, clienteles, sectors or purposes.

What makes care organisations part of a specific ecosystem – the care economy ecosystem – is the shared commitment to providing care. This commitment deeply informs the operation of care economy organisations. Care organisations operate uniquely “in-between control and care” [14, citing 13].

In this context, organisational control mechanisms include internal data practices, regulatory data governance requirements, and investments in data infrastructure to manage data complexity. Care, understood broadly as activities undertaken to meet and manage human needs, involves connecting people in order “to listen and respond to diverse and changing needs” [14].

“Thinking about the well-being of the care ecosystem and whether it is flourishing offers a way to work towards improving outcomes for people who draw on care and support.”

— BURN & NEEDHAM (2023)

We have heard firsthand in our study how commitments to both care and control can sometimes conflict in the provision of care. For example, a staff member meeting a care recipient in distress may be unable to prioritise capturing the data required to fill record fields. An anonymous contributor to the Productivity Commission’s Inquiry Report, ‘Delivering quality care more efficiently’ [15], eloquently observes the immeasurable value of the time spent caring:

“Care is not wasted time. It is what allows life to continue. To measure its efficiency is not to shrink it, but to ask: how well do we help people back onto the road?”

— ANONYMOUS, SUB. 49, P.1
Productivity Commission Inquiry Report,
‘Delivering quality care more efficiently’

Both care and control are time-intensive, as noted in the 2023 Draft National Strategy for the Care and Support Economy [9]. The goal expressed by the Strategy is to free up workers from time-intensive administrative tasks, including “the documenting of care and support given” [9], to allow more time to be spent on care provision. But to understand how that might be possible,

we first need to understand the present data management landscape of care organisations, and their impacts on staff time, from the ground up.

Understanding the care economy ecosystem better could shed light on the day-to-day operational contexts that support an optimal balance of care and control. In this report, we examine some of the key data-related challenges that impact the balance in diverse care organisation settings.



“Human connection is a core part of providing quality care and support with dignity. [...] However, the jobs are also often physical or relate to the documenting of care and support given. It is these strenuous, repetitive or administrative tasks that can be the focus of labour-saving technologies and innovation.”

— AUSTRALIAN GOVERNMENT DEPARTMENT OF THE PRIME MINISTER AND CABINET
‘Productive care and support services: Draft National Strategy for the Care and Support Economy’ (2023)

Australia's Care Economy: An ecosystem of care organisations

The scope of this report does not extend to an audit of Australia's care economy organisations, nor does it make claims about the representativeness of the sample. However, it is our hope that the fundamental concepts of this ecosystem perspective will be adopted, developed and extended as part of future efforts to improve the usage and sharing of data in and about the care economy.

The elements of the ecosystem framework used in this report were developed by consulting a range of sources. These included government reports, research papers and our interviews with care organisations. Following the interviews, we validated the framework in consultation with each organisation. More information about the methodology and development of the ecosystem is available in the Appendix.

Seven characteristics of Care Economy organisations

The seven characteristics of care economy organisations identified by this research are:

- | | |
|---|---|
| <p>1 SIZE
Measured by the number of people employed by an organisation.</p> | <p>5 SECTOR
A description of which area of care or support activity the organisation works within.</p> |
| <p>2 TYPE
Defined as whether the organisation is structured to deliver for individuals (clients, customers) or other businesses and organisations.</p> | <p>6 PURPOSE
Describes the foundational activities of an organisation.</p> |
| <p>3 PROFIT STATUS
Defined as how an organisation is funded and financed.</p> | <p>7 CLIENT
Describes which actors or participants of the care economy the organisation serves.</p> |
| <p>4 REACH OF SERVICE PROVISION
Defined as whether an organisation operates at the local, state or national level.</p> | |

Each characteristic is interrelated to varying degrees. There are, for example, correlations between “Type” and “Clients”. Size, Type, Profit Status, and Reach of Service Provision describe organisational characteristics that would apply to any company or organisation in Australia. We use the features **Sector**, **Purpose**, and **Clients** to describe characteristics that are unique to the care economy, and which differentiate these organisations’ activities and structure from organisations in other industries

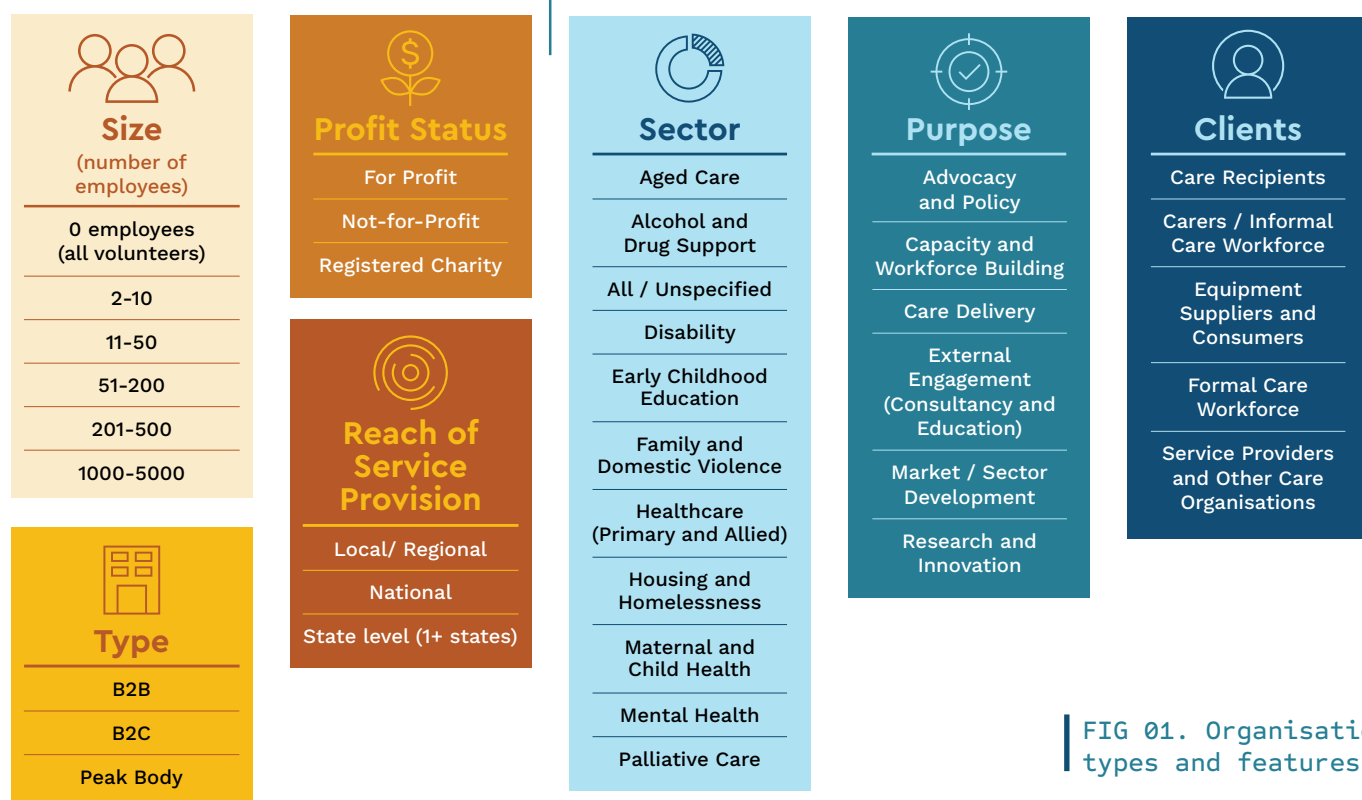
Care Economy Domains


FIG 01. Organisation types and features

How the organisations in the sample fit within the care economy ecosystem

Table 1 shows the characteristics of the seven care economy organisations we spoke to in our research. Five organisations were on the smaller end of the size spectrum, with 50 employees or fewer. Three had 10 employees or fewer. One had only voluntary staff members.

Three organisations served clients or customers exclusively (B2C), two were peak bodies, and one served other services or businesses exclusively (B2B). One organisation served both customers and businesses (B2C + B2B).

All seven were not-for-profit organisations. Six of the seven were registered charities with ACNC. The lack of inclusion of for-profit enterprises is a limitation of the sample.

While many organisations and services in the care economy are not-for-profit or entirely publicly funded, for-profit enterprises play a significant role in Australia's care economy, estimated to make up around 40% of the residential aged care sector [16] and 75% of the childcare sector [17].

In terms of regional and national coverage, four organisations operate nationally. Half of these are industry peak bodies. Two out of seven operate locally, and one operates at the state level (covering more than one state but having less than national scope).

