

**AAG**  
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Gerontology



**FECCA**  
Federation of Ethnic Communities' Councils of Australia

  
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# DEVELOPING AN ETHICAL FRAMEWORK FOR RESEARCH WITH AGEING CULTURALLY AND LINGUISTICALLY DIVERSE (CALD) COMMUNITIES

Hosted by the Australian Association of Gerontology in  
collaboration with the Federation of Ethnic Communities'  
Councils of Australia and the National Ageing Research Institute

REPORT ON A WORKSHOP HELD ON 1 NOVEMBER 2016  
NATIONAL CONVENTION CENTRE, CANBERRA



# ACKNOWLEDGEMENTS

## ACKNOWLEDGEMENT OF COUNTRY

Australian Association of Gerontology (AAG) acknowledges Traditional Owners of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respect to Aboriginal and Torres Strait Islander cultures; and to Elders both past and present. For further information see AAG's Aboriginal and Torres Strait Islander Ageing Advisory Group (ATSIAAG).



## SPONSOR

Funded by the Australian Government through the Dementia and Aged Care Services Fund



**Australian Government**  
**Department of Health**

## CONTRIBUTORS

### Partners

- ▶ Federation of Ethnic Communities' Councils of Australia (FECCA)
- ▶ National Ageing Research Institute (NARI)

### Presenters and facilitators

- ▶ Chaired by Mary Patetsos (then FECCA Healthy Ageing Chair)
- ▶ Facilitated by Associate Professor Briony Dow (Director NARI and Associate Professor of Ageing at the University of Melbourne)
- ▶ Welcome by Dr Helen Barrie (then President of AAG and Acting Director of the Australian Population and Migration Research Centre at the University of Adelaide)
- ▶ Group discussion chairs and scribes:
  - ▷ Jane Mussared
  - ▷ Betty Haralambous
  - ▷ Thomas Camporeale
  - ▷ Erin Gillen
  - ▷ Terrie Leoleos
  - ▷ Dini Liyanarachchi
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Photographs by Michael Blyde Photography



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## EXECUTIVE SUMMARY

This report summarises the proceedings and outcomes of the AAG workshop on Developing an Ethical Framework for Research with Ageing CALD Communities held on 1 November 2016 in Canberra, in partnership with FECCA and NARI.

The idea of the workshop originated from discussions held at a roundtable in March 2016. The workshop aimed to contribute to the development of an ethical framework through a facilitated engagement with key stakeholders. The purpose of the ethical framework was to ensure that CALD Australians were included and that culturally appropriate approaches are used when conducting research with older people from CALD backgrounds. It was proposed that one key component of the ethical framework would be a set of guidelines for researchers.

Twenty-eight people attended the workshop. Participants were stakeholders with knowledge about older people from CALD communities, including consumers, carers, researchers, service practitioners (in aged care, health and allied health), funders and policy makers.

Prior to the workshop, participants had been given draft guidelines for researchers and a case study to consider. The workshop began with an introduction and overview to set the context. Participants then broke up into five small groups for a 'table-top discussion.' Each group spent 15 minutes discussing each of the first five draft guidelines, facilitated by a chair and a scribe. All participants came together for a facilitated discussion of the sixth draft guideline and next steps.

Participants gave detailed constructive feedback to assist with further development of the guidelines. Their reflections are summarised later in this report.

Since the workshop, work commenced on revising the draft guidelines to reflect the comments from workshop participants. However, we recognised that a significant amount of time and resourcing would be required to properly complete this work. There have also been some significant developments over

the past year that have affected the future direction of this project, including:

- ▶ The NHMRC is reviewing the National Statement on Ethical Conduct in Human Research and the Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research upon which the original guidelines were based.
- ▶ In December 2017, the Aged Care Diversity Framework was launched. It provides an overarching structure, which will be supported by individual Action Plans for diverse groups, including Australians of CALD background.

For the above reasons, we decided to discontinue work on the draft guidelines. However, FECCA in collaboration with AAG and NARI has continued to work on developing higher-level components (including underlying principles and priority areas for action, most notably around inclusion and representation of CALD Australians in research into CALD ageing). FECCA is in the process of developing key partnerships to promote the better representation of CALD individuals and communities in Australian research on ageing. This work will be published in a report that examines the challenges faced by academics in ensuring adequate representation of CALD individuals and communities in Australian ageing research. It will also include recommendations to bring about change.

In response to this report, AAG, FECCA and NARI resolve to continue to work collaboratively with our partners and stakeholders to advocate for and support the right of older people from CALD backgrounds to be included in research where the outcomes of that research will be appropriately applied to them or other members of their community.

## ABOUT US

### Australian Association of Gerontology (AAG)



#### AAG's purpose is to improve the experience of ageing through connecting research, policy and practice

Since 1964, the Australian Association of Gerontology (AAG) has been Australia's peak national body linking researchers, educators, policy-makers, practitioners in aged care, health and allied health, consumer advocates and other experts engaged in ageing issues. With a growing membership of over 1200 members across every State and Territory in Australia, our members are passionate about making a difference. AAG has 18 Collaborating Research Centres that represent all major research in ageing in Australia. AAG is the executive office for the International Association of Gerontology and Geriatrics Asia Oceania Region and the International Longevity Centre – Australia.

#### CALD Ageing Special Interest Group

AAG has a well-established CALD Ageing Special Interest Group that shares information about research and policy initiatives and brings members together to discuss and plan emerging issues in this area.

### Federation of Ethnic Communities' Councils of Australia (FECCA)



FECCA is the peak national body representing Australians from culturally and linguistically diverse backgrounds. FECCA's role is to advocate and promote issues on behalf of its constituency to government, business and the broader community. FECCA strives to ensure that the needs and aspirations of Australians from diverse cultural and linguistic backgrounds are given proper recognition in public policy.

### National Ageing Research Institute (NARI)



NARI is Australia's independent research institute dedicated to ageing. For the past four decades, NARI has been bringing research to life to improve health outcomes and aged care practice as well as guide policy to invest in solutions for positive ageing for Australia's older population. NARI was founded in 1975 and has a focus on a range of key research areas including: dementia, mental health, falls and balance, pain, carers' health, healthy ageing, physical activity, cultural diversity and service system evaluation.

## BACKGROUND

### Context

Australia has a culturally diverse ageing population. In 2016, 37% of people aged 65 years and over were born overseas, compared to 28% in the general population (Australian Bureau of Statistics, 2017). When language spoken at home is considered, 18% of older Australians speak a language other than English at home, with Italian, Greek, and Chinese being the top non-English languages (Australian Bureau of Statistics, 2017). These older Australians come from a range of countries, faiths and cultures and represent both newly arrived immigrants and immigrants who have lived most of their adult lives in Australia.

These older Australians are often excluded or underrepresented in mainstream research in ageing. This is often due to language barriers, research not being funded for translations and interpreters, and acknowledging that more time is required to translate information and/or to use interpreters. Compounding the challenge of underrepresentation in mainstream research is the lack CALD-specific ageing research being undertaken and published in Australia.

