



RESEARCH ARTICLE

REVISÉD **Developing consensus-based recommendations for the delivery of dementia services for the LGBTQIA+ community in the Republic of Ireland [version 3; peer review: 1 approved, 3 approved with reservations]**

Megan H. Oglesby , Sinéad M. Hynes

School of Health Sciences, University of Galway, Galway, H91TK33, Ireland

V3 **First published:** 09 Mar 2022, 5:19
<https://doi.org/10.12688/hrbopenres.13505.1>
Second version: 07 Nov 2022, 5:19
<https://doi.org/10.12688/hrbopenres.13505.2>
Latest published: 28 Feb 2023, 5:19
<https://doi.org/10.12688/hrbopenres.13505.3>

Abstract

Background: The number of older LGBTQIA+ adults is set to rise significantly in the coming years. The rising numbers sit together with the rise in the number of people in Ireland diagnosed with dementia. In Ireland, no dementia-specific services exist for people from the LGBTQIA+ community. The aim of this research was to 1) identify the future needs that older LGBTQIA+ people and their care partners living in Ireland have in relation to dementia care service delivery; and to 2) develop consensus-based recommendations for dementia service provision in Ireland.

Methods: A six-phase consensus process was used to develop the lists of needs and recommendations: 1) development; 2) national survey; 3) interviews with key stakeholders; 4) international review of best practice; 5) consensus meeting; 6) final member checking. Participants, aged over 50, were based in Ireland, identified as a member of the LGBTQIA+ community or supported someone who is/was.

Results: Results are reported from the survey (n=49), individual interviews (n=8), and the consensus meeting (n=10). Participants have concerns related to identity management and suppression, creating an LGBTQIA+ affirmative ethos and workforce, and respect and safety. From the results and consensus process, a full list of ten prioritised needs and recommendations have been developed that focus specifically on dementia care in Ireland for the LGBTQIA+ community.

Conclusion: The older LGBTQIA+ community has identified essential priorities for improving healthcare access and safety. These priorities now need to be urgently implemented into clinical and dementia care services.

Open Peer Review

Approval Status ? ? ? ✓

| | 1 | 2 | 3 | 4 |
|------------------|----------------------|----------------------|----------------------|----------------------|
| version 3 | | | | |
| (revision) | | | ? | ✓ |
| 28 Feb 2023 | | | view | view |
| version 2 | | | | |
| (revision) | ? | | | |
| 07 Nov 2022 | view | | | |
| | ↑ | | | |
| version 1 | | | | |
| 09 Mar 2022 | ? | ? | | |
| | view | view | | |

- Miriam Galvin**, Trinity College Dublin, Dublin, Ireland
- Lyn Phillipson**, University of Wollongong, Wollongong, Australia
Keryn Johnson, University of Wollongong, Wollongong, Australia
- Neil Drummond**, University of Calgary, Calgary, Canada
- Lars-Christer Hydén**, Linköping University, Linköping, Sweden

Any reports and responses or comments on the

Keywords

dementia, LGBTQIA+, older adults, healthcare access, healthcare recommendations, public and patient involvement

article can be found at the end of the article.



This article is included in the [Ageing Populations](#) collection.

Corresponding author: Sinéad M. Hynes (sinead.hynes@nuigalway.ie)

Author roles: **Oglesby MH:** Data Curation, Formal Analysis, Investigation, Writing – Original Draft Preparation, Writing – Review & Editing; **Hynes SM:** Conceptualization, Funding Acquisition, Investigation, Methodology, Project Administration, Supervision, Writing – Original Draft Preparation, Writing – Review & Editing

Competing interests: No competing interests were disclosed.

Grant information: This research was funded by the Irish Research Council New Foundations Award 2021 in collaboration with The Alzheimer Society of Ireland.

The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Copyright: © 2023 Oglesby MH and Hynes SM. This is an open access article distributed under the terms of the [Creative Commons Attribution License](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

How to cite this article: Oglesby MH and Hynes SM. **Developing consensus-based recommendations for the delivery of dementia services for the LGBTQIA+ community in the Republic of Ireland [version 3; peer review: 1 approved, 3 approved with reservations]** HRB Open Research 2023, 5:19 <https://doi.org/10.12688/hrbopenres.13505.3>

First published: 09 Mar 2022, 5:19 <https://doi.org/10.12688/hrbopenres.13505.1>

REVISED Amendments from Version 2

We have made a number of minor changes to this version of the manuscript to increase the clarity of the information presented. Specifically we responded to queries regarding the questionnaire itself. We have edited some of the labels in the Tables and Figures. We have addressed some typos that were identified.

We have also added in a paragraph that demonstrates how we identified the full list of needs and recommendations that were taken to the consensus meeting for discussion.

Any further responses from the reviewers can be found at the end of the article

Background

Many older people from the lesbian, gay, bisexual, transgender, queer/questioning, intersex, and asexual + (LGBTQIA+)¹ community have experienced discrimination and marginalisation in their lives. As homosexuality was not decriminalised in Ireland until 24 June 1993, (*Criminal Law [Sexual Offences] Act, 1993*) many of the older LGBTQIA+ people living in Ireland came of age at a time when same-sex behaviour or gender non-conformity was severely stigmatised and criminalised. Countless people left Ireland or concealed their gender and/or sexual identity because they felt uncomfortable or unsafe. Many older LGBTQIA+ people, particularly trans and gender non-conforming older adults, feel increasingly vulnerable as they age and have significant worries related to preparation for aging (*Sharek et al., 2015*). This is often compounded by previous negative life experiences. The number of older LGBTQIA+ adults is set to rise significantly in the coming years, with the number of older people in general rising (*Sheehan & O'Sullivan, 2020*) at the same time as more people are revealing their gender identity or sexual orientation later in life. Research has clearly shown that older LGBTQIA+ adults are less likely to engage with health services (*Higgins et al., 2011*) and community groups and are more likely to report poor general and mental health (*Fredriksen-Goldsen et al., 2015; Fredriksen-Goldsen & Kim, 2017; Wallace et al., 2011*). Some people articulate strong social support networks (*King & Cronin, 2016*) but this is not the case for many (*Kim et al., 2017*), with increased levels of loneliness and isolation seen in this population (*Kuyper & Fokkema, 2010*).

The number of people living with dementia in Ireland is also on the increase (*Alzheimer Europe, 2020*). There are estimated to be between 39,272 and 55,266 people with dementia in Ireland, which is an increase of 7752 new cases per year (*Pierse et al., 2019*). There is also some debate as to whether older people from sexual minorities are at an elevated risk

of cognitive impairment (*Perales-Puchalt et al., 2019*), with recent robust research suggesting that the rates of cognitive impairment appear to be significantly higher among sexual minority older adults than among heterosexual older adults, even when sociodemographic factors are adjusted for (*Hsieh et al., 2021*). This may be due to members of the LGBTQIA+ community being more at risk for conditions such as HIV and depression which in turn increase the likelihood of developing dementias (*Hoy-Ellis & Fredriksen-Goldsen, 2016*).

Health inequalities can be seen in this community and yet in Ireland very little, if anything, has been done to address the lack of diversity in health care delivery for older adults (*Roe et al., 2020*). Internationally examples of good practice in relation to dementia and older adult services for the LGBTQIA+ community exist, for example, the UK Government published National LGBT Action Plan in 2018 and appointed a National Advisor for LGBT Health which appears to be having a positive impact on health and well-being of the older LGBTQIA+ community (*Opening Doors London, 2021*). However, at the time of conducting this study (2021), there were no dementia organizations in the Republic of Ireland that were offering any LGBTQIA+-specific service or advice. Nationally, there is an imperative need to ensure our health and care services are addressing the needs of under-served populations, such as vulnerable groups like older people from the LGBTQIA+ population. Building on recent recommendations in this area (*Roe et al., 2020*), this research aimed to:

1. Identify the future needs that older LGBTQIA+ people and their care partners living in Ireland have in relation to dementia care service delivery.
2. Develop consensus-based recommendations for dementia service provision in Ireland.

Methods

Ethical approval for the research was granted by the National University of Ireland Galway Research Ethics Committee-Reference number 2021.05.010. Data collection commenced on July 2021 until December 2021. The Standards for Reporting Qualitative Research (SRQR; *O'Brien et al., 2014*) were followed in reporting the results and the SRQR checklist can be found in the Extended Data.

Design

The traditional Delphi consensus process (as described in *Hsu & Sandford, 2007*), which involves multiple iterations with highly trained and specialised Delphi participants, is not well suited for a population of people with dementia. The consensus process used here was adapted to ensure accessibility to people with dementia, older people, and care partners (*Morbey et al., 2019*). The research included older LGBTQIA+ + people with and without dementia throughout the research process (with guidance from *Swarbrick et al., 2019*). There was substantial member involvement throughout. A six-phase process took place to reach a consensus on recommendations and prioritised needs.

¹ The acronym LGBTQIA+ is used throughout this article to recognise the desires of people who identify as queer, questioning, intersex or asexual, who have experienced marginalisation within the LGBTQIA+ community, to achieve increased visibility (*George, 2021*). Please note that the acronym LGBTQI+ was used in the survey so resultantly this term is used in this section.

Public and patient involvement (PPI)

This research was led by PPI members. The research funding application was developed in conjunction with The Alzheimer Society of Ireland and a member of their Dementia Research Advisory Team. At the commencement of the research, a PPI Advisory Group was set up. This group was recruited from the target population and advised on all aspects of the research process. The PPI group was involved in the adaptation and development of the questionnaire, advising on recruitment strategies, and working with the wider group to decide on the ranked needs and recommendations that were brought forward from the consensus process.

Procedure

A six-phase consensus process was followed to identify the needs and recommendations, as described below.

Phase One: Development. The questionnaire to be used was adapted as appropriate to the Irish context. The questionnaire was based on the National Health, Aging and Sexuality/Gender Study (Fredriksen-Goldsen & Kim, 2017) from the US and adapted with the help of the PPI group. The PPI group decided on the inclusion of specific items, length, and format of the questionnaire, rating scales, and accessibility of language. Guides to survey design and implementation were also followed as described by Thayer-Hart and colleagues (2010) and Oppenheim (2000).

The questionnaire was hosted on [QuestionPro](#) and consists of several different sections, including 'Demographics', 'Community', 'Service-Use', 'LGBTQI+ identity', and 'Discrimination'. A total of forty-six items were included in the questionnaire and both full and partially completed questionnaires were accepted. The questionnaire went through several rounds of revisions after consulting with the PPI group and was piloted on a small group of seven people prior to being used in the main study. Several small edits and clarifications were made at this stage, but nothing that changed the overall content. A copy of the questionnaire can be found in the Extended data linked at the end of the paper.

Phase Two: National survey of older LGBTQIA+ people and care partners. During Phase Two the questionnaire was distributed. Postal and online completion options were available to participants. Participants also had the option of completing the questionnaire over a phone or video call. To consent to take part in the survey, participants confirmed that they read the information sheet, and ticked boxes associated with the inclusion criteria to provide their consent. Data collection stopped and the survey was closed after no more responses were recorded in the survey for a period of two weeks.

Participants were eligible to participate if they:

- Identified as a member of the LGBTQI+ community or supported someone who is/was.
- Were aged over 50 years.
- Were able to provide informed consent.

People were not eligible to take part if they provided paid care or were based outside of Ireland.

Participants were recruited through an email or social media post from gatekeepers at relevant organisations, including The [Alzheimer Society of Ireland](#), [LGBT Ireland](#), [TENI](#), [Linc](#) and other relevant local and national LGBTQIA+ organisations in Ireland. We used national LGBTQIA+ websites and magazines ([Gay Community News](#)), and radio and television interviews ([TG4](#) and [Radió na Gaeltachta](#)) to recruit participants. We also advertised through social media, Facebook and Twitter, and paper versions of the questionnaire were available in a number of LGBTQIA+ community resource centres.

