



Report launched on 25 October 2019

# **ACKNOWLEDGEMENTS**

# ACKNOWLEDGMENT 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 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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- Carrie Hayter, Carrie Hayter Consulting
- ▶ June Lowe, GLBTI Rights in Ageing Inc
- ► Helen Radoslovich, Helping Hand Aged Care

# NOTE ABOUT TERMINOLOGY

When using the acronym '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 reflected within this acronym. However, this report is intended to be inclusive of all people with diverse sexualities, genders, bodies and relationships.

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# **EXECUTIVE SUMMARY**

### **ABOUT US**

Since 1964, the Australian Association of Gerontology (AAG) has been Australia's peak national body linking researchers, educators, policy-makers, practitioners and other experts engaged in ageing issues. With over 1,455 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 Ageing 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 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. In March 2018, AAG members and Collaborative Research Centres were invited to complete an online survey. Sixty-two respondents participated in the survey. Based on the results, we reached the following conclusions about LGBTI ageing researchers in Australia:

- ▶ There are many researchers who identify as LGBTI.
- ► 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.
- ▶ Researchers consider that:
  - the current funding model does not meet future needs and that lack of resources is a major barrier to future development.
  - collaboration (with older LGBTI people, aged care providers, and health and medical providers) is very important for future development.
  - data collection issues are a barrier to future development.

## INTRODUCTION

By 'lesbian, gay, bisexual, transgender and intersex (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 and intersex, and those who might describe their gender and/or sexuality in different ways (e.g. gender diverse, queer or two-spirit).

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.(1) In November 2017, the Review of the National LGBTI Ageing and Aged Care Strategy noted that despite some progress "it is acknowledged that primary research remains an outstanding need."(2)

In December 2017, the Aged Care Diversity
Framework required 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" for older LGBTI people (Outcome 4).(3)

In February 2019, the *Australian Government Diversity Action Plan* included some specific actions for Government around Outcome 4, including:

- develop a data governance group
- ensure diversity is included in all future aged care funding rounds
- ▶ formalise an ongoing role for the Aged Care Sector Committee Diversity Sub-Group
- improve dissemination of outcomes from diversity-focused aged care projects previously funded, to broaden the evidence base for future program design.(4)

The plan specifically states that "The Aged Care Sector Diversity Sub-Group will monitor the Government's progress and work with the Department of Health to identify further opportunities for action."(4)

### **OBJECTIVES**

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 of this survey could assist the Aged Care Sector Diversity Sub-Group and the Department of Health to identify further opportunities for action in accordance with the Australian Government Diversity Action Plan 2019.(4)

The survey asked Australian LGBTI ageing researchers about what issues they were currently researching; their sources of funding; and what they believed were the priority areas for future LGBTI ageing research.



# RESULTS

### **METHODS**

### Design

The survey was designed by the authors in consultation with the steering group for this project. Ethics approval was obtained from Southern Cross University (approval number ECN-18-008).(5)

#### **Procedure**

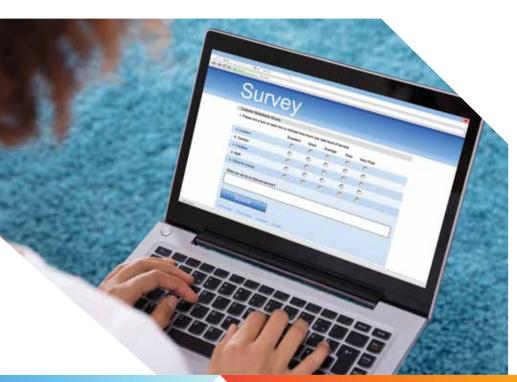
In late March 2018, an email was sent to approximately 1,350 AAG members and 18 AAG Collaborative Research Centres (CRCs) inviting them to read the respondent information sheet and complete an online survey (via Survey Monkey) if they conducted LGBTI ageing research in Australia. CRCs are research centres based in universities and institutes across Australia that engage with AAG on issues affecting ageing and aged care research. A full list of CRCs is provided in Appendix 1. The email also invited recipients to forward the survey to other relevant researchers in their networks. A follow-up email was sent after six weeks. The survey closed in late May 2018.

### Data analysis

Survey responses were analysed using Survey Monkey analysis tools to provide descriptive summary statistics. Free text responses were manually grouped into broad categories of responses.