### Review of research

In 2015, FECCA commissioned a Review of Australian Research on Older People from CALD Backgrounds by the Australian Population and Migration Research Centre at the University of Adelaide (led by Helen Barrie, then AAG President).

### Canberra roundtable

In March 2016, FECCA and NARI held a national Roundtable in Canberra to examine the gaps in research in ageing and aged care for older 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 peak bodies as well as key stakeholders in the multicultural sector with a keen interest in the health and ageing of older CALD Australians. 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.

FECCA and NARI published a joint Outcomes Document from the Roundtable, which included the following statement about 'what needs to happen:'

#### 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 could inform such a framework

### Developing an ethical framework for ageing research with CALD communities

Following the Canberra Roundtable, FECCA and NARI collaborated with AAG on developing a draft Ethical Framework for Ageing Research with CALD Communities ('the draft ethical framework'). The draft ethical framework was predicated on the following principle:

**Older people from CALD backgrounds have a right to be included in research where the outcomes of that research will be applied to them or other members of their community**

The intended purpose of the draft ethical framework was (once developed and endorsed/adopted by the relevant stakeholders) to ensure that researchers fully include CALD Australians in ageing research and are equipped to use culturally appropriate measures when conducting research with older people from CALD backgrounds.

It was proposed that one key component of the ethical framework would be a set of six guidelines for researchers ('the draft guidelines'):

- ▶ Reciprocity
- ▶ Respect
- ▶ Equality
- ▶ Responsibility
- ▶ Cultural Awareness
- ▶ Integrity.

The possibility of including other components in the ethical framework was left open for future consideration.

The draft guidelines were informed by the following NHMRC research guidelines and related documents:

- ▶ Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research (2003)
- ▶ Keeping research on track: a guide for Aboriginal and Torres Strait Islander peoples about health research ethics (2006)
- ▶ Evaluation of the Aboriginal and Torres Strait Islander Guidelines (2013)
- ▶ National Statement on Ethical Conduct in Human Research (2007 updated 2015)

The draft guidelines reflected the structure and content of the NHMRC Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research. It was acknowledged that the National Statement on Ethical Conduct in Human Research is a foundational, binding framework for the Australian research community and that researchers are fully conversant with its principles and guidelines.

The draft guidelines were intended to add an additional and strengthened focus on the importance of trust, recognition and cultural values when researchers engage with CALD communities. They were not intended to be binding rules requiring strict compliance, but rather guidelines to support researchers to respect the rights of older people from CALD backgrounds, and to enhance the inclusiveness, efficacy and value of ageing research.



## REPORT ON THE WORKSHOP

### Workshop proceedings

The workshop aimed to contribute to the development of the Ethical Framework for Ageing Research with CALD Communities, through a facilitated engagement with key stakeholders.

The workshop was held on Tuesday 1 November 2016 from 10 am to 1 pm at the National Convention Centre, Canberra. The workshop preceded the 49th AAG Conference which commenced the following day. This was a free event by invitation only. Further information about the workshop proceedings is provided at Appendix A.

The workshop was a collaborative effort by AAG in partnership with FECCA and NARI. The workshop was sponsored by the Commonwealth Department of Health.

Twenty-eight people attended the workshop. The participants were stakeholders with knowledge about older people from CALD communities, including consumers, carers, researchers, service practitioners (in aged care, health and allied health) and policy makers. Targeted representatives of older people from CALD Communities were offered financial support to attend. A list of participants is provided at Appendix B.

The workshop was intended to give participants an opportunity to provide feedback on the draft guidelines for researchers and to contribute to further development of the ethical framework. Participants were provided with a discussion draft of the guidelines for researchers and a case study in advance of the workshop. A copy is attached at Appendix C.

Mary Patetsos (FECCA Healthy Ageing Chair) began the workshop by giving a brief introduction and some context. Associate Professor Briony Dow (Director of NARI) followed by giving an overview of the draft ethical framework to set the scene for the workshop.

The participants introduced themselves and then broke up into five groups for a 'table-top discussion' of the draft guidelines for researchers. Each group discussed one of the draft guidelines, facilitated by a chair and a scribe. After 15 minutes, each group moved to the next table to discuss another draft guideline. After each group had discussed five draft guidelines, all the participants came together to discuss the sixth draft guideline and next steps (facilitated by Briony Dow). The reflections from participants are summarised in the next section of this report. The workshop closed with a brief summing up by Mary Patetsos.



### Reflections from workshop participants

#### General comments

General comments focused on providing a glossary, more case studies, more emphasis on 'ageing,' a checklist for researchers and considering how to implement the framework.

- ▶ Include a glossary that defines key terms
- ▶ Include more case studies to illustrate the guidelines
- ▶ Incorporate relevant changes (after review is completed) to the NHMRC Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research and the National Statement on Ethical Conduct in Human Research
- ▶ Consider how to balance the responsibility to individual research participants against the responsibility to the relevant CALD group collectively.
- ▶ Consider whether the framework should only cover CALD-specific research or whether it should apply when CALD participants are incidentally included in research projects.
- ▶ Focus more on the issues around responsibility to participants who are "ageing" (i.e. not just on them being from CALD backgrounds)
- ▶ Consider including a practical checklist for researchers to assist them with their ethics applications. This could include some of the question currently included under 'issues to consider.'
- ▶ Consider how to ensure that the framework can be broadly implemented, including through funding bodies, perhaps initially as a voluntary guide and then as a funding requirement when working with CALD communities.

#### Draft guideline 1 - Reciprocity

Comments about this guideline focused on explaining the terminology, spelling out researchers' obligations to the CALD community, and whether this guideline could be incorporated into others.

- ▶ Need to explain the concept of 'inclusion' better and break it down into what it means for each stage of the research process
- ▶ Should be more explicit about requiring 'co-design'
- ▶ Research should focus on problems and priorities defined by the CALD community
- ▶ Need to flesh out the concept of 'benefit'
- ▶ Sometimes the benefit is indirect or aspirational, and even a 'negative' outcome can be of benefit if it helps explain or create change
- ▶ There is an ethical obligation to report back directly to the CALD community, but universities and funding bodies may not facilitate this
- ▶ The community should be included in governance arrangements
- ▶ Not sure if this stand-alone guideline is needed, as key elements could be incorporated into other guidelines.

## Draft guideline 2 - Respect

Comments about this guideline focused on finding appropriate terminology, the relevance of researchers' own cultural backgrounds, and whether there should be limits on what is respected.

- ▶ Some participants felt that 'respect' is a problematic/contestable term. Suggestions included replacing it with another term (e.g. 'value' or 'recognise') and/or providing a better explanation to 'unpack' the concept.
- ▶ Suggested removing the term 'difference blindness' as this is now outdated
- ▶ Researchers need to understand their own cultural backgrounds and be aware of the biases they may be bringing to the research
- ▶ Consider whether the research team should be representative of the group being researched (as required in the UK)
- ▶ Researchers may need to adjust how research is conducted to respond to specific concerns of the CALD community (e.g. an older Muslim community asked if their answers would be reported to ASIO)
- ▶ Discussion about whether there should be limits to respect (e.g. acknowledging the right of for people to have different values 'within legal limits').

