



AAG

Australian
Association of
Gerontology



POSITION PAPER
LGBTI AGEING
RESEARCH
IN AUSTRALIA

Report launched on 25 October 2019

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 past, present and emerging, and to all Aboriginal and Torres Strait Islander peoples including members of the Stolen Generations. For further information see AAG's Aboriginal and Torres Strait Islander Ageing Advisory Group (ATSIAAG)



SPONSOR



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ABOUT US

Since 1964, the Australian Association of Gerontology (AAG) has been Australia's peak national body linking researchers, educators, policymakers, practitioners and other experts engaged in ageing issues. With over 1,450 members across every State and Territory in Australia, our members include researchers, geriatricians, nurses, allied health professionals, aged care practitioners, policy makers, consumer representatives and other experts in ageing. AAG has 18 Collaborating Research Centres that represent all major research in ageing in Australia.

AAG has a well-established LGBTI special interest group (SIG) that:

- ▶ works with the LGBTI community to improve the lives of older LGBTI people
- ▶ fosters networking and collaboration between older LGBTI people, researchers, practitioners and policy makers
- ▶ provides comment and advice on LGBTI ageing issues when called on by AAG..

AAG's purpose is to improve the experience of ageing through **CONNECTING RESEARCH, POLICY and PRACTICE**

EXECUTIVE SUMMARY

The purpose of this position paper is to assess the size and scope of existing LGBTI ageing research and to identify the policy implications for LGBTI ageing and aged care in Australia. In order to develop the position paper, AAG:

- ▶ reviewed the LGBTI ageing **policy context** in Australia and found there have been significant developments over the past ten years.
- ▶ reviewed the LGBTI ageing **research funding** provided by key funding bodies in Australia and found that relatively little funding has been provided by DOH, ARC, NHMRC and MRFF over recent years.
- ▶ conducted a **scoping review** of LGBTI ageing research that has been published in Australia and overseas (see companion publication) and considered other relevant literature reviews. We identified some areas where further research is needed.
- ▶ conducted a **survey** of LGBTI ageing researchers in Australia (see companion publication) and identified some priority future research areas.

Based on the information obtained, we formulated **20 recommendations to government** about LGBTI ageing research.



POLICY RECOMMENDATIONS

The *Australian Government Diversity Action Plan* 2019 notes that the Aged Care Sector Committee Diversity Sub-Group “will monitor the government’s progress and work with the Department of Health to identify further opportunities for action.”(1)

The following recommendations are aimed at the Australian Government (and its departments and agencies) and identify further opportunities for action in relation to LGBTI ageing research. They have been developed based on information summarised in this AAG Position Paper, the AAG Scoping Review and the AAG Survey of Researchers.(2)(3)

POLICY FRAMEWORK

Recommendation 1

The government should monitor and report annually on progress under the *Aged Care Diversity Framework* Outcome 4 which states:

Action required by Government: Collect and use data and evidence on current and emerging trends in diversity to design, implement, evaluate and improve aged care systems and supports.(4)

Recommendation 2

The government should identify further specific opportunities for action to address the implementation of *Aged Care Diversity Framework* Outcome 4 in relation to LGBTI ageing data and evidence.(4)

Recommendation 3

The government should acknowledge that LGBTI ageing research is included under priority 9 of the *Science and Research Priorities 2015*, and monitor compliance with the priority by departments and agencies, including DOH, ARC, NHMRC and MRFF.(5) Priority 9 states that:

‘Departments and agencies should give priority to research that will lead to better models of health care and service that improve outcomes, reduce disparities for disadvantaged and vulnerable groups, increase efficiency and provide greater value for a given expenditure.’(5)

FUNDING

Recommendation 4

The government should undertake further analysis to investigate the amount of LGBTI ageing research funding in Australia provided by:

- ▶ key research funding bodies such as DOH, ARC, NHMRC, MRFF; and
- ▶ other relevant sources of research funding such as universities, charitable bodies, state governments, industry and private funders.

Recommendation 5

The government should develop a funding model to provide appropriate resourcing for LGBTI ageing research.

Recommendation 6

The government should provide quarantined funding for LGBTI ageing research.

PURPOSE AND IMPACT

Recommendation 7

While ‘awareness raising’ is important, there should be a greater focus on research intended to improve the experience of ageing and aged care systems for older LGBTI people.

Recommendation 8

The impact of LGBTI ageing research on the economy, society, environment, culture and individual wellbeing should be measured.(6)

COLLABORATION

Recommendation 9

Strategies should be developed to foster increased engagement of older LGBTI people in ageing research.

Recommendation 10

Strategies should be developed to foster increased collaboration between LGBTI ageing researchers and:

- ▶ policy makers
- ▶ aged care, health and other relevant service providers
- ▶ older LGBTI people and LGBTI advocacy and community organisations.

GROUPS BEING RESEARCHED

Recommendation 11

The government should respect the distinctiveness of people with intersex variations and their rights and experiences, particularly where they are included in data and evidence about the LGBTI community.

Recommendation 12

There should be greater focus on research that explores and reports on findings for lesbian, gay, bisexual, transgender and people with intersex variations separately, rather than grouping all LGBTI people together.

Recommendation 13

Further analysis should be done to assess whether some groups within the LGBTI community are under-represented in ageing research (for example, by conducting a rapid or systematic review of the studies identified in the AAG Scoping Review). This should include relevant groups that are not specifically listed within the LGBTI acronym such as non-binary, gender queer, agendered, and asexual people.

Recommendation 14

There should be greater focus on LGBTI ageing research about under-represented groups, including:

- ▶ older transgender people
- ▶ older people with intersex variations.

TYPES OF RESEARCH

Recommendation 15

There should be a greater focus on the following types of LGBTI ageing research:

- ▶ research translation
- ▶ evaluation
- ▶ longitudinal studies.

TOPICS OF RESEARCH

Recommendation 16

Further analysis should be done to assess priority areas for future LGBTI ageing research. For example, by:

- ▶ seeking the views of older LGBTI people, service providers and policy makers on LGBTI ageing research issues
- ▶ conducting a rapid or systematic review of the studies identified in the AAG Scoping Review
- ▶ considering the results of the updated literature review by Karen Fredriksen-Goldsen (when available) and other relevant literature reviews.(7)

Recommendation 17

While research on LGBTI inclusive aged care is important, there should be a greater focus on research about broader LGBTI 'ageing' issues.

Recommendation 18

There should be a greater focus on LGBTI ageing research about priority topics where there have been fewer published studies, including:

Physical and mental health:

- dementia/Alzheimer's
- HIV/AIDS

Social inclusion / exclusion:

- family – biological and/or of choice
- housing
- regional, rural and remote
- policy and legislation
- social exclusion

Discrimination:

- elder abuse
- media portrayal of older LGBTI people

Finances:

- poverty
- finance
- homelessness
- estates
- employment/unemployment

Special needs groups:

- care leavers
- culturally and linguistically diverse people
- Indigenous peoples
- veterans.