		ORG 1	ORG 2	ORG 3	ORG 4	ORG 5	ORG 6	ORG 7
Size	0 employees (all volunteers)						●	
	2-10 employees				●	●		
	11-50 employees		●					●
	51-200 employees							
	201-500 employees	●						
	1000-5000 employees			●				
Type	B2B	●	●					
	B2C	●		●	●		●	
	Peak Body					●		●
Profit	For Profit							
	Not-for-profit	●	●	●	●	●	●	●
	Registered Charity	●	●	●		●	●	●
Reach	Local / Regional	●					●	
	National		●	●		●		●
	State (1+ states)				●			
Sector	Aged Care	●	●			●	●	
	Alcohol & Drug Support	●						
	All / Unspecified							●
	Disability	●				●	●	
	Early Childhood Education	●						
	Family & Domestic Violence	●						
	Healthcare (Primary & Allied)	●						
	Housing & Homelessness			●				
	Maternal & Child Health	●						
	Mental Health	●		●			●	
	Palliative Care	●			●			
Purpose	Advocacy & Policy	●	●	●	●	●	●	●
	Capacity / Workforce Building	●						
	Care Delivery	●		●	●		●	
	External Engagement	●	●				●	
	Market / Sector Development					●		●
	Research & Innovation		●	●			●	
Clients	Care Recipients	●		●	●		●	
	Carers / Informal Care Workforce	●			●		●	
	Equipment Suppliers and Consumers					●		
	Formal Care Workforce	●	●					●
	Service Providers and Other Care Organisations	●	●		●	●		●

TABLE 01. Characteristics of the sample of care organisations in this research

The sectors that the organisations operate in are very diverse. One organisation works across nine out of the eleven sector categories in the care economy: aged care, alcohol and drug support, disability, early childhood education and care, family and domestic violence, healthcare (primary and allied health), housing and homelessness, maternal and child health, mental health, and palliative care. Perhaps unsurprisingly, this organisation also has the most diverse organisational profile in the Purpose domain (four out of six purpose categories) and in the Clients domain (four out of five client types).

The remaining organisations are more targeted in their scope, operating within a maximum of two care economy sectors. Of the total sample, four out of seven operate in the aged care sector, three out of seven in the disability support sector, two in mental health and housing services, and two in palliative care. One organisation, a peak body, does not work directly in any one sector, but indirectly supports the workforce in all sectors.

In the Purpose domain, four organisations are directly engaged in care delivery. Interestingly, all but one organisation saw advocacy and policy work as one of the fundamental purposes of their activities. Two are mainly involved in market and/or sector development; both are peak bodies with national operations.

The client types served by the organisations are similarly mixed and demonstrate the richness of their interrelationships with the wider care economy. Four of seven organisations support care recipients, three support carers or the informal workforce, and three support only the formal workforce. Only one organisation worked with both a formal and an informal workforce. Five organisations provide services directly to other service providers and care organisations. These client types highlight the diverse and interlinked nature of the wider care economy, in which organisations deliver services to often complementary but interrelated groups of clients.



Dealing with Data

Productivity and data constraints in the care economy

Technological advances, productivity pressures, demographic shifts, and changing societal expectations around care are informing current efforts to invest in the productivity of the care economy. Despite this, understanding the care economy is a challenging task. As an emerging research area [1], the care economy is difficult to define, and suffers from measurement, quantification and categorisation problems that hamper funding, innovation and productivity. In addition, the health, care, and social support sectors in Australia are viewed by some as putting the brakes on economic productivity. Limited opportunities for automation mean that care work is seen as a revenue drain, rather than a boon.

“The care economy is the largest and most rapidly growing sector of Australia’s economy. Yet it is considered the ‘handbrake’ that is limiting productivity growth.”

— PRODUCTIVITY COMMISSION

‘Measuring productivity in the care economy – are conventional approaches working?’ (2024)

The ‘What we heard’ report was published by the Productivity Commission together with the Inquiry Report in December 2025 [17]. It reflects care industry organisations’ and participants’ inputs to the ‘Delivering Quality Care More Efficiently’ inquiry. The report notes that:

“data... constraints” are among the barriers to stronger partnerships between care ecosystem organisations to better distribute the commissioning and provision of care services.

Comments highlighted in the report identify data silos and a lack of data availability as affecting organisations’ ability to prioritise their efforts and to understand the outcomes and the impacts of their investments. The report also highlights the need for better digital infrastructure to support data sharing and improve capacity; “data and evaluation constraints... impede opportunities to identify joint needs and evaluate joint programs” [17].

Submissions observed:

- “Siloed and inaccessible, or non-transparency of data [which] makes it difficult for commissioners and providers to identify allocation and availability of funding, shared priorities, monitor population outcomes, or track the impact of investment across care pathways. (AHHA, sub. 26, p. 11)”
- “Limitations in data sharing, and lags in availability of data for platforms that are available (such as Lumos), which make it difficult to quantify outcomes in short timeframes ... (Murrumbidgee Primary Health Network, qr. 89, p. 3)”

The report notes that “[p]articipants highlighted the need for supporting governance reforms to overcome capability and data and evaluation constraints.” Furthermore, it observes that participants frequently mentioned data sharing arrangements and data interoperability as necessary to embed collaborative commissioning, to support the identification of key health needs, the evaluation of programs and system performance and accountability. Many participants mentioned the need for investment in digital infrastructure, agreement forming and capacity-building.

These observations resonate with several core operational concerns that were reported by participants in our study. Particularly pertinent are the reported limitations on the availability or usability of data “to support the identification of key health needs, the evaluation of programs and system performance and accountability” and “the need for investment in digital infrastructure, agreement forming and capacity-building.” [17] Such capabilities are critical for delivering quality care services efficiently. However, systematic and targeted sectoral support for data management and related processes appears to be lacking across the care economy ecosystem.

“System configurations, including government systems, effectively result in what I described as a data desert. It was surprising to see how little of this data inputting by staff in various digital information systems was able to be accessed—or even seen—by them or their Agency.”

– BURNS (2025)

The importance of standardising data practices in the care economy was acknowledged by the Australian Government’s plan to produce a ‘Data Standards Action Plan’ responding to its ‘Roadmap – The National Care and Support Strategy 2023’. However, the Action Plan does not yet exist as of the time of writing (May 2026).

“Currently there are no common data standards across the care and support economy, meaning data cannot be easily transmitted to different systems or aggregated for analysis. This influences both the quality care of support experience (e.g. those using these services having to repeat their information to multiple providers) and the efficiency of reporting to governments.”

– AUSTRALIAN GOVERNMENT DEPARTMENT OF PRIME MINISTER AND CABINET (2023)

‘Productive care and support services’

Applying a SWOT lens to care organisation data practices



SWOT analyses (Strengths, Weaknesses, Opportunities and Threats) are a common tool used to diagnose and address business issues and design organisational strategies. A SWOT analysis describes the present state of an organisation in terms of the positive capacities promoting its success and the negative barriers hindering its success (Strengths and Weaknesses). It further projects these two dimensions into the future. Opportunities are prospective strengths whose realisation may require support. Threats are prospective risks or barriers to success that must be mitigated.

As our discussions with participants progressed, we began to see common themes emerging that related to current realities and imagined future states. This temporal dimension fits well with the parameters of the SWOT lens. Many, but not all, of the SWOT dimensions reported relate to care data. Dimensions that are not directly related nonetheless provide important context for understanding data-related concerns, and arose in the context of discussions about these concerns.

Thematic coding of the interview data produced a rich picture of each dimension from the perspective of participating organisations. The SWOT analysis is presented in the following four sections of this report. Our goal is to allow the voices of the organisations to speak for themselves through selected quotes, which amplify the summarised issues. Further details on the coding methodology are provided in the Appendix to this report.

Strengths

SUMMARY OF STRENGTHS

Strong Personal Motivation and Purpose — Strong and Diverse Relational Capacity — Data Practices Informed by Lived Experience — Human Rights, Ethics, and Deep Sectoral Knowledge — Use of Data to Inform Policy, Advocacy and Consumer Education — In-House Technical Capacity

The strengths described in our interviews together point to two overarching qualities of care economy organisations. They are purpose-driven organisations with a focus on relational capacity, motivated by care provision as their core ethical concern, and they involve a deep integration of lived experience and sectoral knowledge into organisational knowledge. We heard from participants how these characteristics significantly influence their relationship with data collection and data management practices, and at times, are in tension with these practices.

MOTIVATION AND PURPOSE

Strong personal motivation (1,4,5,6,7)

Five of the seven organisations identified the personal motivation of staff as a key strength and driver of their organisation. Personal motivation was closely aligned with organisational mission and purpose.

“...personal life... really may coincide with [a staff member’s] professional work [bringing] out a strong personal motivation to work in this sector.” (4)

“There is very strong motivation throughout my organisation’s base... to do the right thing for the consumers that they serve. [...] [T]hey’re there to do the right thing to help and support the growth of the people that they serve.” (5)

“I think one of the things we should touch on is what motivates us as well... what appeals to me in particular is trying to destigmatise and to some extent normalise dementia, so that people understand it better and don’t just put people in boxes.” (6)

“What appeals to me in particular is trying to destigmatise and to some extent normalise dementia.”