## Draft guideline 3 - Equality

Comments about this guideline focused on renaming the guideline, unpacking the concept of equality and the type of practical supports that are required to enable equality.

- ▶ Suggested renaming the guideline (possible options included 'fairness,' 'inclusiveness,' 'equity' and 'access and equity')
- ▶ The concept of 'voluntary character of participants' decisions' need to be explained and/or a definition of consent should be included in this guideline
- ▶ Many participants disagreed with the reported community feedback that 'research ideas are too often investigator-driven'
- ▶ Need to further 'unpack' what the concept of equality means
- ▶ Should give more prominence to equality in the recruitment process
- ▶ The cost of interpreting /translation must be built into the research plan and funding arrangements
- ▶ Discussion about adjustments for people with mobility or cognitive impairments (e.g. provision of transport and use of communication mechanisms).

## Draft guideline 4 - Responsibility

Comments about this guideline focused on considering the issues around informed consent, cultural safety, co-design, risk assessment, intersectionality and the role of gatekeepers.

- ▶ Define 'responsibility' better
- ▶ Consider issues around 'informed consent' and who gets to 'speak for' the CALD group
- ▶ Consider issues around providing 'cultural safety'
- ▶ Consider issues around 'co-design'
- ▶ Reframe the guideline more positively (i.e. what researchers 'should do' rather than what they shouldn't do)
- ▶ Acknowledge that there is diversity within and between CALD community groups
- ▶ Consider how to assess risk for a particular individual and CALD group.
- ▶ Consider issues around 'intersectionality' (e.g. gender, socio-economic disadvantage and cognitive impairment)
- ▶ Consider the role of 'gatekeepers' who can facilitate/prevent others within the CALD group from participating.

## Draft guideline 5 – Cultural awareness

Comments about this guideline focused on the provision of definitions, recognising difference within groups and researchers acknowledging their own biases and values.

- ▶ Define:
  - ▷ cultural awareness (e.g. does it include 'spiritual' identity)
  - ▷ values based solidarity
  - ▷ cultural diversity /distinctiveness
- ▶ Focus on what 'actions' are required not just 'awareness'
- ▶ Consider using a different title (e.g. 'cultural engagement or cultural safety')
- ▶ Recognise that
  - ▷ not all people from CALD backgrounds maintain their cultural, linguistic and religious identity
  - ▷ people from different age groups might have different ideas about what those identities are
- ▶ Explain why it is important to be able to maintain culture (e.g. some people revert to first language in older age)
- ▶ There were opposing opinions on whether it is appropriate to recruit participants by approaching people individually
- ▶ Researchers need to be aware of their own cultural values and biases. They need to 'respect' but not necessarily have 'solidarity' with participants' values.

## Draft guideline 6 – Integrity

Comments about this guideline focused on how it relates to the other five guidelines.

- ▶ The relationship between this and the other guidelines needs to be better explained
- ▶ Should make it more apparent that ‘integrity’ an overarching principle that applies to all the other guidelines.
- ▶ If the other guidelines are followed, then integrity will have been demonstrated
- ▶ Agreed that the inclusion of the concept of ‘motivation’ is good.

## SUBSEQUENT DEVELOPMENTS

There have been some significant developments since the workshop was held (in November 2016), which have affected the future direction of this project. These include:

### Review of NHMRC research guidelines

The National Statement on Ethical Conduct in Human Research is subject to rolling review. There was public consultation on new and revised chapters, which closed in December 2016 and (as at the time of writing this report) the submissions received are still being considered by an expert working committee.

The NHMRC is also reviewing the Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research. In mid-2017 it produced a significantly revised version of these guidelines, which were broadened to cover research across all disciplines (whereas the previous guidelines were focused on health research). The public consultation on the draft guidelines closed on 7 July 2017 and (as at the time of writing this report) the submissions received are still being considered by an expert working committee.

### Review of the CALD Ageing and Aged Care Strategy

On 23 November 2017, the Department of Health released the Review of the CALD Ageing and Aged Care Strategy Final Report. This report reviews the actions undertaken to implement the goals of the National Ageing and Aged Care Strategy for People from CALD Backgrounds (2012), and considers stakeholders’ perspectives on the success of the CALD Strategy as well as opportunities for improvement.

Goal 6 of the strategy was to

**‘achieve better practice through improving research and data collection mechanisms that are inclusive of cultural and linguistic diversity in the ageing population.’**

The final report stated that although stakeholders acknowledged the range of activities that had occurred to implement this goal (including the review of research and Canberra roundtable referred to in the background section of this report), they considered that

**‘These initiatives need to be further developed and expanded to build an evidence base from which effective equity planning for older people from CALD backgrounds can be progressed.’**

Specific resourcing suggestions by stakeholders included **‘greater support of research.’**

### Development of the Aged Care Diversity Framework and Action Plans

In February 2017, the Government established the Aged Care Sector Committee Diversity Sub-Group, which included representatives from AAG and FECCA. Following a national consultation process, the sub-group developed the Aged Care Diversity Framework, which was launched by Minister Ken Wyatt on 6 December 2017.

The Aged Care Diversity Framework seeks to embed diversity in the design and delivery of aged care; and support action to address perceived or actual barriers to consumers accessing safe, equitable and quality aged care, while enabling consumers and carers to be partners in this process.

The Aged Care Diversity Framework provides an overarching structure, which will be supported by individual Action Plans focusing on solutions to address specific barriers and challenges affecting particular diverse groups’ ability to access mainstream and flexible aged care services.

The sub-group will develop three Action Plans in the first half of 2018, for:

- ▶ **people from CALD backgrounds**
- ▶ Aboriginal and Torres Strait Islander people
- ▶ people who identify as LGBTI.

Another plan will be developed in the second half of 2018 for older people who are homeless or at risk of homelessness. Further action plans may be considered as the need arises over time.

To inform the proposed CALD Action Plan, FECCA has been consulting with a range of stakeholders through face-to-face consultations and via online surveys in nine languages. As at the time of writing this report, the consultation was still ongoing.

## FUTURE DIRECTIONS

At the time of the workshop (November 2016), AAG and its collaborative partners intended to:

- ▶ revise the draft guidelines for researchers
- ▶ further develop the ethical framework.

Since then, we commenced revising the draft guidelines to reflect the comments from workshop participants and the proposed changes to relevant NHMRC research guidelines.

However, we recognised that a significant amount of time and resourcing would be required to properly complete this work, including:

- ▶ conducting wide-ranging consultation
- ▶ analysing the evidence base
- ▶ obtaining input from ethics experts
- ▶ comprehensive testing of the impact and efficacy of the draft guidelines.