Data from the questionnaires were analysed descriptively and written answers were analysed via conceptual content analysis. The responses were exported into an Excel file and screened for errors and omissions to ensure data integrity. Descriptive statistics were calculated, which include totals (n), and percentages. Open-ended text answers were read and re-read, initial codes were then developed that were reflective of the answers described within the data, and quantified in order to identify the pattern of core concepts.

Phase Three: Interviews with key stakeholders. Older LGBTQI+ adults and care partners were interviewed via Zoom. The aim of the interview was to gain more in-depth information on needs that may not be captured in the survey and to further discuss future care needs. Informed consent was obtained in writing for interview participants. The guidance on evaluation of capacity to consent from the British Psychological Society (2020) was followed. As such, obtaining consent was seen as a continuing process, not a one-off decision. Anyone who expressed an interest in taking part in an interview was interviewed. The online interviews were audio-recorded and deleted following transcription. A copy of the topic guide can be found in the Extended data linked at the end of the paper.

Qualitative data from interviews (phase three and four) were analysed using reflexive thematic analysis. This was an iterative, recursive process. All interviews were audio-recorded and transcribed. All transcriptions were de-identified during the transcription process and audio-recordings were deleted immediately after transcription. Following this, the transcripts were read and re-read, and initial codes were developed. From this there was ongoing formation and revision of themes, which facilitated an inductive approach to identifying, analysing, and reporting the themes identified within the data collected (Braun & Clarke, 2012).

The credibility and trustworthiness of the data was ensured through a number of triangulation strategies. This included having multiple data collection methods, as well as including two data analysts. The researchers immersed themselves in the data to ensure rich descriptions. Working with the PPI Advisory group increased the validity of findings and the likelihood of collecting data that was useful to the group under study.

Phase Four: International review of best practice. This phase involved a review of literature in the area, as well as policies and frameworks developed in other countries. Where a pre-existing technique/policy/framework was used internationally, but not in Ireland, the recommendation was included to be discussed and voted on by the consensus group.

As part of this phase, we also interviewed international experts (via Zoom) working or conducting research in dementia care with/for the LGBTQIA+ community. The aim was to develop a representation of what best practice in the area looked like internationally. Expert interview sampling was guided by principles of data adequacy (Levitt *et al.*, 2017). A copy of the topic guide can be found in the Extended data linked at the end of the paper.

The Development of Initial Key Needs and Recommendations.

The initial set of key needs and recommendations was developed in several independent steps by compiling the findings of Phases 2-4. Where strategies were being implemented internationally, but not in Ireland, we compiled these strategies to the list of initial needs and recommendations. Other needs and recommendations became apparent in the analyses of interview and survey data (Phases 2 and 3), through the repetition of anticipated needs or problems faced by LGBTQIA+ older adults in healthcare contexts, or through the repetition of desires and projection of what good older LGBTQIA+ care may look like. However, all recommendations and needs were subject to the consensus group, in which members were given the agency to completely remove, add or make changes to existing needs and recommendations prior to the commencement of the two rounds of voting and the subsequent member checking (Phases 5 and 6).

Phase Five: (Virtual) consensus meeting. The aim of the consensus meeting was to agree on a set of needs and recommendations. The consensus meeting involved the PPI advisory group (n=6), those who took part in the individual interviews (n=1), and representatives from voluntary and healthcare backgrounds (n=2) working with people with dementia (n=1). Ten key stakeholders, who consisted of LGBTQIA+ people with dementia, LGBTQIA+ older adults, former caregivers of LGBTQIA+ older adults, and people who have worked with LGBTQIA+ older adults and/or people with dementia took part in the consensus meeting. A purposeful sampling strategy was used to ensure a diverse group with varied experiences and backgrounds.

Interview participants (not international experts) were invited to participate in the consensus meeting at the recruitment stage and provided written consent to participate in the consensus meeting. Other consensus participants, representatives from voluntary and healthcare backgrounds, provided oral consent and written confirmation via email. The meeting was not recorded, and no personal information was collected during the consensus event. Only a record of the scoring and ranking as a group was collected. Because of the virtual nature of the meeting and because participants may have been experiencing

cognitive impairment, the number of participants included in the meeting was kept low (maximum 10).

The meeting used a modified nominal group technique to ensure the participation of all members and was guided by similar research in the area (Brett *et al.*, 2017; Keegan *et al.*, 2021; Schneider *et al.*, 2016). The nominal group technique was used because it reduces the burden on participants and results can be obtained quickly and presented back to the group (McMillan *et al.*, 2016). The following process was followed (a copy of the annotated agenda can be found in the Extended data linked at the end of the paper):

- Results of phases 2, 3, and 4 were presented to the group, along with the needs and recommendations that came from the research. The initial list of needs and recommendations were derived from the developed themes from the analysis of the survey, review of literature, interviews, and long-answer survey responses.
- Sli.do, an online polling tool, was used to facilitate the adding, voting, and ranking of items.
- Completed silent generation when participants had the opportunity to think about any additional items they wanted to add.
- Completed a round robin where participants added those items anonymously.
- Participants were provided with the opportunity to discuss any new items or seek clarification.
- Private voting and ranking of items took place- two rounds.
 - Round one- ranked importance of items.
 - Round two- ranked order of importance when “top 10” were identified.

Consensus on a topic was decided if a certain percentage of the votes fell within a prescribed range (Miller, 2006). This range was set at 70% of consensus participants agreeing that an item was important. Each of the needs and recommendations were calculated and ranked as they were scored by participants – this was done by adding the total score for each item and dividing it by the number of overall votes (McMillan *et al.*, 2016).

Phase Six: Final Member checking. Following the consensus meeting, the results were distributed back to the consensus participants for comment and agreement. All participants agreed with the final list of items and their ranking.

Results

Quantitative Survey responses

Participant demographics. Forty-nine responses were recorded in the survey with a 46.94% completion rate. Completion rate refers to the number of participants who completed the survey in its entirety. No postal survey responses were received. Participants were aged between 50 and 75 years old, mean age of 60.88 (SD 7.35). Table 1 contains the breakdown of participant demographic characteristics.

Table 1. Demographic characteristics of participants.

| Participants self-identified as: | Percentage |
|---|------------|
| LGBTQIA+ adult over the age of 50 (without dementia) | 83.33 |
| LGBTQIA+ adult over the age of 50 living with dementia. | 13.89 |
| Care partner of an LGBTQIA+ person with dementia | 2.78 |
| Gender Identity | |
| Woman | 57.14 |
| Non-binary | 0.00 |
| Man | 39.29 |
| Do you consider yourself: | |
| Cisgender | 82.14 |
| Epicene | 3.57 |
| Transgender | 14.29 |
| Unsure | 3.50 |
| Sexual Orientation | |
| Gay | 40.70 |
| Lesbian | 40.70 |
| Bisexual | 3.70 |
| Queer* | 14.80 |
| Heterosexual | 0.00 |
| Pansexual | 0.00 |
| Asexual | 0.00 |
| Questioning | 0.00 |

*A note on the use of the word "Queer"- At pilot stage we received feedback stating that the term Queer may be offensive to some and that it should be removed. The reasoning behind this feedback was that, although the term Queer has been reclaimed by the LGBTQIA+ community, older LGBTQIA+ adults may have experienced this as a slur throughout much of their lives and may still feel disenfranchised by the word.

Following this, the research team discussed the issue with the PPI advisory group. In their feedback they noted that the term Queer is a flexible term that describes people who are in the LGBTQIA+ community who do not fit into the "narrow" definitions that the other labels represent, and that people who use the term to describe themselves are often the most vulnerable in the LGBTQIA+ community. They also agreed that in an Irish context the term could be considered hurtful to some people.

As inclusivity and sensitivity were of upmost importance to the study, the decision was made, in conjunction with the PPI group, to keep the term Queer within the demographic 'Sexuality', with a disclaimer above stating that 'Queer' in the context of this study was meant to reflect LGBTQIA+ identity it was by no means used to offend or cause hurt.

Community participation. The data presented in [Figure 1](#) indicates that there is a strong will and a need for socialization within the older LGBTQIA+ community (only one response permitted). However, as 21.43% stated "As I grow older, I feel increasingly excluded from the community" and 8.57% stated

that they have no contact with the LGBTQIA+ community, there is an indication that despite the general desire to be involved with the LGBTQIA+ community, older LGBTQIA+ adults between 50 and 75 years of age become more isolated from the LGBTQIA+ community.

Participants were asked "Prior to COVID-19, were you involved in any of the following activities?" and respondents answered Yes to a multitude of activities which are seen in [Table 2](#).

However, when asked about their attendance of non-LGBTQIA+- specific services prior to COVID-19, fewer participants were in attendance. This is illustrated in [Table 3](#).

When presented with a list of services and asked whether they would like LGBTQIA+-specific versions of those services, a large majority stated that they would like LGBTQIA+- specific versions of those services to be introduced, as seen in [Table 4](#).

Many of those who selected 'other' made suggestions for other LGBTQIA+-specific services, including an LGBTQIA+ medical support group or forum, an LGBTQIA+ retirement group, LGBTQIA+- specific support for people in the Traveller community, LGBTQIA+ care homes and residential living arrangements, and LGBTQIA+ specific ageing brain support.

Healthcare access. The majority of participants found it easy to access health information except in the instances where that health information was LGBTQIA+ specific. For example, most participants declared that it was easy to find information on health issues that concern them, such as screening or regular health treatments, understand what their doctor said to them, judge the quality of health information from different sources, and to get the information they need from their doctor. However, when asked whether they found it easy to find health information from general sources that address the needs of LGBTQIA+ people, the majority of participants stated that this was difficult or very difficult, as illustrated by [Figure 2](#) below.

Participants were then asked how relevant their LGBTQIA+ identities were in a healthcare context. As illustrated in [Figure 3](#), most participants believed that being LGBTQIA+ is relevant in a healthcare context.

Discrimination. Participants reported that they have experienced multiple forms of abuse throughout their lifetime and within the past 5 years, as seen in [Table 5](#). It is worth noting that 18 participants completed this question. Abuse was reported across all categories by participants during their life, with abuse in some categories being reported in the last five years, for example verbal abuse was reported by 33%.

An optional question surrounding the types of discrimination faced by participants was also included to gain a deeper

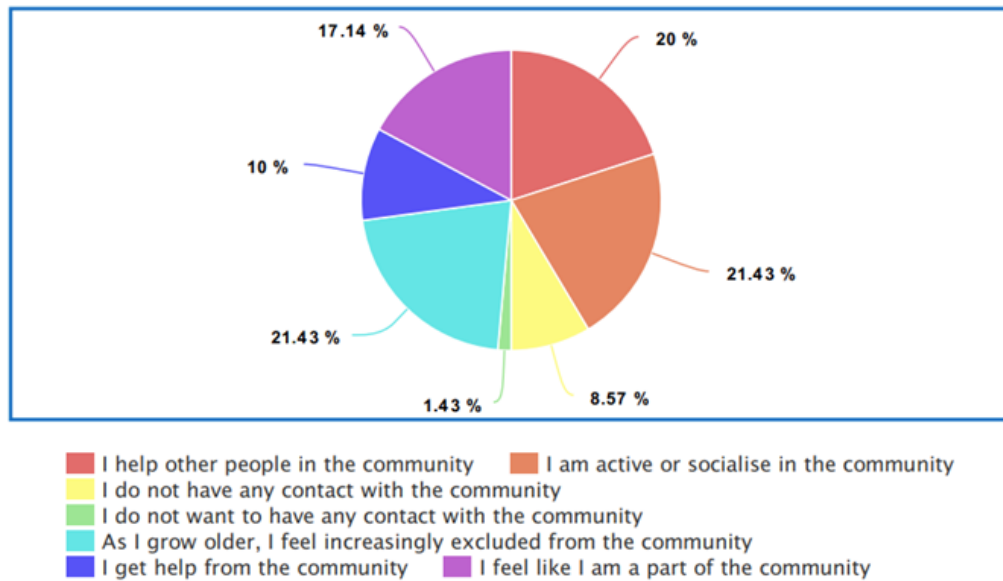


Figure 1. Participant community support.