“People don’t volunteer because there’s an economic benefit, right? But estimating, like, the sort of social, cultural [or] well-being benefits of volunteering is really difficult, because it’s such an individual endeavour. And... how do you put a price or a value on somebody at Lifeline answering the phone and talking someone off that ledge? How do you put a price? How do you put a price on somebody who is in an aged care facility and has no friends or family, but a volunteer comes and sits with them and plays games once a week? Like being able to actually ascribe a value to that is nearly impossible.” (7)

“...particularly at end of life or even with just really serious diseases, it’s that social connection and the humanity that is as much as a part of people’s priorities [rather] than just receiving medical care or whatever it happens to be.” (7)

Prioritisation of client engagement over data capture (1,3,6,7)

For some research participants, staff members’ sense of purpose and commitment to the relational aspect of care were seen as conflicting with a commitment to data collection at times. There was an acknowledgement that the prioritisation of the relationship with the care recipient may impact the quality and completeness of the resulting data records. The trade-off was viewed as essential to preserving the relational dimension of care.

“There’s nothing worse than thinking someone is recording every word I’m saying ... it’s not like when you go to the doctor and they don’t even look you in the eye, they just type in the screen. You know, we don’t do that. We engage with a client and we find out so much more about the client because we engage. And that means technology has to go to the side. [...] So after a visit, staff will then either sit in their car if they’ve got connectivity and type notes, sit in a coffee shop having lunch typing notes, or come back to the office and do it at the end.” (1)

“[I]f you think about an Aboriginal person who has mistrusted all systems, the concept that they will share anything, [...] even as a threshold to be able to access support, is really wrong. [...] Like, I want the data and like the data. But [...] good service provision shouldn’t rely solely on you hav[ing] to give us everything before you come in the door. Yeah, and that’s a real tension, I think...” (3)

“...one thing I hold in mind all the time... a person seeking support is frequently in distress. Yeah, and they’re not always able or willing to share everything that you might want to collect at a first contact... Our... approach is, it’s a relational approach, and we should prioritise relationship over everything, which means that data might be pushed down the... list and it should be” (3)

“So we’re finding our carers... [are] quite open about what works and what doesn’t work for them... that’s why we talk about it as being lived experience learnings, because if we just set the form down and asked them to fill that out, you wouldn’t get any of that [information].” (6)

RELATIONAL CAPACITY

For organisations, relational capacity relates to the ability to support their goals by building and maintaining mutually beneficial relationships with consumers, clients, funders and partners that are founded in trust. The shape of relational capacity is diverse in this sample.

We heard that mid-to-large-sized and established organizations providing B2C care tended to exist in a more unidirectional relationship with the communities they serve, due to efficiency pressures arising from their scale. Even as day-to-day care provision and staff motivation are shaped by lived experience in larger-scale organisations, there are pressures on staff time and relational capacity arising from the need for consistent, timely and complete data collection, interpretation

and record-keeping. These pressures inform how diverse relationships are captured and understood within the organisation through data and the care stories that can be told with data. As the largest organisation we interviewed (1-5k employees) observed, “...one determinant historically of what data we collect is what are we asked to collect. And so that obviously persistently shapes how we collect data.” (3) Yet, as another participant explained, productive relationships are what enable the organisation to “ascertain what the [care] gaps are in the community”.

For peak bodies in the care economy, which mediate between care organisations, community members and government institutions, relational capacity is key. Data is principally collected to support the peak body’s ability to advocate for policy and to demonstrate the impact of its member organisations, thereby strengthening its relationship with all its stakeholders.

Relational capacity is also important, but looks different in smaller local and regional organisations. These may have fewer requirements for funder-related data collection and a stronger emphasis on building informal information networks. Individual and community stories inform the actions taken by the smallest organisation we interviewed, and the stories it tells about the human impacts of its work. Smaller organisations tend to have a stronger capacity to directly represent their individual clients’ and/or local or regional community needs through more informal data collection practices, such as informal gatherings and events and information sessions. Retelling stories of impact collected in these ways can further strengthen their relational capacity within communities.

The flow of information and education back to individuals and communities from the smaller-scale organisation may create a mutually beneficial circulation of knowledge about locally and regionally informed best practices in care. This knowledge can energise local support for both formal and informal carers, including volunteering and community-based philanthropic contributions, which can otherwise remain largely invisible within more formal economic measures of productivity, efficiency and impact.

“The way that you capture, collect and use data... builds relational capacity in those areas.”

Ability to establish productive relationships with diverse community groups (1,3,6,7)

Participants emphasised the importance of relationship-building with diverse community groups for identifying gaps in service provision. As a staff member of organisation (1) explained, data collection supported the visibility of these gaps, enabling proactive outreach to excluded groups. Conversely, organization (7) emphasised the importance of informal relational networks for connecting with community members who might otherwise not access the service. Organisation (6) described productive relationships with community funding bodies leading to grant success.

Thus, while data enabled larger organisations to highlight areas for expanding the reach of their service provision, for others, notably smaller, organisations, word-of-mouth and personal relationships were most productive.

“the way that you capture, collect and use data... builds relational capacity in those areas. [...] We would use it for strategic planning. Yeah, part of our service planning would be to establish these productive relationships and [use] the data to ascertain what the gaps are in the community and how we can fill them and then prove that, monitor that we have increased our relationships.” (1)

“... another area is funding and grants. We’ve been really fortunate that when we’ve applied for a [community] grant and when we’ve been successful [we] have set up amazing relationships with funders [...] we’re in constant communication still with them” (6)

“the number one way that people find out about volunteering is still word of mouth... because it’s such a relational activity.” (7)

Ability to establish productive relationships with diverse experts and advisory groups (1,2,4,6)

Some participants described expanding their organisational and strategic capacities by drawing both formally and informally on information from others, including advisory groups. For some, there was mutual benefit to be gained from also participating as members of expert and advisory groups.

“... our understanding and ability to use the data has me on a couple of advisory groups as an expert, I suppose, or consultant.” (1)

“So we actually have a carers advisory group... And we meet and talk to them regularly, and they are the ones who feed in information.” (6)

“Our board has what we call a critical family around the world, not just Australian experts... we turn to them whenever we need information in a specific area.” (6)

PRACTICE INFORMED BY LIVED EXPERIENCE, HUMAN RIGHTS AND ETHICS

Lived experience supports continuous problem-solving and learning (3,4,5,6)

Our participants described practice informed by lived experience as a strength that also arises from the relational dimension of care. Contact with the lived experience of care participants and carers directly informs the knowledge base of service providers, supporting their continuous identification and prioritisation of the key problems to be addressed in order to improve the support they provide to their clients.

“So everything we do, we do through the carer’s voice and lived experience. [...] Our carers, you know, [are] caring for their loved one, going through the journey, and they get to a stage where they’re now transitioning and having to put the loved one into residential care. And so we’re putting things in place to help with that transition... we embrace and put our arms around them.” (6)



“[the data] we collect is mostly about... how Australians are providing... informal care to people who are receiving end of life care.”

Data practices informed by an understanding of trauma, human rights, data sovereignty and other ethical frameworks (3)

One organisation underlined the importance of explicitly applying ethical frameworks to guide their data practices, including understanding the impact of frequent and repeated data collection on vulnerable care participants.

“... one of the things that we do pay attention is to human rights and ethical issues around data capture. [...] Because people tell us that’s what matters to them. [...] [I]f we’re thinking about First Nations, collecting data from First Nations clients, we’re actually thinking about data sovereignty issues and some of those things. But also... only collecting what we absolutely need and... thinking really carefully about any... sharing of information, even within a team or across the organisation.” (3)

“We’re really trying to pay attention to people’s rights and balancing the rights of... not having to tell your story and share your information constantly with your right to not have everyone know your information...” (3)

DATA PRACTICES INFORMED BY DEEP SECTORAL KNOWLEDGE

Collection of uniquely rich information about informal care (4,6)

Two participant organisations described the development of rich insights into informal care as a critical aspect of their service provision (4,6). However, only one organisation (4) had processes in place to document this

information in the form of data. The other organisation (6) described acting immediately on informal care-related insights arising from conversations with the communities they served. However, they also acknowledged the opportunity to better document and share their insights in future.

“[the data] we collect is mostly about... how Australians are providing... informal care to people who are receiving end of life care.” (4)

“[there are concerns] that we’ve captured [from informal meetings with carers] and we immediately put things in place to rectify that.” (6)

Generation of sector-specific evidence and data to inform operations and strategic decision-making (1,2,3,4,5,6,7)

Every organisation we spoke to emphasised the vital importance of data collection, whether formal or informal, to inform their operations and strategic decision-making.

