



# Fairer Start Initiative

## Co-designing Ageing Futures: A Critical Policy Brief

### Overview

The COVID-19 pandemic has unveiled huge questions about equality, access, how we socialise with each other, and who and what we value. COVID-19 has also laid bare severe structural issues in the formal aged care sector, including understaffing and ‘leaned out’ work organisation,<sup>1</sup> which has left aged care service users, their families and aged care workers particularly vulnerable.<sup>2</sup> During this time, the already stressed aged care sector has seen unprecedented failures—identified in the Royal Commission Aged Care & Quality COVID-19 special report (2020), which details how this under-resourced, overworked workforce is now traumatised.<sup>3</sup> We need to demonstrate our support for and the value of aged care workers; increase resources and make sustainable this workforce so they are supported through the current and future uncertainties facing the sector.

For older adults ageing in place (i.e. at home) challenges have emerged around ageing well during the pandemic—especially around lack of access to networks, increased isolation, depression, and anxiety.<sup>4</sup> As identified by the Commissioner for Senior Victorians, “Ageing Well in a Changing World” report, the priorities for wellbeing and ageing well include mobility, feeling safe, having the ability to make independent decisions, and having meaning and purpose. It also identifies barriers to ageing well such as isolation and loneliness, the significance of the digital divide, and lack of opportunities that meet their interests. We need to address systemic ageism in society by reframing older adults as designers of their own lives which contribute immense value to our society, and in turn society benefits. We need to change the conversations we are having publicly to ensure older adults’ lives are celebrated and respected, and this cuts across individual, interpersonal, community and societal approaches.<sup>5</sup>

Co-design is crucial moving forward. Older adults need to be central to all facets of life. Consultation and engagement with the care sector’s diverse stakeholders are key quality indicators for the elderly and aged care workers—specifically for culturally and linguistically diverse (CALD) communities. While there are many positive examples of effective engagement, there’s an opportunity to harness the potential of research and creative forms of engagement to address key challenges for the community and the sector that have emerged post COVID-19.

As part of RMIT’s Fairer Restart Initiative, the Co-Design Ageing Futures Working Group (CAF) works to address these urgent issues.

### Critical Issues

CAF group members respond to several critical issues: ageism, digital connection, workforce issues such as chronically low wages, poor working conditions, and the gendered undervaluation of aged care work.

Although expressed differently across diverse domains, there are dominant and institutionally reinforced narratives of ageism that cast older adults as burdens on the economy, having no or little potential and/or as the “disposable elder.” These narratives, which depict older people as having lesser value than others, have been heightened, exposed and amplified during the COVID-19 pandemic. For example, questioning the ‘value’ of COVID lockdowns to protect older people, given they may disrupt young people’s lives.<sup>6</sup> Further, the invisible care older people offer others has been overlooked and put at risk.

The COVID-19 pandemic highlights the vulnerability of unpaid community-based care provided by older people; care that is frequently hidden, overlooked and taken for granted, existing as it does outside the aged care system. Respondents were deeply concerned about care arrangements if they contracted the virus, or were at risk (i.e. had contact with a potential carrier) and could not carry out their caring role.<sup>7</sup>

This explicit surfacing of ageist tropes during COVID-19 also presents an opportunity to challenge and revise existing narratives about ageing. Many communities, such as First Peoples, see older people as knowledge holders and keepers of tradition, not as a burden to be locked away or silenced. These contra-narratives may be communicated by highlighting the diversity and contributions of older communities, including First Peoples, LGBTQI+ and those of migrant backgrounds.

CAF group members also address loneliness and isolation, finding innovative ways to connect to and with seniors and to assist them to stay connected to their family, or friends, or kinship groups. While digital technologies have kept people connected during the pandemic, they do not necessarily provide the sense of belonging that face-to-face contact brings.