### **SAMPLE**

We note that there may be LGBTI ageing researchers in Australia who did not participate in this survey. In addition, not all respondents answered every question in the survey (there were only 7 compulsory questions). The number (N) who answered each question is reported in the results below. Finally, this survey only asked questions about individual researchers' work. As a consequence, the results do not give a 'global view' of LGBTI ageing research activity in Australia. See further information in the limitations section of this report.



## 1. Demographics

Sixty-two respondents consented to participate in the survey. A range of demographic data about the respondents was collected. Respondents could select more than one answer for the gender question (there were 63 responses from 62 people). Responses are presented in Table 1.

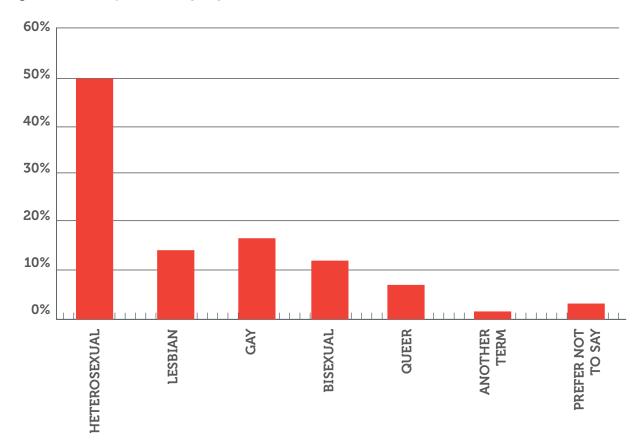
Table 1: Demographics of LGBTI Ageing Researchers

Characteristic	Sample	Characteristic	Sample
State/Territory	N=62	Age	N=62
Victoria	39% (n=24)	20-29	11% (n=7)
New South Wales	29% (n=18)	30-39	19% (n=12)
Queensland	10% (n=6)	40-49	19% (n=12)
South Australia	10% (n=6)	50-59	35% (n=22)
Western Australia	5% (n=3)	60-69	11% (n=7)
Tasmania	3% (n=2)	70 or more	3% (n=2)
Overseas	3% (n=2)		
Australian Capital Territory	2% (n=1)		
Gender	N=62	Where employed	N=28
Female	65% (n=40)	University	39% (n=11)
Male	32% (n=20)	Community	36% (n=10)
Transgender	2% (n=1)	Industry	11% (n=3)
Another term	2% (n=1)	Research institute/centre	7% (n=2)
Prefer not to say	2% (n=1)	Hospital	4% (n=1)
		Other	4% (n=3)
		Government	-
Highest qualification	N=62		
Degree	31% (n=19)	_	
Other postgraduate	29% (n=18)	_	
PhD	27% (n=17)	_	
Doctor of Medicine	11% (n=7)	_	
Other	2% (n=4)	_	

## 2. Sexuality

100% (n=62) of respondents told us about their sexuality. Respondents could select more than one answer for the sexuality question (there were 65 responses from 62 people). Responses are shown in Figure 1.

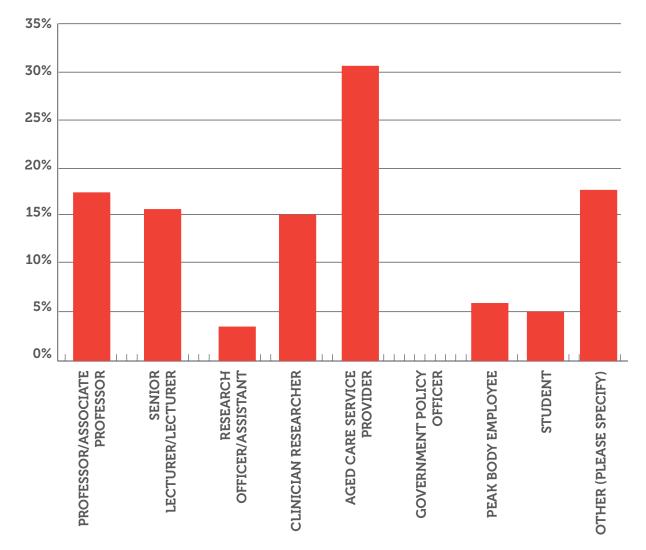
Figure 1. Sexuality of LGBTI ageing researchers



## 3. Primary position

100% (n=62) of respondents told us about their primary position. Responses are shown in Figure 2.