Table 2. LGBTQIA+ Community Involvement (prior to COVID-19).

| Community Activities | N | Attending Activity % |
|--|----|----------------------|
| Visited an LGBTQIA+ pub or club | 30 | 73.33 |
| Attended an LGBTQIA+ social group or outing | 28 | 67.86 |
| Attended or involved in an LGBTQIA+ community event | 29 | 68.97 |
| Used a web-based LGBTQIA+ discussion group/forum/dating site | 30 | 50.00 |
| Visited an LGBTQIA+ community centre | 28 | 53.57 |
| Attended an LGBTQIA+ support group | 27 | 22.22 |
| Other LGBTQIA+ related activity or group | 28 | 35.71 |

Table 3. Non-LGBTQIA+ Community Involvement (prior to COVID-19).

| Community Activities | N | Attending Activity % |
|---------------------------------------|----|----------------------|
| Residents' Group | 28 | 35.71 |
| Sport Group | 28 | 17.86 |
| Religious Group | 27 | 3.70 |
| Political Group | 27 | 33.33 |
| Older person/ Active Retirement Group | 27 | 11.11 |
| Cultural/arts Group | 28 | 53.57 |
| LGBTQIA+ Group | 30 | 63.33 |
| Other Group | 23 | 26.09 |

understanding into where participants faced the most of their lifetime discrimination. As illustrated by Table 6, older LGBTQIA+ people have experienced discrimination in occupational, healthcare, and civil contexts. Importantly, 78.95% of people have felt unable to be open about their identity twice or more.

Participants also reported some day-to-day discrimination that they have experienced. For example, 39.13% of participants reported that people do things to humiliate and devalue them a few times per year. 39.13% also reported that people suggest that they are inferior to others a few times per year and 39.13% report that they are treated with less courtesy and respect than others, a few times per year. However, a

Table 4. Participant responses to need for LGBTQIA+ dementia services.

| Service | N | Percentage Answered "Yes" |
|------------------------------------|----|---------------------------|
| Support groups/ memory café | 28 | 85.71 |
| Social groups | 27 | 96.30 |
| Reminiscence walking trails | 26 | 92.31 |
| Community events/ social calendars | 27 | 100.00 |
| Community Centre | 27 | 92.59 |
| Support and befriending services | 29 | 96.55 |
| Memories Choir | 25 | 80.00 |
| Other | 17 | 64.71 |

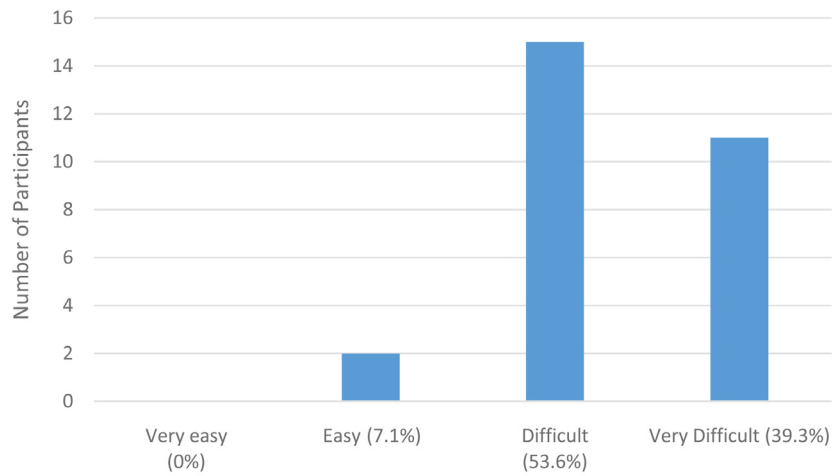


Figure 2. How easy is it to obtain LGBTQIA+ healthcare information?

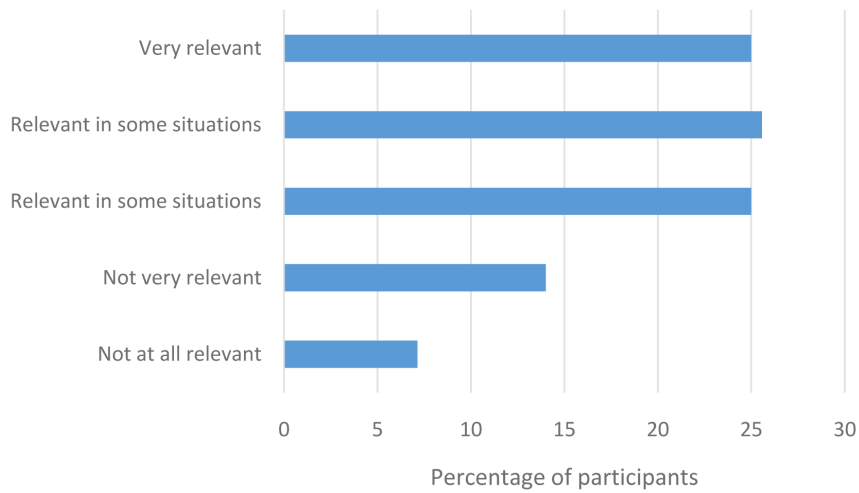


Figure 3. How relevant is LGBTQIA+ identity to healthcare?

Table 5. Lifetime abuse experienced by participants.

| Type of abuse | N | Lifetime % | Past 5 years % |
|--|----|------------|----------------|
| Emotional abuse | 16 | 87.50 | 12.50 |
| Physical abuse | 14 | 100.00 | 0.00 |
| Verbal abuse | 18 | 66.67 | 33.33 |
| Sexual abuse | 7 | 100.00 | 0.00 |
| Psychological abuse | 14 | 92.86 | 7.14 |
| Racial abuse | 3 | 66.67 | 33.33 |
| Financial abuse | 10 | 90.00 | 10.00 |
| Organisational/ Institutional abuse | 11 | 81.82 | 18.18 |

Table 6. Discrimination experienced by participants.

| | N | Never % | Once % | Twice or more % |
|---|----|---------|--------|-----------------|
| I was not hired for a job | 20 | 55.00 | 5.00 | 40.00 |
| I was not given promotion | 19 | 42.11 | 15.79 | 42.11 |
| I was fired from a job | 16 | 68.75 | 6.25 | 25.00 |
| I was prevented from living in the area I wanted | 16 | 68.75 | 6.25 | 25.00 |
| I was denied or provided inferior care such as healthcare | 17 | 35.29 | 11.76 | 52.94 |
| I felt unable to be open about my identity | 19 | 10.53 | 10.53 | 78.95 |
| My property was damaged or destroyed | 17 | 58.82 | 11.76 | 29.41 |
| I was hassled by the police | 16 | 68.75 | 6.25 | 25.00 |

majority of participants never receive poorer service in shops or restaurants, are never made to feel less intelligent than others and have never had someone threaten to ‘out’ them to someone who they did not wish to disclose their identity to.

When asked why they experience discrimination several reasons were given by participants. One participant cited the lack of hate crime legislation in Ireland, causing a lack of legal protection from discrimination as a reason why people do not feel protected from discrimination in Ireland. Some participants mentioned that they were new to the community they were living in, others cited ageism, and many simply cited the fact that they were a gender or sexual minority.

Microaggressions were also experienced to some degree by participants. For example, 50% reported that people were dismissive of their “alternative” family structures and stable relationship and 54.55% of participants experienced negative stereotypes, a few times per year. However, between 13.64% and 31.82% did not experience the microaggressions listed in the survey.

Participants also displayed strong resilience in adverse situations, with 54.55% agreeing with the statement “I tend to bounce back quickly after hard times”. 30.43% of participants also agreed with the statement “I usually come through difficult times with little trouble”, with 21.74% strongly agreeing.

Identity management. All participants in the survey have disclosed their sexuality or gender identity at least once, and the majority have disclosed this more than once. 42.86% agreed that they are open about their sexuality whenever it comes up, and 38.10% strongly agreed. 40.91% agreed when they were assumed to be heterosexual/cisgender that they would correct them and 22.73% strongly agreed.

61.9% strongly disagreed with the statement “I make things up to hide my sexual orientation or gender identity”, further suggesting that older LGBTQIA+ adults are open about their sexuality. A majority of participants also indicated that they display objects in their homes to suggest their sexual orientation or gender identity, which may be relevant for care providers entering the home.

42.86% strongly disagreed with the statement “I feel uncomfortable dealing with health professionals and official organizations where my LGBTQIA+ identity is known”. However, different experiences were expressed regarding the statement “I have to work harder for my concerns to be heard and acted upon by health professionals where my LGBTQIA+ identity is known.”- see [Figure 4](#).

Analysis of qualitative data- interviews and survey

Inductive thematic analysis was performed on the six interviews conducted with international experts and two LGBTQIA+ people over the age of 50. Four main themes were derived from these data:

1. Identity suppression and anticipated concerns
2. Creating an LGBTQIA+ affirmative ethos and workforce
3. Understanding the variety of LGBTQIA+ networks and life experiences
4. Experiences specific to those who are transgender.

Identity suppression and anticipated concerns.

Many participants reported that they anticipated some forms of disrespect, such as homophobia, transphobia, humiliation, or isolation if they were to enter a nursing home or become dependent on formal care. The ethos of a care home had the potential to contribute to anticipated disrespect. As one survey participant stated:

“As most care facilities are run by religious charities, there is a higher-than-average possibility that a person

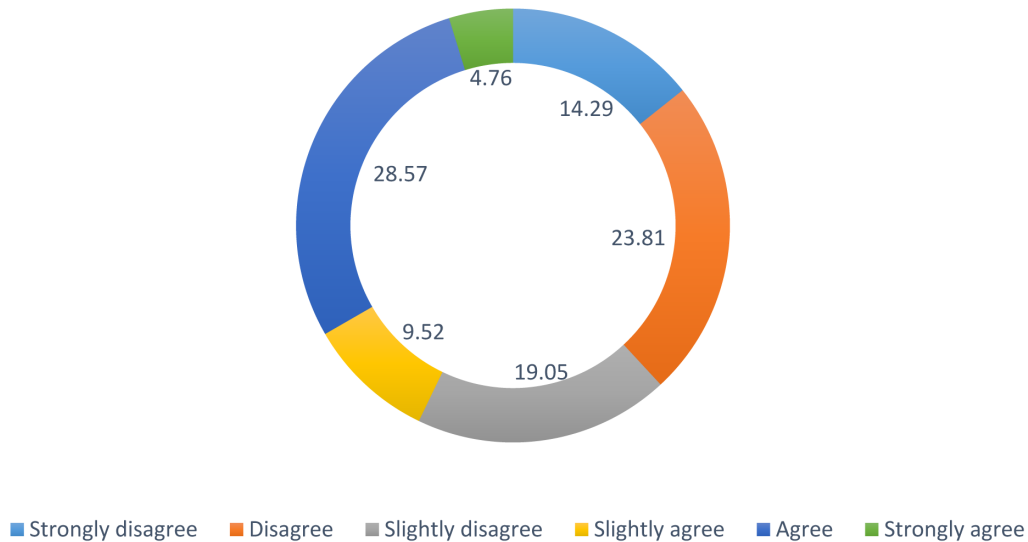


Figure 4. Percentage ranks for question: *“I have to work harder for my concerns to be heard and acted upon by health professionals where my LGBTQIA+ identity is known”.*

could encounter homophobia”. Survey participant, lesbian cis-gender woman, 65 years.

