

Communique

Research Incubator 16 - 18 May 2023



The CKE team acknowledges Aboriginal and Torres Strait Islander peoples as the First Australians and Traditional Custodians of the lands where we live, learn and work.

Image credit: Devon Bunce, Digital Storytellers

About the CKE

The Carer Knowledge Exchange (CKE) is a partnership project delivered by Carers NSW and the Institute for Public Policy and Governance (IPPG) at the University of Technology Sydney, proudly funded by the NSW Government. It brings together researchers, policy makers, practitioners and family and friend carers to share their knowledge and learn from each other.

The CKE aims to improve outcomes for carers by connecting research to practice. It features:

- an online **research library** for people to search, browse and share knowledge about carers
- a range of **opportunities to connect** and share knowledge about carers with others, both online and in person
- a diverse national **network and communities of practice** where knowledge about carers can be shared and developed

Find out more

To find out more about the CKE or to get involved, visit the digital platform at www.carerknowledgeexchange.com.au where you can:

- subscribe for email updates
- register for upcoming events and view recordings of past events
- browse or add to the Research Library
- read about caring and carer support services
- participate in the Discussion Forum

You can contact the CKE team by emailing research@carersnsw.org.au or phoning 02 9280 4744.

Introduction

The CKE Research Incubator is an annual event which aims to address gaps in knowledge to inform future research directions and policy development and implementation. The Research Incubator 2023 was held across a series of eight online sessions from Tuesday 16 to Thursday 18 May 2023.

The overarching theme for the Research Incubator 2023 was *Making Connections: Exploring carer health and wellbeing*, with each session having a unique topical focus. A total of 30 researchers, policy makers, practitioners and carers shared their expertise and insights through presentations, panel discussions and workshops.

This communique outlines the main themes emerging from the event, supported by direct quotes from participants and digital canvases drawn by Devon Bunce from Digital Storytellers.



Emerging evidence

Researchers presented recent and emerging findings about carers' health and wellbeing



Lived experience

Carers shared their diverse lived experience perspectives on health and wellbeing



Policy and practice

Presenters and participants discussed key challenges and opportunities relating to carers' health and wellbeing



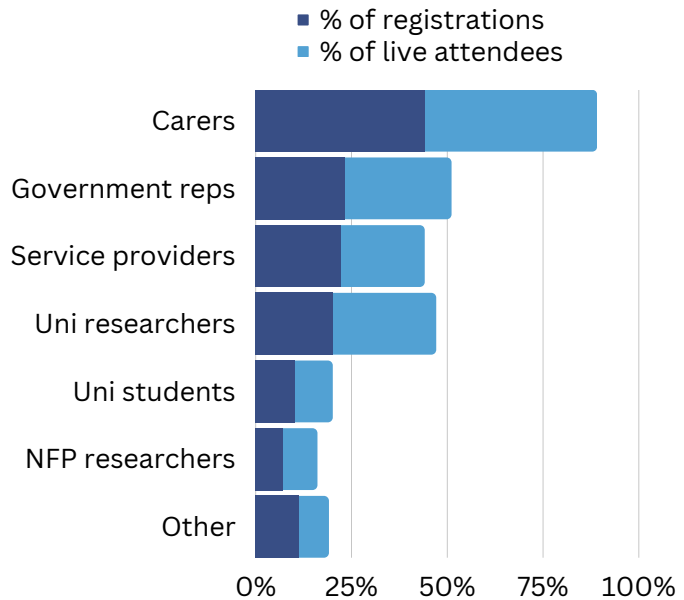
New connections

Researchers, policy makers, practitioners and carers shared their knowledge and learned from each other

Participants

A total of 169 researchers, policy makers, practitioners, carers and other stakeholders from every Australian state and territory other than the Northern Territory (NT) registered to attend one or more sessions.

There were 92 live attendees in total (54%), with the session recordings viewed on demand an average of 35 times each as at 26 September 2023.



