"Translational research is key…"

National Roundtable on research in ageing and aged care for older people from culturally and linguistically diverse backgrounds

Outcome Document

Background

The Federation of Ethnic Communities' Councils of Australia (FECCA) and the National Ageing Research Institute (NARI) held a national Roundtable in Canberra in March 2016 to examine the gaps in research in ageing and aged care for older culturally and linguistically diverse (CALD) Australians, and to develop a research strategy to address the gaps. This was an innovative collaboration between industry and research, providing a unique opportunity to make a real difference for older CALD Australians and their families.

Participants in the Roundtable included leading academics in population and ageing issues, national consumer peaks, as well as key stakeholders in the multicultural sector with a keen interest in the health and ageing of older CALD Australians.[1]

The aim of the Roundtable was to inform the development of a research strategy and a plan of action to further advance the understanding of the needs of older CALD Australians, in a coordinated and collaborative way. The underlying philosophy of the Roundtable was that better policy and practice must be informed by robust evidence gained through research that can be translated into action.

This document provides the outcomes of the discussion that will inform the development of the research strategy and a plan of action.

Why a research strategy

To date, developments in research in relation to older CALD Australians have been fragmented and sporadic. To take stock of the existing research and assist with identifying thematic gaps in research, FECCA commissioned a review and in March 2015 released its seminal report: *A Review of Australian Research on People from Culturally and Linguistically Diverse Backgrounds*[2] ('the Research Review')*.* The Research Review identified a range of

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[1] List of organisations that participated in the Roundtable is provided in Appendix A.
[2] http://fecca.org.au/wp-content/uploads/2015/06/Review-of-Australian-Research-on-Older-People-from-Culturally-and-Linguistically-Diverse-Backgrounds-March-20151.pdf

completed research, as well as the thematic gaps in research, and noted CALD population groups and certain topic areas that require further research. The Research Review recommended to continue to grow the body of research about older people from CALD backgrounds and made, *inter alia,* the following suggestions to improve the status and value of Australian research in this area:

- improving comparability of research results, datasets and data sources;
- increasing participation by older people from CALD backgrounds in research; and
- mining existing data sources for more information about older people from CALD backgrounds.

The *Madrid International Plan of Action on Ageing 2002*[3] adopted by the United National Member States, including Australia, emphasises the need to encourage and advance comprehensive, diversified and specialised research on ageing. It is argued that research provides essential evidence for effective policies, and the availability of reliable information is indispensable in identifying emerging issues and adopting recommendations.

The Australian Government supports enhancement of diversified research, including for CALD population groups. In its *National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse (CALD) Backgrounds*[4], Goal 6 aims to 'Achieve better practice through improving research and data collection mechanisms that are inclusive of cultural and linguistic diversity in the ageing population.' The Principles outlined in the Strategy also include the principle that 'research and translation of research into better practice is encouraged to support development of appropriate policies and programs for older people from CALD backgrounds, their families and carers.'

Research is critically important to inform better and more responsive policy and practice, and requires adequate funding. Researchers should be encouraged to engage in more CALD-specific or CALD-related research projects, through opening up new funding options.

Developing a strategy, and a plan of action, will provide a forward looking framework for collaboration among key stakeholders in identifying issues, conceptualising and implementing research, translating findings into policy initiatives and providing a more equitable and inclusive approach.   The strategy for research into the future should focus on solutions. Research needs to feed into policy development, and policy solutions need to capture the diverse experiences of older CALD Australians.

A strategic framework with a whole-of-system approach will help to ensure that future research is not fragmented, and to reduce duplication of effort by researchers. With clear directions and priorities set, it will be easier to identify the best types of research for the priorities and use this to craft collaborations. A framework will allow for greater collaboration and sharing of information, including data.

Such a framework could encourage more older people from CALD backgrounds to participate in research, and would lead to a better experience for them in doing so, with a coordinated approach that helps to avoid 'consultation fatigue' where the same people are repeatedly asked to provide input. For policy makers, it will help to provide targeted research and cost savings due to better collaborative research projects, as well as to ensure that the diverse experiences of older CALD Australians are also part of general research.