We found that many LGBTQIA+ older adults felt it necessary to conceal their gender/ sexual identity when accessing care/healthcare or stopped expressing their gender or sexual identity. As one survey participant stated:

“I fear many gay people are forced to pretend they’re straight as they get older and more isolated, just not to rock the boat”. Survey participant, lesbian cis-gender woman, 57 years

Additionally, another survey participant stated,

“Well being gay is who I am. I have gay desires and sensitivities. They are part of my being, not some sort of aberration or problem. I think anyone who has to care for me should know this and act in a respectful way as a result. I should add that I have always had a positive experience in this regard to date.” Survey participant, lesbian cis-gender woman, 72 years.

An international expert stated that she would *“rather die than be cared for in this place”* when she visited a care home with a very large crucifix on the wall.

“We hear stories of people being told you know ‘it’s not too late’ and being given Bibles and being prayed over.” Interview participant, international expert

This suggests that even if a particular religious-run service is LGBTQIA+ inclusive, the religious ethos alone may deter LGBTQIA+ service users from making use of it. Interestingly

a transgender interview participant cited very positive surgical and person-centred care experiences in a German hospital run by a Lutheran charity. His positive surgical experiences in Germany were followed by very poor experiences in Ireland, which has caused him to worry about what will happen when he is older and unable to challenge mistreatment.

“It was amazing apart from having a very good surgeon, the whole care staff, the housekeeping staff, everyone was really, really affirming it was wonderful experience, and that makes it so hard to come back here be on your own and be raging at the national gender service because you have just been treated like a human and now you are back to just being a nuisance and left to fend for yourself.” Interview participant, gay transgender man.

Hearing and reading about accounts of older LGBTQIA+ people in care and suppressing their identity in care due to fears of social exclusion, discrimination, abuse, or even differential treatment, can also contribute to older LGBTQIA+ people anticipating their own identity suppression. As one interview participant stated:

“I’ve been reading too many reports of cisgender gay and lesbian people who were forced to hide their sexuality in care settings, that’s all in the United States, but I think oh gee how will it turn out when it’s my turn?” Interview participant, gay trans gender man.

High staff turnover was also considered a contributing factor to identity suppression and anticipated disrespect as it reduces consistency in care and can increase concerns over acceptance when trying to express one’s identity. An international

expert participant discussed an instance in which she interviewed a lesbian woman in her 80s who only first disclosed her sexuality to the manager in her nursing home, following her husband's death:

"[The manager] was very supportive and found her a local lesbian group...but the manager left and the next one she didn't like and she's now very frightened because she doesn't know who knows and doesn't know what people might say." Interview participant, international expert.

Finally, the inability to conceal was reported to leave older LGBTQIA+ people with dementia vulnerable, particularly in potentially unfriendly environments.

"...But for people who are old now, things can be revealed that are then held against them, which they've been able to manage, and the secrets they've been able to manage for all that time and the illness then robs them of that." Interview participant, international expert.

Creating an LGBTQIA+ affirmative ethos and workforce.

Numerous participants suggested that a service that is LGBTQIA+ positive should display visual signs of acceptance, such as badges, flags, symbols, leaflets, or pictures of same sex couples. It was, however, emphasised that this should not be done without the adequate training of staff members. Multiple participants also suggested the creation of an LGBTQIA+ accepting environment. LGBTQIA+ dedicated dementia services that reflect the heterogeneous needs of the LGBTQIA+ community need to be created. For instance, one participant stated:

"Ireland should have purpose-built residential care for LGBTQI+ older adults like they have in most other EU states and North America." Survey participant, gay epicene participant, 66 years

Some participants did not like the idea of differentiated services and would prefer to be in a mixed setting. As a survey participant stated:

"I would like inclusive good quality services available generally in Ireland, not ghettoised services if no service is up to standard." Survey participant, lesbian cis-gender woman. 64 years

Creating an explicitly LGBTQIA+ affirmative workforce was seen as paramount in creating safer and more welcoming care environments for LGBTQIA+ people with dementia, and several participants suggested that in order to create this affirming workforce, a number of steps needed to be set in place, including specific recruitment techniques, training, the use of visual signs of acceptance and the creation of dedicated services. One participant noted the visibility of same-sex couples of all ages in a Canadian LGBTQIA+ healthcare center was very positive.

"It was like I had died and gone to heaven surrounded by images of LGBTQ people of all ages and same sex couples and also people who were gender fluid and

exploring, it was just glorious". Interview participant, international expert

To ensure that all new members of staff are LGBTQIA+ positive, or at least are open to being trained in LGBTQIA+ affirmation in care, it was suggested that care services advertise an explicit pro-LGBTQIA+ ethos. As one interview participant stated:

"Now on their website there is a proactive, 'we don't tolerate any kind of discrimination, we are fully inclusive we welcome LGBTQ people', I mean it's screaming, 'don't work for us if you don't like LGBTQ people' because we do." Interview participant, international expert

Some participants suggested the need to diversify the workforce by hiring more LGBTQIA+ care workers. Other participants, however, stated that the identity of the care provider was not as relevant as their dedication and level of training. Mandatory and comprehensive training was suggested by multiple participants, as people who were more biased towards LGBTQIA+ people would most likely skip the training if it were not mandatory.

"I am concerned about an apparent absence of training specifically built into medical, nursing, and social care training in relation to sexuality and its impacts on older people because the attitudes towards older people are generally very poor in this country." Interview participant, lesbian cis-gender woman.

When the topic of dedicated services was discussed, participants had differing views. Some did not like the idea of differentiated services and would prefer to be in a mixed setting. An international expert stated that lesbian women, particularly those who live separatist lives, often preferred women-only services rather than LGBTQIA+-specific services. An interview participant stated that though he had never considered the idea of an LGBTQIA+ specific service, he was very interested in the idea.

"It would feel very enticing to be with your own people, also that way you have people with whom you can talk. I do know that current seniors LGBTQ seniors in care facilities is that they find it very isolating, the heteronormativity of their peers. How do you have conversations...folks like us...today's young people are so much more integrated... In our generation you lived such a life apart in many ways and it would be so nice to live with people who know what that is." Interview participant, gay transgender man.

Understanding the variety of LGBTQIA+ networks and life experiences.

Heteronormative assumptions were reported to be problematic and embarrassing for many participants. Survey participants emphasized the need to understand and respect the variety of networks and life experiences of LGBTQIA+ people. Many people noted that they are often assumed to be heterosexual or cisgender until told otherwise which can cause discomfort and puts the responsibility of

disclosing gender and sexuality on the service user. As a survey participant stated:

“I’m okay with straight people caring for me and assume they would be tolerant - but the structures assume a heteronormative life”. Survey participant, queer cis-gender woman. 59 years

One participant stated that she strongly disliked the fact that responsibility for “coming out” always rested on her. Instead, she stated that she would prefer it if people just asked her rather than assuming. As one survey participant stated:

“Older people are treated as though they have little or no interest in sexual relationships. In a heteronormative society, this means that they are generally assumed to be ‘weakly heterosexual’. For individuals requiring personal care, this can be distressing.” – Survey participant, lesbian transgender woman. 65 years.

There is a need for non-nuclear family structures and friend networks to be respected and understood by professional dementia-care providers. It is important to avoid assumptions and ask questions about a person’s available network. As one interview participant stated:

“Those explicit questions about what social groups do we have now [...] how can we maintain that without assuming that [...] people will have a particular type of interest or hobby that people will engage in, and actually actively supporting peoples engagement with queer communities if they are engaged in those communities.” – Interview participant, international expert.

It was suggested by an international expert, that an independent advocate should be triggered upon a dementia diagnosis, who could act in an older person’s best interests in cases where an individual’s social network was smaller, or in cases where unaccepting families of origin or other potentially exploitative people are acting against the best interest of the service user.

Experiences specific to those who are transgender.

Unlike with the experiences of sexual minorities, trans identity is often over-focused on in a healthcare context, which can both waste a service-user’s time when trying to focus on non-transgender related health issues and can feel uncomfortable and unnecessary.

“I sometimes don’t like how I am outed by default, by all sorts of specialists who don’t really need to know...why would they need to know, and I am uncomfortable so it’s more the opposite, I am not so happy about every care provider in whatever remote context knowing I’m trans, you know sometimes I think it’s not necessary.” Interview participant, gay transgender man.

A transgender interview participant cited prior negative healthcare experiences as influencing his concern that he may be mistreated and humiliated in a care context, stating:

“My biggest concern I become very care dependent, would be to have my body mocked, or to be alienated, or

that they would get sloppy with my medication regime. I’m honestly not even sure what medical recommendations would be about hormone treatment in high old age because again our cohort are sort of a natural experiment...this kind of neglect of our particular situation.” – Interview participant, gay transgender man.

Regarding transgender dementia care, an international expert noted that there are two opposing schools of thought about gender affirmation in dementia. One school of thought, which the participant was opposed to, was to rigidly affirm the gender as expressed by the transgender person, before their diagnosis with dementia. In many reported cases, transgender people with dementia can experience gender dysphoria and different gender identities can become more salient at different times, which can be confusing and distressing. She believed that to address someone as their previously preferred gender identity, whilst they are presenting or feeling like another would be “well-meaning coercion, but coercion nonetheless”. Instead, this participant suggested the second school of thought, which is a more person-centred “take me as I am” approach, in which care providers address a person as the gender that they are most comfortable with at that moment.

Consensus-based needs and recommendations

Following the analysis of the interview and survey data, the consensus meeting was held with ten key stakeholders (described in Phase Five above). There were ten core needs and sixteen recommendations derived from the data and literature gathered. The complete unranked list of needs and the complete unranked list of recommendations can be seen in the Extended data.

The final top ten need and recommendations, along with the associated rank score are presented in [Table 7](#).

Discussion

This research has identified a prioritised, consensus-developed, and PPI-driven list of needs and recommendations for health-care delivery for people with dementia from the LGBTQIA+ community. Having developed this list, the next crucial step is the implementation of these findings into practice to ensure we are delivering a human rights-based care for people with dementia, as recommended by the [World Health Organization \(2015\)](#).

The importance of maintaining identity came across in all phases of the research. For those living with dementia there is a duality in terms of managing dementia and managing one’s own identity ([McParland & Camic, 2018](#)). The conflict that people face in terms of whom to disclose their identity to and in what context was evident in the findings and echoes previous research describing the challenge of “giving yourself away vs. holding onto yourself” ([McParland & Camic, 2018](#)). With a diagnosis of dementia, it can also be difficult for people to remember whom they told what to, which can be distressing.

