

Communique

Research Incubator 24 - 26 May 2022



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

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 carers and carer support services
- participate in the CKE Discussion Board

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 identify gaps in carer-related knowledge, research, and policy to inform future research and policy directions. The first Research Incubator was held across a series of online sessions in May 2022.

The overarching theme for the 2022 Research Incubator was 'Transitions' in relation to carers' financial wellbeing and economic opportunities, with each day having a distinct focus. A total of 15 researchers, policy makers, practitioners and carers shared their expertise and insights through presentations and panel discussions, and the CKE digital platform was officially launched on the third day.

This communique outlines the themes emerging from the event and includes supporting quotes from participants, along with digital canvases created to capture the outcomes of each session.



Emerging evidence

Researchers presented recent findings on transitions in the caring role and transitions to economic participation.



Lived experience

A number of carers shared their diverse lived experience perspectives on transitions in the caring role.



Policy and practice

Presenters and participants discussed key challenges and opportunities relating to carers' economic participation.

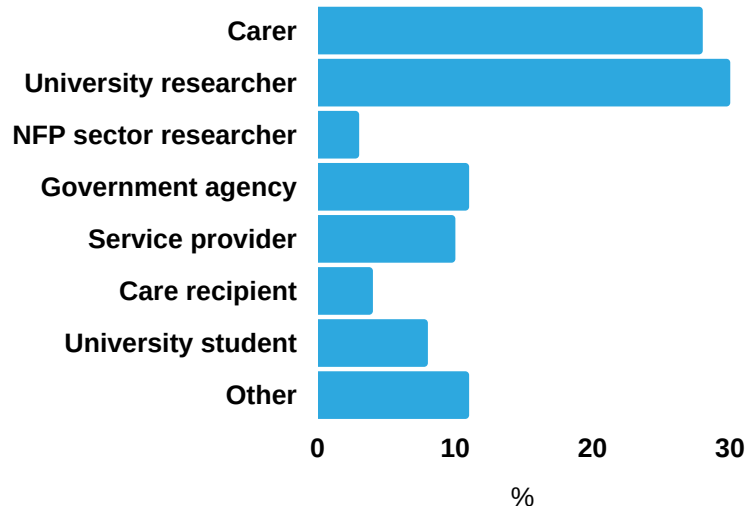


New connections

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

Participants

A total of 136 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.



Program

The Research Incubator included three modules featuring a range of speakers, followed by breakout room discussions and 'virtual cafes'.

Module One: Transitions in economic participation (84 registrations)

- A carer's perspective of working and caring roles
- Caring Costs Us - new data and implications for policy making
- A young carer's perspective on economic participation
- Understanding the mental health effects of being a young carer

Module Two: Transitions in the caring role (96 registrations)

- A culturally and linguistically diverse (CALD) perspective
- Social welfare needs, bereavement & transitioning out of a caring role
- Transitions in the caring role: A carer's insights from a regional community
- Practical, financial and emotional considerations when planning for end-of-life in lesbian, gay, bisexual, transgender and queer (LGBTBQ) communities
- In-depth carer experiences shared through survey responses

Module Three: Connecting research to practice (77 registrations)

- Official launch of the Carer Knowledge Exchange digital platform
- Existing knowledge exchange initiatives

Findings

Recordings of presentations and breakout room discussions were analysed to identify key themes. Thematic analysis categorised the findings and outcomes into eight key areas, which are outlined in the following pages.

1. Carer identity and identification

A local focus is essential in developing carer awareness. Local community groups, schools, teachers, counsellors, churches, sporting groups, libraries, and GP practices should be engaged in improving carer identification.

Carers and their caring situations are diverse. The diversity of carers, their relationships with the people they care for, and the reasons they care need to be acknowledged.

Some communities experience particular barriers to carer identification. Lived experience of discrimination and stigma can lead LGBTQ and CALD carers to remain 'hidden' and miss out on services and supports.

"...it can feel like we are put into a box and lose our identity."

- Carer

"Diverse voices need to be part of the process."

- Policy maker / practitioner

"Interesting questions are raised in terms of who identifies as a carer, and what is caring in different cultures?"

- Researcher

"To best serve our community, we needed to know from them what their needs were."

- Policy maker/practitioner

"My focus has been to make change in my community so I wasn't isolated."