“...even where we are trying to adapt to the requirements of funders... our intent [is] to capture more richly the diversity of the consumers, not just for our rhetorical purpose, or our ability to advocate, [but] because we think it’s important to, you know, shape the practice by asking the right questions...” (3)

“...we collect the data of three different groups of people, people who are receiving care, people who are providing care... and those who are coordinating the care. [...] [W]e are trying to know who is receiving care... in which age group they lie, the relationship [to the carer(s)] and the reason they are in the [organisation’s support] network” (4)

“...we actually collect data on events. So the date and the time and... who attended the events and then we usually give people, if they come to an event, a sheet [to fill out]. We haven’t got to actually putting that [data] onto a spreadsheet yet because we’re busy doing other things, but we’ve gathered spreadsheets from our participants who’ve come. [...] We also collect information on the carer and participants’ interests.” (6)



Generation of sector-level evidence and data to inform policy, advocacy and consumer education (1,2,3,4,5)

Most organisations in our study asserted that the sector-related data and information they held were important for the purpose of advocating for better policies and regulatory environments, workplace practices, or for promoting increased consumer awareness in their area of concern.

“The board is extremely encouraging of collecting our data for advocacy so that we can actually build an evidence base for that.” (1)

“Part of what [we do as an organisation] is create an evidence database [to support] translation of research into practice [by directly addressing known barriers]. One of those barriers being access to the evidence and the second barrier being being able to understand, synthesise and then apply that evidence. “ (2)

“So we identified two major problems for the sector and what we decided to do was have a collaborative approach to solving those problems, whereby we actually bring multiple providers together to work on solving the problem, rather than it just being one provider...And so the two topics, one was around the use of data... So how to collect, how to sort, how to translate... And the other one was around workforce leadership.” (3)

“we are trying to provide education and training to volunteers, general practice, health service providers to prescribe, you know, to help people mobilise, you know, to advocate for social mobilisation.” (4)

“...of course we’re talking to government about the fact that there’s huge inequities across the different reforms... and that some people can get really good access to [product type] to support their ability to be part of society and others can’t. So that inequity... is something that we talk to all the time.” (5)

In-house technical capacity supports data processing and reporting (1,2,3)

Only three of the seven organisations reported having strong in-house technical data processing expertise, extending in one case to the use of a data warehouse to facilitate reporting.

“We’ve been doing a quality project for the last two years, my other [CMS] worker and I, where we talk to the program managers and the main staff in each team, and work out what is it you collect, what is it we need to put into the data to report properly, and what extra do the managers need to know, or need you to collect so we can pull out reports for you.” (1)

“... with the data warehouse, we can pull up the data and say, for this particular field, 0.5% of the agency have marked it as not stated, instead of having to manually go through and pull this information out. So it will help us [to] check the quality of the work that’s been recorded in the systems, which also then has a flow-on down to the client level service.” (1)

“...in terms of that integration and interoperability, though, that you were talking about... I guess there’s already quite a degree here of that integration from different sources.” (1)

“There are some services where the funder requires us to put the data into their system and we have negotiated in whole or in part to hold the data, collect the data ourselves and then give them the data.” (3)

All three organisations linked their capacities directly to resourcing. One highlighted that, even in an organisation with a strength in this area, the motivation to improve data processing and associated reporting capabilities exceeded the available resourcing:

“We are an agency that’s fairly well technically enabled, and we have a number of people who want it to be more technically enabled, even supported by the CEO. [...] But if we don’t get enough money in to do that, it’s very difficult” (1)

“There are some services where the funder requires us to put the data into their system and we have negotiated in whole or in part to hold the data, collect the data ourselves and then give them the data.”

Another described the transformative impacts of recent improvements in data processing and automation capabilities.

“And it’s only really been more recently that we actually have the... capability within the team now to be able to actually look at how we’re collecting data and automation around the processes as well. So we’ve certainly been able to rectify some of the issues that we’ve had and... to use the systems that we have access to... to set up really great processes and automations. [...] And so in terms of data collection and reporting, we are definitely on a good trajectory. [...] So yeah, we’ve actually invested in things and it’s working... [...] we’ve just really been able to dramatically transform how we’re doing things.” (2)

Weaknesses

SUMMARY OF WEAKNESSES

Inadequate Data Infrastructure and/or Data Management Processes — Conflicting and/or Burdensome Data Collection Requirements — Lack of Staff Capacity for Data Collection and/or Documentation of Learnings — Poor Data Integration — Poor Data Visibility — Lack of Trust and/or Lack of Resources Impact Data Sharing

The weaknesses described in our interviews demonstrate the deep impacts of current data-related issues on the organisations' ability to conduct their day-to-day business and to plan for future growth or improvement.

DATA INFRASTRUCTURE AND DATA MANAGEMENT PROCESS ISSUES

Data infrastructure is not fit-for-purpose or supportive of future growth (1,3,4,5,7)

Organisations described data infrastructure that fails to facilitate their ability to capture and/or report data for strategic and operational purposes, including evaluating the impact of current services in order to develop future strategies for improving efficiency or enabling growth.

"Well, the version [of our internal CRM] we've got, we've got the real cut-down community model only, so it can't do any scripting. So we can't use it across the board because the [partner organisation] couldn't use it. The [care workforce] couldn't use it because they can't do any script writing in it... It also doesn't have any billing capacity at the moment, but we are pursuing this fairly urgently with them." (1)

"[The organisational leadership] always want to know what is the unique number of clients we see for the total agency, and that's really hard to pull out... So there could be between 30 and 50% duplication of clients, but we don't know unless we can pull out this [data]." (1)

"And I think in total, we have 48 different types of analytics or extracts that we have

to get out just to provide monthly data." (1)

"It's difficult for us to build any clear picture on a consistent basis about what are the needs that our services are responding to at a service level or at an organisation level or a stream level." (3)

"Here we have been persistently trying to add a place into our consumer data system to identify if a consumer identifies as LGBTQIA+ for three years. And we can't do it because we don't have... a field that we can [re]purpose to collect that information. It seems hard, it seems ridiculous, but... we can't... [T]here isn't a field available for us to put that information into [and] we can't add a new field. We have to go to the provider of our software and... either it can't be done in that location, or it can be done, but it will cost a prohibitive amount of money and so that imposes constraints on... how much data we collect and what data we collect. So, we are much more restricted in what data we collect." (3)

"Like populations of high-need and identified-need people, who have, you know, had itinerant housing or [are] veterans, or LGBTQIA+, or come from a migrant background, etc. All of these things [are] really useful for us to be able to paint a picture, inform what sort of supports we need to provide our teams to provide better support for these consumers, and also... to build a profile, because again, like... in this environment, it's important that we are able to communicate the value of these services to funders and to government." (3)

"We've asked [the software provider] to keep [important data that is not automatically collected by the software]. It's ... a nightmare for them and [increases the cost exponentially as we grow]...it's just a real huge jump." (4)

Data collection is complicated by conflicting demands (3)

One organisation described situations in which conflicting data collection requirements (operational and funding-related) have resulted in a lack of capacity to prioritise the types of data that would support deeper insight into the communities they serve. These issues in turn affect the organisation's capacity to support funders' need to understand the impact arising from their funding of services.

"And so we might get into a situation where with the funder, they're saying, why is your waiting list growing... and we can't necessarily speak back to [that]. The people on that waiting list are showing up differently. So there's an increase in complexity of people. So we need more time... [W]e can push more people through, but it might decrease the quality of care because of a different need. So it's actually very hard to have any of those supported by data without, like, extreme effort. [...] There's potential for us to speak to unmet need, but we don't actually have a way of capturing that ." (3)

"So there's all sorts of contract-related information that determine KPI's and set data requirements... they come from lots of different directions." (3)

A B2B organisation highlighted a sector-wide issue with poor quality data collection and management resulting in reduced reporting capabilities:

"...if we do want to look at [the] future in terms of what we do with technology [...] we need to get better as a sector around how we collect and store and use data." (2)

A peak body highlighted how a lack of systematic data around market share and market capacity made it harder to advocate for appropriate policy support for their work:

"So of course, one of my jobs is to speak about the sector to government and to address reform issues and regulation changes and such. And it is very difficult for me to do that if I can't express what my market share is, what the capacity of our market is, how much they do, what they deliver on, what they bring in terms of, you know, income into the Australian marketplace. So it does become really difficult for us... [...] [I]t is quite frustrating for myself and my advocacy team in particular to not have a lot of that detailed data, to not know how much of the pie [we're] representing." (5)

Lack of systematic data collection processes in place within the organisation (2,3,5,6)

Participants from a B2C and B2B organisation described the impacts of not having a Relationship Management System [RMS] to collect data to support and streamline the management of their complex network of relationships:

"it would be very sensible and useful for us to have a Relationship Management System and I know that exists in other organisations. We didn't acquire one when that was stated as an intent about two years ago... due to other things happening, that didn't happen. So we don't have a system managing that, not a formal system anyhow. And that that has obvious implications because that's data that should be captured and managed effectively and that's instead captured and managed in ad hoc ways..." (3)

“...if we do want to look at [the] future in terms of what we do with technology [...] we need to get better as a sector around how we collect and store and use data.”