Respect was another clear message that came from the research data. As well as respect for identity, respecting

Table 7. Needs and Recommendations identified through the consensus process.

| Rank | Top 10 Needs | Score | Rank | Top 10 Recommendations | Score |
|------|--|-------|------|---|-------|
| 1 | To feel respected and for your partner to feel respected. | 9.6 | 1 | At first contact with services/ at diagnosis, <u>everyone</u> should be given a multitude of resources including information about LGBTQIA+ services. | 7.25 |
| 2 | To feel safe in expressing your identity if you want to. | 9.5 | 2 | LGBTQIA+ older adults should have a choice between integrated and dedicated services. | 6.63 |
| 3 | To know that you, or your partner, are entering into a safe environment. | 9.5 | 3 | Integrated services with mandatory comprehensive training for staff should be available where dedicated services are unavailable. | 6.63 |
| 4 | To have dignity in all areas of treatment, especially end of life care. | 9.4 | 4 | LGBTQIA+ specific services for older adults and people with dementia should be introduced. | 6.38 |
| 5 | Care that values your needs as individuals and as LGBTQI or A+ people. | 9.3 | 5 | Services' LGBTQIA+ inclusiveness and training should be auditable by a relevant health authority. | 6.13 |
| 6 | To be safe from abusive families of origin (if you have an abusive family of origin). | 9.3 | 6 | Service-users should be asked who they would like to help them in their care and decision making as their dementia symptoms progress | 6.0 |
| 7 | In a nursing home/ residential care setting, to be safe from homophobic/transphobic bullying/mistreatment from other residents. | 9.1 | 7 | Independent advocates for people with dementia should be triggered upon diagnosis. Advocates can work with people with dementia and their close networks to give them the care they desire most. | 5.0 |
| 8 | Not to feel pressured into expressing your identity if you don't want to/ or don't feel safe. | 8.8 | 8 | Training should include understanding differences in LGBTQIA+ networks and how to incorporate an individual's network in care without making assumptions; as well as intervening with homophobic/transphobic bullying/mistreatment from family of origin/other. | 4.25 |
| 9 | Provide specific trans* and intersex medical training for doctors and care staff working with older LGBTQIA+ people, to enable them to work safely with unfamiliar bodies. | 8.8 | 9 | When working with transgender people with dementia, care providers should address them as the gender they are presenting as in the current moment and not engage in any kind of coercion regarding their gender expression. | 4.13 |
| 10 | The need to support trans* people with dementia while also recognising the reality of biology and that some supports may require a focus on sex and not gender. | 8.3 | 10 | An explicitly LGBTQIA+ inclusive ethos message and visible displays of LGBTQIA+ acceptance should be clearly displayed in leaflets and webpages of dementia services. This must be accompanied by staff trained in LGBTQIA+ affirmative care. | 3.0 |

families of choice and including them in care decisions, when appropriate, was apparent from the research findings. Previous research has referred to relationships for people with dementia from the LGBTQIA+ community as “*sheltered harbours*” where people feel safe and comfortable (McParland & Camic, 2018). The focus on including family of choice in care decisions and plans came across clearly in this research. It can also be challenging for people to maintain healthcare regimes, such as long-term hormone therapy without assistance, and using the support systems that people already have in place has the potential to improve outcomes for people with dementia.

Safety when accessing services was also a priority for participants in this research. It is evident from previous research that avoidance of healthcare services can lead people to be admitted to residential care when it could have been avoided

(Westwood, 2016). The fear expressed by participants in becoming dependent on healthcare services because of possible neglect or mistreatment has been seen in earlier research (Putney *et al.*, 2018). This deep-seated anxiety has been found to lead to identity concealment and chronic distress (Putney *et al.*, 2018). Ensuring people feel safe when accessing services should be fundamental. As older people from the LGBTQIA+ community do not feel safe (see the focus on safety in the “top 10” needs identified) this should be addressed immediately at a service level.

There were conflicting views in relation to the need for dementia-specific services for LGBTQIA+ community. Even if not requested by all, participants agreed that it would be beneficial to have the choice to engage with these services as they are needed by some. The importance of welcoming, open, and non-judgemental services was identified as both

a need and a recommendation. The importance of having an “*explicit ethos*” was discussed at length, as well as the need for visual representation of all types of older people in services, including sub-groups such as older LGBTQIA+ people from the Travelling community. Linked with this was mandatory training for healthcare professionals and the need to integrate this at the beginning of career training. The importance of this type of training being mandatory, integrated, and comprehensive was clear from the research data collected and has been reported elsewhere (Fredriksen-Goldsen *et al.*, 2014; Nowaskie & Sewell, 2021).

Limitations

The number of participants included in the research was small. This was anticipated by the research team and several steps were taken to ensure a consensus-based process, for example, the research contained multiple phases; the research was led by a representative PPI advisory group; the consensus meeting used purposive sampling to ensure representation across groups; and a number of recruitment avenues were used.

The questionnaire itself was lengthy and required a level of concentration that may have unintentionally excluded those with more severe dementia. Although the research included incomplete questionnaires (46.94% completion rate) and allowed for the questionnaire to be completed by or with a caregiver, there are likely people who were unable to take part because of this. The challenges posed by the COVID-19 pandemic limited the possibility of in-person data collection. Although the research team placed paper versions of the questionnaires in LGBTQIA+ community centres, many older people were sheltering at home and not attending these locations.

The questionnaire did not capture the views of caregivers (only 13.89% of the total sample) and it is suggested that further research looks at this cohort separately, as we know that this group often has fears about the future that are coloured by their own experiences of caregiving (Price, 2011). We included caregivers in the interview and consensus stages, but this is limited to a small number of caregivers.

Finally, the research team acknowledge that the term “older”, set for this research as 50+, will vary in terms of ethnicity and life expectancy due to health disparities. For instance, in 2016 only 3% of people from the Travelling community in Ireland were aged 65 or older and ageing in this community has been redefined as being aged 40+ as their life expectancy is 17% lower than the non-Travelling Irish community (Gibney *et al.*, 2018). Future researchers may also consider allowing participants to decide if they identify as “older” rather than having a cut-off for the research.

Conclusion

Although older LGBTQIA+ adults demonstrate strong resilience, many have significant worries about the future, particularly in the context of dementia care. This research has provided a clear list of needs and recommendations that have been identified by the older LGBTQIA+ community as urgent and essential for improving healthcare access, safety, and quality of life in

care. It is vital that the staff in healthcare, voluntary, and community services working with older people are trained in understanding the needs of LGBTQIA+ older adults with dementia, and that services are explicitly welcoming and respectful when supporting LGBTQIA+ people with dementia and their care partners.

This research has identified key recommendations which may be used to further develop best practice in this area. Prior to this study, no research had been completed in Ireland to identify the needs and recommendations in this area in Ireland. Importantly, this research has had a strong PPI focus and has been directed by older LGBTQIA+ people. Throughout the work with PPI members and participants stressed the urgent need for the translation of this research into improved and more welcoming care for those from the LGBTQIA+ community.

Data availability

Underlying data

The data that support the findings of this study, including the questionnaire answers, and transcripts, are available on request from the corresponding author [S.M.H]. The data are not publicly available due to their containing information that could compromise the privacy of research participants. Due to the smaller sample of interview participants, and the specific and unique nature of some of the described life events of the participants that were paramount to analysis, de-identification is not sufficient to prevent possible recognition of the individuals.

Extended data

Open Science Framework: Dementia service needs and recommendations for LGBTQIA+ community. <https://doi.org/10.17605/OSF.IO/P3UJE> (Hynes, 2022).

This project contains the following extended data

- Paper version of National Survey (a copy of the questionnaire)
- Topic Guide (interviews with LGBTQIA+ older adults)
- Document (Interview guide with experts)
- Consensus Event Annotated Agenda 9th December 2021 (Topic guide – consensus meeting)
- Are you LGBTQIA+ and aged 50 or over (Sample social media and physical recruitment poster)
- SRQR_Checklist_dementia (SRQR checklist)

Data are available under the terms of the [Creative Commons Attribution 4.0 International license](https://creativecommons.org/licenses/by/4.0/) (CC-BY 4.0).

Author contributions

SMH conceptualised the research; acquired funding; was responsible for investigation, methodology, project administration, and supervision, SMH also wrote the original manuscript draft, and was involved in reviewing and editing. MHO was

responsible for data curation, formal analysis, investigation, writing the original manuscript draft, and reviewing and editing.

Acknowledgements

We are very grateful for the advice and expertise that was provided by the PPI Advisory Group for this research. Without them this work would not have been possible.

Thank you to occupational therapy student Rebecca Boylan who helped in recruitment and in refining the survey. We would also like to thank Kashie Prendergast for his assistance throughout this project. His words of advice helped at various stages of the research. Thank you to all our gatekeeper organisations and in particular the support shown by The Alzheimer Society of Ireland and LGBT Ireland.

References

- Alzheimer Europe: **Prevalence of Dementia in Europe**. 2020. [Reference Source](#)
- Braun V, Clarke V: **Thematic analysis**. In: H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbook of research methods in psychology. Research designs: Quantitative, qualitative, neuropsychological, and biological*. American Psychological Association, 2012; 2: 57–71. [Publisher Full Text](#)
- Brett J, Stanisewska S, Simera I, et al.: **Reaching consensus on reporting patient and public involvement (PPI) in research: methods and lessons learned from the development of reporting guidelines**. *BMJ Open*. 2017; 7(10): e016948. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Criminal Law (Sexual Offences) Act**. Dáil Éireann, Act [20]. 1993. [Reference Source](#)
- Fredriksen-Goldsen KI, Hoy-Ellis CP, Goldsen J, et al.: **Creating a vision for the future: Key competencies and strategies for culturally competent practice with lesbian, gay, bisexual, and transgender (LGBT) older adults in the health and human services**. *J Gerontol Soc Work*. 2014; 57(2–4): 80–107. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Fredriksen-Goldsen KI, Kim HJ: **The science of conducting research with LGBT older adults- an introduction to aging with pride: National health, aging, and sexuality/gender study (NHAS)**. *Gerontologist*. 2017; 57(suppl_ 1): S1–S14. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Fredriksen-Goldsen KI, Kim HJ, Shiu C, et al.: **Successful aging among LGBT older adults: Physical and mental health-related quality of life by age group**. *Gerontologist*. 2015; 55(1): 154–168. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- George MA: **Expanding LGBT**. *Fla L Rev*. 2021; 73(2): 243. [Reference Source](#)
- Gibney S, Zhang M, Taaffe C, et al.: **Developing Indicators of Positive Ageing for Irish Travellers**. Healthy and Positive Ageing Initiative, 2018. [Publisher Full Text](#)
- Higgins A, Sharek D, McCann E, et al.: **Visible Lives: Identifying the experiences and needs of older Lesbian, Gay, Bisexual and Transgender (LGBT+) people in Ireland**. Dublin: GLEN, 2011. [Reference Source](#)
- Hoy-Ellis CP, Fredriksen-Goldsen KI: **Lesbian, gay & bisexual older adults: Linking internal minority stressors, chronic health conditions, and depression**. *Aging Ment Health*. 2016; 20(11): 1119–1130. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Hsieh N, Liu H, Lai WH: **Elevated risk of cognitive impairment among older sexual minorities: Do health conditions, health behaviors, and social connections matter?** *Gerontologist*. 2021; 61(3): 352–362. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Hsu CC, Sandford BA: **The Delphi technique: making sense of consensus. Practical assessment, research, and evaluation**. 2007; 12(1): 10. [Publisher Full Text](#)
- Hynes SM: **Dementia service needs and recommendations for LGBTQIA+ community**. 2022. <http://www.doi.org/10.17605/OSF.IO/P3UJE>
- Keegan D, Heffernan E, McSharry J, et al.: **Identifying priorities for the collection and use of data related to community first response and out-of-hospital cardiac arrest: protocol for a nominal group technique study [version 2; peer review: 2 approved]**. *HRB Open Res*. 2021; 4: 81. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Kim HJ, Fredriksen-Goldsen KI, Bryan AE, et al.: **Social network types and mental health among LGBT older adults**. *Gerontologist*. 2017; 57(suppl_ 1): S84–S94. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- King A, Cronin A: **Bonds, bridges and ties: applying social capital theory to LGBT people's housing concerns later in life**. *Qual Ageing Older Adults*. 2016; 17(1): 16–25. [Publisher Full Text](#)
- Kuyper L, Fokkema T: **Loneliness among older lesbian, gay, and bisexual adults: The role of minority stress**. *Arch Sex Behav*. 2010; 39(5): 1171–1180. [PubMed Abstract](#) | [Publisher Full Text](#)
- Levitt HM, Motulsky SL, Wertz FJ, et al.: **Recommendations for designing and reviewing qualitative research in psychology: Promoting methodological integrity**. *Qual Psychol*. 2017; 4(1): 2–22. [Publisher Full Text](#)
- McMillan SS, King M, Tully MP: **How to use the nominal group and Delphi techniques**. *Int J Clin Pharm*. 2016; 38(3): 655–662. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- McParland J, Camic PM: **How do lesbian and gay people experience dementia?** *Dementia (London)*. 2018; 17(4): 452–477. [PubMed Abstract](#) | [Publisher Full Text](#)
- Miller LE: **Determining what could/should be: The Delphi technique and its application**. Paper presented at the meeting of the 2006 annual meeting of the Mid-Western Educational Research Association, Columbus, Ohio, 2006.
- Morbey H, Harding AJ, Swarbrick C, et al.: **Involving people living with dementia in research: an accessible modified Delphi survey for core outcome set development**. *Trials*. 2019; 20(1): 12. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Nowaskie DZ, Sewell DD: **Assessing the LGBT cultural competency of dementia care providers**. *Alzheimers Dement (N Y)*. 2021; 7(1): e12137. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- O'Brien BC, Harris IB, Beckman TJ, et al.: **Standards for reporting qualitative research: a synthesis of recommendations**. *Acad Med*. 2014; 89(9): 1245–1251. [PubMed Abstract](#) | [Publisher Full Text](#)
- Opening Doors London: **The Health and Well-being of LGBTQ+ People Over 50- Results of the 2021 Opening Doors survey**. Opening Doors, London, 2021. [Reference Source](#)
- Oppenheim AN: **Questionnaire design, interviewing and attitude measurement**. Bloomsbury Publishing, 2000. [Reference Source](#)
- Perales-Puchalt J, Gauthreaux K, Flatt J, et al.: **Risk of dementia and mild cognitive impairment among older adults in same-sex relationships**. *Int J Geriatr Psychiatry*. 2019; 34(6): 828–835. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Pierse T, O'Shea E, Carney P: **Estimates of the prevalence, incidence and severity of dementia in Ireland**. *Ir J Psychol Med*. 2019; 36(2): 129–137. [PubMed Abstract](#) | [Publisher Full Text](#)
- Price E: **LGBT sexualities in social care research**. Methods review (2). NIHR School for Social Care Research, London, UK, 2011. [Reference Source](#)
- Putney JM, Keary S, Hebert N, et al.: **"Fear Runs Deep:" The Anticipated Needs of LGBT Older Adults in Long-Term Care**. *J Gerontol Soc Work*. 2018; 61(8): 887–907. [PubMed Abstract](#) | [Publisher Full Text](#)
- Roe L, Galvin M, Booi L, et al.: **To live and age as who we really are: Perspectives from older LGBT+ people in Ireland [version 2; peer review: 3 approved]**. *HRB Open Res*. 2020; 3: 6. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Schneider P, Evaniev N, Rendon JS, et al.: **Moving forward through consensus: protocol for a modified Delphi approach to determine the top research priorities in the field of orthopaedic oncology**. *BMJ Open*. 2016; 6(5): e011780. [PubMed Abstract](#) | [Publisher Full Text](#) | [Free Full Text](#)
- Sharek DB, McCann E, Sheerin F, et al.: **Older LGBT people's experiences and concerns with healthcare professionals and services in Ireland**. *Int J Older People Nurs*. 2015; 10(3): 230–240. [PubMed Abstract](#) | [Publisher Full Text](#)
- Sheehan A, O'Sullivan R: **Ageing and Public Health – an overview of key statistics in Ireland and Northern Ireland**. Dublin: Institute of Public Health, 2020. [Reference Source](#)