For the above reasons, we decided to discontinue work on the draft guidelines. However, FECCA in collaboration with AAG and NARI has continued to work on developing higher-level components including underlying principles and priority areas for action, most notably around inclusion and representation of CALD Australians in research into CALD ageing. As discussed earlier, FECCA will prepare a report on this work in due course.

## AAG, NARI AND FECCA RESPONSE TO THIS REPORT

### We believe that:

older people from CALD backgrounds have the right to be included in research where the outcomes of that research will be applied to them or other members of their community.

### We resolve to:

continue to work collaboratively with our partners and stakeholders to advocate for and support this this objective.

### We thank:

the Department of Health and the stakeholders who participated in the workshop for their valuable contribution to this project.



## APPENDIX A - WORKSHOP FLYER

Presented by

### EXCLUSIVE INVITATION

#### DEVELOPING AN ETHICAL FRAMEWORK FOR RESEARCH WITH AGEING CALD COMMUNITIES

**HOSTED BY**  
AAG's Culturally and Linguistically Diverse (CALD) Special Interest Group in partnership with the Federation of Ethnic Communities' Councils of Australia (FECCA) and COTA Australia (Council on the Ageing).

**CHAired BY**  
Mary Patetsos  
FECCA Healthy Ageing Chair

**FACILITATED BY**  
Associate Professor Briony Dow  
Director of the National Ageing Research Institute (NARI) and Associate Professor of Ageing at the University of Melbourne.

In 2015, FECCA commissioned a Review of Australian Research on Older People from Culturally and Linguistically Diverse (CALD) Backgrounds by the Australian Population and Migration Research Centre at the University of Adelaide.

Building on this review, FECCA and NARI held a national round-table in Canberra in March 2016 to examine the gaps in the research and develop a strategy to address them. The round-table outcomes document included developing standards of scientific rigour as a priority area for action and concluded that an ethical framework for research with CALD communities is needed.

This workshop will contribute to the development of the framework, through a facilitated engagement with participants, who will be given opportunity to provide feedback to all elements of the framework and contribute to the further development of the framework. A draft of the framework will be provided in advance of the workshop for consideration.

The partners invite input from key stakeholders with expertise in older people from CALD communities including consumers and carers, researchers, service practitioners (in aged care, health and allied health) and policy workers to ensure that the draft framework is considered from consumer, multidisciplinary, evidence and practice-based perspectives, as well as the policy environment.

**THIS IS A FREE EVENT**

Tuesday 1st November, 2016 10:00am to 1:00pm

National Convention Centre  
31 Constitution Avenue Canberra ACT 2601

To reserve your place please [click here](#) or call 03 8506 0525 by Friday 28 October 2016 indicating any dietary requirements

## APPENDIX B - LIST OF PARTICIPANTS

First Name	Last Name	Position	Company Name
Mahjabeen	Ahmad	Independent Researcher and Advocate	
Helen	Barrie	Deputy Director	University of Adelaide
James	Beckford Saunders	CEO	AAG
Irene	Blackberry	Associate Professor and Director	La Trobe University - John Richards Initiative
Thomas	Camporeale	General Manager	Co.As.It.
Briony	Dow	Director	National Ageing Research Institute
Erin	Gillen	Acting Director	FECCA
Helen	Grinbergs	Assistant Secretary, Ageing and Sector Support Branch	Department of Health
Betty	Haralambous	Research Fellow	National Ageing Research Institute
Michelle	Jones	Principal Health Analyst	Health Performance Council Secretariat
Sarang	Kim	Research fellow	Australian National University
Terrie	Leoleos	NSW Multicultural Ageing and Disability Access Officer	Ethnic Communities Council of NSW (ECCNSW)
Dini	Liyanarachchi	Policy and Project Officer	FECCA
Susan	McGrath	National Policy Manager	COTA Australia
Jane	Mussared	Chief Executive	COTA SA
Mary	Patetsos	Healthy Ageing Chair (Board Director)	FECCA
Melinda	Petrie	Unit Head (A/g), Disability & Ageing Unit	Australian Institute of Health & Welfare
Ljubica	Petrov	manager	Centre for Cultural Diversity in Ageing
Frank	Quinlan	CEO	Mental Health Australia
Helen	Rawson	Research Fellow	Deakin Univeristy
Kay	Richards	National Policy Manager	Leading Age Services Australia
Nikolaus	Rittinghausen	Aged care policy officer	Ethnic Communities Councils of Victoria
Tonye	Segbedzi	Senior Policy Officer	Australian Association of Gerontology
Marian	Simms	Executive Director, Social Behavioural and Economic Sciences	Australian Research Council
Yvonne	Wells	Head, Lincoln Centre for Research on Ageing	La Trobe University
Veronica	Wensing	Member	National LGBTI Health Alliance
Rachel	Winterton	Research Fellow	La Trobe University
Ian	Yates	CEO	COTA Australia

## APPENDIX C - WORKSHOP DISCUSSION DOCUMENTS

### DRAFT ETHICAL FRAMEWORK FOR AGEING RESEARCH WITH CALD COMMUNITIES

#### Context

Australia has a culturally diverse ageing population. In 2011, of people aged 65 years and over, 36% were born overseas, compared to 26% in the general population (Australian Bureau of Statistics, 2012).<sup>1</sup> When language spoken at home is considered, 17% of older Australians speak a language other than English at home, with Italian, Greek, and Chinese being the top non-English languages (Australian Bureau of Statistics, 2012). These older Australians come from a range of countries, faiths and cultures and represent both newly arrived immigrants and immigrants who have lived the majority of their adult lives in Australia.

These older Australians are often excluded or underrepresented in mainstream research in ageing. This is often due to language barriers, research not being funded for translations and interpreters, and acknowledging that more time is required to translate information and/or to use interpreters.

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. 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. An [outcomes document](#) was produced with thematic priority areas, which identifies representativeness as an integral aspect of scientific rigour in research.

Following this Roundtable, FECCA and NARI collaborated with Australian Association of Gerontology (AAG) and Council on the Ageing (COTA) to develop an 'Ethical Framework for Ageing Research with CALD communities'. This framework is predicated on the following principle:

**Older people from CALD backgrounds have a right to be included in research where the outcomes of that research will be applied to them or other members of their community**

<sup>1</sup> Australian Bureau of Statistics. (2012). *Reflecting a Nation: Stories from the 2011 Census, 2012-2013*. Canberra: Australian Bureau of Statistics.

## DRAFT ETHICAL FRAMEWORK FOR AGEING RESEARCH WITH CALD COMMUNITIES

### The Framework

The proposal is that the draft Ethical Framework for Ageing Research with CALD Communities contain six guidelines:

- Reciprocity;
- Respect;
- Equality;
- Responsibility;
- Cultural Awareness; and
- Integrity

The draft guidelines are based on the following frameworks:

- [NHMRC Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research](#) (2004)
- [National Statement on Ethical Conduct in Human Research](#) (2007 updated 2015)
- [Evaluation of the Aboriginal and Torres Strait Islander Guidelines](#) (2013)

The NHMRC Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research identify six guidelines. These Guidelines are currently under review. Pending completion of the complete review, an evaluation report titled 'Evaluation of the Aboriginal and Torres Strait Islander Guidelines' was produced in 2013.