Funders' data reporting requirements impact metadata structures and create a data management burden (1,3)

Changes in data reporting rules associated with shifting funder requirements impacted one organisation's ability to maintain consistent use of its metadata fields across funders.

“[Funders are] saying, why aren't you reporting [specific demographic] status? You know, so they're telling us off with a threat of removing funding, and yet we're saying, but our system says we are entering it, but they changed the field they're collecting it from. So we went from reporting 78% to reporting 0[%], but we weren't aware that it was even a mandatory field. It was not listed anywhere.” (1)

“We could customise [that field], but again, because of the number of funders that we have, and sometimes they do use different language, it was decided we stick with the original one we had and just interpret it differently.” (1)

This organisation also expressed frustration at the inconsistent data formats required by funders, and the data management burden this imposes on care organisations such as theirs:

“And the other stumbling block is the state funding bodies. State government [funders from] four different departments are major funders of ours that we have to submit data [to] and they all want it in a different format in different portals, slightly different collection tables. And that's the biggest nuisance... [W]hy can't you all get together and just choose one set of information for

us to collect and submit the same way? And why can't you share this information because it's all de-identified? [...] [W]e should just spit out one report that says what department it goes to and you guys should play with it... instead of building your own analytics portals that we actually have to make our data fit into, instead of us being able to supply the data and you guys work out how to integrate it. (1)

Another organisation underlined the cost burden incurred by care organisations when funders' data reporting requirements change:

“...it's not just the changing data because changing data requirements at an organisation at scale like this has massive change processes, and... cultural implications in teams.... If the changes keep coming— like there's one funder I can think of at the moment who is doing some fairly frequent changes. And it really... frustrates staff... they're confused, they're not sure what they're meant to do. And they talk about it as one of the biggest burdens of their work.” (3)

Data capture technology is unsuited to the circumstances in which staff are working with clients (1,3)

Some organisations feel compelled to seek external technical solutions to manage the complexity and scale of their data. However, these solutions may not be well adapted to care contexts, which must prioritise care experience and delivery over data collection.

“For years, we've had very bad connectivity, you know, at [regional location], because it's very hilly... It's got a lot better now, but staff are very much not used to actually sitting there with a laptop in front of them, talking to people. And that's what I've had to explain to [our data management systems provider] a number of times. They've set up a process and I've said, well, that won't work because the person doesn't have their laptop in front of them while they're doing counselling for grief.” (1)

Balancing the burden and benefit of data collection (1,3,4)

One organisation observed a tension between data governance (application of consent and privacy guidelines) and funder requirements for visibility into who receives the care they fund. This tension creates a burden on the care organisation and care participants to manage conflicting requirements:

“So one of the examples [...] is around navigating issues of consents and what consents... are collected, should be provided, for what purposes, what burden does that impose upon a consumer... [For example] if you ask [consumers] [...] do you consent for us to share this information with the funder of this service [...] consumers are confused by the question because [that funder is] paying for [the service]. [...] If there's [...] clearer guidance on how we should approach this that is informed by lived experience, then I feel like that would make it easier for us to navigate some of these issues internally. Because otherwise then the burden falls upon us to make decisions about this. That's hard... [...] Who gets to speak for this issue? What's the process that we should [use] as an

organisation to be in the right position to make those decisions? [...] That's a high burden for us to take on as an organisation.” (3)

Another organisation observed the need to weigh the benefits of in-app data collection against the usability of the app.

“So we have to this kind of trade off, like, do we want all these [data collection] questions or do we want people to use [our app]?” (4)

Lack of organisational (staff) capacity for documentation of learnings and insights (6)

The smallest (volunteer-only) organisation we interviewed underscored the risks of having important organisational knowledge and learnings held only in the memory of its director. Though this is likely an issue experienced in organisations at every scale, the lack of resourcing for undertaking thorough documentation and knowledge transmission to other senior staff members was felt to be particularly acute within this organisation.



“this is what we’re working on at the moment... we need to take a lot from my head and have it down here [in writing].” (6)

“I think it’s really important to have [more formal structures of data collection], but it’s a case of we’re a community organisation [and] don’t have funding. We don’t have the wherewithal to do it unless we can chase to get some funding from somewhere...” (6)

“Because, you know, we’re busy doing the doing and not so we don’t have paid staff or anything like that. So we just, you know do it when we can do it.” (6)

DATA SILOS AND FRAGMENTATION

Several organisations reported challenges with data integration across diverse databases and infrastructures. These challenges are found both within and between organisations. Participants attributed these challenges to several distinct causes:

01. within organisations, operational and resourcing constraints on staff capacity to undertake data integration and data visualisation work across data silos;
02. a lack of investment by governments in supporting data integration systems, in cases where care organisations are required to share data and metrics with government agencies;
03. barriers to sharing data across data storage systems, related to privacy regulations;
04. competitive barriers (IP-related) to data sharing with other organisations.

One of the characteristics of B2C organisations in the care context is that, in order to understand the care recipient’s journey through the care system and provide wraparound care, they often need to collect data on client interactions both within their organisation and with partner service providers. As one participant explained, “... you have individuals who are accessing your service, but you are also liaising and have relationships that you need to trace with different service organisations.” (3) These organisations may sit in distinct sectors such as mental health, family violence or primary health.

Diverse regulatory constraints between sectors may contribute to data being separated or duplicated and held in siloed databases.

If data cannot be integrated across contexts, this may result in data gaps which can impact the quality of care experienced by care recipients. One organisation gave the example of a refugee needing an interpreter in their native language. If that language information is collected by one organisation but cannot be shared with a partner organisation, this may result in the client receiving poorer service from the latter service. Having better data integration would allow both organisations



to compare the information about the care receiver stored in their respective Customer Resource Management systems “and then flag when the information is different in both.” (1)

The same organisation described their work on data-privacy-preserving data integration strategies. These would allow them to share key features of client interactions that matter for each organisation serving a client. Despite its promise, they told us that the proposed data integration method could not progress to full structural integration through an API due to funding challenges.

“We’re developing... an SLK, statistical linkage key... to work with [our partner organisations’ CRM] and taking a statistical linkage key from [our internal CRM] as well, so that for this data warehouse we can see, for our client, all the systems that they’re in. You don’t know who they are, and you can’t read any notes, but you know that they had OT for half an hour last week and they had counselling for an hour the week before. [...] [S]o that key allows you to... match the individual participant across all those different services, but you don’t know who they are exactly. [...] [S]omeone could go into the data warehouse and see the different levels of alerts [for this client]... But we will never be able to do it because we have to license every single person and we have about 300 who would be using it.” (1)

“[W]hen it was first started... this [project] was stage one and stage two was to get an API built for both [our partner organisations’ CRM] and [our internal CRM] to upload that data on a regular basis. [But] [t]he budget was way too big for that.” (1)

Another organisation described the fragmentation of data across all sectors of the care economy as a fundamental issue for their ability to advocate effectively for their cross-sectoral client base:

“... in general, data collection is fragmented. [...] [W]e’re piecing together different bits of data... It might be from the census, it might be from the general social survey, it might be from an aged care survey, and then almost having to kind of like, ‘Frankenstein’s monster’ [the] data to come to conclusions.

[...] It’s improved a little bit with some of the work that’s happened in the aged care space recently... But then what we see is that, okay, in aged care, they’re doing some work... but what does that look like when we bring in disability? What does that look like when we bring in mental health? And the fragmentation of data collection, even just in terms of methodology and questions that are asked, makes it really difficult ... [to draw] conclusions, which then obviously hampers policy and advocacy efforts, because we might have a statistic in aged care that we don’t have in mental health.

So how we are able to represent the care economy becomes very difficult and convoluted... we can’t just say, here’s the shiny package of numbers.” (7)

Lack of trust limits data sharing between care economy organisations (1,3,5)

Organisations had concerns around sharing data and the IP which exists in data structures. These concerns may point to a sector-wide weakness resulting from competitive funding pressures. Partnership models that require sharing data or data structures can result in distrust and organisations being incentivised to protect their IP. Unwanted sharing of background IP may constitute both a weakness and a threat. As one organisation explained,

“...we’re having more and more staff [who work] between... other public agencies and ourselves. So they’re able to access both systems. [And] I’m finding there’s an infiltration of, well, we use this form to collect this data at this agency, can we do the same here? And then we worry about, are they doing the same, taking our forms and our data types to their other agencies and using them over there? I see it as a risk. I don’t know if it’s occurring, but I think it’s a risk.” (1)

Lack of resources limits data sharing and data integration between organisations (3)

Another organisation took a different view on the issue of cross-organisational data sharing and integration. This organisation linked the lack of data sharing to budget and resourcing

constraints and associated pressures to compete with similar care organisations, undermining the basis of trust.