Swarbrick CM, Doors O, Scottish Dementia Working Group, *et al.*: **Visioning change: co-producing a model of involvement and engagement in research (innovative practice)**. *Dementia (London)*. 2019; **18**(7–8): 3165–3172.
[PubMed Abstract](#) | [Publisher Full Text](#)

Thayer-Hart N, Dykema J, Elver K, *et al.*: **Survey fundamentals: A guide to designing and implementing surveys**. University of Wisconsin, 2010.
[Reference Source](#)

Wallace SP, Cochran SD, Durazo EM, *et al.*: **The health of aging lesbian, gay and bisexual adults in California**. *Policy Brief UCLA Cent Health Policy Res*. 2011;

(PB2011–2): 1–8.

[PubMed Abstract](#) | [Free Full Text](#)

Westwood S: **Dementia, women and sexuality: How the intersection of ageing, gender and sexuality magnify dementia concerns among lesbian and bisexual women**. *Dementia (London)*. 2016; **15**(6): 1494–1514.
[PubMed Abstract](#) | [Publisher Full Text](#)

World Health Organization: **Ensuring a human rights based approach for people living with dementia**. World Health Organization, Geneva, 2015.
[Reference Source](#)

Open Peer Review

Current Peer Review Status: ? ? ? ✓

Version 3

Reviewer Report 14 September 2024

<https://doi.org/10.21956/hrbopenres.14976.r34669>

© 2024 Hydén L. This is an open access peer review report distributed under the terms of the [Creative Commons Attribution License](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.



Lars-Christer Hydén

Linköping University, Linköping, Sweden

This manuscript is about the development of recommendations for the delivery of dementia services for the LGBTQIA+ community. The aim was to explore future care needs in the LGBTQIA+ community in relation to dementia care services, as well as to develop consensus-based recommendations. The study is based on a consensus process involving key stakeholders. A questionnaire was developed and tested, and then distributed nationally to persons who identified as members of the LGBTQIA+ community (or supported someone who were), were over 50 years of age and could provide informed consent. In total 49 responses were recorded. The questionnaires were analysed statistical and conceptually (open-ended answers). As a third step, six interviews were performed with international experts and two members of the LGBTQIA+ community. A thematic analysis of the interview was performed, and four main themes identified: anticipated concerns, the need for a LGBTQIA+ affirmative ethos and workforce as well as an understanding of the variety of the LGBTQIA+ community and its needs, and issues related to persons who are transgender. A review of international best practices was conducted and used together with the survey. From this analysis a preliminary list of needs and recommendations was created. This list was submitted to a group of key stakeholders. The list was revised and then re-submitted to the PPI group and finalized as a list of priorities.

The manuscript is clearly written and makes an important contribution to the policy development concerning being members of the LGBTQIA+ community. I have some suggestions, mainly about clarifications of the methods used and recruitment of participants.

(1) 49 responses to the national questionnaire is fairly low. Maybe the reasons for the low number could be discussed. Table 1 should also contain the absolute numbers not just percentage (as all other tables show).

(2) Some more information about the respondents and their relation to the total community is needed. A central concern is if the respondents can be seen as representative of the whole community - or if some group or groups are left out.

(3) It would be good with some more information about the interviews. Why just six interviews, and why these interviewees? Why not interviews with many more members from the LGBTQIA+ community? How were the interviewees recruited?

(4) It is unclear what the basis is for the results presented in the section "Analysis of qualitative data- interviews and survey". Is it based only on the interviews, or is based on the interviews and the survey? If the survey data was included this needs to be described and clarified how it was used.

(5) How were the participants in the PPI advisory group recruited? What do "purposeful sampling strategy" mean in this context? Could the PPI group be seen as representative for the LGBTQIA+ community as a whole?

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Partly

If applicable, is the statistical analysis and its interpretation appropriate?

Yes

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Dementia studies

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 10 July 2023

<https://doi.org/10.21956/hrbopenres.14976.r34667>

© 2023 Drummond N. This is an open access peer review report distributed under the terms of the [Creative Commons Attribution License](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.



Neil Drummond

University of Calgary, Calgary, Alberta, Canada

This paper presents the findings from a mixed method study of health and social service needs of aging LGBTQIA2S people living with dementia. Methods applied include an internet and mailed quantitative survey, semi-structured interviews, a consensus conference using a nominal group approach and the identification of needs and recommendations for fulfilling them. The study was strongly guided by principles of participatory community-based research.

I enjoyed reading this report. The study was well done and thorough and I think the findings will be useful in improving care for people with dementia in the Irish context, if policy makers are convinced by it. I think there must be concern that the sample sizes involved are not really large enough to strongly support the evidence being presented, but the authors acknowledge this and I don't think this alone is reason for rejecting the report for indexing and dissemination.

I do have some niggling issues that I think should be addressed, as follows.

1. In Table 1 14% of respondents were LGTBQ2 etc. living with dementia. This translates to 6-7 people. Despite the fact that doing so highlights the small samples I think the numbers involved should be reported alongside the percentages. This is science after all and we should be honest.
2. Tables 2 and 3 are said to indicate that older LGTBQ2 people become more isolated from their community, but that's true for most people as they age. Some acknowledgement of this would help readers judge the impact of the tendency.
3. Despite the above, Fig 1 appears to show that most respondents had maintained community engagement, at least to their own satisfaction.
4. Fig 3 contains duplication of the "Relevant in some situations" response.
5. Table 5 displays responses to a "Lifetime experience of abuse" item. This is probably misleading unless contextualized by presenting general population norm data. Everybody suffers abuses of some kinds over a lifetime.
6. As above, for Table 6. And the item "I was denied or provided inferior care" could be read as "I was denied inferior care or provided inferior care", and is hence ambiguous.
7. In the qualitative data section the international expert's comment about the crucifix sounds equivalent to judging a book by its cover. It may not signify what she assumes it does.
8. In the "Limitations" section the authors state that the questionnaire was returned by 13.89% of care partners. As noted above, Table 1 reports that 13.89% (or 14%) of respondents were LGTBQ2 living with dementia, and 2.78% (2 people?) were care partners. I would round up these percentages.
9. In the questionnaire, the responses to the Q15 "use of services" items leap from 1/y to "never", which seems a bit unreasonable and may have led to serious undercounting. An intervening <1/y before the "never" might have been useful. The same goes for Q16.

10. In the Topic Guide, the "Many people in the survey commented that Has this happened to you?" structure is clearly leading.

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Not applicable

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Dementia epidemiology, primary care, population health surveillance using primary care EMR data.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Version 2

Reviewer Report 22 December 2022

<https://doi.org/10.21956/hrbopenres.14924.r33136>

© 2022 Galvin M. This is an open access peer review report distributed under the terms of the [Creative Commons Attribution License](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.



Miriam Galvin

Academic Unit of Neurology, School of Medicine, Trinity College Dublin, Dublin, Ireland

Could respondents answer more than one response in the community participation question?

Tables 2 and 3 LGBTQIA in the label but not in the response categories, or text.

Only two activities were attended by participants in the majority of cases, these were LGBTQI+ groups and Cultural/arts groups. - Not sure what this means

Percentages in Figure 2 and 3 would be useful.

Figure 3 is LGBT identity interchanged with LGBTQIA or + etc?

There were ten core needs and sixteen recommendations derived from the data and literature gathered
- How?

Some typos throughout.

The authors' revisions are good. There are no major, significant changes required but feel still some work needed.

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Yes

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 08 Feb 2023

Sinéad Hynes

Thank you for re-reviewing this manuscript. We appreciate the time and effort involved. We

have addressed all of the areas raised in the newest version of the manuscript. In summary it is as follows:

- Could respondents answer more than one response in the community participation question?
 - It was only possible to provide one answer here. This note has been added for clarification.
- Tables 2 and 3 LGBTQIA in the label but not in the response categories, or text.
 - This has been changed, thank you.
- "*Only two activities were attended by participants in the majority of cases, these were LGBTQI+ groups and Cultural/arts groups*". - Not sure what this means.
 - This meant that participants reported taking part in no more than two activities. We have deleted this sentence as it is not clear and not important additional information to have in the text.
- Percentages in Figure 2 and 3 would be useful – percentages provided for both.
 - Percentages are now available for both.
- Figure 3 is LGBT identity interchanged with LGBTQ!A or + etc?
 - This has been changed.
- There were ten core needs and sixteen recommendations derived from the data and literature gathered - How?
 - A paragraph has now been added that we hope clarifies this.
- Some typos throughout.
 - We hope we have now spotted all of the typos and made required corrections. Thank you.

Competing Interests: No conflict of interest to declare.

Version 1

Reviewer Report 09 September 2022

<https://doi.org/10.21956/hrbopenres.14732.r32684>

© 2022 Phillipson L et al. This is an open access peer review report distributed under the terms of the [Creative Commons Attribution License](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.