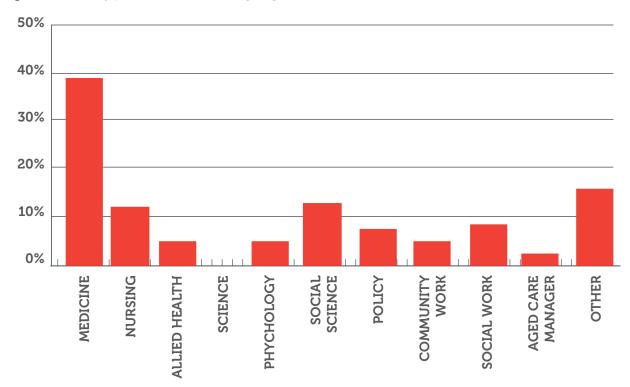
Figure 2. Primary position of LGBTI ageing researchers



## 4. Primary profession

100% (n=62) of respondents told us about their primary profession. Responses are shown in Figure 3.

Figure 3. Primary profession of LGBTI ageing researchers



# CURRENT LGBTI AGEING RESEARCH

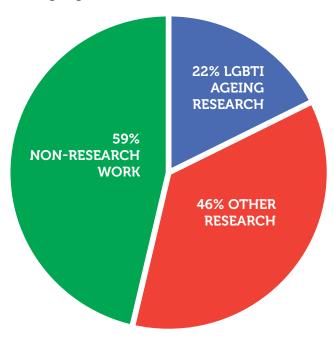
### 5. Primary research interest

53% (n=33) of respondents told us whether they consider LGBTI ageing research to be their primary research interest. 73% answered 'no' and 27% answered 'yes.'

### 6. Time spent on research

45% (n=28) of respondents told us about the percentage of work time that they spend on LGBTI ageing research. Responses are depicted in Figure 4.

**Figure 4.** Average percentage of work time spent on LGBTI ageing research



### 7. LGBTI ageing research interests

52% (n=32) of respondents briefly described their LGBTI ageing research interests. Their free text responses were grouped into seven themes. Figure 5 shows the percentage of respondents who described research interests within each theme.

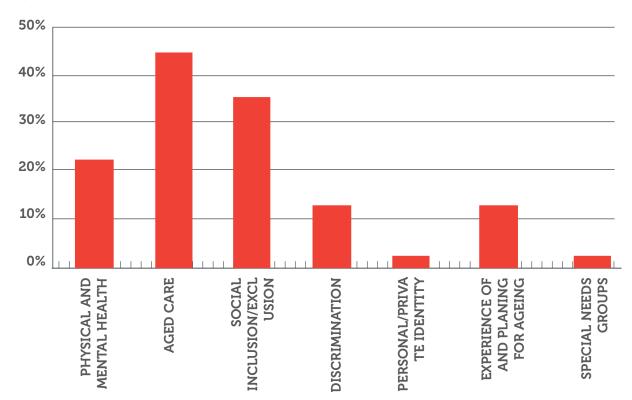


Figure 5. LGBTI ageing research interests

### 8. Main field of LGBTI ageing research

56% (n=35) respondents told us about their main field of LGBTI ageing research. Responses were aged care (46%), health (29%), social issues (20%) and other (6%). No respondents nominated economic, housing or legal as their main field.

### 9. Which people are the focus

53% (n=33) of respondents told us which people are the focus of their LGBTI ageing research. Respondents were asked to tick all that apply (i.e. not just their primary focus). There were 149 responses from 33 people. Responses are shown in Figure 6. We believe there is insufficient data to draw inferences about whether particular groups are under-researched (see note 5 in the limitations section).

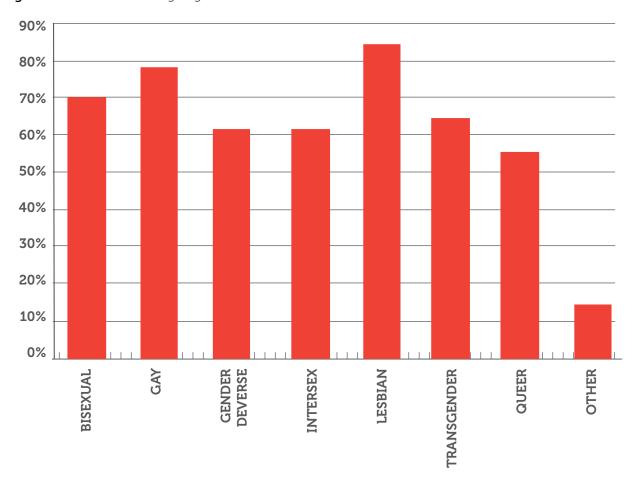


Figure 6. Focus of LGBTI ageing research

### 10. Involvement of older LGBTI people

44% (n=27) of respondents told us whether they have involved older people in their research processes. 74% answered 'yes' and 26% answered 'no.'