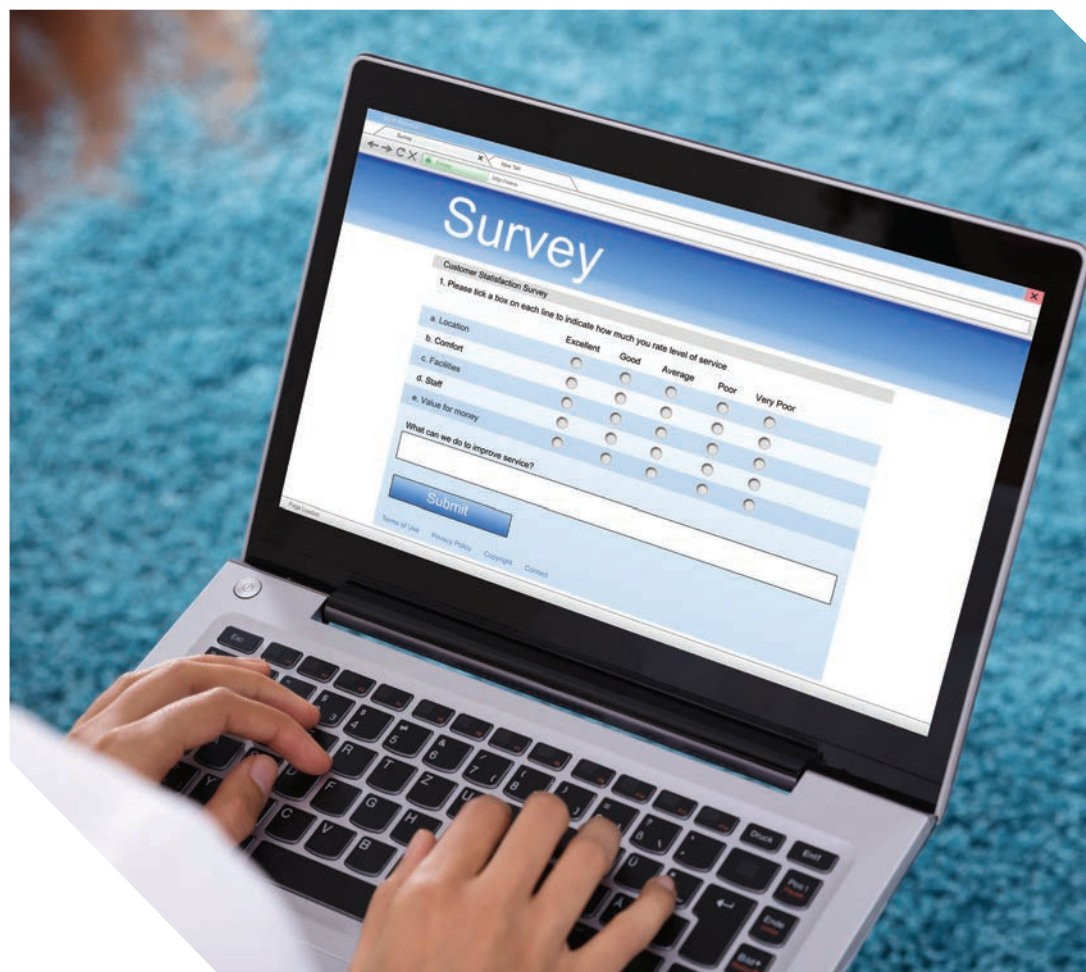
ACCESSIBILITY

Recommendation 19

An LGBTI ageing research clearing house should be established.

Recommendation 20

The government should fund relevant organisations to facilitate knowledge sharing and collaboration between LGBTI ageing researchers, policy makers and service providers. For example, via conferences, workshops, webinars, special interest groups, newsletters and social media.



TERMINOLOGY AND SCOPE

WHY WE HAVE USED THE TERM LGBTI

When using the term 'LGBTI,' we are using the language that is known within the ageing and aged care sector. We recognise and acknowledge that there are people of diverse relationships, bodies, sexualities and genders who are not overtly named in this acronym. However, this position paper is intended to be inclusive of all people with diverse bodies, genders, relationships or sexualities who might describe themselves in different ways.

WHAT WE MEAN BY LGBTI AGEING RESEARCH

By 'LGBTI ageing research' we mean research that is related to the process of growing old, the experiences of those typically categorised as older, and the delivery of services or other resources (e.g. informal care) to older people who identify as lesbian, gay, bisexual, transgender, people with intersex variations, and those who might describe their gender, relationships or sexuality in different ways.

NOTE ABOUT DATA

While we acknowledge that the collection and use of data about older LGBTI people is critical to research, it is beyond the scope of this position paper to examine that area in detail. Further information is provided in this paper about the work being done on data by the *LGBTI Data Roundtable 2017* and under the Australian *Government Diversity Action Plan 2019*.

ACRONYMS

AAG	Australian Association of Gerontology
ABS	Australian Bureau of Statistics
ACSIHAG	Aged Care Service Improvement and Healthy Ageing Grants
AIHW	Australian Institute of Health and Welfare
ARC	Australian Research Council
CALD	Culturally and Linguistically Diverse
DACS Fund	Dementia and Aged Care Services Fund
DOH	Department of Health
DoHA	Department of Health and Ageing
GLBTI	Gay, lesbian, bisexual, transgender and intersex
HIV	Human immunodeficiency virus
LGBTI	Lesbian, gay, bisexual, transgender and intersex
MRFF	Medical Research Future Fund
NHMRC	National Health and Medical Research Council
SIG	Special interest group

INTRODUCTION

Until relatively recently, older LGBTI people were invisible in the health and aged care systems, with their needs often unknown or overlooked. In more recent times, researchers in Australia and internationally have been working to improve our knowledge about LGBTI ageing. However, we do not have a clear picture of what research has been done and what more is needed to inform policy on LGBTI ageing and aged care in Australia.

RAINBOW CAFÉ

In late 2015, AAG hosted a ‘world café’ style workshop at its National Conference in Alice Springs, titled *“Rainbow Visions: LGBTI Ageing Research, Policy and Practice”* (the Rainbow Café).⁽⁸⁾ The event was facilitated by Carrie Hayter (Carrie Hayter Consulting), Associate Professor Ruth McPhail (Griffith University) and Dr Deb Selway (Integrated Living Australia Ltd).

The Rainbow Café aimed to explore questions about future priorities for LGBTI ageing research. Nineteen stakeholders participated, including LGBTI ageing researchers, service providers, peak bodies and advocacy groups. Participants were asked *‘what areas of research with older LGBTI people should be a key priority area?’* Some of the key areas they identified were:

- ▶ older transgender people
- ▶ older bisexual people
- ▶ older LGBTI Aboriginal and Torres Strait Islander people
- ▶ older LGBTI culturally and linguistically diverse people
- ▶ older queer people
- ▶ older LGBTI living with dementia
- ▶ older LGBTI people living with HIV
- ▶ palliative care for older LGBTI people.

Participants recommended that AAG should develop a policy paper on LGBTI ageing research priorities. That recommendation was the impetus for the development of this position paper.

THIS POSITION PAPER

In late 2017, the AAG policy team commenced work on developing this position paper, steered by a panel of gerontologists with knowledge and experience in LGBTI ageing. The purpose of this position paper is to assess the size and scope of existing LGBTI ageing research and to identify the policy implications for LGBTI ageing and aged care in Australia.

In order to develop the position paper, AAG obtained background information from four main sources:

1. We reviewed the LGBTI ageing **policy context** in Australia
2. We reviewed the LGBTI ageing **research funding** provided by key funding bodies in Australia in recent years
3. We conducted a **scoping review** of LGBTI ageing research that has been published in Australia and overseas (**see companion publication *AAG Scoping Review LGBTI Ageing Research***).⁽²⁾
4. We conducted a **survey of LGBTI ageing researchers** in Australia about what issues they are currently working on; about their sources of funding; and about what they believe are the priority areas for future LGBTI ageing research (**see companion publication *A Survey of LGBTI Ageing Researchers in Australia***).⁽³⁾

Based on the information obtained, we formulated **20 policy recommendations** about LGBTI ageing research.

AUSTRALIAN POLICY CONTEXT

KEY POINTS

- ▶ Up to 11% of the Australian population are LGBTI. (9)
- ▶ There have been significant policy developments in relation to LGBTI ageing over the past decade.
- ▶ In 2011, the inquiry into *Caring for Older Australians* found that consideration of the development of a specific LGBTI strategy was warranted.(10)
- ▶ In 2012, the *National LGBTI Ageing and Aged Care Strategy (2012-2017)* included a goal that LGBTI people would be a priority for ageing and aged care research.(9)
- ▶ In 2013, additional legislative protections were provided for older LGBTI people receiving aged care.(11)(12)
- ▶ Work is being done on data collection and use.
- ▶ In 2017, the *Review of the National LGBTI Ageing and Aged Care Strategy* noted that despite efforts, primary research remains an outstanding need.(13)
- ▶ In 2017, the new *Aged Care Diversity Framework* was launched.(4) It requires the Government to collect and use data and evidence on current and emerging trends in diversity to design, implement, evaluate and improve aged care systems and supports.
- ▶ In 2019, the *Australian Government Diversity Action Plan 2019(1)* and *Actions to Support LGBTI Elders (A Guide for Consumers and A Guide for Aged Care Providers)* were launched(14).