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[3] http://www.un.org/en/events/pastevents/pdfs/Madrid_plan.pdf
[4] https://www.dss.gov.au/sites/default/files/documents/07_2015/dss1582_aged_care_strategy_cald_a4_vaccessible.pdf

The strategy may encourage greater collaboration among researchers—including between social researchers and economic researchers—to maximise diverse strengths in identifying potential solutions to achieving positive outcomes for older CALD Australians, along with any associated costs or savings. It may also encourage more generalist researchers to undertake research on CALD community-related issues.

The development of the research strategy and the plan of action will also support the implementation of FECCA's *2020 Vision for Older CALD Australians*[5] launched in November 2015.

Priority thematic areas: What should be researched

The research covered by FECCA's Research Review and other relevant work provide sufficient evidence about the needs of older CALD people, and the barriers they face. It is now timely for research to look forward and to seek solutions to the barriers, i.e. to identify what approaches would work and achieve better outcomes for older people from CALD backgrounds.

The thematic areas where the need for more research was identified by the Research Review included:

- religious, spiritual and faith considerations;
- CALD care workers as part of the aged care workforce;
- an intergenerational perspective on CALD care and support needs and expectations, and how this varies across generations;
- more in-depth understanding of treatment and approaches to care for older CALD Australians once a dementia or mental health diagnosis has been made; and
- an understanding of how the experiences of older CALD Australians differ from those of older Anglo-Australian groups across a range of demographic factors.

Areas where more solutions-focused research is identified as necessary can be broadly grouped around the following three streams:

Priority Area One – Active participation

It is important to acknowledge the contribution made by older CALD people. Older CALD Australians have contributed enormously to the Australian economy and they should be able to continue contributing, if they want to. Research into how to normalise and celebrate ageing can lead to a more holistic approach to thinking about productive ageing. It would also address broader policy questions, such as how to keep older people in the workforce for longer.

Priority Area Two – Better health and well-being

Low health literacy is a problem throughout Australia, not just for older CALD people. In older people generally, low health literacy is associated with a poorer health status and a higher risk of premature death[6].

Research into ways of reducing the stigma associated with dementia for some CALD communities could help prevent people from being unnecessarily placed in residential care,

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[5] http://fecca.org.au/wp-content/uploads/2015/11/FECCA2020Vision.pdf
[6] http://www.safetyandquality.gov.au/wp-content/uploads/2014/08/Health-Literacy-National-Statement.pdf

and enhance access to supports during the early stage of the condition through timely diagnosis.

Further research is required into treatment of older CALD Australians with mental health issues to reduce over-prescription of medicines and promote more effective treatments.

Research in ageing of CALD people should better engage general practitioners, nurses, and allied health workers in view of the important role of Primary Health Networks as purchasers of services.

<u>Priority Area Three – Appropriate and enabling services and supports</u>

Research needs to take into account the enormous amount of change driven by the Australian Government's aged care reforms, recognising the current transition period which presents both challenges and opportunities.

It should also aim to contribute to de-stigmatise acceptance of services from outside the family, particularly at the end of life.

Research is required to support the development of culturally appropriate screening tools to ensure accurate and early diagnoses of CALD people with dementia or other conditions, and early access to support, with a view to preventing the need for acute and residential care. Engagement with general practitioners, nurses, allied health workers and beyond—to include hospital care settings—is critical in this regard.

Research should contribute to identifying strategies to support culturally diverse and culturally competent workforce to provide appropriate care for older CALD people.

Principles to underpin the research agenda: How the research should be conducted

Research must be strengthened by applying a human rights-based approach. Research that aims to be translated into, and influence, policy and practice should be framed around a person-centred approach that promotes disaggregation of data collection and analysis. It should be undertaken in a manner that is non-discriminatory and which promotes equality, supports meaningful participation, and commits to adequate monitoring and accountability.

Research about ageing must be created with the person as the underlying foundation, from the beginning. Qualitative research with scientific rigour is highly valuable, as it is translational, appropriate for exploring issues impacting on CALD groups through consumer engagement, and recognises the need to explore and understand members of CALD communities as individuals, not just members of a particular ethnic or language group. And within this, data that is specific to the group being researched should be collected. While it is important to understand different cultures, people also need to be understood as individuals.

<u>Principle One - Equality and non-discrimination</u>

While there are some universal issues related to ageing that would impact on all older Australians, there are some more specific issues to CALD groups. There is a need to look at similarities of experience as well as differences.