“I do think data in itself has value and data structures have value. And... I think some organisations hold them close because that’s part of their commercial value. [...] I think the reason they hold it as their individual value is because the resources are constrained. Like we’re in an environment of scarcity. [...]

[T]he reason we have trust issues is perhaps a function of the fact that we’re in a resource constrained environment and we feel like, despite our statements to the contrary, that we’re in a competitive environment and we need to maintain positive distinctiveness. And the way that we do that is by holding on to our data assets.” (3)

Conversely, the same organisation noted that strengthening trust could foster a greater commitment of resources to mutually beneficial data sharing with similar organisations in the ecosystem:

“...if we were overcome with a great sense of collegiality and goodwill, then maybe we would allocate more of our scant resources to [finding ways to share data]. [...]

I can say right now, the prime constraint feels like resources because the resources are a really present constraint. But if... we had a very open and trusting relationship with peer organizations, then perhaps we would make more liberal use of those scant resources because we had an understanding, [a] shared understanding of the value of that, and the shared advantage [better data sharing would provide]...” (3)

“I’m just thinking in terms of this ecosystem metaphor... there would be more of an actual ecosystem where there’s... interdependencies or supportive interrelationships more than kind of silos.” (3)

“...almost having to kind of like, ‘Frankenstein’s monster’ [the] data to come to conclusions.”

Data silos within an organisation (1, 3, 7)

Organisations observed that understanding and visualising data coming from distinct sources is an overarching challenge for care sector organisations. Internal operational integration and visualisation of data from different data systems is a particular challenge, as we heard from two organisations. One organisation noted that data governance concerns also constrain the extent to which data can be made visible to staff across the organisation.

“we don’t have anyone who is 100%, you know, functional in Power BI... I can pull out things and set up basic dashboards, but I literally don’t have time and we don’t have any supplementary staff who can do my job so I can spend the time.” (1)

“...the principal barrier is the information is located in different locations. Secondary barrier is we have an organisational principle that you have access to what you need to have access to. So in principle we partition.” (3)



Opportunities

SUMMARY OF OPPORTUNITIES

*Create Fit-for-Purpose Data Systems
(Flexible, Streamlined, Supportive of Growth)*
— Share Learnings from Lived Experience
— Improve Stakeholder Engagement

The challenges of operating in a resource-constrained environment and attempting to share information in a siloed landscape are well-documented in the Weaknesses section above.

However, many organisations also identified their know-how as an untapped asset.

With the technical expertise, sectoral knowledge, and strategic capacity to design better, more fit-for-purpose data systems, these organisations felt both equipped and motivated to move beyond ad-hoc or siloed solutions toward greater interoperability across the sector.

CREATE FIT-FOR-PURPOSE DATA SYSTEMS

Make data systems flexible enough to grow with the organisation (3,4,5,7)

There is an opportunity for organisations of all sizes in the care economy to create fit-for-purpose data systems. Even the largest organisation in our study, with 1-5k employees, described using informal data integration methods. This organisation (3) is now seeking

the benefits that will stem from implementing systematic data integration infrastructure:

“The fact that we don’t have a mechanism for integrating that information is less of an urgency because someone can be across all of that informally, but as we grow and [begin to have] a more managerial structure, it becomes harder for people to have any meaningful oversight of it... And the importance of having that... integrated information increases.... we’re at a point where I think in the next couple of years we will be rethinking the systems...” (3)

Two other organisations, one a B2C and one a peak body, explained how better data systems would support their growth:

“I think... it’s worthwhile building... a progressive web application [where we can collect]... international data... because the New Zealanders really want [to use this IP]... [With the new system, we’re planning the] ability to integrate with local care service providers and other locally based health and social care providers...” (4)

“[Previously, we collected data] in the form of case studies mostly... So it’s been a huge growing process over the last two years to try and get [data infrastructure] in place to pull more data and understanding.” (5)

One peak body highlighted the opportunity to introduce systematic data collection processes

to capture the scope, scale and nature of volunteer contributions across the care economy:

“I think it would be so helpful for all organisations that involve volunteers to have a consistent way of capturing that information and being able to report on it. [...] So even as simple as how many volunteers you have and the types of roles they do and you know, broad outcome metrics and things like that, just so we actually have an idea about what that looks like around Australia.” (7)

Reduce the complexity of data systems (1,4,5,7)

Several organisations described exploring options to reduce the complexity of their data management infrastructure, to provide seamless data integration with partner service providers, and to improve their ability to extract insights and understanding from their data. As participants observed, the value it would offer to the wider care community clearly motivates this work.

“We’re always looking to reduce the number of [client management systems] programs that we have to use. We’ve got [six] built into the agency that don’t talk to each other. And [leadership] was talking about getting an app [built] to integrate but [because of Commonwealth restrictions] you can’t.” (1)

“... just being better able to utilise the data. Like I always think, if you automate [the data collection and management] processes, then you can spend your time focused on doing something with the data. And sometimes we’re sacrificing that because we are spending so much time doing really manual processes...” (7)

Align data collection with systematic market / sector research on client needs (5)

One peak body described paying for an external research data collection to facilitate their access to the market share information they needed to support strategic advocacy efforts, but were not able to obtain directly from their members:

“...if you automate so much of the earlier processes, then you can spend your time focused on doing something with the data. ”

“We’re... just about to look at a major data project for us, because we want to look at market share and the only way we’ve tried, I think this has been tried numerous times before, but the only way that we can really get this done is through a completely independent body that would collect that data... [This data collection] is something that our bigger members are pushing for at the moment... of course the cost involved is much easier to be worn and they understand the need for data and knowing about their market share.” (5)

SHARE LEARNINGS

Document and share observations and learnings (6,7)

One organisation described their desire to better document and share the knowledge they gained from their day-to-day interactions with the lived experience of care recipients and carers:

“... there’s some really... good reasons... why we should be capturing and documenting more of what we’re doing because people would learn a lot from what it is that we’re doing, yeah. [...] Because there are a whole lot of learnings here that would be wonderful for other organisations.” (6)

Another saw an opportunity to collect data on the diverse backgrounds of volunteer managers they encountered, in order to highlight the nuances of this important but overlooked group of informal care workers:

“And even if you’re not collecting [information about the diversity of volunteer managers], even in spreadsheets or something like this, maybe there is a case [that it] might be nice to know that or have that in a more centralised place.” (7)

IMPROVE STAKEHOLDER ENGAGEMENT

Expand stakeholder engagement to support service provision (2)

One organisation described an opportunity to improve their engagement and collaboration with stakeholders in their sector by gaining a more data-driven understanding of who they have connected with and who else they might reach out to:

“...I’ve been leading... stakeholder engagement, so that we’re able to get the reach, because we know that there are a lot of providers and... workforce out there. So, understanding who we have and who we haven’t actually engaged with is definitely a key piece of work for us. Because we have these opportunities and we want to make sure that everybody is across those opportunities, and that we’re not just, you know, sending it to the people that... have already connected in with us... [W]e want to try and get it out there broader...” (2)

Threats

SUMMARY OF THREATS

Limited Control over, Access to and Visibility of Strategically Important Data — Concerns over Partnerships Devolving into Competition — Concerns over Sharing IP of Data Systems and Metadata Schemas — Data Governance Risks — Knowledge Management Risks

Several organisations told us that they are limited in how much strategically and operationally important data they have access to, even when that data is created by their organisation. This constitutes both a present weakness and a future threat, as it may constrain visibility into important drivers of business growth and success.

Participants cited several reasons for the lack of access to data: the limitations of their own technical data infrastructure; data that is stored by a third-party organisation; limited in-house technical capacity (or resources), forcing the use of data management systems that constrain access to data; data management systems increasing in cost over time; and the terms of funding agreements which require an organisation’s data to be held by the funder(s).

Organisations are also impacted by dependence on third-party apps or data systems, hampering their ability to improve their services.

At the ecosystem level, systemic organisational data issues such as these may limit the efficiency, productivity and growth of the care economy.

LIMITED CONTROL OVER, ACCESS TO AND VISIBILITY OF STRATEGICALLY IMPORTANT DATA

Control of and access to important data sits outside the organisation (1,3,4,7)

Two organisations described challenges in working with primary healthcare providers, which store patient data without the data, including the services provided, being visible to the referring organisation.