DEMOGRAPHICS

The size of Australian LGBTI communities is difficult to determine (due in part to a perceived lack of safety by LGBTI people that inhibits disclosure). However, the proportion of LGBTI people in Australia is estimated to be **up to 11 per cent of the population**.(9) There is very little information available about the number of people in each of the subgroups within the LGBTI acronym:

- ▶ A recent population-based sample of over 20,000 Australians aged 16–69 found that 14.7% of women are same-sex attracted, 13.5% engage in same-sex behaviour, 1.2% are lesbian and 2.2% bisexual; and 6.8% of men are same-sex attracted, 6.0% engage in same-sex behaviour, 1.6% are gay and 0.9% bisexual.(15)
- ▶ In the 2016 Census, 340 people described themselves as transgender, but the Australian Bureau of Statistics considers this to be a substantial under-reporting.(16) The Royal Children's Hospital Melbourne estimates that around one per cent of children and adolescents experience gender identity issues, although not all of these will continue into adulthood.(17)
- ▶ There are no firm figures for the number of Australians with intersex variations. A low-range statistic for traits evident at birth is around 1 in 2,000 people (0.05% of births) but a more likely figure may be closer to 1.7% (18)

We acknowledge that the relationship between people with intersex variations and the lesbian, gay, bisexual and transgender communities is complex. (19) We note that the Darlington Statement: Joint consensus statement from the intersex community 2017, says:

“Intersex is distinct from other issues. We call on allies to actively acknowledge our distinctiveness...”(20)

CARING FOR OLDER AUSTRALIANS (2011)

In 2010-2011, the Productivity Commission conducted an inquiry to systematically examine the social, clinical and institutional aspects of aged care in Australia. The Commission's final report *Caring for Older Australians* was published in August 2011. (10) Among other things, it found that:

"In the Commission's view, consideration of the development of a specific GLBTI strategy is warranted given the anticipated increase in demand for aged care services by this group and the limited recognition of their needs and preferences in the current policy framework, delivery of services and accreditation processes. Initiatives that increase the awareness of GLBTI issues within the aged care industry, such as training for aged care workers, are important in creating an environment in which sexual diversity is respected and catered for. There should be further initiatives between DoHA and peak bodies to help create an aged care system that can better cater for and respond to the needs and preferences of GLBTI older people. Service providers have an obligation to ensure both policies and practices acknowledge these needs and respond appropriately." (10)

LGBTI AGEING AND AGED CARE STRATEGY (2012)

The *National LGBTI Ageing and Aged Care Strategy* (the LGBTI Strategy) was released by the government in December 2012(9) It was designed to inform the way the government supports the aged care sector to deliver care that is sensitive to and inclusive of the needs of LGBTI people, their families and carers. The LGBTI Strategy was given a five-year implementation time frame (2012-2017). The LGBTI Strategy included a goal about research (goal 6), supported by seven action areas (action area 6.6 is the most relevant to research):

"GOAL 6 – GLBTI people, their families and carers will be a priority for ageing and aged care research.

Note: Some LGBTI people may elect not to disclose their sexual orientation, sex or gender identity.

ACTION AREAS

DoHA will:

- 6.1 Increase the knowledge base, and practice guidelines about the health, wellbeing and experiences of LGBTI people within the residential and community aged care system.
- 6.2 Engage with the Australian Bureau of Statistics to include LGBTI indicators in the Australian Census and the Survey of Disability, Ageing and Carers (SDAC). Encourage the inclusion of LGBTI indicators within all ageing-related research projects.
- 6.3 Identify opportunities for appropriate inclusion of LGBTI indicators within aged care datasets and other monitoring mechanisms, following further consultation with the LGBTI sector.
- 6.4 Include LGBTI-related data and research in the Australian Institute of Health and Welfare (AIHW) data clearinghouse.
- 6.5 Engage with the AIHW to develop more available data related to older LGBTI people as part of research projects.
- 6.6 **Identify opportunities for qualitative and quantitative research to be used in the development and evaluation of service provision to LGBTI people, and in healthy ageing initiatives that are inclusive of LGBTI people.**
- 6.7 Evaluate DoHA-funded projects specific to LGBTI people and establish partnerships with existing research bodies with LGBTI expertise to establish best practice approaches in aged care." (9)

LEGISLATIVE PROTECTIONS (2013)

In 2013, the 'special needs' groups identified in the *Aged Care Act 1997* were amended to include LGBTI people.(11) In the same year (2013), the *Sex Discrimination Act 1984* was amended to provide new protections against discrimination on the basis of a person's sexual orientation, gender identity, and intersex status, and to provide protection against discrimination for same sex de facto couples. (12) The amendment also removed the religious exemptions related to aged care, meaning that all Commonwealth-funded aged care service providers (regardless of their organisation type) are required to provide non-discriminatory services to LGBTI people.

LGBTI DATA ROUNDTABLE (JUNE 2017)

While we acknowledge that the collection and use of data about LGBTI elders is a critical part of the evidence-base, it is beyond the scope of this position paper to examine that area. However, the following information is provided as background context:

Under Goal 6 of the LGBTI Strategy, there were four Action Areas related to improving the collection and use of data about older LGBTI people.(9) In 2013, the National LGBTI Health Alliance wrote a discussion paper on *LGBTI Data: Developing an evidence-informed environment for LGBTI health policy*. (21) Among other things, the paper recommended the government fund a project to explore and discuss the issues involved in obtaining LGBTI data.

In June 2017, an *LGBTI Data and Statistics Collection Roundtable* (the LGBTI data roundtable) was held with the Department of Health, the Australian Bureau of Statistics, the Australian Institute of Health and Welfare, the Attorney-General's Department and the LGBTI Working Group.(13) The LGBTI data roundtable discussed:

- ▶ Data to be collected by the ABS
- ▶ How to appropriately ask about a person's sexuality and/or gender identity and/or intersex status
- ▶ Data collection and sampling methodologies across the various agencies, with a focus on harmonising and linking matching metadata

- ▶ Establishing a consistent LGBTI data standard to improve the specific application and usage of the data by the various government agencies
- ▶ What questions should be asked, what questions need to be answered and why that information needs to be known
- ▶ Data collected in the My Aged Care client record
- ▶ Data to be collected on departmental IT systems."(13)

Further information about the work currently being done on data is provided in the section on the Australian policy context - *Australian Government Diversity Action Plan*.

REVIEW OF THE LGBTI AGEING AND AGED CARE STRATEGY (NOVEMBER 2017)

During the first half of 2017, the government conducted a review of the LGBTI Strategy in consultation with stakeholders. AAG made a written submission to that consultation in May 2017.(22) AAG's submission made the following comments about improving the evidence base:

- ▶ The LGBTI Action Plan should retain the goal that LGBTI people, their families and carers will be a priority for ageing and aged care research.
- ▶ We need to identify the gaps in the evidence-base for LGBTI ageing, including both research and data.
- ▶ We should focus on research translation to inform future policy and practice, and evaluation of current policy and practice.
- ▶ We should work in partnership with LGBTI communities to design research activities.
- ▶ We need to develop a framework to provide appropriate resourcing for LGBTI ageing research activities.(22)

On 8 November 2017, Minister Ken Wyatt (Minister for Aged Care and Indigenous Health) invited a group of key stakeholders (including AAG and two members of the reference group for this position paper) to participate in an LGBTI Aged Care Think Tank to discuss improving the ageing and aged care experiences of LGBTI people, their families and carers. AAG raised the importance of having a good evidence-base to inform policy and practice.

On 23 November 2017, Minister Ken Wyatt launched the Review of the National LGBTI Ageing and Aged Care Strategy Final Report (the LGBTI Strategy Final Report).⁽¹³⁾ The report provided the following information about the government's progress on the research action area:

"Action Area 6.6: Identify opportunities for qualitative and quantitative research to be used in the development and evaluation of service provision to LGBTI people, and in initiatives that are inclusive of ageing LGBTI people

As detailed under Action Area 2.5, all three ACSIHAG grants rounds (2012, 2013 and 2014) and the subsequent 2016 DACS round have prioritised projects addressing the aged care needs of, or trialling services to assist, people from diverse backgrounds, including LGBTI people. Details of the projects funded under ACSIHAG were outlined under Action Area 2.5. On 11 July 2017, Aged Care Minister Ken Wyatt MP announced \$34 million in funding grants to support innovation in dementia care and other aged care services, including the \$5.2 million for two projects focussing on the LGBTI community.