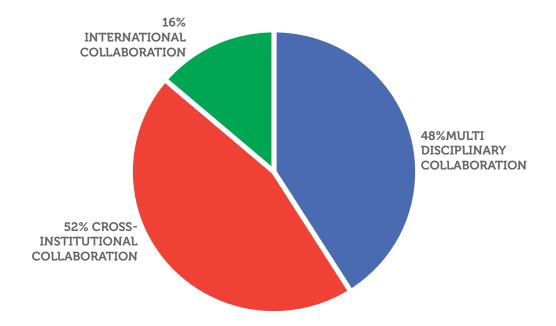
#### 11. Collaboration with other researchers

45% (n=28) of respondents told us whether they are involved in collaboration with researchers from other areas. 57% answered 'yes' and 43% answered 'no.'

### 12. Types of collaboration

23% (N=14) of respondents told us how much of their collaborative research time is spent on three types of collaboration. Respondents were able to choose more than one option. Responses are depicted in Figure 7 (see note 2 in the limitations section).

Figure 7. Average percentage of collaborative research time spent on three types of collaboration

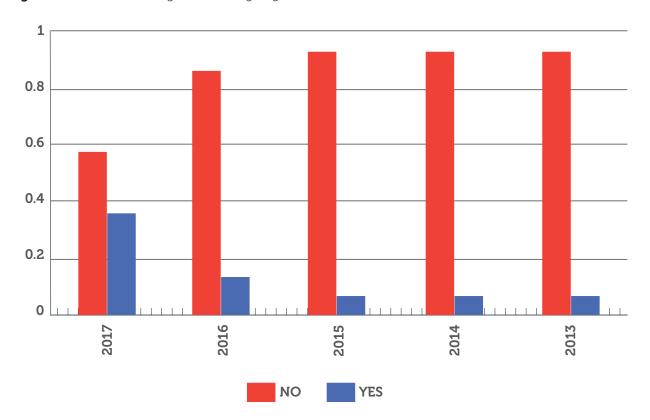


## FUNDING FOR LGBTI AGEING RESEARCH

### 13. Whether funding received

44% (n=27) of respondents told us whether they received any funding for LGBTI ageing research in 2013, and 42% (n=26) of respondents told us whether they received any funding in each of the years 2014, 2015, 2016 and 2017. In total, only 21 respondents received funding over the five years period (2013-2017). Responses are shown in Figure 8.

Figure 8. Whether funding for LGBTI ageing research was received (2013-2017)



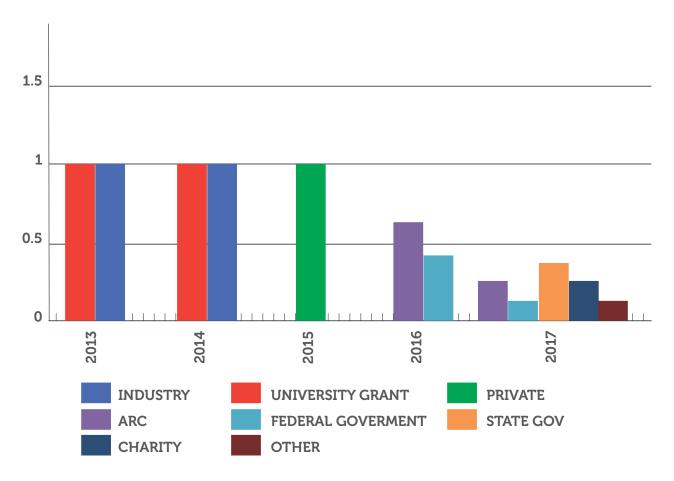
### 14. Amount and source of funding

Very few respondents (ranging from n=1 to n=9 for each year) provided information about the amount or source of funding they received for LGBTI ageing research during the years 2013 to 2017. The total amount of funding disclosed for each year is shown in Table 2, and the source of the funding disclosed is shown in Figure 9. However, we do not believe there is sufficient data to draw inferences about the amount and source of funding in recent years (see note 3 in the limitations section).