In addition to these two main documents, the draft guidelines draw principles and guidelines from National Statement on Ethical Conduct in Human Research.

This initial draft closely follows the structure and content of the aforementioned frameworks, especially the NHMRC Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research and there are some duplications of content which has been incorporated into the draft to provide clarity.

### Purpose

It is acknowledged that the National Statement on Ethical Conduct in Human Research is a foundation, binding framework for the Australian research community and that researchers are fully conversant with the principles and guidelines therein. The draft guidelines add an additional and strengthened focus on the importance of trust, recognition and cultural values when researchers engage with CALD communities. They are not designed to be binding, quasi-legal instruments requiring strict compliance, but rather to support researchers to respect the rights of older people from CALD backgrounds and to enhance the inclusiveness, efficacy and value of ageing research.

The guidelines, once developed and endorsed/adopted by the relevant stakeholders, will ensure that research in the ageing and aged care sector is proportionately representative of people from CALD backgrounds and is equipped to use culturally appropriate measures when conducting research with older people from CALD backgrounds.

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## DRAFT ETHICAL FRAMEWORK FOR AGEING RESEARCH WITH CALD COMMUNITIES

### GUIDELINE 1 – RECIPROCITY

In the CALD ageing research context, reciprocity implies **inclusion** and means recognising partners' contributions,<sup>2</sup> feeding back research findings, and ensuring that research outcomes include equitable **benefits** of value to CALD communities. Reciprocity implies negotiation and exchange, although in research context, it is important to recognise this often involves unequal power relationships. When research includes older people from CALD communities, researchers must consider how the research demonstrates the value of reciprocity.

Reciprocity includes:

- Inclusion;
- Benefits.

### Inclusion

Inclusion is the basis for mutual obligation, and describes the degree of equitable and respectful engagement with CALD communities, their values and cultures in the proposed ageing research.

### Benefits

Benefit in this context describes the establishment or enhancement of capacities, opportunities or outcomes that advance the interests of the relevant CALD community and that are valued by them.

The participating CALD community has the right to define 'benefits' according to their own values and priorities.<sup>3</sup> Benefits may be to the participating CALD community, to the relevant CALD community more generally, or to the wider Australian community as well. However, they must be valued by the participating CALD community.

### Issues to consider

- Has the researcher demonstrated willingness to modify research in accordance with the participating CALD community's values and aspirations? (GEC 2.2.1)<sup>4</sup>
- Is there evidence of support for the research project from the relevant CALD community or groups? Does the research methodology engage with their social and cultural practices? (NS 4.7.2)<sup>5</sup>
- Does the research proposal demonstrate evidence of respectful engagement with the relevant CALD community? Depending on the circumstances, might this require letters of support from organisations accepted by the participating community? (NS 4.7.10)
- Does the research approach value and create opportunities to draw on the knowledge and wisdom of the relevant CALD community by their active engagement in the research processes, including the interpretation of the research data? (NS 4.7.11)
- If the project is national or multi-centre, have researchers taken care to gain local level support for research methods that risk not respecting cultural or language practices? (NS 4.7.12)

<sup>2</sup> The issue of contributions is discussed under Guideline 2 - Respect.

<sup>3</sup> Values of CALD communities also discussed under Guideline 5 – Cultural awareness

<sup>4</sup> GEC refers to guidelines in the [Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research](#) 2004 (under review).

<sup>5</sup> NS refers to guidelines in the [National Statement on Ethical Conduct in Human Research](#) 2007 (updated 2015).

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## DRAFT ETHICAL FRAMEWORK FOR AGEING RESEARCH WITH CALD COMMUNITIES

- Will the researchers feedback and translate research findings back to the CALD community?
- How does the proposed research demonstrate intent to contribute to the advancement of the health and wellbeing of participants and communities? (GEC 2.2.1)
- Does the proposal link clearly to CALD community, local, state, national or international ageing priorities and/or respond to existing or emerging needs articulated by the CALD community? (GEC 2.2.1)
- What is the nature of benefits for the participating CALD community or the relevant CALD community more generally? Is there evidence of clear and truthful discussions about the potential benefits of the research proposal prior to approval? (GEC 2.2.1)
- Will the proposed research enhance the capacity of the relevant CALD community to draw benefit beyond the project (e.g. through the development of skills and knowledge or through broader social, economic or political benefits at local, state, national or international level)? (GEC 2.2.1)
- Is the proposed research justifiable by its potential benefit, which may include its contribution to knowledge and understanding, to improved social welfare and individual wellbeing, or to the skill and expertise of researchers? Does the question of what constitutes potential benefit and whether it justifies research require consultation with the relevant CALD community? (NS 1.1 (a))
- Does the likely benefit of the research justify any risks of **harm**<sup>6</sup> to participants? The likely benefit may be to the participants, to the wider community, or to both. (NS 1.6)
- Do the potential benefits of the research include the enhancement or establishment of capabilities, opportunities or research outcomes that advance the interests of the CALD community? (NS 4.7.7)
- Have the described benefits of the research been discussed with and agreed to by the CALD community research stakeholders? (NS 4.7.8)
- Will the realisable benefits for CALD community participants from the research processes, outcomes and outputs be distributed in a way that is agreed to and considered fair by these participants? (NS 4.7.9)

### DISCUSSION QUESTIONS

- Are the explanations and content under the guideline sufficiently clear?
- What elements of this guideline do you agree/disagree with?
- Can you suggest any other issues to consider?
- Do you have any examples/case studies of either good or bad practice?

<sup>6</sup> The issue of harm is discussed under Guideline 4 - Responsibility

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## DRAFT ETHICAL FRAMEWORK FOR AGEING RESEARCH WITH CALD COMMUNITIES

### GUIDELINE 2 – RESPECT

Respect for human dignity and worth as a characteristic of relationships between people, and in the way individuals behave, is fundamental to a functioning and moral society. A respectful relationship encourages trust and co-operation (GEC 2.2.2).<sup>7</sup> Strong culture is a personal and collective framework built on respect and trust that promotes dignity and recognition.<sup>8</sup>

Respect includes:

- Respect for people and their contribution;
- Minimising difference blindness;
- Understanding the consequences of research for the individuals and communities.

#### Respect for people and their contribution

Respect acknowledges the individual and collective contribution, interests and aspirations of older people from CALD backgrounds, researchers and other partners in the research process.