Program

The Research Incubator 2023 included a total of eight live sessions:

- **Panel:** *Evidence-based carer health and wellbeing initiatives*
- **Panel:** *Improving service literacy and service access*
- **Workshop:** *Social connectedness and carer wellbeing*
- **Symposium** delivered in partnership with the Rehabilitation, Ageing and Independent Living (RAIL) Research Centre at Monash University: *Understanding hidden carers and carer diversity*
- **Workshop:** *Measuring carer wellbeing in research and practice*
- Daily screening over three days of a series of **ten Spotlight Series recordings**, short virtual poster presentations on new and emerging evidence

Recordings of all sessions from the CKE Research Incubator 2023 are available to watch on demand on the ['Get involved' page](#) of the CKE digital platform.

Findings

Key themes were identified through analysing recordings of presentations and breakout room discussions. The findings and outcomes were categorised using thematic analysis into eleven key areas, which are outlined in the following pages.

1. Carer wellbeing is important but not often prioritised

A focus on carer health and wellbeing is critical to ensuring that caring arrangements remain sustainable. Carers often do not have much time or many resources to allocate toward their health and wellbeing. The health and wellbeing of the person they care for often takes precedence.

“If the wellbeing of carers falls apart, everyone around them is affected, the carer themselves, the person they are caring for, the broader family and if the individual is employed then their workplace is affected.”

- Researcher

“Often carers put the needs of the person that they are caring for first and therefore they put their own health and wellbeing secondary to that.”

- Practitioner

2. Carers of different ages face distinct challenges

Caring can have a significant impact on young people's mental health. In addition to sharing the same challenges that their peers experience navigating school and becoming an adult, young carers often have less time, energy and resources to seek, establish and maintain supportive relationships.

*"...in addition to normal worries, they have additional worries.
Particularly about the person they are caring for."*

- Practitioner

*"...schools in Victoria employ mental health practitioners to help identify
young carers and assist linking them to services."*

- Researcher

Older carers often have chronic and serious health issues of their own to manage. In many cases they are balancing the deteriorating health of the person they care for with their own health care needs. Juggling both can add to carer stress.

*"Caring for an older person in declining health can bring satisfaction and
personal growth for the caring partner, however, overtime the demands
of the caring can negatively impact the carers wellbeing."*

- Researcher

"I am very tired, you don't have a break. It's relentless."

- Carer

*"...older carers of older people provide highly valuable role that is poorly
recognised."*

- Practitioner

3. Social connection can improve carers' wellbeing

It is important for carers to feel connected to their peers and to others in the community. There are a number of new services and programs being implemented to create opportunities for carers to interact with others who are in a similar situation.

"Being a part of this group has been the best carer support I have had."

- Carer

"The most practical and psychological support comes from family and friends."

- Researcher

4. Carer recognition is key

Many carers do not identify with the term 'carer'. A lack of recognition in the caring role can contribute to psychological distress, physical health problems, social isolation and reduced wellbeing. Recognising and responding to these impacts of caring in service delivery and research settings is also important.

"We need to talk about caring and caring responsibilities so that people understand and identify as a carer."

- Carer

"People move between the carer role and requiring a service themselves."

- Practitioner

"There are blurred lines in caring. You engage in being the family member, the carer, the case manager, the financial guardian, the person who just wants to have a laugh with somebody all at the same time and in research we also have to understand those ambiguities and develop our research scales in relation to that."

- Researcher

5. Sexuality and gender diverse carers can experience additional service barriers

Recognition and identification can be complex for carers who are part of LGBTQI+ communities, and/or caring for someone in these communities. LGBTQI+ carers report difficulties accessing services and often experience higher levels of distress than other carers. These communities also experiencing health disparities and psychological vulnerabilities that can exacerbate the adverse health and wellbeing impacts associated with caring.

"Despite being told that we were married, nursing staff insisted on referring to me as my husband's 'friend.'"