Online technologies could be harnessed to provide social support networks and a sense of belonging, although there might be disparities in access to or literacy in digital resources. Interventions could simply involve more frequent telephone contact with significant others, close family and friends, voluntary organisations, or health-care professionals, or community outreach projects providing peer support throughout the enforced isolation.<sup>9</sup>

Challenges facing the aged care sector remain and are more urgent than ever in the wake of the COVID-19 crisis. Carers are under more stress with greater demands on their time and increased risk to their health and wellbeing. The pandemic has brought focus to aged carers as essential and valuable workers, but COVID-19 has also highlighted longstanding issues related to their pay and working conditions.<sup>9</sup>

## Creative Approaches to Research in Ageing and Aged Care

Socially engaged research requires new approaches to engaging this community and to addressing key challenges of the pandemic, including decent work and high-quality care, social and mental health, ageism, and the crises of value and meaning for care workers. The CAF Working Group addresses these challenges using innovative interventions that place lived experience at the centre of shared revisioning of existing narratives about ageing.<sup>10</sup> These interventions aim to restore inclusion and connection within a healthier society, to enable older adults to fully participate and create meaning in later life.

The CAF working group uses arts-based, co-designed workshops, collaborative and digital interventions, theatre, performance, intergenerational and peer mentoring and collaborative networks.

Creative methods and ethnography engage with personal experiences, sensory perceptions and cultural values, accessing other ways of knowing, thinking and doing. It is important that people have an active role in shaping how they receive care, what that care constitutes, and what services best address their needs. This type of engagement creates a sense of ownership, agency and belonging. Creative and co-design approaches can be especially effective in providing a sense of inclusion, empowerment, and visibility while at the same time challenging the common narratives of ageing and aged care.

## Mapping RMIT Capabilities

RMIT has the expertise to provide unique approaches to understanding the challenges faced by ageing populations. Through CAF's inclusive, ethnographic **co-design** approaches to research we focus on **cross-disciplinary, cross-national, collaborative**, creative approaches to technological innovation around ageing and the challenges facing aged care in the post COVID-19 world.

We have a strong team of researchers whose expertise is **co-design & creative methods** for engagement and implementation. This approach offers all stakeholders an opportunity to contribute to the formulation and solution of some of these critical issues in unique and thoughtful ways. The group emphasises equal collaboration between people who are affected by or who are trying to address particular issues related to aged care, counter ageist tropes, and the specific challenges faced by the CALD community. In other words, the people affected are central to the research process.

We have key ongoing projects with key partners such as Melbourne Ageing Research Collaboration (MARC), U3A, Bolton Clarke, NDIS, City of Whittlesea, Cherished Pets Foundation, ACCAN (Australian Communications Consumer Action Network), Decent Work Good Care, Healthtalk, Imagining Age Friendly Communities within Communities.



## CAF MEMBERS

### **CAF Co-director Professor Sara Charlesworth:**

together with international colleagues uses ethnographic approaches and regime mapping (i) in the *Decent Work Good Care* project, which includes shadowing workers across shifts, to surface the shared challenges experienced by aged care workers and the resident and clients to whom they provide care and support; and (ii) in the *Imagining Age Friendly Communities within Communities* project, which investigates through city ethnographies, cultural studies and arts-based methods how culture and gender matter in creating inclusive and equitable 'age-friendly' cities.

**Dr Christina David:** is a lecturer in social work in the Social Work and Human Services cluster and teaches in both the under and post graduate programs. Her research interests relate to disability, human rights-based approaches, community inclusion, and social support policy and practice including individualised funding approaches and the impacts of marketisation on those using and providing services. These include an 18-month action research project co-designing opportunities for social participation and inclusion in the NDIS context.

**Dr Ruth De Souza:** is a nurse, academic and community engaged researcher in gender, race, health and digital technologies. She engages health professionals in finding new ways to understand, co-design and implement sustainable cultural safety initiatives in a range of health contexts in response to health inequities. Most recently, De Souza has lead research and delivered programs that address the specific needs of CALD communities. For the CAF group, she launched *Alone Together* (AT) is a research project that aims to understand the experiences of older people from culturally and linguistic diverse community backgrounds during COVID-19. AT sought participants over 65 to take part in a study to better understand its impact on older people who live independently and whose networks might not be as accessible as before. AT researchers investigated how the lockdown affected their daily lives, how they coped, and what public services were helpful to them. The aim of these conversations will help provide better support to older people from these communities in the future.

**Associate Professor Bernardo Figueiredo:** researches Globalisation of Markets and Culture. His interests include consumer culture theory (CCT), value creation, customer experience, social isolation and connectedness, collaborative networks, consumers relationship with technology, mobility, cosmopolitanism, and emerging markets. He is especially interested in understanding how the globalisation of markets and cultures shapes consumption and marketing practices. Figueiredo is Chief Investigator of Shaping Connections ACCAN project—a program which seeks to understand better how technology use supports seniors' connectedness and enhances social inclusion and participation.