- Researchers should inform themselves about local structures and seek to engage with these in a spirit of respect and integrity. Where CALD community structures exist, these should be used as the best means of community and institutional engagement by researchers. (GEC 2.2.2).
- The contributions to the research enterprise come in a variety of connected forms and all those contributions should be respected. (GEC 2.2.2).
- Respect for human beings involves giving due scope, throughout the research process, to the capacity of human beings to make their own decisions. (NS 1.12)<sup>9</sup> For example: understanding the complexities in relation to obtaining or withdrawing consent of older people from CALD backgrounds and respecting their cultural practices and norms.

#### Minimising difference blindness

Respectful research relationships acknowledge and affirm the right of people to have different values, norms and aspirations. (NS 4.7.11) Those involved in research should recognise and minimise the effect of difference blindness through all stages of the research process.

When conducting research involving humans, the guiding ethical principle for researchers is respect for persons which is expressed as regard for the welfare, rights, beliefs, perceptions, customs and cultural heritage, both individual and collective, of persons involved in research. (NS 1.2)

Understanding that CALD communities are not a homogenous group and that there is diversity within diversity and diversity across diversity are important aspects of respectfully conducting research. In addition to the differences of opinions across different ethnic, linguistic and religious groups, personal experiences including migration background and settlement experience will also have an impact on research outcomes.

<sup>7</sup> GEC refers to guidelines in the [Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research](#) 2004 (under review)

<sup>8</sup> NHMRC, Values and Ethics: Guidelines for Ethical conduct in Aboriginal and Torres Strait Islander Health Research, p. 11

<sup>9</sup> NS refers to guidelines in the [National Statement on Ethical Conduct in Human Research](#) 2007 (updated 2015).

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## DRAFT ETHICAL FRAMEWORK FOR AGEING RESEARCH WITH CALD COMMUNITIES

### Understanding the consequences of research for the individuals and communities

Researchers understand that research has consequences for themselves and others, the importance of which may not be immediately apparent. This should be taken into account through all stages of the research process.

- It is critical that respect underlies all aspects of the research process, especially sensitive<sup>10</sup> negotiations such as those related to publication of research findings (GEC 2.2.2)
- Researchers should make the publication of research findings as great a priority as feedback of findings to the community, in an appropriate and understandable way. (GEC 2.2.2)

### Issues to consider

- Does the research proposal respond to the diversity and endeavour to proportionally engage older people from CALD backgrounds? For instance, acknowledging the individual and collective contribution of older people from CALD backgrounds, minimising and eliminating effects of difference blindness in the research process. (GEC 2.2.2 pp 12/13)
- What are steps adopted to mitigate the possible effects of an unequal or dependent relationship between the treating health professional or researcher and the potential participants? (NS 3.3.16 (c) p.33)
- How does the proposal plan to use the knowledge and experience of older people from CALD backgrounds and in a respectful, culturally sensitive and an appropriate manner? (GEC 2.2.2 p13)<sup>11</sup>
- Are the participants aware of issues such as management of data, publication arrangements and protection of individual and community identity and other privacy concerns? (GEC 2.2.2 p13)
- How do the researchers and other research bodies gain local level support for research methods that risk not respecting cultural and language protocols? (NS 4.7.12)
- Does the research adopt necessary precautionary measures to cater for older people with physical disabilities, cognitive impairments and other special needs?
- Do the researchers and participants understand and take into account the consequences of research finding on the individuals and broader communities.
- How does the proposal aim to understand the cultural diversity and the demographics (in the locality/across Australia) for research purposes and provide any follow up reporting back to the community?

### DISCUSSION QUESTIONS

- Are the explanations and content under the guideline sufficiently clear?
- What elements of this guideline do you agree/disagree with?
- Can you suggest any other issues to consider?
- Do you have any examples/case studies of either good or bad practice?

<sup>10</sup> Sensitivity may arise from tensions between, the independence and integrity of research and, the risk of vilification and exploitation of older people from CALD backgrounds.

<sup>11</sup> Valuing knowledge and wisdom' will also be discussed under Guideline 3 - Equality.

## DRAFT ETHICAL FRAMEWORK FOR AGEING RESEARCH WITH CALD COMMUNITIES

### GUIDELINE 3 - EQUALITY

Equality is also a feature of the fundamental dignity of humanity. To treat people less favourably is not only unethical, but discriminatory. (GEC 2.2.3)<sup>12</sup>

Equality does not always translate to mean sameness. One of the ways in which equality is reflected is a commitment to distributive fairness and justice. Equality affirms a person's right to be different, irrespective of their background. (GEC 2.2.3)

Equality could also extend to include equal and equitable representation. The researcher's flexibility to ensure that the participants have an opportunity to contribute to framing the research will yield in better outcomes for both the researcher and the community. This could also include collaborating with researchers from diverse cultural backgrounds.

Research is a two way process; both researcher generated and community generated. 'The process is back to front – research ideas should come from the community'. Communities also felt very strongly that research ideas are too often investigator-driven rather than community driven, and that findings were too often presented from the researcher's perspective rather than that of community.<sup>13</sup>

Equality involves:

- Valuing knowledge and wisdom;
- Equality in partnerships;
- Ensuring fair distribution of benefit.

### Valuing knowledge and wisdom<sup>14</sup>

Older people from migrant and humanitarian backgrounds bring their knowledge and wisdom from their countries of origin, pre-migration experiences and their cultural inheritance. It is important for researchers to appreciate the value of such knowledge and the effect of those experiences on a person's outlook on life, mental and physical health and the like. Lack of understanding about the cultural and linguistic background on the part of the researcher may result in creating mistrust, misinterpreting data or otherwise limit quality or may overlook a potentially important benefit of research.

### Equality in partnerships

Ethical research processes treat all partners as equal notwithstanding that they may be different. In the absence of equal treatment, trust among research funders, researchers, host institutions, CALD communities and other stakeholders are not possible. Without such trust ethical research is undermined. (GEC 2.2.3)

Appropriate use of communication mechanisms to engage and interact with participants is also important to ensure that there is equality in partnership. This means that the CALD participants have access to appropriate language and other necessary supports that will place them in an equal footing with the other non-CALD participants.