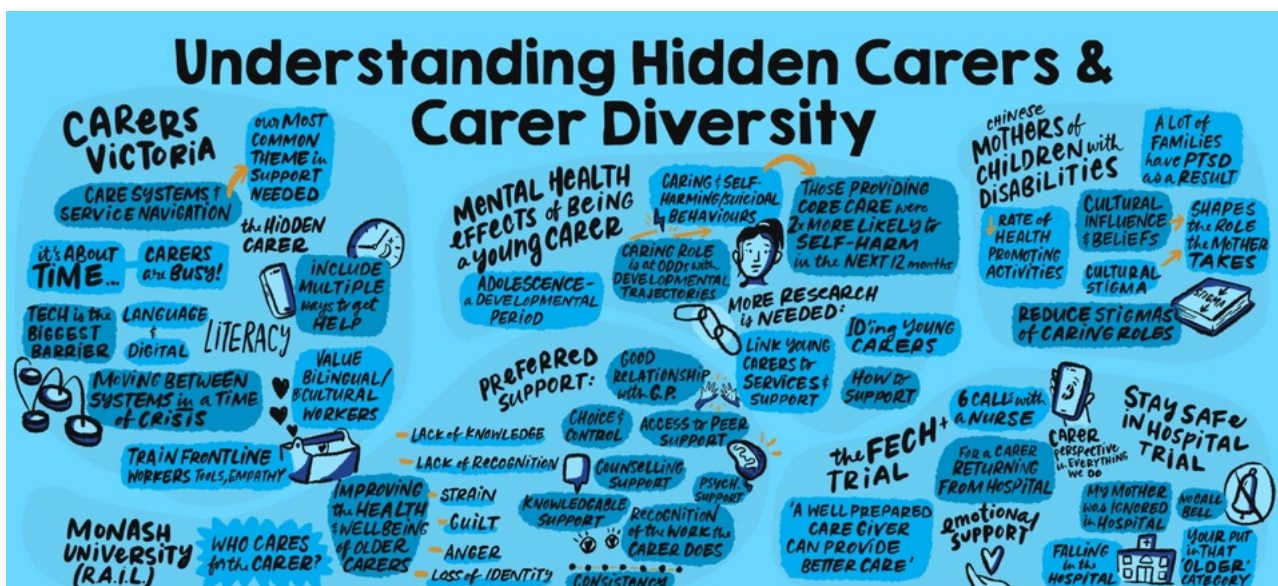
- Carer

"Presenting as cis-gendered made it easier to deal with medical professionals."

- Carer

"61 cancer care organisation websites were reviewed and...87% did not mention LGBTQI+ people."

- Researcher



6. Cultural differences can impact how carers access services

Cultural influences and belief systems can significantly impact the way carers use services. Culturally and linguistically diverse (CALD) carers can be reluctant to access help due to cultural stigma or shame associated with disability. Past experiences with services in one's country of origin can be a particular barrier, especially for carers from refugee backgrounds.

“Removing disability vs embracing disability. There is a struggle in their mind.”

- Researcher

“What I ever experienced in my country is nothing in comparison to what I experienced from the NDIS.”

- Carer



7. Navigating unfamiliar systems can be a challenge

Not all carers are aware of the services available to them, and many are not comfortable with digital access to information and services. These challenges can make navigating and accessing health and wellbeing services challenging.

"Carers are not getting the services they need because they have such difficulty either finding the service or navigating the service."

- Practitioner

"We need to identify how to best identify carers and how to link carers to services."

- Researcher

"Technology may be the answer... but technology is also the biggest barrier."

- Researcher

8. Services can make a difference

Many new services and programs are being developed to support carers' health and wellbeing. Some help with managing stress, others bring carers together providing emotional and mental support, and others provide flexible online learning. These initiatives are valued by those involved, but more needs to be done to ensure that the carers who need these services can access them.

"I think your programme carried me, and I really mean that from the bottom of my heart."

- Carer

"I feel more confident in that I know that there is help out there... I didn't know how to access it [before], so I do feel that it has made a huge difference in my life."