Research must recognise the diversity within diversity. It is essential to recognise that the older CALD Australians are not a homogenous group; they encounter different outcomes based on individual experiences and backgrounds. This diversity means that understanding and meeting the needs of older CALD Australians is highly complex, and needs to be

informed by research and evidence. The *National Ageing and Aged Care Strategy for people from Culturally and Linguistically Diverse (CALD) backgrounds* reiterates that older CALD Australians are not a uniform group, but that there is significant diversity within Australia's CALD communities[7].

In this regard, the CALD population groups identified by the FECCA Research Review as requiring further research included:

- older people from new and emerging communities;
- small CALD population groups;
- older people from refugee backgrounds;
- people from CALD backgrounds who arrive in Australia at an older age; and
- older CALD Australians who live outside of the most populous states and metropolitan areas.

Older CALD people in rural and regional areas should also be included in research, factoring in their social and physical isolation.

Further, research should aim to capture older CALD individuals in generalist community and care settings.

Qualitative research of older CALD people's life experience—not just their 'CALD status'— will lead to understanding in a range of areas, including the impact on their wellbeing of racism and discrimination against particular groups. 'CALD status' is only one driver of complexity—other factors like gender, economic status, and life experience should be considered.

Research must understand people through their life experiences and the consequences of such experiences. There is a lot of diversity within CALD communities, and more needs to be known about how ethnicity, migration experience and settlement experience affect the ageing experiences of groups, and individuals, within CALD communities.

A meaningful person- and community-centric approach requires research to prioritise needs, aspirations and desired outcomes of the person and the community. It also requires the researcher to challenge any existing prejudice often resulting in no change to how research undertaken.

Principle Two - Participation

Older CALD people must be included in all research about older people, ageing and aged care.

The *United Nations Principles for Older Persons*[8] state that older persons should participate actively in the formulation and implementation of policies that directly affect their well-being. Being an equal partner in the research that informs the policies is an important avenue for such participation.

The older CALD population is a large proportion of the general older Australian population. The 2011 Census indicated 20.1% of Australians 65 and older were born in non-English speaking countries. On current projections, this number will rise by 2030 to 30% of the

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[7] https://www.dss.gov.au/sites/default/files/documents/07_2015/dss1582_aged_care_strategy_cald_a4_vaccessible.pdf
[8] http://www.un.org/documents/ga/res/46/a46r091.htm

population aged 65 years and above being from CALD backgrounds[9]. Yet older CALD Australians are often excluded from research. This can be for a number of factors, including the following:

- Costs associated with quality an culturally sensitive interpreting and translating services;
- Costs and efforts associated with engaging with ethnic communities;
- Language and health literacy issues among some cohorts of ethnic communities; and
- Researchers' cultural awareness and capacity to understand cultural and migration experiences.

With regards to participation, the *National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse (CALD) Backgrounds* includes an action area that requires the government agency responsible for aged care policy to ensure that the diversity of the Australian population is represented in all elements of health and medical research, and to work with ageing research bodies to help ensure CALD communities are represented in proportion to the size of their community.

Ensuring adequate and meaningful participation of older people from CALD backgrounds in research about older people, ageing and aged care will not only achieve better evidence, but will also contribute to empowering older people from CALD backgrounds to seek support when they need it.

Principle Three - Monitoring and accountability

As a minimum, participants and partners in the research must be informed of the outcomes—this is central to the principles of co-design/co-production of research. To achieve change in how research is undertaken and translated into policy and practice, it is necessary to implement monitoring and accountability mechanisms whereby researchers, older people from CALD backgrounds who participate in research, and other partners, such as the multicultural sector or policy makers, take stock of learnings, both positive and negative, from a research project. Having such mechanisms in place would also provide the opportunity to improve research collaboration models, and inform the work on identifying thematic gaps in research. Implementing monitoring and accountability would help to bring a more positive approach to research about ageing.

Areas for action: What needs to happen

Action Area One - Developing research partnership models

Older CALD people should be empowered as equal partners in the research. All research must be inclusive, from funding, to design, to carrying out the research and the reporting of the research. It is also important to let communities know the results of the research, which does not always happen. Following the person-centric approach, research should be, whenever possible and appropriate, co-produced with individuals/consumers (as well as carers, where appropriate) and communities. This requires investment by research in building a trusted relationship with community. Involving the individual and the community at the beginning of the development of research is essential to better understand their aspirations for the research they participate in. Working with CALD community groups and considering CALD issues should not be just an add on, but a foundational part of research.