Lyn Phillipson

Health and Society, Arts, Social Sciences and Humanities Faculty, University of Wollongong, Wollongong, NSW, Australia

Keryn Johnson

School of Health and Society, Arts, Social Sciences and Humanities Faculty, University of

Wollongong, Wollongong, Australia

The aims of the paper were to 1) Identify the future needs of older LGBTQIA+ people and their care partners living in Ireland have in relation to dementia care service delivery (note that the abstract has LGTBQIA+) and 2) develop consensus-based recommendations for dementia service provision in Ireland. It should be noted that the research itself is orientated to the people with dementia and does not give recommendations on the needs of caregivers.

The research is topical and needed however there are some fairly major issues that need to be resolved in how the research is described in this paper. There is a lot of data being reported on in the papers, yet not enough detail on methods to allow the reader to really assess the integrity of the findings. Further detail on methods is required. There is little justification of the methods except perhaps for the modified Delphi. Further justification is required.

The authors may need to consider the potential benefits of breaking this research up into perhaps 2 or even 3 papers: survey, qualitative, and overall consensus process to address the level of detail that is required to ensure the rigour of the article is not in question

Overall recommendation: Major Revisions required

Page 3

The background literature is current and relevant.

However, a few more references supporting the lived experience of LGBTQIA+ would be appropriate.

Please revise and tighten the narrative and improve punctuation over the next few pages (the use of short and longer dashes e.g. Phases 1 & 2 headings).

There are also grammatical mistakes throughout the paper that require corrections ('s' where there should be, missing 'the's, incorrect were/was, the use of '&' within the text) that need to be addressed.

Please provide further details of the make up of the PPI.

Please provide further details about what the survey was about – what was its content and how did it change throughout the Delphi process.

The statement 'thorough review of the literature' is not sufficient evidence of support for the design of the survey. Please provide more details on the process used and what results it provided.

It says PPI decided on inclusion of items etc – did the researchers collaborate on this, or was this totally PPI decision-making?

You state the survey was piloted in Phase 1 – but don't mention it in Phase 1. Please clarify.

Page 4

Not sure what you mean by interviews through an online platform. Zoom? Email?

How was Phase 4 used within the research? Please provide further detail on the process or what you asked the experts. Were these results incorporated into the interview results? This is not clear. Please provide more specifics with regards to participant backgrounds - 'Voluntary and healthcare backgrounds' is not sufficient.

Please provide further details with regards to how the results of Phases 2,3,4 were presented to the group. Also on how you present the needs and recommendations at the same group – who developed these? You?

Who were presented the results for member checking? Please specify.
Please give details of the PPI group -somewhere in the paper.
How many in the pilot group?

Page 5

Survey data collection ceased – not sampling ceased. Please correct.

Please describe the data analysis more clearly i.e. quantitative data was analysed i.e. descriptive statistics, open-text (qualitative data) was analysed via content analysis (although you don't really present the findings as per a content analysis – more like a thematic so I am not sure what process was used. Please clarify).

Quite a detailed qualitative analysis and then only 2 themes? Please justify/explain further.

Explain what you mean by verification of data integrity. How?

What were the multiple observer/observations that you did?

How did the PPI work with the qualitative data?

Please consider reporting demographics in a table. This would improve clarity and ease of reference for readers.

In academic writing it is convention to spell out a number if it starts a sentence. Please correct.

Page 6

Please work on introducing your survey results better - please provide further background into what you asked and to improve the readers capacity to understand the results.

Figure 1 is not really a good graphic to present these results. Please revise.

Also is it not clear if people could only tick one box, as it adds up to 100%? A bar chart might be better.

Page 7

These tables are easier to understand but I don't understand why means and standard deviations are here – they are not appropriate to this data. Please revise.

Page 8

Again these pie charts are overly big and use a lot of space, and difficult to read in black and white– consolidate these into a table.

Figure 3 label – missing QAI+.

Page 9

The open text results need more introduction. Please provide.

'Like in prior research' – please provide references to support this statement.

Please attribute the quotes in the paper with the appropriate participant identifiers to ensure adequate context. This is usual practice and should be followed e.g. Carer, age 55.

Please make further comment on the results in the tables – e.g. what were the highest forms of discrimination.

Page 10

Lack of protection 'from' discrimination. Please correct.

If reporting all these percentages, a table is better.

Again the pie chart uses up too much room for the information it imparts – try to consolidate with other data.

Page 11

You said 8 interviews earlier – now 6? Please correct and ensure accuracy.

I think there could be some sub-themes here. Please clarify and improve depth of responses.

Page 12

'Additional note' is not a theme, and should be labelled differently.

Page 13

I think your headings are getting a bit lost in the text. Please revise.

Please give specific numbers for people in your consensus process e.g. former carers (n=3).

Still not quite sure how the recommendations came from the data and who did it.

Page 14

Needs and recommendations should be put into a table or box or something to set them apart – they are the crux of your paper.

Page 15

Discussion is ok. But further information is required to address what this research adds to current knowledge specifically.

Page 6

Normally you do not reference within a conclusion, as you are just summarising what you have already said. Please correct.

Is the work clearly and accurately presented and does it cite the current literature?

Partly

Is the study design appropriate and is the work technically sound?

Partly

Are sufficient details of methods and analysis provided to allow replication by others?

No

If applicable, is the statistical analysis and its interpretation appropriate?

No

Are all the source data underlying the results available to ensure full reproducibility?

No source data required

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Dementia, qualitative research methods

We confirm that we have read this submission and believe that we have an appropriate level

of expertise to confirm that it is of an acceptable scientific standard, however we have significant reservations, as outlined above.

Author Response 24 Oct 2022

Sinéad Hynes

Dear Dr Phillipson and Dr Johnson,

Many thanks for your review and comments. We have considered each comment and have amended the manuscript considering your review. We have also answered some of your queries and comments here:

Comment 1: The aims of the paper were to 1) Identify the future needs of older LGBTQIA+ people and their care partners living in Ireland have in relation to dementia care service delivery (note that the abstract has LGTBQIA+) and 2) develop consensus-based recommendations for dementia service provision in Ireland. It should be noted that the research itself is orientated to the people with dementia and it does not give recommendations on the needs of caregivers.

The research is topical and needed, however, there are some fairly major issues that need to be resolved in how the research is described in this paper. There is a lot of data being reported on in the papers, yet not enough detail on methods to allow the reader to really assess the integrity of the findings. Further detail on the methods is required. There is little justification of the methods except perhaps for the modified Delphi. Further justification is required. The authors may need to consider the potential benefits of breaking this research up into perhaps 2 or even 3 papers: survey, qualitative and overall consensus process to address this level of detail that is required to ensure the rigour of the article is not in question.

Response: The authors considered detailing the results of the survey, interviews, and consensus process individually, however, we believe that this would remove vital context from each individual paper. We concluded that our findings were more valuable if presented as a whole, particularly because the results and findings from the survey and the interviews, for example, were very closely tied and intrinsically linked. The aim of the research was to identify the needs and recommendations and we feel it necessary to report on the entire process together in order to do this. However, we have made some formatting changes and substantial restructuring of the manuscript, particularly the results section, in relation to your review and comments from other reviewers which should help to simplify the presentation of our results.

We have noted the typo in the abstract relating to the acronym LGBTQIA+ and changed it as such. Please note that we use both LGBTQI+ and LGBTQIA+ in the manuscript- as addressed in Reviewer 1 response. We have also added further justification to our methods section which will hopefully clarify the rigor of this article. We have done this while also trying to reduce the length of the manuscript, as requested by reviewers.

We also acknowledge that further research should be oriented towards creating recommendations and core needs for the caregivers of LGBTQIA+ people with dementia in our limitations section as this would be beneficial to further establishing international best practices for this group of service users.

Comment 2: The background literature is current and relevant. However, a few more references supporting the lived experiences of LGBTQIA+ people would be appropriate.

In the interest of reducing the length of the manuscript we did not include additional reference to the lived experience of LGBTQIA+ people. We feel that the main areas are covered in the background and adding additional discussion would make the background overly-lengthy. We hope this is acceptable to you.

Comment 3: Please revise and tighten the narrative and improve punctuation over the next few pages (the use of short and longer dashes e.g. Phases 1&2 headings) There are also grammatical mistakes throughout the paper that require corrections (s' where there should be, missing 'the's' and the incorrect were/was, b and use of '&' within the text.) this needs to be addressed.

Response: We hope that all grammatical and punctuation errors have been addressed now.

Comment 4: Please provide further details of the make-up of the PPI.

The PPI members were not participants and as a result, it is not appropriate to provide detailed description of the group. They were, however, all older people from the LGBTQIA+ community or carers for an older person from the LGBTQIA+ community.

Comment 5: Please provide further details about what the survey was about - what was its content and how did it change throughout the Delphi process?

Response: The survey provided information on participants, previous experiences with healthcare use, general discrimination, community participation, how important they viewed their sexual or gender identity to be in a healthcare context, and how participants viewed their identity. The survey also utilized text-response questions in which participants could elaborate on their experiences surrounding accessing care and what they believed their future use of healthcare might look like.

We are not sure if the reviewer is referring to changes to the survey during the piloting phase rather than the Delphi process? Several small edits and clarifications were made at this stage, but nothing that changed the overall content.

Data from the survey were analysed descriptively and via content analysis and were used to inform the initial needs and recommendations for presentation to the consensus meeting. Further information on how these recommendations and needs were developed have been added to the manuscript. The questionnaire itself can be viewed in the linked Extended data (at the end of the manuscript before the References section).

Comment 6: The statement 'thorough review of the literature' is not sufficient evidence of support for the design of the survey. Please provide more details on the process used and what results it provided.

We did not create the survey. The questionnaire that we used has been developed by researchers in the US and used on an American group of participants. This survey was adapted for use in Ireland. We have added to our description of the survey design. The reference for the original survey is included in the paper.

Comment 7: It says PPI decided on the inclusion of items - did the researchers collaborate on this or was this totally PPI decision-making?

Response: This was a collaboration between the researchers and the PPI group. Items from the questionnaire (Fredriksen-Goldsen & Kim, 2017) were adapted and the addition of dementia-specific questions or phrases used (such as the inclusion of the word queer) was also discussed with the PPI group.

Comment 8: You state the survey was piloted in Phase 1 - but don't mention it in

Phase 1. Please clarify.

Response: This has been clarified in Phase 1. This section has been restructured and we hope it is now easier to follow.

Comment 9: Not sure what you mean by interviews through an online platform. Zoom? Email?

Response: Zoom was used for all interviews.

Comment 10: How was Phase 4 used within the research? Please provide further detail on the process or what you asked the experts. Were these results incorporated into the interview results? This is not clear.

Interviews with international experts were interviewed to provide information on best practice. They were included in the thematic analysis. We have expanded somewhat on this in the manuscript.

Comment 11: Please provide more specifics with regards to participant backgrounds – Voluntary and healthcare backgrounds is not sufficient.

Response: We have added more to the backgrounds in relation to whom we were recruiting, however, we cannot include any potential identifiers in this report.

Comment 12: Please provide further details with regards to how the results of phases 2,3,4 were presented to the group. Also on how you present the needs and recommendations at the same group – who developed these? You?

Response: Phases 2,3,and 4 were presented to the consensus group via a zoom presentation. A PowerPoint presentation was used and each step of the research was described along with the results from each of these phases a discussion was then opened up to the group following the presentation. This description can be found in both our results section under the heading Consensus process and in our method section under the heading 'Phase 5'. We used Slido to facilitate the voting. Participants could see the results "in real-time" during the meeting using this online tool.

A detailed description of how the initial needs and recommendations were developed has also been included in light of this comment.

Comment 13: Who were presented the results for member checking? Please clarify.

Response: The consensus group were presented with the results for checking. We have clarified this in the manuscript.

Comment 14: Please give details of the PPI group – somewhere in the paper.

Please see Comment 4 for this.

Comment 15: How many in the pilot group?