- Carer

"The term 'former carer' or 'ex-carer' does not articulate or resonate with carers and does not reflect their experience."

- Researcher

2. Young carers have distinct experiences

Young carer specific recognition and supports are essential. Many young carers are not aware they are in a caring role and do not have the language or resources to access information and services. Young carers need their experiences and identities to be prioritised.

"Being a carer can be a beautiful thing, but it comes with considerable barriers to a person's career, study and being a typical young adult."

- Carer

"There is a need to support young informal carers to mitigate mental health impacts, particularly for those providing more frequent caring."

- Researcher



3. Mental health and wellbeing are important

The mental health of carers and the people they care for needs greater **recognition**. Mental health support needs are often present alongside other conditions, including disability and frailty from age, but are less likely to be addressed by service providers and are often considered “someone else’s problem”. Carers are also more likely than others to develop poor mental health.

“Very little opportunity sometimes to recharge and have that quiet time for myself and that physical and mental rest... I am always on.”
- Carer

“If you are carrying out daily caring, your mental health was poorer as a young informal carer.”
- Researcher

4. Financial impacts of caring

The financial impacts of caring are gendered. Women are more likely to be in a caring than men, resulting in reduced income and superannuation.

Caring can result in a 'double penalty' for families. The partner earning more may remain in paid work, preventing the other partner from meeting the eligibility threshold for income support. However, if both carers stop working, income, superannuation and career progression are lost.

"We all know that caring for a loved one...is economic participation."

- Policy maker / practitioner

"For a quarter of all Australian carers their main source of income was a government pension or allowance."

- Researcher

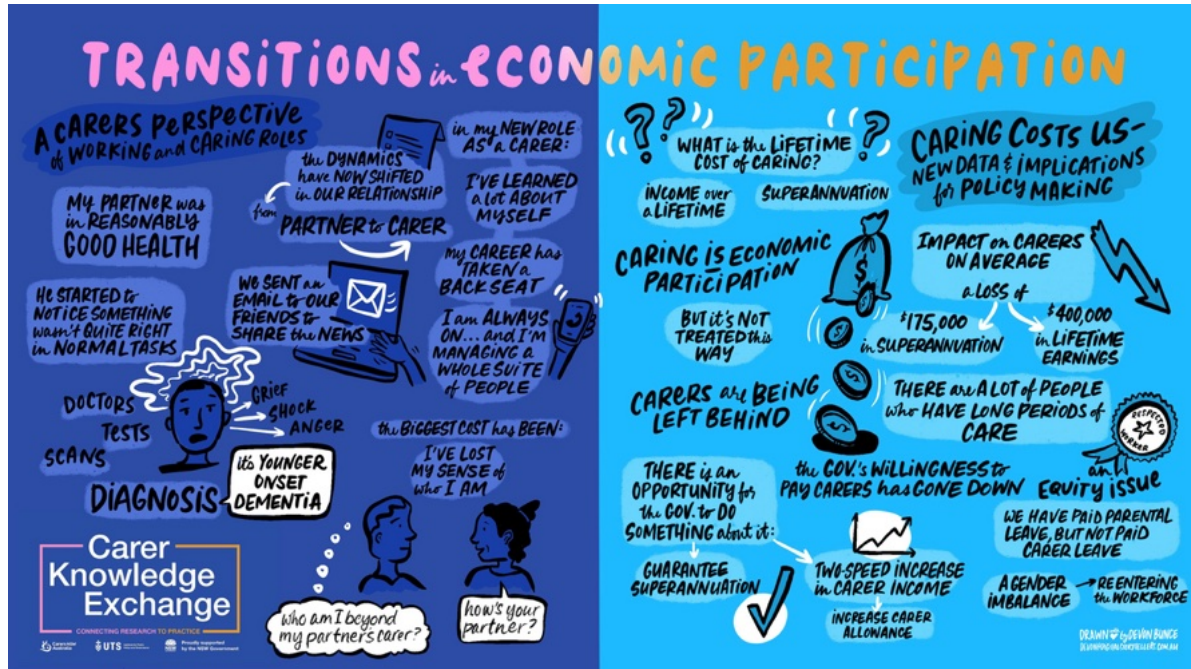
"I had to put my life on hold, being the oldest daughter. I transitioned from daughter to carer overnight."

- Carer

5. Managing services and service providers

Coordinating access to services can have significant impacts on carers.