“[A partner organisation says] the data in the medical practice belongs to the doctors [not us]... so therefore they won’t share it.” (1)

“But broadly speaking, the threats that we see ... are situations where we are operating without access to the data that we are collecting. [...] It’s hard for us to monitor the quality of those services. It’s hard for us to speak to what’s going on in those services because we don’t have access [to data from those services].” (3)

“[Primary Health Networks are]... one of our major sources of funding. [In some situations] some PHNs understand that they are the service provider and [there are] other situations where the PHN understands that we are the service provider. And in the context where they see themselves as a service provider, [the PHN] tend to provide us [with] a system where the data is held, and they hold and control the data.” (3)

While third party data management becomes necessary for organisations who lack internal resources, one organisation noted that this arrangement made ongoing data access a costly process, while decreasing oversight and control into their own data and relevant infrastructure:

“So we own the IP of [the data collection instrument], but we don’t actually have [access to] the [data or collection instrument internally].”(7)

In one case, third-party data management software created a burdensome layer of data cleaning work for the organisation that owns the data:

“We own the IP and the data, but they [the third party company] own the software. [...] [W]e have to wait for [them] to export the data at the beginning of every month and often we have to chase it and it’s a mess.... So, [we have] to spend a good day organising the data...and then [we have to] clean the data every single time because it’s like a dump every month and it’s not an accumulative amount.” (4)

COMPETITORS’ ACCESS TO / VISIBILITY OF STRATEGICALLY IMPORTANT DATA

For some organisations, the undesired sharing of their IP related to data collection processes and structures is both a weakness and a potential threat.

Partnerships devolving into competition (1,4)

In one case we heard that a public-private partnership had devolved into competition, with knock-on effects for the technical knowledge being developed by the organisation we spoke with. This case exemplifies how data hoarding can be incentivised within a sector where the possession of sensitive data conveys a potential business advantage.

“So one of the problems we’ve got is that [the private company which developed the data collection and analysis software has] trademarked [the] tech... [W]e’ve gotten [into] this really weird relationship with them, in that we’re a customer, but they’re also a competitor... [T]hey’re not... bound by ethics. So they can just do whatever they want with the data.” (4)

DATA GOVERNANCE AND KNOWLEDGE MANAGEMENT RISKS

Ad hoc technical environments that are built to react to issues as they arise rather than designed strategically can place organisations in difficult positions when it comes to data privacy and consent. Organisations told us that a lack of standardisation across funders’ and partners’ requirements for data collection, storage, and sharing creates real risks for both organisations and their clients.

Consent and data privacy infrastructure and governance are not fit for purpose (1,3)

Data infrastructure concerns are particularly acute in a funding environment characterised by multiple funders, project-based funding cycles, and unclear or changing standards.

Two organisations described navigating data governance decisions in this context.

“The issue we have [with a service that supports carers]... is [that] the funding body also wants us to collect [data on the person the carer supports] . And we’ve just said no, because [that person] doesn’t give us consent to store their information and report it to a third party. We only have consent to store the carers’ information.” (1)

“[T]here’s not a clear structure that we could apply that would necessarily help us navigate the internal challenges of [obtaining consent to share data]... [For example...] navigating issues of ... what consents should be ... collected, should be provided, for what purposes, what burden does that impose upon a consumer, what can be assumed [...] If there’s a clearer foundation [...] that is informed by lived experience, then I feel like that would make it easier for us to navigate some of these issues internally.” (3)

Organisational risk from not having key information and knowledge explicitly documented (3,6)

This issue was felt by both the largest and smallest organisation in our sample, who described the challenges that come with scaling up and maintaining effective staff oversight of information:

“... as an organization [we have] become more complex over time [...] The fact that we don’t have a mechanism for integrating [some kinds of] information is less of an urgency because someone can be across all of that informally. But as we grow [...] and we have a more managerial structure, it becomes harder for people to have any meaningful oversight of it.” (3)

“I think that one of the biggest challenges [and risks] is that we have a visionary [leader who carries] a lot ... in the head and we’re a community organisation that absolutely has relied on that vision to carry it... it’s the sustainability and how you don’t lose that... it’s very hard to replicate a visionary leader” (6)

INCREASING COSTS OF DATA MANAGEMENT

The financial burden of building efficient data infrastructure is felt by organisations of all sizes and types.

This was identified both as a weakness and as a keen threat. Participants especially singled out the increasing costs of data management and identified a lack of control over funders’ requirements.

Changing data reporting requirements from funders are costly (1, 3)

“And we now [coming out of the changes in Commonwealth funding] have to capture fees collected per visit or invoiced, which we were a bit airy-fairy with before. [...] So that’s a whole big project based on a change of funding.” (1)

“[E]ven where we are trying to adapt to the requirements of funders ... or to capture more richly the diversity of the consumers our [data management] system doesn’t allow us to add ... fields [or] add fields in the right locations.... [E]ither it can’t be done in that location or it can be done, but it will cost a prohibitive amount of money and so that imposes constraints ...on how much how much data we collect and what data we collect.” (3)

Increasing costs of data infrastructure (1,3)

Data management work is essential to meet mandatory reporting requirements. However, the costs of technical upgrades or other data management tasks often fall into a funding gap. This leads to organisations being compelled to cover the expense themselves, further entrenching silos and incentivising data and expertise hoarding.

“We’re funded per hour of service or per case of service and there’s not a very big... overhead to cover [these costs]. We internally try to recuperate XX% to cover all the management, all the cars, all the fuel, all the technology, people like me, et cetera, who aren’t funded to do all this work that the funding bodies actually want. So yeah, money is the biggest thing.” (1)



“... there are increasing costs associated with diversification and new accreditation standards ... But one of the complications is that... the growth in the available funds provided under tender is not keeping up with the growth in [the] costs of service provision. So there’s less resource available to allocate to back-of-house functions like data management.” (3)

REGULATORY RISK

Data infrastructure and regulation, evaluation and monitoring regimes are deeply linked. Throughout the care economy, especially as regulations and expectations change and care systems are put under more pressure, care organisations felt the potential future risk of non-compliance.

Regulatory exposure arising from data management and workplace settings (1,7)

One organisation gave the example of a regulatory non-compliance risk arising from an unexpected change to data fields:

“Yeah, and we’ve had another one which we’re made aware of this year only because our [data management system] was changed a few years ago and we skipped a cycle when we submitted our drug and alcohol reports from July. [The funder was] saying, why aren’t you reporting refugee status? You know, so they’re telling us off with a threat of removing funding, and yet we’re saying, but our system says we are entering it, but [the data management system] changed the field they’re collecting it from. So we went from reporting 78% to reporting 0[%], but we weren’t aware that it was even a mandatory field. It was not listed anywhere.” (1)

Another organisation discussed the difficulty of combining volunteer workers within a formal workforce environment – particularly in care settings, where the involvement of volunteers may be difficult to record and trace to ensure compliance with sector-specific regulations:

“the unpaid workforce being volunteers work alongside a paid workforce and [complying with regulatory] requirements and all of those sorts of things are sometimes more onerous, I suppose, in healthcare settings or aged care settings or mental health settings compared to maybe something... environmental, like tree planting...”(7)

Need to constantly adjust to changing regulations and standards, including accreditation standards and processes (1)

Changes in regulations and accreditation standards can produce an unseen burden on organisations’ data management practices.

Failure to adapt data systems may lead to compliance risks:

“But then when you drill down into [the changed requirements under the new Aged Care Act], they’re requiring us to change systems in order to meet them. And if you weren’t a systematic data... person, you would think, oh, yeah, these are all fine. And so, management would go ahead and implement what they think and then find three years later that we fail... because it hasn’t been spelt out correctly.” (1)

Key Takeaways

Resource constraints, conflicting funder requirements, and regulatory pressures negatively impact care organisation data systems.

○ **Data collection often sits in tension with care work,**

Care economy organisations are fundamentally purpose-driven, and **relational care practice can sit in tension with systematic data collection**. At times, the work of personal connection and care may need to be prioritised over maintaining data records, and participants saw this as a necessary and legitimate trade-off. However, one consequence is that **data systems not directly related to care may be de-prioritised** – especially by resource-constrained organisations.

The impact of scarce resourcing is that a significant body of ethical and practical knowledge grounded in lived experience risks remains invisible to the broader sector – under-documented, informal in nature, or concentrated in the minds of individuals rather than captured and transmitted by data systems. Because of this, **the sector loses the opportunity to integrate and build upon these best practices**.

○ **competing funder requirements produce reactive and ad-hoc data practices,**

Funder-driven reporting requirements reinforce a pattern of reactive data infrastructure. Changing and inconsistent reporting requirements impose financial and administrative burdens, constrain metadata structures, and reduce organisations' capacity to collect data that would serve their own strategic needs. **Funder-driven data requirements appear to be actively shaping – and in some cases undermining – the sector's data capability**.