Table 2. Amount of funding received 2013-2017

Year	Amount
2013	\$10,000
2014	\$10,000
2015	\$15,000
2016	\$335,000
2017	\$455,500

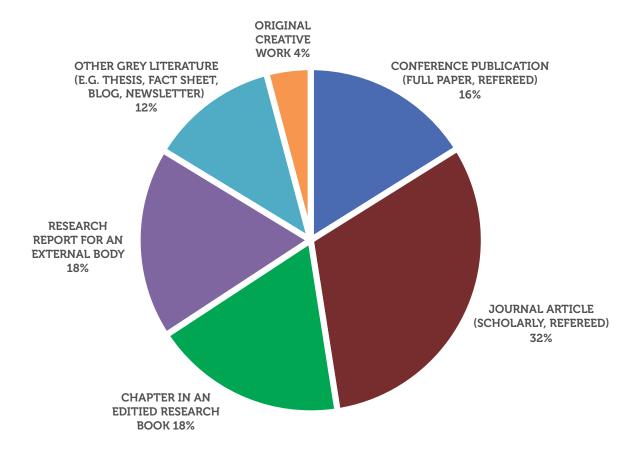
Figure 9. Source of funding received 2013-2017



### 15. Research outputs

27% (n=17) of respondents told us about the outputs of their LGBTI ageing research over the past five years. Respondents were asked to specify the number produced for each type of output. A total of 49 outputs were produced. Responses are shown in Figure 10. No respondents indicated that they had produced any commercialisation/patents, nor had any respondents authored a research book. (See note 2 in the limitations section).

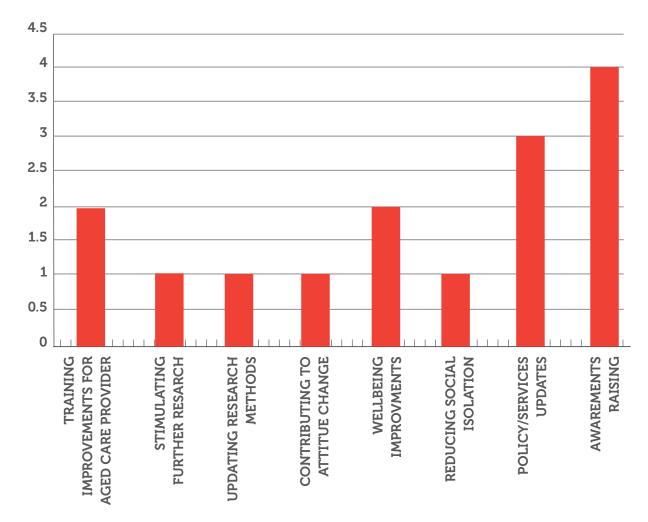
Figure 10. Outputs of LGBTI ageing research over past five years



#### 16. Research benefits

44% (n=27) of respondents told us whether their research had led to any benefits for older LGBTI people. 63% answered 'yes' and 37% answered 'no.' Some (n=19) respondents also briefly described these benefits. Their free text responses were grouped into eight themes and these are shown in Figure 11.

Figure 11. Benefits of LGBTI ageing research



## BARRIERS TO LGBTI AGEING RESEARCH

# 17. Difficulty of obtaining funding for LGBTI ageing research in comparison to other research areas

44% (n=27) of respondents told us how difficult they thought it was to obtain funding for LGBTI ageing research, compared to obtaining funding for other research. No respondents said it was 'much easier' to obtain funding. Responses are shown in Figure 12.

SIMILAR
HARDER
HARDER
HARDER
NOT
APPLICABLE

Figure 12. Difficulty of obtaining funding for LGBTI ageing research

### 18. Major barriers to development

24% (n=15) of respondents told us what the major barriers are to developing LGBTI ageing research in Australia currently. Their free text responses were grouped into four themes: 60% reported lack of respondents; 47% reported lack of resources; 33% reported that older LGBTI people are often not identified in standard research methodology (e.g. by including a sexuality question); and 27% reported lack of understanding that LGBTI older people have unique needs (see note 2 in the limitations section).

## PRIORITIES FOR FUTURE LGBTI AGEING RESEARCH

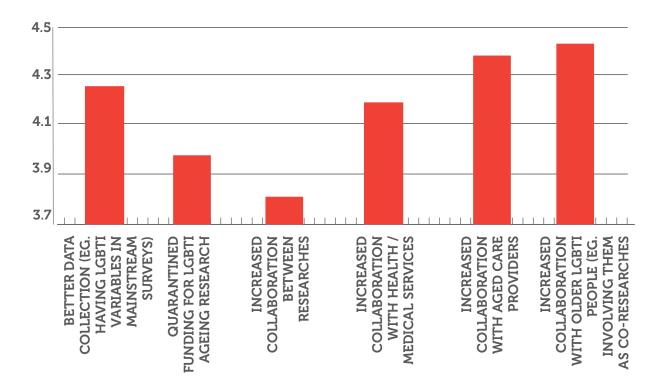
### 19. Adequacy of current funding model

44% (n=27) of respondents told us whether the current funding model for LGBTI ageing research in Australia meets foreseeable needs. 89% answered 'no' and 11% answered 'yes.'