- Carer



9. Language options can improve service access

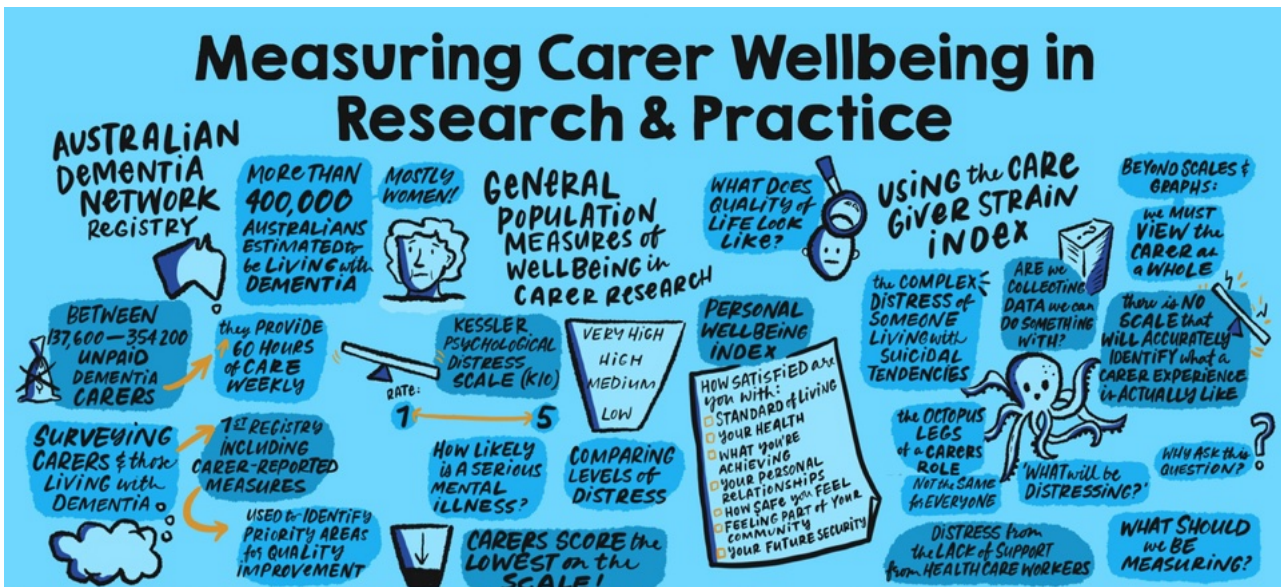
New services and programs are being introduced to carers with language options to prevent language barriers. When services and programs are available in different languages, carers feel a sense of trust and comfort in interacting with other carers

"I didn't know there were supports for carers."

- Carer

“...include bilingual/bicultural workers with system knowledge.”

- Researcher



10. Researchers have a duty of care to carers

Researchers need to carefully consider how they can best support the wellbeing of participants who provide insight into the lived experience of caring. Collecting data from carers can be onerous and even triggering. Participating in research should be a positive experience for carers.

“We need to ask ourselves as researchers what is the value in asking that question in the first place and are we collecting data that we can do something with.”

- Researcher

"It is important to show how this data has been used to inform practice."

- Researcher

11. Research should reflect the lived experience of caring

Wellbeing measures used with carers may not always accurately represent their experience. Hearing from carers can help make sense of the data, as can involving carers in research design and implementation.

"There is sometimes a little bit of disconnect between what the scales tell us and what the person in front of us says."

- Researcher

"I think we always need to recognise that there is no scale that will actually accurately identify what that experience is about."

- Researcher

"There is no greater way to get carer insight then to have them actually working with you."

- Practitioner

Opportunities

The findings from the CKE Research Incubator 2023 will inform the development and delivery of future CKE events and Communities of Practice. Additionally, the following opportunities were identified:

- A focus for future events on carer empowerment in health services, especially around end of life transitions and dealing with cognitive decline
- More regular recording and sharing of Spotlight Series virtual poster presentations to feature new and ongoing research, as well as recent research findings
- Producing a paper or guideline to apply and communicate the principles identified in the workshop on carer wellbeing measures

Get involved

To join future CKE events, watch event recordings on demand, receive email updates or participate in the CKE discussion forum, visit the '[Get involved](#)' page of the CKE digital platform at www.carerknowledgeexchange.com.au or follow the Carer Knowledge Exchange on [Facebook](#) or [LinkedIn](#).