Navigating service systems, following up with service providers and coordinating care staff take time and resources, especially given the high rates of staff turnover, the casual nature of the paid care workforce, and the lack of staff training.



Management of service providers does not end when the person receiving care moves into residential care. At home, circumstances can be more 'controlled', but limited communication and challenges with staffing can make coordination more difficult when the person lives in a residential care facility.

6. Transitions in the caring role

Caring can involve a range of different transitions over time. Common transitions include: developing knowledge and confidence, changes in life circumstances, moving between multiple caring roles, adjusting to changes in the nature of caring responsibilities or changing family dynamics, dealing with the emotional, practical and relational impacts of moving into residential care, and adjusting to the progression of a person's illness, condition or capacity to cope with their symptoms. Significant transitions also take place when a caring role ends.

"It was not a transition to being a young carer, but a leap."

- Carer

"The caring journey started for me the day we received the diagnosis."

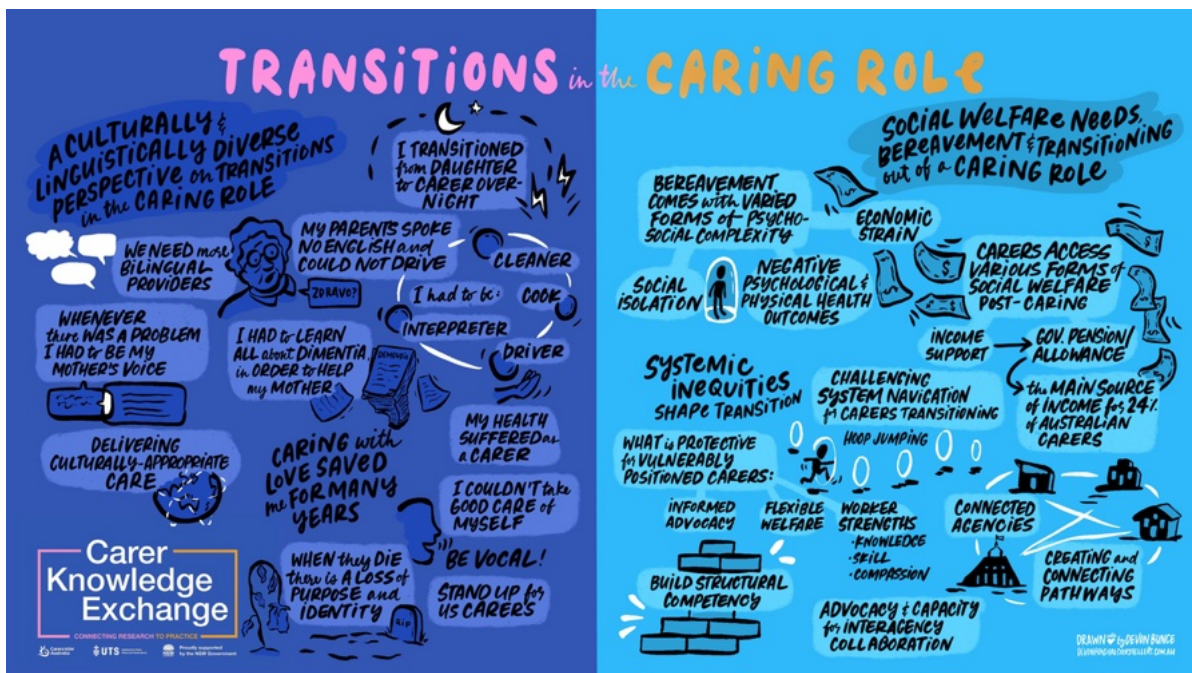
- Carer

"Carers were provided inconsistent and incorrect advice during transition period after bereavement; carers describe this period as 'Hoop-jumping'.."

- Researcher

"There is grief and loss, there is emptiness, and mostly, there is loss of the identity when your loved one dies."

- Carer



7. Policy design and implementation

High-level carer inclusion policies are not necessarily reflected in practice. Frontline workers are not always aware of their responsibilities to carers, how to support carers or what services are available. This is particularly the case with carers of people with complex support needs, who can be turned away from supports and services such as respite.

“As somebody who has been a young carer and continued to be a carer growing up into adulthood, I’ve seen there is often times where research does not link to practice and carers are the ones who miss out.”