### 20. Important factors in development

34% (n=21) of respondents rated the importance of six factors in developing LGBTI ageing research in Australia. The weighted averages of their responses are shown in Figure 13.

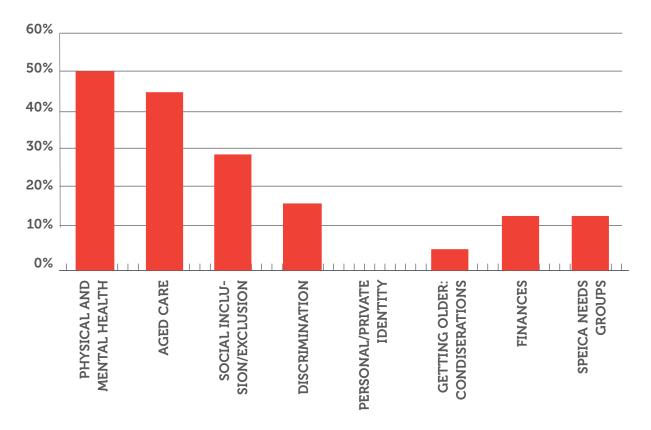
Figure 13. Importance of six factors in developing LGBTI ageing research



### 21. Priority areas for future research

29% (n=18) of respondents told us about priority areas for LGBTI ageing research in Australia. Their free text responses were grouped into thirty-two topics and then further grouped into eight key themes and these are shown in Figure 14 (see note 2 in the limitations section).

Figure 14. Priority areas for future LGBTI ageing research



### 22. Top three research areas for people in aged care

34% (n=21) of respondents told us about the top three LGBTI ageing research areas that could provide dividends in terms of equity of access and outcomes for LGBTI people in community and/or residential aged care. The weighted averages of their responses are shown in Figure 15 (see note 5 in the limitations section).

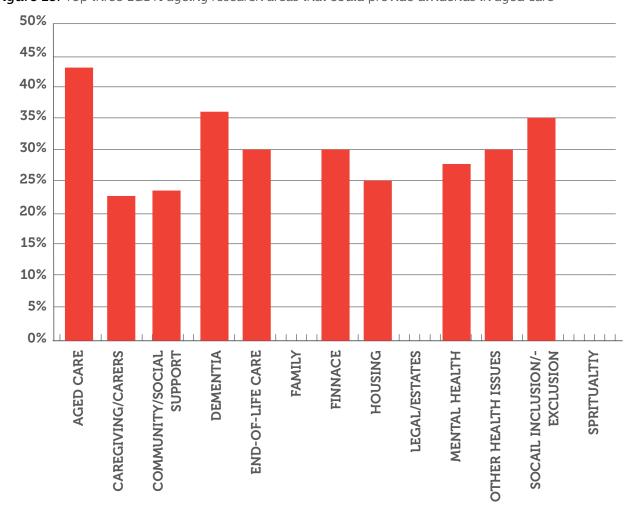


Figure 15. Top three LGBTI ageing research areas that could provide dividends in aged care

### 23. Further comments

13% (n=8) of respondents gave us further comments. Their free text responses were grouped into five themes. Responses are shown in Table 3.

Table 3. Further comments

Number	Description
1	Include more diverse older LGBTI people in research
2	Focus on research that promotes resilience
3	Distribute research more widely
4	Be more innovative in research design
5	Pursing this area of research is highly important

# DISCUSSION

### **INSIDER RESEARCHERS**

LGBTI ageing researchers identified as lesbian, gay, bisexual, queer or another term in 52% (n=34) of the responses (see paragraph 2), which appears to be a higher rate than in the general Australian population (LGBTI people estimated at up to 11% of the population).(1) We were pleased to see this as it is consistent with the general principle of 'nothing about us without us.' Susan Westwood (2014) also notes there is a significant body of research on the benefits of 'insider research,' which is:

when researchers conduct research with populations of which they are also members... so that the researcher shares an identity, language, and experiential base with the study participants...This insider role status frequently allows researchers more rapid and more complete acceptance by their participants. Therefore, participants are typically more open with researchers so that there may be a greater depth to the data gathered.(6)

### **FUNDING ISSUES**

We did not obtain enough data to draw inferences about the amount and source of funding in recent years. However, funding issues emerged as a strong theme in the results. 48% of respondents said it was much harder or harder to get funding for LGBTI ageing research (compared with only 26% who said it was easier or similar) (see paragraph 17). 'Lack of resources' was seen as a major barrier to development by 47% of respondents (see paragraph 18). 89% of respondents said the current funding model does not meet foreseeable needs (see paragraph 19).