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[9] http://fecca.org.au/wp-content/uploads/2015/11/FECCA2020Vision.pdf

Establishing partnerships with the multicultural sector is critical for community engagement and getting quality insights. Researchers often state that to work with CALD communities is difficult and expensive. While on some occasions there may be some higher costs, researchers should use the right pathways (such as through ethno-specific, multicultural and faith sector organisations) to work with CALD communities, however, not assuming that community organisations can be partners in research without a financial contribution. Where this may take extra time and resources, including extra cost, this should be built into funding applications. Funders should also recognise this and enable these additional costs to be built into research grant budgets. Partnering with the multicultural sector is also fundamental for influencing change in policy and practice.

Other partners in co-production include the aged care sector, as they are delivering care and may be implementing any outcomes from research. This includes both aged care sector management and service delivery workforce who would be an important source of information for researchers.

Policy makers must also be included as a partner in co-production from the beginning. This is essential to ensure useable outcomes for future policy making.

Community based participatory research has proven to be valuable when researching Aboriginal and Torres Strait Islander peoples, and could be an appropriate model to consider.

Action Area Two - Developing standards of scientific rigour

Scientific rigour of research must be ensured. One important aspect of scientific rigour is representativeness. If older people from CALD backgrounds are excluded from research, the findings are not representative of the whole older population. Cultural diversity should be an integral part of research. One way to ensure this would be to make the inclusion of CALD people in research a mandatory requirement before funding is granted, with the need for an explanation for any exemption sought.

An ethical framework for CALD research is needed. The National Health and Medical Research Council ethical guidelines for conducting research with Aboriginal and Torres Strait Islander communities[10] could inform such a framework.

Action Area Three - Establishing better data linkages

In addition to the Australian Census of Population and House, there is a lot of data collected through other sources, for instance, the National Aged Care Data Clearinghouse at the Australian Institute of Health and Welfare[11] or *My Aged Care* portal, and more can be done to enhance data linkage and analysis. Some of the complexity has to do with the terminology used to describe older people from CALD backgrounds and its change over time, and well as the variations in the definitions used across different studies and different data sources. This increases the challenge of making direct comparisons over time and across data sets. To help improve data linkage, it would be worthwhile to map data on older people from CALD backgrounds across large, comprehensive datasets, taking into account variations in terminology. This would improve the comparability and comprehensiveness of these valuable data sources. Such an analysis would allow greater scope for existing datasets to be used to fill the research gaps about older people from CALD backgrounds.

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[10] https://www.nhmrc.gov.au/guideline s-publications/e52 - currently under review.
[11] The National Aged Care Data Clearinghouse (NACDC) is a central, independent repository of national aged care data based at the AIHW. NACDC's data holdings cover programs delivered to older Australians both in the community and in a residential care setting.

Other data sources include the My Aged Care website and call centre, which collects information about visitors and callers, sometimes including CALD status, and for the purposes of a service finder function, holds data about aged care service providers.

Measuring outcomes

A set of indicators would be developed for actions under each priority area to assist with measuring progress both for individual actions, and the overall impact of the strategy.

National Roundtable on research in ageing and aged care for older people from culturally and linguistically diverse backgrounds

List of Participant Organisations

Federation of Ethnic Communities' Councils of Australia
National Ageing Research Institute
Adelaide University
Aged and Community Services Australia
Alzheimer's Australia
Australian Association of Gerontology
Australian Bureau of Statistics
Australian Catholic University
Australian Greek Welfare Society
Australian Institute of Health and Welfare
Australian Multicultural Council
Australian National University
Australian Nursing Homes Foundation
Canberra Multicultural Community Forum
Carers Australia
Centre of Excellence in Population Ageing Research
Centre for Cultural Diversity in Ageing
Centre for Research on Ageing, Health and Wellbeing
Charles Sturt University
Co.As.It. Italian Language & Community Services
Council on the Ageing
Deakin University
Ethnic Communities' Councils of Victoria
LaTrobe University
Leading Age Services Australia
Mental Health Australia
National Institute for Dementia Research, National Health and Medical Research Council
Palliative Care Australia
Queensland University of Technology
RMIT University
Royal District Nursing Service
Royal Melbourne Hospital
Sydney University