- Carer

“My boys have been put in the “too hard basket”...there are no community participation programs available to my boys in this region, even though they have their own fully-funded support workers.”

- Carer

8. Knowledge exchange and knowledge translation

Co-production of research means hearing carers' needs and lived experience. There is value in giving carers the opportunity to participate in research and moving from consultation to co-production, including allowing carers to witness the 'end product', impact and outcomes of a project.

“Treat [people with lived experience] as co-researchers, actively listening, paying people for their time, and building rapport and tailoring your engagement to their needs.”

- Researcher



Knowledge translation involves bringing things back to the local level. A wide range of voices should be involved, not just those already engaged.

“Knowledge is not just academic research and there is much to be gained from...research conducted by the not-for-profit and policy space, so called ‘grey literature’.”

- Policy maker / practitioner

“Linking research data and analysis to carer voice is really important, especially when that hasn’t always been happening.”

- Carer

“People from diverse cultural backgrounds, people from disadvantaged backgrounds, people from caring backgrounds, from LGBTI, care leavers and other special needs groups – all those voices need to be at the table.”

- Carer

Knowledge translation and knowledge exchange are built on reciprocity. There are benefits for all parties from working together.

"Nothing about us without us' should be the way we do research and projects moving forward."

- Carer

"It has allowed us as a peak body to have a voice to government that is credible, and it means people can speak for themselves and alongside us."

- Policy maker / practitioner

"It has been enriching beyond what I could have imagined in terms of our research project, for us as researchers but also the people involved in our lived experience group."

- Researcher



Opportunities

The findings from the CKE Research Incubator 2022 will inform the development and delivery of future CKE webinars and Communities of Practice. In particular, a range of opportunities for each of the key CKE audience groups - researchers, policy makers, practitioners and carers - were identified.

Opportunities for researchers

Connecting and collaborating with carers, policy makers and other researchers to design and deliver better outcomes for carers, including on the identified topics of managing services and service providers, the financial impacts of caring and transitions in the caring role.

Following best practice to include lived experience in research design, including through grant applications, project co-design and consultation.

Recognition of the diversity of carer identities, the reasons why they care and the relationships with the person(s) they care for.

"We can now take our research to policy makers and government and promote with other academics."

- Researcher

"It is a great opportunity to translate the carer evidence base and...work alongside carers, policy, advocacy and service providers and those who are on the ground and have the lived experience."

- Researcher

Opportunities for policy makers and practitioners

Finding more effective ways to translate high-level policy into service delivery outcomes on the ground, including raising awareness among staff at different levels.

Developing different formats of engagement and collaboration, including in-person and online opportunities to maximise access.

Connecting with networks or other policy makers and practitioners and with researchers and carers to co-design, collaborate, and share knowledge.

Following best practice to include lived experience in policy development, from service design through to evaluation.

“This has been an amazing opportunity to hear from and engage with people who are users of the system...they have the advice to the government and system of what needs to change and what services should look like on the ground.”

- Policy maker / practitioner

“The advantage of [online engagement] was we could get more diverse voices involved, people from across the country, people from diverse backgrounds to participate and advise us on what we need to do.”

- Policy maker / practitioner

Opportunities for carers

Sharing their lived experience, including their diverse caring identities, the reasons why they care, and the relationships they have with the person(s) they care for, and with policy makers, practitioners and researchers.

Engaging with policy makers, practitioners and researchers to highlight gaps and barriers in research, policy and service design and delivery, and to identify topics and themes of importance from a carer's perspective.

Connecting with other carers, as well as policy makers, practitioners and researchers to co-design, collaborate and share knowledge.

"[This project is] an opportunity to have access to information in a language that is accessible, friendly, easy to use but more importantly, for different stakeholders."

- Researcher

"Having access to research that is publicly available, and in easy-to-understand research language, is a great way for carers to potentially be able to advocate for funding and services."

- Carer

Recorded sessions

Recordings of all sessions from the CKE Research Incubator 2022 are available to watch on demand on the 'Get involved' page of the CKE digital platform at www.carerknowledgeexchange.com.au.

Future events

To join future CKE events live, subscribe for email updates on the 'Get involved' page of the CKE digital platform at www.carerknowledgeexchange.com.au or follow the Carer Knowledge Exchange on Facebook or LinkedIn.