Given that the new *Aged Care Diversity Framework* requires the Government to collect and use data and evidence to design, implement, evaluate and improve aged care systems and supports for older LGBTI people, further consideration should be given to how this evidence-base will be funded.(3) We note that the Australian Government Diversity Action Plan requires the Government to ensure diversity is included in all future aged care funding rounds.(4)

# PURPOSE AND IMPACT OF RESEARCH

The survey raised some issues for consideration about the purpose and impact of LGBTI ageing research. 63% of respondents said they thought their research had led to benefits for older LGBTI people (see paragraph 16). The most commonly mentioned benefit was 'awareness raising', which may simply reflect the focus in the initial National LGBTI Ageing and Aged Care Strategy 2012 (see Figure 11).(1)

There were fewer mentions in the survey results of more direct benefits from research (such as wellbeing improvements and training improvements for aged care providers) (see paragraph 16). Given that improving aged care systems and supports for older LGBTI people is the goal of the new Aged Care Diversity Framework, consideration should be given to how to foster research intended to achieve this, and how to evaluate the impact of such research.

# AGED CARE VS. AGEING RESEARCH

The results of the survey showed a high focus on aged care research, including:

- when asked about their 'main field' of research,
   46% of respondents said aged care (see paragraph
   8)
- when asked about priority areas for future research, 44% of respondents talked about topics in the aged care area (see paragraph 21).

We suspect that this focus on aged care research simply reflects the focus in the initial *National LGBTI Ageing and Aged Care Strategy 2012*.(1) This has both positive and negative implications. On the one hand, it is important to build a good evidence base for aged care policy and practice improvements. On the other hand, this narrow focus may have a dampening effect on research about broader issues associated with LGBTI 'ageing.'

Some broader ageing issues were identified as areas of current research interest, including social inclusion/exclusion (35%) and physical and mental health (22%) (see paragraph 7). Similar issues were also seen as high priority areas for future research, including physical and mental health (50% - i.e. higher priority than aged care) and social inclusion/exclusion (28%) (see paragraph 21).

#### Collaboration

The survey results highlight the importance of collaboration. 57% of respondents said they are already involved in collaboration with researchers from other areas (see paragraph 11) and 74% said they involved older LGBTI people in their research processes (see paragraph 10). However, researchers said the most important factor for developing LGBTI ageing research was increased collaboration with older LGBTI people (see paragraph 20). Lack of older LGBTI participants was the most frequently mentioned barrier to development of LGBTI research (60%) (see paragraph 18). Strategies that foster increased engagement of older LGBTI people should be considered to address these issues.

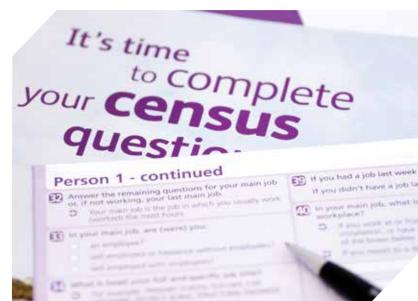
The second most important factor in developing LGBTI ageing research was increased collaboration with aged care providers and the fourth was increased collaboration with health and medical providers (see paragraph 20). The third most important (27%) barrier to development of LGBTI research was the lack of understanding that LGBTI older people have unique needs (see paragraph 18). Strategies that foster collaboration with aged care, health and medical service providers should be considered to address these issues and facilitate a closer connection between research and practice improvements.

We also note that no researchers were employed in government (see paragraph 1) and no researchers were government policy officers (see paragraph 3). This raises the question of whether increased collaboration with policy-makers may be required in order to facilitate a closer connection between research and policy improvements.

### DATA COLLECTION

Data collection issues rated highly as both a barrier to future development of LGBTI ageing research (33%) (see paragraph 18) and as important for future development of LGBTI ageing research (see paragraph 20). We note that the *Australian Government Diversity Action Plan* included some specific actions for Government around data, including:

- develop a data governance group which will:
  - oversee the integration and analysis of existing data
  - identify and implement strategies to address data gaps
  - monitor actions taken to improve data gaps.
- ▶ Initiate a co-design process to identify new data points and/or business process changes required to improve the collection and availability of data(4).