In addition, work undertaken by La Trobe University and the AAG sought to build the evidence base for inclusive care. A consortium has recently been awarded an Australian Research Council Linkage Grant to develop a database on the health and wellbeing needs of older LGBTI people.¹

Despite these efforts, it is acknowledged that primary research remains an outstanding need."⁽⁸⁾

The LGBTI Strategy Final Report provided the following information about stakeholder perspectives on the implementation of the research goal:

"Goal 6: LGBTI people, their families and carers will be a priority for ageing and aged care research

In general, stakeholders suggested that while some specific research has been undertaken, which has contributed to improved practice, further effort is required to realise this goal.

Some progress noted in stakeholder submissions included:

- Funding provided (to the AAG) to develop a position paper that will help to:
 - Identify gaps in the evidence-base for LGBTI ageing
 - Provide a focus on research translation and policy/practice evaluation
- Studies into LGBTI needs by Gay and Lesbian Health Victoria (GLHV) and Val's Café (Now Val's Ageing and Aged Care)
- Research by RDNS into the Partnering with Consumers engagement model
- Research on the needs and experience of carers is slowly growing
- Funding for projects to promote LGBTI-appropriate care.

One stakeholder noted that it is now easier to access research, but ***there is a continuing need to support the translation of knowledge and evidence into practice...***

One stakeholder highlighted the opportunity and ***need for longitudinal studies exploring LGBTI aged care needs over time.***⁽¹³⁾

¹ The consortium partners are La Trobe University, University of New England, Southern Cross University, University of Washington, National LGBTI Health Alliance, COTA Australia, Carers Australia and Sane Australia.

The LGBTI Strategy Final Report also provided the following information about future challenges in relation to research, data and monitoring:

“Stakeholders noted that a lack of data regarding numbers of LGBTI aged care consumers (often due to a perceived lack of safety that inhibits disclosure – see section 5.3.2) means it is difficult to assess levels of need or access to services for LGBTI people.

While multidisciplinary research was noted to foster innovation and be ‘good for promoting best practice’ (aged care provider), **a number of stakeholders felt that more could be done – both in terms of more research and better translation of research into practice.** One suggested that the use of client narratives, as well as other forms of data and evidence, could help to promote and support improvements in inclusive care.

In particular, many stakeholders felt that data collection, evaluation and reporting has been a key element missing from the implementation of the LGBTI Strategy, as the initial commitment to annual reporting was replaced with this end of implementation review.”(13)

AGED CARE DIVERSITY FRAMEWORK (DECEMBER 2017)

During 2017, the Government established the Aged Care Sector Committee Diversity Sub-Group (which included representatives from AAG and a member of the reference group for this position paper).² The Sub-Group was tasked with conducting national consultations and developing an Aged Care Diversity Framework and supporting Action Plans.

In addition, the review of the LGBTI Strategy also asked stakeholders what issues should be addressed in the proposed Diversity Framework and LGBTI Action Plan. The LGBTI Strategy Final Report noted that one of the strong themes that emerged was that **“the Diversity Framework should facilitate relevant research to inform best practice.”**(13)

The Aged Care Diversity Framework (the Diversity Framework) was launched on 6 December 2017.(4) It builds on the previous LGBTI and Culturally and Linguistically Diverse (CALD) Ageing and Aged Care Strategies, with the vision that:

“All older people experience a high-quality aged care system that ensures equitable access and outcomes and embraces their diverse characteristics and life experiences.”(4)

The Diversity Framework lists six overarching imperatives (the sixth is the most relevant to research):

1. Equity of access and outcomes
2. Empowerment
3. Inclusion
4. Quality
5. Capacity building
6. Responsive and accountable –

The aged care system embeds the diverse characteristics and life experiences of all older people in system planning, delivery, monitoring, and transparent reporting. The aged care system is responsive and flexible in adapting to the current and emerging needs and expectations of older people, their families, carers and representatives, to ensure services are appropriate and inclusive.(4)

The Diversity Framework also lists six key outcomes for consumers and the actions required by Government to achieve them (the fourth is the most relevant to research):

1. Making informed choices
2. Adopting systematic approaches to planning and implementation
3. Accessible care and support

² The relevant members of the Diversity Sub-Group are James Beckford Saunders, Helen Barrie and Samantha Edmonds.

4. Supporting a proactive and flexible system

- Outcome for Consumers: A proactive and flexible aged care system that responds to the needs of existing and emerging diverse groups, including an increasingly diverse aged care workforce.
- Action required by Government: Collect and use data and evidence on current and emerging trends in diversity to design, implement, evaluate and improve aged care systems and supports.

5. Respectful and inclusive services.

6. Meeting the needs of the most vulnerable.(4)

ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY (2018)

The Royal Commission into Aged Care Quality and Safety was established on 8 October 2018. (23) The Honourable Richard Tracey AM RFD QC, Ms Lynelle Briggs AO and Tony Pagone QC have been appointed as Royal Commissioners. The revised Letters Patent made on 6 December 2018 outline the Commission's terms of reference. Hearings commenced on 18 January 2019. The Commissioners are required to provide an interim report by 31 October 2019 and a final report by 12 November 2020. The Commission has scheduled hearings that will focus on diversity in aged care, including LGBTI people. However, these hearings had not yet taken place as at the time of writing.

DIVERSITY ACTION PLANS (FEBRUARY 2019)

The Diversity Framework is supported by four *Diversity Action Plans* that are relevant to older LGBTI people, which were launched in February 2019:

- ▶ Australian Government Diversity Action Plan 2019 (discussed further below)
- ▶ Actions to support LGBTI elders: a guide for aged care providers (discussed further below)
- ▶ Actions to support LGBTI elders: a guide for consumers

- ▶ Shared actions to support all diverse older people: a guide for aged care providers.(24)

In addition, there are action plans for other diversity groups, including older Aboriginal and Torres Strait Islander people and older Culturally and Linguistically Diverse people.(24) There is also work in progress on an action plan for older people who are homeless.(25)

Australian Government Diversity Action Plan

The Australian Government Diversity Action Plan outlines actions the government needs to take to meet its goals of inclusive ageing and aged care services.(1) Under **Outcome 4: Collect and use data and evidence on current and emerging trends in diversity to design, implement, evaluate and improve aged care systems and supports**, there are seven specific actions for government including:

- ▶ Develop a data governance group
- ▶ Initiate a co-design process to identify new data points and/or business process changes
- ▶ Ensure diversity is included in all aged care funding rounds
- ▶ Prioritise Community Visitors Scheme grant applications
- ▶ Formalise an ongoing monitoring and advisory role for the Diversity Sub-Group
- ▶ Improve dissemination of outcomes from diversity-focused aged care projects previously funded
- ▶ Consider the findings of the Partners in Culturally Appropriate Care program evaluation.(1)

None of the government actions for 2019 appear to specifically relate to LGBTI ageing research. However, the Action Plan notes that **"the Aged Care Sector Committee Diversity Sub-Group will monitor the government's progress and work with the Department of Health to identify further opportunities for action."**(1) The recommendations provided later in this position paper are aimed at government and identify further opportunities for action in relation to LGBTI ageing research.

Actions to support LGBTI elders

The *Actions to Support LGBTI Elders* include a guide for consumers and a guide for aged care providers.⁽¹⁴⁾ These guides address the challenges affecting older LGBTI people's ability to access mainstream and flexible aged care services. They were based on extensive consultations held across Australia from August 2017 to March 2018, co-ordinated by the National LGBTI Health Alliance.