**Dr Leah Heiss:** While the importance of co-designing with care workers is widely recognised, such engagement needs to increase and be responsive to new challenges

such as the COVID-19 pandemic. Co-director of the Wearable + Sensory Network (WS+N) has created playful and engaging co-design workshops—Tactile Tools™ methodology—to assist the healthcare sector to develop innovative to wearable technologies used in diagnosis and helping those who are living with chronic disease. Co-design approaches workshops facilitate impact in key areas of engagement and enable the group to collect data from participants in an engaging and immersive way to then create visualisations to aid decision-making. Workshop activities coalesce and cohere participants and team members by building a diagram together in a fun and haptic way.

**Distinguished Professor Larissa Hjorth:** is a digital ethnographer who uses creative methods for engagement, codesign, knowledge exchange and research translation/ implementation. She has two decades leading collaborative, interdisciplinary and cross-cultural funded research projects in the Asia-Pacific region including four ARC projects. Her digital ethnographies into intergenerational use of digital media explores play, intimacy, sociality, loss and grief. She is on the MARC (Melbourne Ageing Research Collaboration) advisory board and is member on the Shaping Connections ACCAN grant into older adults' perceptions and practices of risk around technology.

**Professor Renata Kokanovic:** Convenor of the HASH (Health, Art, Science, Humanities) Network. She is a Vice-Chancellor's Senior Research Fellow and leads the Social Research in Health Program at RMIT University, which generates critical sociological understandings about experiences of health and illness. She is co-founder and director of Healthtalk Australia, a unique digital archive of health and illness narratives promoting lived experiences as evidence base for the improvement of health systems. Healthtalk Australia is part of an international collaboration led by Oxford University, involving universities across Australia, Asia, Europe and the U.S.

**CAF Co-director Dr Peta Murray:** is a Vice-Chancellor's Postdoctoral Research Fellow, a professional playwright, and was co-founder and the former Creative Director of The Groundswell Project.<sup>11</sup> Peta is working on a creative arts project called *How to Dress for Old Age* with Professor David Carlin from RMIT's non/fiction lab.<sup>12</sup> This project deploys personal essays, photographs and a proposed podcast series as works of cultural activism against ageism. It sets out to illustrate the transformative powers of everyday creativity by showing how collaboration, play, and joy can be health-promoting activities. This aligns with WHO's Global Strategy on Ageing (2016) which calls for public health "strategies that reinforce resilience and psychosocial growth...to challenge many of the stereotypes that currently define what it is to be "old." In a related-project (in development) Murray and Carlin plan to extend their research into the community and aged care sectors to develop, prototype, test and evaluate creative-based protocols and practices in on-the-ground settings.

## Key Messages

This briefing draws upon the expertise of RMIT's Co-designing Ageing Futures (CAF) Working Group which coalesces expertise in psychology, design, business, social policy, health sociology, regulatory studies, economics and art to work alongside innovations in health technology. Conventional forms of consultation do not adequately engage communities or the sector about what aspects of their lives and care are important to them, and generally have limited reach into culturally and linguistic groups (CALD).

This policy brief signals the ways in which the working group counter ageist tropes through creative and ethnographic methods of engagement that will inform best practice. The future of ageing gets recalibrated as celebration and resilience.

### IMPACT

The aged care sector seeks to actively engage researchers, including designers and creative practitioners, in reimagining how to address some of these critical issues. The sector and senior community benefit from creative methods and co-design approaches to achieve the outcomes they seek.

The first step with this engagement comes with the novel methods and ethos deployed in the research projects. With each project, impact is conceptualised as an iterative process, beginning with the research.<sup>13</sup> The group identifies pathways to impact, using translation in the form of creative methods, to progress that pathway toward an intended goal. They can then evidence the outcomes and impact according to the initial research question that arose as a result of the project. For example, the CAF group will develop a resource toolkit for the design and commissioning of creative approaches to address critical issues facing ageing populations and those who care for them.