# CONCLUSIONS

Based on the survey results from 62 respondents, we reached the following conclusions about LGBTI ageing researchers in Australia:

- There are many researchers who identify as I GRTI
- ➤ 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.



# LIMITATIONS

- 1. Only 62 people participated in the survey (see paragraph 1). We acknowledge that there may be other LGBTI ageing researchers in Australia who did not participate. There may be a number of reasons for the low number of responses, including:
  - We do not know how many people conduct LGBTI ageing research in Australia. It is possible that 62 responses are a reasonable sample of that population, but we have no way to assess this accurately.
  - The survey was only emailed to members of AAG (approximately 1,350) and 18 CRCs. There may be LGBTI ageing researchers who are not members of AAG or a CRC.
  - We do not know if AAG members and CRCs acted on the invitation to forward the survey to other researchers in their networks. There may be LGBTI ageing researchers who are not within their networks.
- 2. There were only seven compulsory questions in the survey, and the survey automatically skipped questions that were irrelevant (based on earlier answers). As a result, only 22 respondents completed every question in the survey. Some questions had a very low number of responses and the results for those questions must be considered in that context. For example:
  - types of collaboration (n=14) (see paragraph 12)
  - research outputs (n=17) (see paragraph 15)
  - major barriers to development (n=15) (see paragraph 18)
  - priority areas for future research (n=18) (see paragraph 21).

- 3. Only 21 respondents said they had received funding over the past five years (2014-2017). We do not believe the results for the amount and source of funding received during that period (see paragraph 14) are reliable given:
  - the very low number of respondents (n=1 to 9). We do not know why people chose not to answer these questions but possible reasons include that they did not want competitors to know how much funding they received, the information was commercial-in-confidence and/or there was no 'free-text' option to explain their funding situation.
  - that more than one respondent may have reported on funding for joint projects (possibly resulting in double counting of the amount).
- 4. This survey only asked questions about individual researchers' work. As a consequence:
  - the results do not give a 'global view' of LGBTI ageing research activity in Australia. There may be other research activity occurring that is not reflected in these results.
  - joint projects, grants and publications (i.e. that involve more than one survey respondent) may have been reported by more than one respondent and may therefore be double counted.
- 5. With hindsight, we recognise that the wording of some questions limits the usefulness of the results:
  - One question (see paragraph 9) asked 'which people are the focus of your LGBTI ageing research' (i.e. not about the primary focus). Respondents were asked to 'tick all that apply' and it appears that many people ticked multiple answers (there were 19 responses from 33 people). Respondents may have ticked a listed group (e.g. intersex) even if very few or no individuals from that group actually participated in their research.
  - In the question about 'top three research areas for people in aged care', one of the listed areas was 'aged care' itself and unsurprisingly 73% of respondents selected this as their top choice. This effectively left respondents with only two other research areas to nominate as being high priority (see paragraph 22).

# **APPENDIX 1:**

## AAG COLLABORATING RESEARCH CENTRES

### **Australian Capital Territory**

- Centre for Research on Ageing, Health and Wellbeing (CRAHW), Australian National University
- Colloquium for Ageing Perspectives and Spirituality (CAPS), Charles Sturt University

### **New South Wales**

- Ageing, Work and Health Research Group, University of Sydney
- ► ARC Centre of Excellence in Population Ageing Research (CEPAR)
- Centre for Education & Research on Ageing (CERA), University of Sydney/Concord Repatriation General Hospital
- ▶ Dementia Collaborative Research Centres (DCRCs), UNSW /ANU / QUT
- Priority Research Centre for Generational Health & Ageing (RCGHA), University of Newcastle

#### Queensland

► Institute for Future Environments, QUT

### South Australia

- ► Flinders Centre for Ageing Studies, Finders University
- Sansom Institute for Health Research, University of South Australia

#### **Tasmania**

 Wicking Dementia Research and Education Centre, University of Tasmania

#### **Victoria**

- ► La Trobe University Healthy Ageing Research Group (HARG)
- ► National Ageing Research Institute (NARI)
- ▶ The Bolton Clarke Research Institute
- ▶ John Richards Initiative
- ► Hallmark Ageing Research Initiative (HARI)

#### Western Australia

- Western Australian Centre for Health & Ageing (WACHA)
- ► Curtin Ageing Research Network (CARN)

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# NOTES

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To improve the experience of ageing through **CONNECTING RESEARCH, POLICY** and **PRACTICE** 

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