The guide for aged care providers identifies actions they could take to deliver more inclusive and culturally appropriate services for older LGBTI people.⁽¹⁴⁾ It acknowledges that there is no 'one-size-fits-all' approach to diversity, and that each provider will be starting from a different place and operating in a different context. Therefore, the action plan is designed so that providers can work through three levels of actions – *Foundational, Next Steps, and Leading the Way* – and decide which are most relevant to their organisation, in consultation with consumers, their support people, and staff.⁽¹⁴⁾

Throughout the guide, there are references to actions for service providers that could and should be informed by LGBTI ageing research, for example:

- ▶ Provide education and training to staff at every level to understand the different lived experiences within and amongst L, G, B, T & I peoples
- ▶ In consultation with consumers and their families, develop, review, implement, monitor and evaluate policies and practices on the inclusion of L, G, B, T & I peoples
- ▶ Plan and develop actions to combat social isolation and cultural safety risks for LGBTI older people
- ▶ Ensure all staff are skilled in and sensitive to providing personal care for older people who are trans, gender diverse or intersex.⁽¹⁴⁾

NATIONAL PLAN TO RESPOND TO THE ABUSE OF OLDER AUSTRALIANS (MARCH 2019)

The *National Plan to Respond to the Abuse of Older Australians* was launched on 19 March 2019.⁽²⁶⁾ It sets out the commitment of the Australian government and each of the eight state and territory governments to work together on five priority areas of action:

1. Enhancing our understanding
2. Improving community awareness and access to information
3. Strengthening service responses
4. Planning for future decision making
5. Strengthening safeguards for vulnerable older adults.

Despite the recommendation by the Australian Law Reform Commission in its 2017 report *Elder Abuse A National Legal Response*, the recent National Plan does not include any specific actions in relation to LGBTI elder abuse.⁽²⁸⁾

AGED CARE QUALITY STANDARDS (JULY 2019)

The delivery of safe and inclusive services to older LGBTI people is built into the Aged Care Quality Standards, which are contained in the Quality of Care Amendment (Single Quality Framework) Principles 2018.(29) The standards come into effect from 1 July 2019. The Aged Care Quality and Safety Commission will monitor and assess aged care providers based on the quality of the service experienced by consumers. The Actions to Support LGBTI Elders for aged care providers are underpinned by:

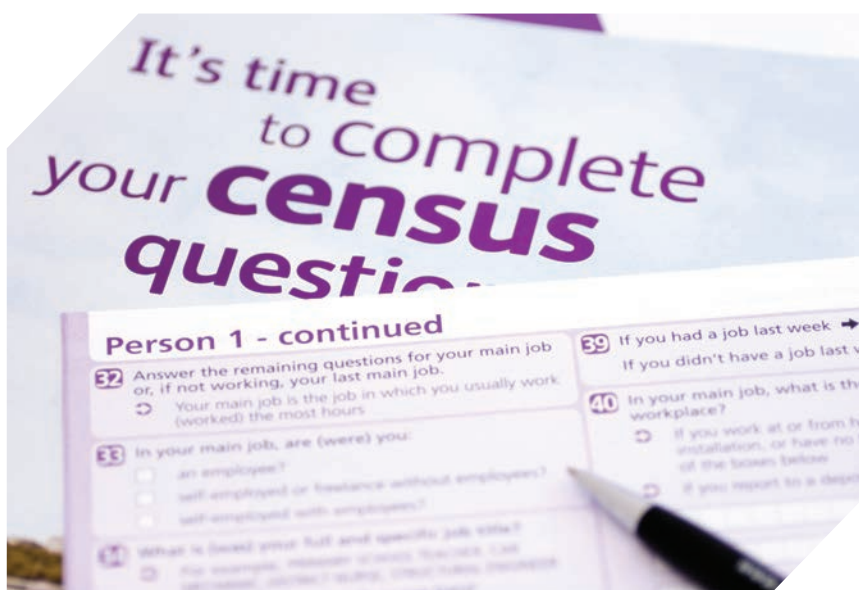
Standard 1 – Consumer dignity and choice

Requirements

The organisation demonstrates the following: each consumer is treated with dignity and respect, with their identity, culture and **diversity valued**:

- a) each consumer is treated with dignity and respect, with their identity, culture and diversity valued;

- b) care and services are culturally safe;
- c) each consumer is supported to exercise choice and independence, including to:
 - i. make decisions about their own care and the way care and services are delivered; and
 - ii. make decisions about when family, friends, carers or others should be involved in their care; and
 - iii. communicate their decisions; and
 - iv. make connections with others and maintain relationships of choice, including intimate relationships;
- d) each consumer is supported to take risks to enable them to live the best life they can;
- e) information provided to each consumer is current, accurate and timely, and communicated in a way that is clear, easy to understand and enables them to exercise choice;
- f) each consumer's privacy is respected, and personal information is kept confidential.(29)



AUSTRALIAN LGBTI AGEING RESEARCH FUNDING

KEY POINTS

Relatively little funding has been provided by the key Australian research funding bodies for LGBTI ageing research in recent years. A summary is provided in Table 1 and detailed information is provided in the section on key research funding bodies.

Table 1. LGBTI ageing research funding by key Australian research funding bodies 2000-2018

Funding body	Research budget 2017-18 (\$)	Years of data examined	Funding for LGBTI ageing research
DOH	N/A	2012-2017	\$10,000 (but \$8 million was provided for programs, projects and services)
ARC	\$789.7 million	2001-2017	\$558,652
NHMRC	\$818 million	2000-2018	\$144,726
MRFF	\$122 million	2017-2018	\$NIL
			\$713,378 TOTAL

We acknowledge that there are many other potential sources of funding for LGBTI ageing research, including:

- ▶ universities
- ▶ industry
- ▶ charitable bodies
- ▶ private funders
- ▶ state and territory governments.

It was beyond the scope of this paper to explore these other funding sources fully. We did ask a question about funding sources in the *AAG Survey of LGBTI Ageing Researchers* but did not obtain enough data to draw any conclusions (further information provided later in the section on *AAG survey of LGBTI ageing researchers*).

SCIENCE AND RESEARCH PRIORITIES 2015

The Australian Government's *Science and Research Priorities 2015* are intended to result in an increased proportion of government research investment being allocated on a strategic basis to areas of critical need. (5) Priority 9(1) states that:

'Departments and agencies should give priority to research that will lead to better models of health care and service that improve outcomes, reduce disparities for disadvantaged and vulnerable groups, increase efficiency and provide greater value for a given expenditure.'(5)

We consider that LGBTI ageing research falls within this priority.

KEY AUSTRALIAN RESEARCH FUNDING BODIES

Prior to publication, we contacted each funding body and gave them the opportunity to correct the information we had obtained. The information provided in this paper incorporates their comments and corrections.

1. Department of Health (DOH)

Australian Government funding for LGBTI ageing and aged care falls under the DOH portfolio. The ***LGBTI Strategy Final Report 2017*** provided the following information about DOH funding under the research-related action area of the LGBTI Strategy 2012-2017:

- ▶ *‘During the 2012, 2013 and 2014 ACSIHAG grant rounds and the 2016 DACS grant round, the Department spent \$8 million on 13 grants for LGBTI ageing programs, projects and services.’* However, based on the details provided for these 13 grants (see table 2 below), we believe that only \$10,000 of this funding was used for LGBTI ageing research.³
- ▶ *‘In 2017, the Department also announced \$5.2 million for two projects to support innovation in dementia care and other aged care services for the LGBTI community.’* We believe these grants were made to Uniting (for a project called Rainbow of Difference Project – Creating a Safe Environment for LGBTI people) and National LGBTI Health Alliance (for Silver Rainbow Training and national co-ordination work).(13)



³ We understand that Evergreen Life Care spent around \$10,000 of its DOH funding (matched by \$10,000 from Southern Cross University) on a Survey on the Health and Wellbeing of LGBTI Older People in NSW 2013-14 (31)