### CO-DESIGNING AGEING FUTURES SEEK IMPACT IN THE FOLLOWING AREAS

- Increased community awareness and a more nuanced public understanding about the capacity and diversity of older people. The group's work with MARC and Shaping Connections demonstrates how ageing populations are fundamental to their communities and society as a whole. *Alone Together* brings this focus to CALD communities.
- Changes in public and policy narratives around value of older adults including the co-design using ToolsTM methodology leads to the curation of bespoke rituals for people entering later stages of life.
- Development of intergenerational and peer-to-peer mentorship models to support major transitions in later life including grief, loss, threshold-crossings into diagnoses/prognoses, threshold crossings into care (in-home, aged care sector) and other rites-of-passage. Creative works such as *How to Dress for Old Age* counter ageist tropes but also contribute to forming new rituals and models for ageing well.
- Codesigning with older adults bring stories resilience and joy into public discussion and celebration to counter ageism with Australian society.

<sup>1</sup> Sara Charlesworth. "COVID-19 and Long-term Care." Blog post on CPOW in the times of COVID-19, 29 May 2020. See <https://cpow.org.au/covid/>

<sup>2</sup> Sara Charlesworth and Fay-Lee-Dow "Updated country report: The Long-Term Care COVID-19 situation in Australia" 31 October 2020 See: <https://ltccovid.org/wp-content/uploads/2020/10/Australia-LTC-COVID19-situation-12-October-2020-1-2.pdf>.

<sup>3</sup> Royal Commission Aged Care & Quality. Aged Care and COVID-19: A Special Report. 2020. <https://agedcare.royalcommission.gov.au/publications/aged-care-and-covid-19-special-report>

<sup>4</sup> Nicolette R Holt, Johannes T Neumann, John J McNeil and Allen C Cheng. "Implications of COVID-19 in an ageing population," *Medical Journal Australia*. Published online: 6 May 2020. <https://www.mja.com.au/journal/2020/implications-covid-19-ageing-population>

<sup>5</sup> Victoria State Government: A Report by the Commissioner of Senior Victorians. 2020. <https://www.seniorsonline.vic.gov.au/-/media/seniors/files/commissioner-for-senior-victorians/report-ageing-well-in-a-changing-world-2020.pdf>

<sup>6</sup> Chip le Grand. "Melbourne Uni chief says Victoria must address difficult ethical questions" *Sydney Morning Herald*, 19 September 2020. See: <https://www.smh.com.au/national/melbourne-uni-chief-says-victoria-must-address-difficult-ethical-questions-20200919-p55x82.html>

<sup>7</sup> Seniors Speak about Hidden Impact of COVID-19 pandemic. A Short National Seniors Report. 27 March, 2020. <https://nationalseniors.com.au/uploads/National-Seniors-Short-Report-COVID-19-Hidden-issues.pdf>

<sup>8</sup> Richard Armitage and Laura B Nellums. "COVID-19 and the consequences of isolating the elderly." *The Lancet Public Health*. 19 March 2020.

<sup>9</sup> Sara Charlesworth. Sara Charlesworth. "COVID-19 and Long-term Care." Blog post on CPOW in the times of COVID-19, 29 May 2020. See <https://cpow.org.au/covid>. See also: <https://decentworkgoodcare.com/wp-content/uploads/2019/11/CharlesworthEditedWitnessStatement.pdf>

<sup>10</sup> See for example: A New Approach, 2020, 'Health and wellbeing: Transformative impacts of arts, culture and creativity' [Factsheet 4]. Produced by A New Approach think tank with lead delivery partner the Australian Academy of the Humanities, Canberra; Fancourt, Dand Finn, S. 2019. What is the Evidence on the Role of the Arts in Improving Health and Well-being? A scoping review." Copenhagen: WHO regional office for Europe, 2019, Health Evidence Network synthesis report 67.

<sup>11</sup> Murray, Peta. "An elegy for every little thing." *Progress in Palliative Care*, 2019-12-20. DOI: 10.1080/09699260.2019.1702336.

<sup>12</sup> Murray, Peta and David Carlin. 2020. *Invisible Mending (a disintegrated essay)*. <https://www.speculativenonfiction.org/contributions/2020/6/25/invisible-mending>

<sup>13</sup> Hjorth, Larissa, Kat Jungnickel, Anne Harris and Gretchen Coombs. 2019. *Creative Practice Ethnographies*. New York: Rowman & Littlefield.