Building and maintaining efficient and compliant data and reporting regimes is costly and data management costs frequently fall into a funding gap. Despite data management being essential to mandatory reporting, technical upgrades and other data management expenses are often not covered by funding agreements, leaving organisations to cover costs themselves. **This may exacerbate incentives toward data and expertise hoarding as costs for the organisation increase**.

○ **shifting regulations undermine coherence and continuity of data.**

As regulations change and care systems come under increasing productivity pressures, organisations' risk of regulatory non-compliance due to data issues may also increase. Ad-hoc technical environments, conflicting funder requirements, and third-party data dependencies all contribute to data governance frameworks that are hard to maintain. The burden of compliance is more likely to be felt by organisations that are experiencing greater resourcing pressures.

The resulting data systems tend to be ad-hoc rather than strategically designed and fit-for-purpose.

○ Data silos both reflect and reinforce inadequate data integration,

Data silos are pervasive, both within and between organisations. Internal silos arise from operational constraints and resourcing pressures. Cross-organisational silos arise from competitive dynamics within the funding landscape. Both are related to a lack of government investment, and challenges related to privacy regulations.

Furthermore, a lack of trust and **competitive funding dynamics actively disincentivises data sharing**. Partnership models that require data sharing can – contrary to intentions – generate distrust and incentivise IP protection. **Frameworks and capacities that recognise these issues and support interoperability would benefit organisations, care recipients, policymakers and research.**

“Implementing data standards across large and diverse sectors would require an upfront investment but could then support better uptake of digital innovation.”

– AUSTRALIAN GOVERNMENT DEPARTMENT OF PRIME MINISTER AND CABINET (2023)
Productive care and support services'

○ reducing the data visibility that is necessary for care visibility.

Despite generating valuable care data, many **organisations lack meaningful visibility into even their own data**. Data created by the organisation may be stored by a third party, held by funders under complex agreement terms, or simply inaccessible due to infrastructure or capacity constraints. In some cases, organisations own the IP in a database but are unable to obtain direct access to their own data. **This compounds the broader dearth of accessible, sector-level information about the care economy, and hinders strategy and operations at an organisation and sector level. The resulting ‘data invisibility’ [14] has multiple knock-on effects for the sector and for care recipients.**

Resolving these complex, interdependent issues will require a whole-of-care-ecosystem approach.

Fixing Care Data Matters Now

“One of the biggest tests for the spread of AI tools and capabilities is human services, where high and rising opportunity and gathering demand is too often misaligned with tools and platforms struggling to fit the contours and rhythms of the “human” part of human services. In other words, the bit that matters.”

— STEWART-WEEKS (2026)

As we noted in our introduction, artificial intelligence has become central to discussions about data and data analysis in organisations across all economic sectors. There is a keen desire for organisations and enterprises to leverage data to extract powerful insights and promote productivity.

And yet, the data workers we spoke to pointed to significant, foundational data collection and data management problems and the need for stronger investment in accessible, integrated care data infrastructure.

If we are to avoid, in the words of Martin Stewart-Weeks, ‘tools and platforms struggling to fit the contours and rhythms of the “human” part of human services’, these issues will need to be resolved. We believe the first step is to listen to the people who work with the data every day. [18]





Appendix

Methodology and research design

This study used an exploratory, consultative approach within a qualitative research design.

The purpose was to develop a deeper understanding of the types of data collected and managed by care organisations, and the strategic and operational logic behind the data collection, categorisation and use. The unit of analysis was the organisation. The focus of the research was the perspective of the organisations themselves in relation to their data, rather than perspectives external to the organisation.

To capture how the organisations viewed their own data practices and capacities, the researchers used an iterative, two-phase interview structure applying the principles of ‘member checking’ – an established technique [19] for strengthening rigour in qualitative research.

A first round of semi-structured interviews produced preliminary findings. For each organisation, this comprised an initial thematic analysis; a draft organisational characteristics typology, showing our understanding of how the organisation was positioned within the ecosystem, and the draft SWOT analysis. Both documents were reviewed during the second interviews and validated, corrected, and refined. This ensured the analysis reflected each organisation’s own framing of their data-related activities.

Participants

Seven organisations participated in the study.

Recruitment was conducted through an existing professional network which facilitates collaboration between research and industry organisations in the care economy. This approach was chosen to accommodate the prescribed timeline for this internally funded pilot project. The researchers attempted to recruit a range of organisations from within the care economy network, representing a mix of characteristics such as sector and size. However, due to the project’s limited scope and timeline, no attempt was made to ensure the sample was representative of all organisations within the broader care economy.

Data Collection

Each organisation took part in two semi-structured interviews, conducted over two rounds. A total of 14 interviews were conducted.

The first interview was inductive and exploratory. Open-ended questions prompted participants to reflect on the types of data their organisations collect, their reasons for collecting it, and the processes and constraints shaping how data is collected, stored, and used. The question prompts and structure of the interviews were designed to surface organisations’ own framing and priorities.

As noted above, prior to the second interview, the research team produced an initial thematic analysis, a draft SWOT analysis, and a draft organisational ecosystem typology derived from the first-round findings. These materials — including the quotes and preliminary



findings on which they were based — were shared with participants in advance. The second interview was correspondingly more focused: participants were invited to review, validate, and where necessary correct the researchers' analysis. This process was intentionally transparent, enabling participants to engage critically with the emerging findings before endorsing or adjusting them.

Analysis

Analysis proceeded in two stages, structured around the two interview rounds.

Following the first round of interviews, the research team conducted a thematic analysis. This was inductive in orientation: analytical categories were derived from the data rather than imposed in advance. The researchers deliberately avoided pre-coding participant responses, allowing themes to emerge from the material.

A small number of organisational characteristics – including size, sector, profit status, and organisational type – were confirmed with participants during the first interview, with participants invited to check and correct these descriptors. More abstract characteristics, including organisational purpose and client base, were left open during the first interview and subsequently synthesised by the researchers into a draft organisational ecosystem typology.

The decision to organise findings into a SWOT framework emerged from the initial thematic analysis. As themes were identified and grouped, the relationship between domains – and the alignment of certain themes with strengths, weaknesses, opportunities, or threats – suggested this as a natural organising logic, considering the organisational perspective.

The SWOT analysis and ecosystem typology together formed the basis of the materials shared with participants prior to the second interview.

In the second interview, participants were invited to validate, adjust, or extend their earlier remarks. Where participants wished

to revise a code or correct a characterisation of their organisation, the researchers accommodated these requests. This choice was a conscious element of the research design: given that the research is intended to reflect organisational self-perception, participant interpretation takes precedence over researcher interpretation. In some cases, participants reflected on aspects of their data practice that had not been covered in the first interview and asked to amend their SWOT accordingly.

The organisational ecosystem typology was developed separate to the SWOT analysis. The diversity of organisations in the sample revealed significant complexity in how care organisations operate. The typology attempts to capture this in order to contextualise each organisation's technical and data environment. It draws on definitions from a range of sources, including ASIC, LinkedIn, and the Prime Minister's Cabinet policy documents on the care and support economy. The typology was co-validated with participants during the second round of interviews.

In summary, this project adopts a bottom-up, proof-of-concept approach. The working hypothesis was that understanding how organisations themselves conceptualise and manage data would surface informational gaps not visible through top-down approaches. Our aim was to begin to establish a framework for improving data collection capacity and infrastructure at the service level of the care economy.

Limitations

While we believe that the insights recorded in this report are largely applicable sector-wide and reflect systematic conditions within the care economy, more research is needed to validate and build on the findings here.

We hypothesise that the data management pressures present in organisations may vary depending on their ecosystem characteristics. However, a larger sample will be needed to establish connections of this kind. The following limitations are noted in relation to the present study.

Sample size. The sample of seven organisations is small. While some patterns were observed across organisation types, these should be treated as indicative rather than conclusive. The findings are intended to inform and motivate further research rather than serve as definitive claims about the care economy sector. The organisational ecosystem typology should be treated as a flexible, preliminary framework, subject to revision as the evidence base grows.

Sample representativeness. The sample was not designed to be representative of the care economy. While efforts were made to include organisations with a broad range of characteristics, findings should be interpreted with this in mind.

Ecosystem completeness. The organisational ecosystem was co-designed and validated with participants, but it is not exhaustive. Location data was not captured, though the researchers consider it likely that geography — and in particular a rural/metropolitan divide — would be a meaningful variable.

Data and technical maturity. The study did not include a formal measure of organisational data and technical maturity.

AI use statement

1. The Anthropic Claude large language model (Sonnet 4.6) was used to produce an initial synthesis of the key takeaways from the text of the report excluding the quotations and with full human review.
2. The Transcription function in Microsoft Word was used to produce initial transcriptions of interview data. Quotes were reviewed and edited as required. Final approval was given by interview participants for the use of quotes.



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Data (In)visibility and (Dis)connection in the Care Economy Ecosystem

SOME CROSS-ECOSYSTEM OBSERVATIONS



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