Table 2. LGBTI ageing programs, projects and services funded by DOH 2012-2016

Project funded by DOH 2012-2016	Lead Organisation
The LGBTI Elders Wellbeing Project	Evergreen Life Care
The LGBTI Dementia Program	Alzheimers' Australia
Project L.O.V.E (Living Older Healthy Visibly Engaged)	ACON
Free to Be	ACH Group
Reaching OUT: Ageing and LGBTI Rights	Aged Care Rights Service
Senior People Living with HIV: Voices Project	Living Positive Australia
Diversity in Aged Care: Improving Services for LGBTI Seniors	Queensland Association for Healthy Communities
Transgender Age Care Support Officer	Gender Centre
Promoting Inclusive Health Care Program	Royal District Nursing Service
Support for LGBTI People	National LGBTI Health Alliance
LGBTI Sensitivity Training	National LGBTI Health Alliance
Supporting LGBTI-inclusive aged care services	LaTrobe University
Health Ageing Project	Australian Association of Gerontology

2. Australian Research Council (ARC)

The ARC is a Commonwealth entity within the Australian Government. Its purpose is to grow knowledge and innovation for the benefit of the Australian community through funding the highest quality research, assessing the quality, engagement and impact of research and providing advice on research matters.⁽³²⁾ The ARC's budget for research in 2017-18 was \$789.7 million.⁽³³⁾

The ARC provides searchable information online about the grants it has made since 2001.⁽³⁴⁾ In December 2017, we did searches for the years 2001 to 2017 using each of the following terms:

- ▶ LGBTI
- ▶ lesbian
- ▶ gay
- ▶ homosexual
- ▶ bisexual
- ▶ transgender
- ▶ homophobia
- ▶ queer
- ▶ intersex.

We then manually reviewed the resulting project summaries to assess whether they related to ageing. The only research grants that appeared to be relevant to both LGBTI and ageing were:

- ▶ Project ID: DP 0986666. Investigator: Gorman-Murray. Project summary: Men on the home front: spatialities of domesticity and masculinity (included a case study on mental and physical capacities of older gay men). Funding amount: **\$262,652** over 3 years from 2009.
- ▶ Project ID: LP 160100221. Investigators: Lyons, Barrett, Minichiello, Hughes, Fredriksen-Goldsen & Ansara. Project summary: Reducing health disparities for older LGBTI Australians. Funding amount: **\$296,000** over 3 years from 2016.(35)

The LGBTI Strategy Final Report 2017 states that a consortium has recently been awarded an Australian Research Council Linkage Grant for a research project on the health and wellbeing needs of older LGBTI people.⁴(13)

3. National Health and Medical Research Council (NHMRC)

The NHMRC is an independent statutory agency that is the leading expert body on health and medical research in Australia.(36) The NHMRC's budget for research in 2017-2018 was almost **\$818 million**.(30)

The NHMRC provided AAG with data on funding for LGBTI research (all age groups) for the period 2000 to 2018 based on the following keywords used by the NHMRC in previous similar data searches:

- ▶ lesbian
- ▶ gay
- ▶ homosexual
- ▶ bisexual
- ▶ transgender
- ▶ homophobia
- ▶ intersex
- ▶ transsex
- ▶ heterosexual
- ▶ single sex
- ▶ same sex.

We then manually reviewed the resulting project summaries to assess whether they related to ageing. The only research grant that appeared to be relevant to both LGBTI and ageing was:

- ▶ *Grant ID: 1013353. Investigator: A/Prof Templeton. Project summary: The presence of anal pre-cancer in mature aged homosexual men. Funding amount: \$144,726 over 5 years from 2011.*

⁴ The consortium partners are La Trobe University, University of New England, Southern Cross University, University of Washington, National LGBTI Health Alliance, COTA Australia, Carers Australia and Sane Australia.

In a letter dated 23 August 2019, NHMRC advised us that,

“Over the last 10 years, NHMRC has received an average of approximately 12 applications per year that are related to LGBTI research, for a total of 115 applications received between 2009 and 2018. Of these, 26 grants relating to all aspects of LGBTI research have been funded, for an overall funded rate of 22.6%. There is strong demand for NHMRC funding and the process is very competitive so not all high quality research proposals are able to be funded, however the funded rate for LGBTI related research over the last ten years is above average when compared to other areas of research that NHMRC supports.”(37)

The letter from NHMRC also noted that

“NHMRC also provides funding to the Dementia Centre for Research Collaboration, which has produced a number of LGBTI-related guides and resources, including an e-learning module to inform carers of the additional considerations required when caring for LGBTI peoples who present with behavioural and psychological symptoms of dementia.

NHMRC supports a broad range of research from discovery science through to clinical research (including clinical trials), health services and public health research. With the exception of Targeted Calls for Research and priority areas, NHMRC funding is not directed to any specific disease or health issue. Research topics are investigator driven and funding decisions are an outcome of a competitive process that relies on the collective judgement of independent peer reviewers.”(37)

4. Medical Research Future Fund (MRFF)

In the 2014-2015 Budget the Australian Government created the MRFF, which will build to \$20 billion by 2020-21.(38) The MRFF's budget for research in 2017-2018 was just over **\$121.5 million**.(30) In November 2018, the MRFF published its Australian Medical Research and Innovation Priorities 2018-2020. (39) One of the twelve priorities is:

"Ageing and Aged Care

Research into the diseases of ageing and the means to prolong quality of life, including tackling cognitive decline and dementia, and compressing the period of intense morbidity in later years through biomedical discovery and health service innovation.”(39)

We consider that LGBTI ageing research falls within this priority.

In a letter dated 27 August 2019, DOH advised us that *“since the commencement of the MRFF in 2017, \$28.38 million has been provided for 17 ageing and aged care research projects.”(40)* However, it appears that none of the grants allocated in 2017 and 2018 relate specifically to **LGBTI** ageing research.(38)

The letter from DOH also noted that,

“The MRFF's Ageing, Aged Care and Dementia Mission, through which the Australian Government will invest \$175 million over ten years from 2019-2020 is a significant opportunity to support research that improves outcomes among the elderly. I can confirm that an Expert Advisory Panel has been established to advise the government on the priorities for the Mission. I understand the Panel is expected to consider all older people, irrespective of their background or life experience and that research proposals which focus on older LGBTI Australians can be considered.”(40)

LITERATURE REVIEWS OF LGBTI AGEING RESEARCH

AAG SCOPING REVIEW LGBTI AGEING RESEARCH (2019)

In 2018, AAG conducted a scoping review of LGBTI ageing research in Australia and internationally. The results are reported in a companion publication *AAG Scoping Review LGBTI Ageing Research*, available online at [\(2\)](http://www.aag.asn.au)

The aim of this scoping review was to map the range of the available LGBTI ageing research. English-language studies from all countries were included in this Scoping review and the results section also separately reports on research from Australia and New Zealand.

Seventeen academic databases were searched using a selected list of relevant terms related to LGBTI, ageing and dementia. 'Grey' literature was also considered for inclusion. The 5,617 results identified through the searches were screened for inclusion by removing duplicates and assessing titles and abstracts/text. A summary was prepared of the 837 included studies, including information about:

- ▶ year of publication
- ▶ geographical region of study
- ▶ type of study
- ▶ genders explored
- ▶ sexualities explored
- ▶ topics explored.

Key conclusions included:

- ▶ Australia has a relatively high proportion of publications exploring LGBTI ageing relative to population size when compared to North America.
- ▶ Based on the findings of this scoping review, AAG has identified the following areas where there potentially may be enough evidence to conduct further evidence assessments and develop guidance for Australian aged care and other service providers:
 - o Social connectedness of older lesbian women and gay men in later life, including identity commitment, concealment and development; mental health and mental healthcare services;

community/social support; relationships, intimacy and sexuality, and; discrimination.

- o Housing needs and preferences of older lesbian women and gay men, including residential aged care
- ▶ There is a need for evaluations of services that aim to improve the ageing experience for LGBTI people.
 - o This scoping review found that studies that explore and define issues faced by older LGBTI people are the most common. Service provision models and other approaches to meeting the needs of older LGBTI people must be developed and assessed.
 - o For example, a 2018 systematic review on community-dwelling LGBT people's perceptions of sexuality in residential aged care identified the urgent need to further explore the actual experiences of older residents in LGBT-specific facilities and non-LGBT specific facilities.
- ▶ Future research should explore and report on findings for lesbian, gay, bisexual, transgender and intersex people separately. Grouping all LGBTI people together fails to acknowledge or capture the diversity between and within and between each group and may lead to over-simplifications and erroneous generalisations.
 - o Most the systematic literature reviews identified in this scoping review grouped findings for all older LGBTI people together, an approach that is also noted as problematic by other authors of reviews.
- ▶ Future research is needed on the specific ageing needs of, and service provision for, older transgender people and issues specific to transgender people's ageing.
 - o This scoping review found that transgender people are underrepresented in publication when compared to men and women.
 - o The three non-systematic literature reviews focussing specifically on older transgender people published in the last decade all concluded that there is an underrepresentation of older transgender people in research.