<sup>12</sup> GEC refers to guidelines in the [Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research](#) 2004 (under review)

<sup>13</sup> Review of Values and Ethics & Keeping Research on Track, p.16  
[https://www.nhmrc.gov.au/files/nhmrc/file/health\\_ethics/human/issues/nhmrc\\_evaluation\\_values\\_et\\_hics\\_research\\_on\\_track\\_150513.pdf](https://www.nhmrc.gov.au/files/nhmrc/file/health_ethics/human/issues/nhmrc_evaluation_values_et_hics_research_on_track_150513.pdf)

<sup>14</sup> Valuing knowledge and wisdom' will also be discussed under the Guideline 2 - Respect

## DRAFT ETHICAL FRAMEWORK FOR AGEING RESEARCH WITH CALD COMMUNITIES

In instances where there are pre-existing relationships between participants and researchers or between participants and others involved in facilitating or implementing the research, the relationships may compromise the voluntary character of participants' decisions, as they typically involve unequal status, where one party has or has had a position of influence or authority over the other. (NS 4.3)<sup>15</sup>

### Ensuring fair distribution of benefit

The distribution of benefit stands as a fundamental test of equality. If the research process delivers benefit in greater proportion to one partner in the initiative than other partners, the distribution of benefit may be seen as unequal. (GEC 2.2.3)

### Issues to consider

- Does the way in which participating communities are included in the research processes demonstrate equality? (GEC 2.2.3)
- Is there equality in terms of use of appropriate communication mechanisms?
- Do the research agreements have the strength necessary to sustain equality? (GEC 2.2.3)
- Have the participating communities understood and expressed satisfaction with the proposed research, its potential benefits and their distribution? This includes the Researchers responsibility to ensure that the information that they provide is understood and usable in decision making by participating communities. (GEC 2.2.3)
- Is there fair distribution of the benefits and burdens of participation in research and, for any research participant, a balance of burdens and benefits, including,
  - mechanisms or processes to avoid imposing on particular groups, who are likely to be subject to over researching, an unfair burden of participation in research;
  - the design of research is developed to ensure the selection, recruitment, exclusion and inclusion of research participants is fair; and
  - not discriminate in the selection and recruitment of actual and future participants by including or excluding them on the grounds of race, age, sex, disability or religious or spiritual beliefs except where the exclusion or inclusion of particular groups is essential to the purpose of the research. (NS 1.5 as per GEC 2.2.3)

### DISCUSSION QUESTIONS

- Are the explanations and content under the guideline sufficiently clear?
- What elements of this guideline do you agree/disagree with?
- Can you suggest any other issues to consider?
- Do you have any examples/case studies of either good or bad practice?

<sup>15</sup> NS refers to guidelines in the [National Statement on Ethical Conduct in Human Research](#) 2007 (updated 2015).

## DRAFT ETHICAL FRAMEWORK FOR AGEING RESEARCH WITH CALD COMMUNITIES

### GUIDELINE 4 – RESPONSIBILITY

When research involves older people from CALD backgrounds, researchers must consider how the research proposal and the conduct of the research demonstrate the value of responsibility.

Responsibility includes;

- Doing no harm;
- Accountability.

#### Doing no harm

When engaging with older people from CALD communities, researchers must **minimise the risks of harm** to participants, particularly in relation to the social and cultural dimensions of community life.

#### Accountability

Researchers and participants must establish processes to ensure researchers' **accountability** to CALD individuals, families and communities, particularly in relation to the social and cultural dimensions of community life.

### Issues to consider

- Researchers are responsible for:
  - designing the research to minimise the risks of harm or discomfort to participants
  - clarifying for participants the potential benefits and risks of the research
  - the welfare of the participants in the research context. (NS 1.7)<sup>16</sup>
  - undertake the research in a culturally responsive manner (ensuring information is translated, interpreters are used and the research is explained appropriately).
- Does the research methodology engage with the participating community's social and cultural practices? (NS 4.7.2)
- The researcher should seek to identify any potential negative consequences of the proposed research, to design processes to monitor them, and to advise steps for minimising them. (NS 4.7.4)
- What measures are used to demonstrate transparency in negotiations with the participating community (including about the purpose, methodology, conduct, dissemination of results and potential benefits/harm from the research)? (GEC 2.2.4)<sup>17</sup>
- What provisions are made for ongoing advice from and review by the participating community (including to monitor compliance with ethics standards and to minimise the likelihood of any unintended consequences arising from the research)? (GEC 2.2.4)
- What does the proposal say about feedback obligations to the participating community (including how the feedback is relevant to the expectations and concerns of participants)? (GEC 2.2.4)
- Are there agreed arrangements about publication of the research results (including provisions about sign-off and the protection of individual/community identity if appropriate)? (GEC 2.2.4)
- The researcher should ensure mutually agreed mechanisms for such matters as:
  - appropriate recruitment techniques

<sup>16</sup> NS refers to guidelines in the [National Statement on Ethical Conduct in Human Research](#) 2007 (updated 2015).

<sup>17</sup> GEC refers to guidelines in the [Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research](#) 2004 (under review).

## DRAFT ETHICAL FRAMEWORK FOR AGEING RESEARCH WITH CALD COMMUNITIES

- suitable information about the research
- notification of participants' consent and of research progress
- final reporting. (NS 4.7.3)

### DISCUSSION QUESTIONS

- Are the explanations and content under the guideline sufficiently clear?
- What elements of this guideline do you agree/disagree with?
- Can you suggest any other issues to consider?
- Do you have any examples/case studies of either good or bad practice?

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## DRAFT ETHICAL FRAMEWORK FOR AGEING RESEARCH WITH CALD COMMUNITIES

### GUIDELINE 5 - CULTURAL AWARENESS

People from CALD backgrounds in Australia continue to maintain their cultural, linguistic and religious identity. Researchers must understand the cultural diversity in Australia and have an appreciation for the distinctiveness of the different cultural, linguistic and religious backgrounds. In instances where sampling strategies are used, it is important to ensure that the samples are reflective of Australia's cultural diversity.

There should be evidence of support for the research project from relevant CALD communities or groups and the research methodology should engage with their social and cultural practices.

Researchers should be wary of making generalisations about an entire community based on their experience with a group of people from a particular cultural background as the experiences vary based on the migration experience, and length of time spent in Australia, educational backgrounds, experience of migrants in rural and remote parts of Australia.

Cultural Awareness includes:

- Importance of values-based solidarity with CALD communities;
- Respect for social cohesion;
- Commitment to acknowledging cultural distinctiveness and diversity.

#### Importance of values based solidarity to CALD communities<sup>18</sup>

It is important to respect the distinctive values in different communities. Researchers must be aware of the history and background of this cohort and the continuing potential for research to encroach on these values. In instances where the communities act as a collective, it is important to ensure that the participants are recruited, approached through the community establishments, and not approach people individually. (GEC 2.2.5)<sup>19</sup>

#### Respect for social cohesion

The importance of personal and collective bond within CALD communities and its critical function in their social lives must be understood. (GEC 2.2.5) The role of the community and/or religious leaders and the community groups must be valued in the research process.

#### Commitment to acknowledging cultural distinctiveness and diversity

The cultural distinctiveness of people from CALD backgrounds is highly valued by them. Within the scope of these guidelines, researchers must find ways of working that do not diminish the right to the assertion or enjoyment of that distinctiveness. This distinctiveness extends to culture, religion, linguistic and ethnic background depending on the person. (GEC 2.2.5)

#### Issues to consider

- Could the research project contribute to or erode the social and cultural bonds among and between older people from CALD backgrounds, their families and communities?
- What safeguards are in place to ensure that for the research project does not contribute to discrimination or derision of individuals from CALD backgrounds or cultures?

<sup>18</sup> Also discussed under Guideline 1 – Reciprocity.