- ▶ Future research is needed on the specific ageing needs of, and service provision for older people with intersex variations and issues specific to the ageing of people with intersex variations.
 - People with intersex variations were underrepresented in the individual publications identified in this scoping review.
 - People with intersex variations were included in none of the systematic literature reviews and only one of the non-systematic literature reviews published in the last decade that were identified in this scoping review.(2)

OTHER LITERATURE REVIEWS

AAG's scoping review identified eight systematic literature reviews and fourteen 'other' literature reviews published from 2009 onwards.(2) A detailed list, including the key findings, of these reviews are provided in Appendix 1 of the AAG scoping review.

It appears that (apart from *Ageing and Sexual Orientation: a 25-Year Review of the Literature* discussed below) most of these other literature reviews do not provide an overview of what LGBTI ageing research is available, but instead focus on narrower areas of interest – such as a specific group (e.g. lesbians) or field (e.g. social work) or topic (e.g. mental health).

In 2010, Karen Fredriksen-Goldsen and Anna Muraco published *Ageing and Sexual Orientation: a 25-Year Review of the Literature*.(7) This review covers a narrower range of research than AAG's scoping review, and is limited to research:

- ▶ published in the years 1984 to 2008
- ▶ conducted in the USA and Canada only
- ▶ about lesbian, gay and bisexual older people (but does not cover transgender people or people with intersex variations)
- ▶ included in peer-reviewed journals
- ▶ excluded research focussed specifically on HIV/ AIDs.

The Fredriksen-Goldsen and Muraco review analyses 58 research articles and concludes that:

- ▶ The initial research on LGB ageing focussed on dismantling stereotypes.
- ▶ Psychosocial adjustment to ageing was the theme of the next wave of research.
- ▶ The third wave focussed on identity development in the lives of older LGB people.
- ▶ The most recent wave of research examines the social support and community-based needs and experiences of older LGB adults.
- ▶ One last trend in the most contemporary wave of research is the greater inclusion of bisexual and transgender experiences in studies on ageing.(7)

Fredriksen-Goldsen and Muraco set out a blueprint for future research that included the following recommendations:

- ▶ Pay greater systematic attention to ageing LGB populations⁵
- ▶ Future studies need to examine the effects and interaction of specific factors such as age, gender, ethnicity, socio-economic status, health, disability, family, discrimination and community-engagement
- ▶ While most research clusters lesbian, gay and bisexual issues, it is important to better understand the similarities and differences between these diverse groups
- ▶ Apply a life-course perspective to future research
- ▶ Use longitudinal studies that follow LGB individuals over time
- ▶ Address the unique methodological issues in studying 'hidden' populations
- ▶ Be more inclusive about capturing the experiences of traditionally under-represented groups.(7)

We understand from correspondence with Professor Fredriksen-Goldsen that she is in the process updating this literature review to cover LGB ageing research done since 2008.(41) As at the time of writing, the updated review had not been published.

⁵ We note that this review did not cover research about older transgender people or people with intersex variations

AAG SURVEY OF LGBTI AGEING RESEARCHERS

In 2018, AAG conducted a survey of researchers who conduct LGBTI ageing research in Australia. The results are reported in a companion publication *A Survey of LGBTI Ageing Researchers in Australia*, available online at www.aag.asn.au.⁽³⁾

The objective of this survey was to obtain evidence from researchers to inform policy on LGBTI ageing research in Australia. We envisage that the results could help identify further opportunities for action in accordance with the *Australian Government Diversity Action Plan 2019*.⁽¹⁾

The survey was conducted by sending an email to approximately 1,350 AAG members and 18 AAG Collaborative Research Centres (CRCs) inviting them to complete an online survey if they conducted LGBTI ageing research in Australia. The survey asked about what issues they were currently researching; their sources of funding; and what they believed were the priority areas for future LGBTI ageing research.

Sixty-two respondents participated in the survey. Survey responses were analysed provide descriptive summary statistics, and free text responses were manually grouped into broad categories. Several limitations affecting the survey results were noted.

Based on the survey results, we reached the following conclusions about LGBTI ageing researchers in Australia:

- ▶ There are many researchers who identify as LGBTI.
- ▶ There was insufficient evidence to draw inferences about whether particular groups within the LGBTI communities are under-researched.
- ▶ There appears to have been a high focus on aged care research in recent years.
- ▶ Researchers consider that future research should focus on more general ageing issues.
- ▶ Apart from aged care, top priority research areas include:
 - physical and mental health
 - social inclusion /exclusion
 - discrimination.
- ▶ Within aged care, top priority research areas include:
 - Dementia
 - Social inclusion/exclusion
 - Finance
 - End-of-life care
 - Other health issues.
- ▶ There was insufficient evidence to draw inferences about the amount and source of research funding in recent years.
- ▶ However, researchers consider that the current funding model does not meet future needs and that lack of resources is a major barrier to future development.
- ▶ Researchers consider that collaboration (with older LGBTI people, aged care providers, and health and medical providers) is very important for future development.
- ▶ Researchers consider that data collection issues are a barrier to future development.⁽³⁾

DISCUSSION

In addition to the issues discussed in the previous sections on the *Scoping Review* and the *Survey of Researchers*, we raise the following issues for consideration:

IMPLEMENTATION OF RESEARCH GOAL

Up to 11% of the Australian population are LGBTI.(9) The previous policy goal (set under the LGBTI Strategy 2012) was that GLBTI people would be a priority for ageing and aged care research.(9) However, there is acknowledgement (in the Strategy Review 2017) that despite previous efforts, LGBTI ageing research remains an outstanding need.(13)

The current policy goal (set under the Diversity Framework 2018) requires the Government to ***‘collect and use data and evidence on current and emerging trends in diversity to design, implement, evaluate and improve aged care systems and supports.’***(4) None of the Australian Government Action Plan items for 2019 appear to specifically relate to LGBTI ageing research. (1) However, the Action Plan notes that ***‘the Aged Care Sector Committee Diversity Sub-Group will monitor the government’s progress and work with the Department of Health to identify further opportunities for action.’***(1) The recommendations provided later in this position paper identify further opportunities for action in relation to LGBTI ageing research.

FUNDING MODEL

Our review of data from key Australian funding bodies (DOH, ARC, NHMRC and MRFF) appears to show that only \$713,000 has been granted for LGBTI ageing research in recent years. Our survey did not obtain enough data to draw inferences about the overall amount and sources of funding for LGBTI ageing researchers in Australia.(3)

Our survey found that 89% of respondents thought the current funding model for LGBTI ageing research in Australia does not meet foreseeable needs. We asked respondents to rate the importance of various factors in developing LGBTI ageing research in Australia and 70% rated ***‘quarantined funding for LGBTI ageing research’*** as high or medium-high importance.(3)

Despite these uncertainties around funding, our scoping review identified 94 publications about LGBTI ageing research from Australia and New Zealand and concluded that this was a relatively high proportion of publications for our population size (compared to North America). However, the scoping review noted that the number of studies identified may be an overestimate as individual research projects may be reported in more than one publication.(2)

The key research funding bodies in Australia appear to have a mandate from the Science and Research Priorities 2015 to give priority to research on vulnerable groups such as older LGBTI people. (5) The MRFF also has a mandate from the Australian Medical Research and Innovation Priorities 2018-2020 to give priority to research on ageing and aged care, including for older LGBTI people.(39)

The 2017-18 Federal Budget announced significant allocations for research, as shown in Table 3.(30) The key research funding bodies in Australia appear to have enough resources to increase the amount of grants they make for LGBTI ageing research in future. This could be addressed by acknowledging LGBTI ageing research as a priority area and by quarantining funding.

Table 3. 2017-18 Federal Budget allocations for research

Research funding body	2018-19	2019-20	2020-21
ARC	\$760 million	\$787 million	\$804 million
NHMRC	\$829 million	\$844 million	\$855 million
MRFF	\$215 million	\$386 million	\$643 million
University research block grants	\$1,939 million	\$2,016 million	\$2,097 million

ACCESSIBILITY OF RESEARCH

It is clear that the current research goal in the *Diversity Framework* is not about doing LGBTI ageing research for its own sake, but rather about using research *‘to design, implement, evaluate and improve aged care systems and supports.’*⁽⁴⁾ In order for research to be used in this way, it needs to be accessible to the policy makers and service providers who are involved in designing and delivering aged care systems and supports. A recent Australian study by Boreham, Cherney and Head identified a range of issues impeding the uptake of academic research in policy development, including:

- ▶ difficulties for the public sector in accessing full-text versions of articles
- ▶ academic reward systems which do not adequately recognise dissemination
- ▶ insufficient forums to bring together researchers with end-users.⁽⁴²⁾

Much of the LGBTI ageing research identified in our scoping review was searched and accessed via subscription databases and were behind journal paywalls, rather than available via open or free access.⁽⁴³⁾ Our survey also noted the that no LGBTI ageing researchers were employed in government or as policy officers.⁽³⁾

GROUPS BEING RESEARCHED

At the beginning of this position paper project, we received some anecdotal feedback from stakeholders that there was little research being done about some groups within the LGBTI acronym (in particular, about people who identify as bisexual, transgender people, and people with intersex variations). Participants in AAG's Rainbow Café (2015) also identified research on transgender and bisexual people as priority areas.(8)

Our survey did not obtain sufficient data to draw any inferences about the groups being researched. (3) Relevant results from our scoping review of LGBTI ageing research publications are set out in Table 4.(2) Please note that each publication may have explored more than one group and many publications included other terms for sexuality, gender or body type.

Table 4. AAG Scoping Review of LGBTI Ageing Research: Groups being researched

Group being researched	Publications about this group in Australia and New Zealand		Publications about this group across all regions	
	Percentage	Number Total N=94	Percentage	Number Total N=837
Men	88%	83	78%	655
Women	64%	60	72%	604
Transgender	46%	43	34%	286
Lesbian	65%	61	71%	594
Gay (male or female)	89%	84	77%	646
Bisexual	48%	45	45%	374
People with intersex variations	29%	27	4%	35

Our scoping review also considered the findings of other literature reviews and concluded that:

- ▶ future research should explore and report on findings for each group separately.
- ▶ transgender people and people with intersex variations are underrepresented in the LGBTI ageing research and future research is needed for these two groups.(2)

The Fredriksen-Goldsen and Muraco literature review reached similar conclusions.(7)

TYPES OF STUDY

The current research goal in the *Diversity Framework* includes a reference to using **evaluation** to improve aged care systems and supports.(4) During the Strategy Review of the previous research goal, stakeholders noted the need to support the **translation** of knowledge and evidence into practice, and the need for **longitudinal studies** exploring LGBTI aged care needs over time. (13)

Our scoping review:

- ▶ found that the most common type of studies were descriptive studies (reported in 325 out of 837 publications). This appears to align with the finding in our survey that the most commonly mentioned benefit of research was “awareness raising.”(3) However, it is unclear how much descriptive studies contribute to direct improvements in aged care systems and supports.
- ▶ found relatively few publications that appear to be translation of knowledge (including frameworks, policies, guidelines or training). There were just 113 publications out of 837 in this category.
- ▶ found very few evaluation studies (total of 46 out of 837 publications). The scoping review concluded that there is a need for evaluations of services that aim to improve the ageing experience for LGBTI people.
- ▶ did not assess whether studies were longitudinal. (2)

The Fredriksen-Goldsen and Muraco literature review also recommended the use of longitudinal studies that follow individuals over time.(7)

COLLABORATION WITH OTHER STAKEHOLDERS

Our survey focussed only on LGBTI ageing researchers in Australia.(3) Survey respondents told us that the most important factor in developing LGBTI ageing research was increased collaboration with older LGBTI people. The survey also found that increased collaboration with aged care and health service providers were important factors in developing LGBTI ageing research. Finally, the survey noted that none of the researchers who participated were employed in government.(3) It was beyond the scope of this project to seek the views of older LGBTI people, service providers and policy makers on LGBTI ageing research issues.

PRIORITY TOPICS FOR FUTURE RESEARCH

Aged care topics

Our survey found a strong focus on ‘aged care’ research among researchers in Australia (almost half of the respondents said it was their main field of research).(3) This aligned with the finding in our scoping review that there were proportionately more studies on aged care in Australia and New Zealand, compared to all regions combined.(2) We suspect this result may simply reflect the aged care focus in the initial LGBTI Strategy 2012.(9) Within the area of **aged care research**, our survey participants identified the following topics as their top three priorities:

1. Dementia
2. Social inclusion/exclusion
3. Equal ratings for:
 - Finance
 - End-of-life care
 - Other health issues.(3)

Ageing topics

While we acknowledge the importance of building a good evidence base for aged care, the narrow focus on aged care research in Australia may have had a dampening effect on research about broader issues. Our survey participants rated a number of general ‘ageing’ topics as priority areas for future research (see Table 5).(3) A number of these ageing topics were also identified as priorities or areas warranting further attention in our scoping review (2), the Fredriksen-Goldsen and Muraco literature review (7), or the AAG Rainbow Café.(8) We have noted these topics in Table 5.

Our scoping review identified the number of studies from Australia and New Zealand found on each of these topics (see Table 5).(2) The scoping review found similar numbers/proportions of studies on these topics in the review of publications across ‘all regions.’ There were very few studies found for most of the priority topics identified in the survey. There were only four priority topics that appear to have relatively high numbers of research papers already published (marked with an asterisk in Table 5).

However, we note that it possible that individual research projects may have been reported in more than one publication.(2)

Funding bodies should carefully consider giving priority to funding LGBTI ageing research on the topics in Table 5.

Table 5. Priority LGBTI ageing research areas identified in AAG Survey of Researchers

Priority LGBTI ageing research areas identified in AAG Survey of Researchers (N=18)	Topics included within each priority area identified in survey	Also identified as a priority by: -Scoping Review (SR) -Frederiksen-Goldsen (FG) -AAG Rainbow Café (RC)	Number of Australian & New Zealand studies on each topic found in AAG Scoping Review (N=94)
Physical and mental health	Dementia/Alzheimers'	RC	6 (6%)
	*Physical health/access to healthcare	FG	24 (26%)
	HIV/AIDS	RC	8 (9%)
	*Mental health and mental health care services	SR	24 (26%)
Social inclusion/exclusion	*Community/informal support networks	SR	23 (24%)
	Family – biological / of choice	FG	7 (7%)
	Housing	SR	4 (4%)
	Regional, rural and remote		2 (2%)
	Policy and legislation		5 (5%)
	Social exclusion		7 (7%)
Discrimination	*Discrimination	FG, SR	37 (39%)
	Elder abuse		1 (1%)
	Media portrayal of older LGBTI people		0 (0%)
Finances	Poverty	FG	4 (4%)
	Finance		2 (2%)
	Homelessness		0 (0%)
	Estates		1 (1%)
	Employment/unemployment		4 (4%)
Special needs groups	Care leavers		1 (1%)
	Culturally and linguistically diverse people	RC, FG	3 (3%)
	Indigenous People	RC	1 (1%)
	Veterans		0 (0%)

*These topics appear to have relatively higher amount of published research

APPENDIX

This paper has been endorsed by the following organisations:

- ▶ Ageing with Pride
- ▶ Carrie Hayter Consulting
- ▶ Celebrate Ageing – Alice's Garage
- ▶ GLBTI Rights in Ageing Inc (GRAI)
- ▶ Helping Hand Aged Care
- ▶ Southern Cross University
- ▶ University of Melbourne

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NOTES



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