<sup>19</sup> GEC refers to guidelines in the [Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research](#) 2004 (under review)

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## DRAFT ETHICAL FRAMEWORK FOR AGEING RESEARCH WITH CALD COMMUNITIES

- Whether the proposal respect the intrinsic values based expectations and identity of older people from CALD backgrounds and communities including the balance between collective and individual identity.
- How the proposal contributes to the opportunity for older people from CALD backgrounds to better advocate for or enjoy their cultural distinctiveness.
- What strategies have been identified to eliminate any threats to older person's ability to enjoy their cultural distinctiveness?

### DISCUSSION QUESTIONS

- Are the explanations and content under the guideline sufficiently clear?
- What elements of this guideline do you agree/disagree with?
- Can you suggest any other issues to consider?
- Do you have any examples/case studies of either good or bad practice?

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## DRAFT ETHICAL FRAMEWORK FOR AGEING RESEARCH WITH CALD COMMUNITIES

### GUIDELINE 6 – INTEGRITY

Integrity is an overarching value that binds all the others into a coherent whole. Any behaviour that diminishes any of the previous five values could not be described as having integrity.

Integrity includes:

- Motivation and action;
- Intent and process.

#### Motivation and action

Researchers must approach the conduct of research in CALD communities with respect for the cultural, religious, ethnic and linguistic background. (GEC 2.2.6)<sup>20</sup>

#### Intent and process

Researchers must exhibit integrity in both intent and process when engaging with CALD communities. In many circumstances, this will depend not only on being able to demonstrate that the research proposal is in keeping with these guidelines, but also on the behaviours and perceived integrity of the researchers during and after the conduct of the research.

#### Issues to consider

- Whether the researchers are able to demonstrate personal integrity, specifically in relation to the research proposal. (GEC 2.2.6)
- Research that is conducted with integrity is carried out by researchers with a commitment to:
  - searching for knowledge and understanding
  - following recognised principles of research conduct
  - conducting research honestly
  - disseminating and communicating results, whether favourable or unfavourable, in ways that permit scrutiny and contribute to public knowledge and understanding. (NS 1.3)<sup>21</sup>

### DISCUSSION QUESTIONS

- Are the explanations and content under the guideline sufficiently clear?
- What elements of this guideline do you agree/disagree with?
- Can you suggest any other issues to consider?
- Do you have any examples/case studies of either good or bad practice?

<sup>20</sup> GEC refers to guidelines in the [Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research](#) 2004 (under review).

<sup>21</sup> NS refers to guidelines in the [National Statement on Ethical Conduct in Human Research](#) 2007 (updated 2015).

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## DRAFT ETHICAL FRAMEWORK FOR AGEING RESEARCH WITH CALD COMMUNITIES

### CASE STUDY

A group of researchers undertook a study to explore the issues of depression and anxiety amongst older Chinese immigrants. The overall aim of this project was to improve understanding of depression and anxiety amongst older immigrant Chinese Australians and in turn to improve detection and treatment of these psychological disorders. The study was based on NARI's Cultural Exchange Model<sup>22</sup>; an iterative process of exchange between researchers and stakeholders recognising that knowledge development is not a one-way flow of information from researchers/experts to health professionals or consumers but a process of knowledge exchange. The project involved the following components:

- A literature review
- Consultations with health professionals and community workers
- Piloting the Chinese version of the GDS and GAI through interviews with older Chinese immigrants
- Education and promotion activities.

The way in which this study was consistent with the guidelines outlined in the ETHICAL FRAMEWORK FOR AGEING RESEARCH WITH CALD COMMUNITIES is outlined below:

#### GUIDELINE 1 – RECIPROCITY

**The researchers modified the study approach in accordance with the community's values and aspirations.** For example, in recognition of the sensitivity of the subject matter, a two staged ethics approval process was implemented. Initially, participants were provided with an opportunity to understand the study, but instead of the usual process of gaining informed consent at the start of the interviews for use of the information collected, participants signed an agreement to participate in the interview and only at the end of the interview were they asked for permission to use the information collected for the research project. This was done as previous research with this community had shown us that older Chinese people may be reluctant to sign the usual consent forms until they knew exactly what information would be asked of them.

#### GUIDELINE 2 – RESPECT

**The research was undertaken with respect to the community for their participation.** For example, in recognition of participation, feedback to the community was as equal a priority as other aspects of study dissemination. Participants were fed back study outcomes in an information session and provided with a chance to ask questions and comment on the research findings. Approximately 70 older Chinese people attended the feedback session, which was held at a community venue that was familiar to them with culturally appropriate food supplied by the research team. The session was held in three languages.

<sup>22</sup> Haralambous B, Dow B, Tinney J, Lin X, Blackberry I, Rayner V, Lee S-M, Vratsidis F, Lautenschlager N, and LoGiudice D. (2014). Help seeking in older Asian people with dementia in Melbourne: Using the Cultural Exchange Model to explore barriers and enablers. *Journal of Cross-Cultural Gerontology*. 29(1), 69-86

## DRAFT ETHICAL FRAMEWORK FOR AGEING RESEARCH WITH CALD COMMUNITIES

### GUIDELINE 3 - EQUALITY

**Appropriate use of communication mechanisms were in place.** For example, bicultural and bilingual researchers were involved in the study, including one researcher who was a well-known member of the Chinese community as she had previously worked as an aged care service provider. She was recruited specifically for this study. Both researchers were able to engage and interact with participants in their own languages and understand their cultures.

### GUIDELINE 4 – RESPONSIBILITY

**The researchers met their feedback obligations to the participating community.** For example, at the completion of the project, the research team fed back the findings to older Chinese participants via an afternoon tea, which provided participants with an opportunity to discuss the study and process with the research team. Also described above under "respect"

### GUIDELINE 5 - CULTURAL AWARENESS & GUIDELINE 6 – INTEGRITY

**The researchers undertook this study with integrity and with a commitment to acknowledging cultural distinctiveness and diversity.** The rationale for the study was based on the need for culturally appropriate screening tools for depression and anxiety and culturally appropriate education on older age mental health. With the exception of the writing of the original application for funding, all aspects of the project were done in consultation with the Chinese community, including an advisory group and a community consultation process and the project methodology, the tools used and the format of the education was adapted based on this consultation.. It was recognised that all older Chinese immigrants were not homogenous and the range of cultural, religious, ethnic and linguistic backgrounds were considered and included in the advisory committee and the targeting of participants. This was via ensuring researchers and advisory committee members were of varied Chinese backgrounds, information was translated in different languages and interpreters were able to

#### Final Note

This approach led to some unexpected findings. We found significant differences in prevalence of depression and socio-demographic factors between the different groups of ethnic Chinese. This finding deepened both the researchers' and the Chinese communities' understandings of mental health issues amongst their older members and therefore how they might be addressed. The findings were communicated to the Chinese community workers and the broader community via the feedback session, reports to beyondblue and three academic papers.



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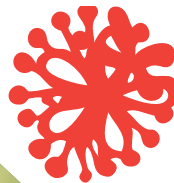
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