Seven people completed the pilot (this data was not included in the results).

Comment 16: Survey data collection ceased – not sampling ceased. Please correct

Response: This was a grammatical error on our part and has been changed.

Comment 17: Please describe the data analysis more clearly i.e. quantitative data was analysed i.e. descriptive statistics, open text (qualitative data) was analysed via content analysis (although you don't really present the findings as per content analysis – more like thematic so I am not sure what process was used. Please Clarify).

The data analysis has now been included across each of the Phases for ease of reading. We hope this has adequate information. We can provide additional information if required for any of the phases of analysis. We have not provided an lengthy description because of the length of the manuscript.

Comment 18: Quite a detailed qualitative analysis and then only 2 themes? Please justify/explain further.

We have presented this slightly differently now as four themes (and additional theme was added on request of reviewer 1).

Comment 19: Explain what you mean by verification of data integrity.

The data was screened when exported into Excel. The data was cleaned and the source data was checked to ensure there were no omissions or errors.

Comment 20: What were the multiple observer/observations?

This term has been removed as it is somewhat confusing. We had meant that we are multiple data collection methods- e.g. survey and interviews.

Comment 21: How did the PPI work with the qualitative data?

The PPI group advised on the creation of the topic guides.

Comment 22: Please consider reporting demographics in a table. This would improve clarity and ease of reference for readers.

This has now been done and can be seen in Table 1.

Comment 23: Please work on introducing your survey results better and open text results need more introduction.

More information has now been provided and the manuscript has been re-structured to ease understanding.

Comment 24: Please revise Figure 1. Is it not clear if people could only tick one box, as it adds up to 100%? A bar chart might be better.

We have changed the other figures (from pie-charts) that were presented in the manuscript. We are, however, reluctant to change Figure 1 as PPI advisors have expressed a desire to keep this figure as is for ease of understanding. People could only tick one box here- this is why it adds up to 100%.

Comment 25: Please attribute quotes in the paper

This has now been included for each quote.

Comment 26: Please make further comment on the results in the tables.

We have included some further discussion. This is not exhaustive and the tables are included for further reference.

Comment 27: I think there could be some sub-themes here

We have broken this down further into four separate themes that we believe improves the reporting of the results, while staying true to the analysis process.

Comment 28: Needs and recommendations should be put into a table or box or something to set them apart – they are the crux of your paper.

These are now included as a table.

Comment 29: Discussion is ok. But further information is required to address what this research adds.

This has now been added to the end of the manuscript. We have also deleted the reference, as requested.

We would like to thank you again for your contributions, which we believe have greatly increased the standard and rigor of this article.

Kind regards,

Megan H. Oglesby & Sinéad M. Hynes

Competing Interests: None

Reviewer Report 02 September 2022

<https://doi.org/10.21956/hrbopenres.14732.r32612>

© 2022 Galvin M. This is an open access peer review report distributed under the terms of the [Creative Commons Attribution License](#), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.



Miriam Galvin

Academic Unit of Neurology, School of Medicine, Trinity College Dublin, Dublin, Ireland

The aim of this research was to identify the future needs that older LGTBQIA+ people and their care partners living in Ireland have in relation to dementia care service delivery; and to develop consensus-based recommendations for dementia service provision in Ireland. This is a relevant and interesting area for exploration. And translating their work into recommendations is a welcome addition.

This study employed multiple methods – survey, interviews and consensus meeting. Background includes relevant literature on LGTB+ people from Ireland and on an international scale.

Ethical approval for this work was granted, and clearly stated. Reporting standards were used, with PPI involvement as per good practice.

General:

- A lot of data and information are presented in this paper. The authors could present the survey findings or the interview findings in individual papers and the consensus and recommendations in another paper for example.
- While it is useful to detail the whole process that was undertaken, and report the findings from each phase in this paper, if the whole work is included could the authors condense the information presented?

Specific issues:

- Could the authors explain the addition of QIA+ to the more common LGTB+ for readers to understand?
- Could the authors say a bit more about why dementia services in particular are the focus of their work? Are the requirements for those services different to healthcare services more generally?
- Are the 6 phases described (pp 3-4) part of the consensus process or the research process?
- It may be clearer for readers if the 'data collection tools' were linked with each of the phases identified rather than in the following subsection (p4)?
- Page 4 *Sampling stopped after no more responses were recorded in the survey for a period of two weeks.* – does that mean the survey was closed to data being collected, how is this sampling?
- More information on the survey is needed:
- How was the survey undertaken, on-line? Postal?
- How are the authors defining completion rate? How many people were asked to do the

survey? How many responded? How were paper versions of surveys returned to authors?
How were the survey data uploaded/downloaded etc?

- Could the authors describe how and why they used content analysis from the survey data?
It is not clear to this reader how these data were analysed – is it the quotes presented?
- Could the authors clarify why they present means and standard deviations in the tables e.g.,
Table 1, what does a mean of 1.27 indicate?

How is the reader to differentiate the quotes in the survey section from those in the interview
analysis section?

Interview data (p11) as a heading – should this be analysis of interview data?

Could the authors comment on why they did 6 interviews? Were more than 6 recruited etc?

Why were international experts included in the interviews?

Page 12 – additional note on transgender experiences and identity – the heading type is similar to
those used for the themes – suggest this should be changed or else it is a 3rd theme?

Page 13 Consensus process How were 10 key stakeholders identified? Were there criteria used to
include people?

How were the core needs and recommendations derived from the data (before ranking)?

Page 16 Limitations: *This indicates that there may be older people who have not disclosed to anyone
at this point that have been excluded from the data.* Not clear what this means, how do the authors
know this?

Did the authors consider adapting the survey to make it shorter?

Looking at the National Survey document– was there an 'A' as in LGBTQIA+?

Is the work clearly and accurately presented and does it cite the current literature?

Partly

Is the study design appropriate and is the work technically sound?

Partly

Are sufficient details of methods and analysis provided to allow replication by others?

Partly

If applicable, is the statistical analysis and its interpretation appropriate?

Partly

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: No competing interests were disclosed.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 24 Oct 2022

Sinéad Hynes

Dear Dr Galvin

Many thanks for your review and comments. We have considered each comment and have amended the manuscript in light of your review. We have also answered some of your queries and comments here:

Comment 1: A lot of data and information are presented in this paper. The authors could present the survey findings or the interview findings in individual papers and the consensus and recommendations in another paper for example. While it is useful to detail the whole process that was undertaken and report the findings from each phase in this paper, if the whole work is included could the authors condense the information presented?

Response: The authors considered detailing the results of the survey, interviews and consensus process individually, however we believe that this would remove vital context from each individual paper. We concluded that our findings were more valuable if presented as a whole particularly because the results and findings from the survey and the interviews, for example, were very closely tied and intrinsically linked.

We have, however, made formatting changes and substantial restructuring and revision of the manuscript, particularly the results section, in relation to your review and comments from other reviewers which should help to simplify the presentation of our results. We have also reduced the text and the length of the quotes in some places which has reduced the text by approximately 1500 words.

Comment 2: Could the authors explain the addition of QIA+ to the more common LGBT+ for readers to understand?

Response: The addition of QIA+ was discussed with our PPI group, as the authors have noted the increase in the popularity of this acronym due to its increased inclusiveness in comparison to LGBT (George, 2021). Although we considered using LGBT+, with the plus symbol signaling further inclusiveness, our PPI group members preferred the specific inclusiveness to Queer/Questioning, Intersex and Asexual people who are becoming increasingly visible within the community and whose needs have been marginalised within the LGBT community (George, 2021). We also believed that it would specifically highlight our aim to include Intersex, asexual and people who identify as queer or questioning into our study. We have inserted a small explanatory section in the manuscript as a footnote to justify this decision.

Comment 3: Could the authors say a bit more about why dementia services in particular are the focus of their work? Are the requirements for those services different to healthcare services more generally?

Response: Dementia services were the focus of this study because prior studies have found

that some members of the LGBTQIA+ community are more likely to develop dementia due to secondary reasons such as being more likely to experience social isolation, or being more likely to develop HIV or depression which increases their risk factor for developing dementia. Research in the area of LGBTQIA+ dementia has increased in the last number of years, however there were no specific data relating to LGBTQIA+ people with dementia and their access to care, except for the open letter (Roe et al., 2020) in which more research into the accessibility of care for older LGBTQIA+ older adults was called for. Additionally, as in Ireland there were no existing LGBTQIA+-specific dementia service at the time of writing the manuscript, we believed that it would be beneficial to specifically examine care provision for this demographic. Many of these findings may be generalisable to older LGBTQIA+ adults accessing care services in Ireland whether they have dementia or not.

Comment 4: Are the 6 phases described (pp 3-4) part of the consensus process or the research process?

Response: The six phases described are a part of the consensus process, but this is also the overall research process that was followed by the research team. The consensus process is the method used (with a consensus meeting forming a phase of this).

Comment 5: It may be clearer for readers if the 'data collection tools' were linked with each of the phases identified rather than in the following subsection (p4)

Response: This has been amended and much of this section has been merged with the phases section.

Comment 6: Sampling stopped after no more responses were recorded in the survey for a period of two weeks. – Does that mean the survey was closed to data being collected, how is this sampling?

Response: This was a grammatical error on our part and has been amended.

Comments 7-12: More information on the survey is needed:

The survey was postal and online based. However no postal responses were received. Questionpro was the online survey platform, on which we calculated how many people completed the entire survey as opposed to partial completion, this is what we are referring to when we write about the "completion rate". Unfortunately, we cannot know how many people were asked to complete the survey as we used a number of social media platforms as well as dementia and LGBTQIA+ organisations for recruitment purposes. Forty-nine people responded to the survey.

Content analysis was used on the survey responses because the survey included long answer questions. However, the responses to these questions tended to be quite short, varying in length between a single paragraph to a single sentence. The authors believed it would be helpful to analyse the frequency of coded answers throughout the survey, as opposed to recurring themes within a single answer. An explanation of why we used content analysis on these data has been added to the manuscript.

Quotes in the survey sections were quotes from the long-answer survey questions and quotes presented under the heading of 'Interview Data' were from the Interviews. However, this has been restructured as the long-answer questions were used to create themes from the content analysis. The themes derived from this analysis were very closely related to the themes that were developed during the thematic analysis of the interview data and therefore they are now be presented together. To help the reader differentiate between quotes we have included a descriptor of what type of participant created the quote (i.e. – interview participant or – survey participant).

The inclusion of standard deviations and means was an error and they have been removed.

Comment 13: Interview data (p11) as a heading – should this be analysis of interview data?

This has been amended.

Comment 14: Could the authors comment on why they did six interviews? Were more than six recruited etc?

Response: There were a total of eight interviews. Six interviews were with international experts and two were with LGBTQIA+ older adults. Older LGBTQIA+ adults were recruited for an interview through social media and relevant organizations and therefore we cannot comment on how many people in this cohort were approached for recruitment. The six international experts were recruited via email, more than six were approached but six responded and followed through with the interview. We have clarified this in the manuscript.

Comment 15: Why were international experts included in the interviews?

Response: International experts were included to gather more information surrounding the development of international best practice. International experts were not invited to take part in the consensus meeting- including ranking of items (as described in Phase 5).

Comment 16: Additional note on transgender experiences and identity – the heading type is similar to those used for the themes – suggest this could be changed or else it is a third theme?

Response: Thank you- the authors have substantially restructured this section and this has now been included as an overall theme.

Comment 17: Consensus process: How were the 10 key stakeholders identified? Were the criteria used to include people?

Ten key stakeholders, who consisted of LGBTQIA+ people with dementia, LGBTQIA+ older adults, former caregivers of LGBTQIA+ older adults, and people who have worked with LGBTQIA+ older adults and/or people with dementia took part in the consensus meeting. A purposeful sampling strategy was used to ensure a diverse group with varied experiences and backgrounds. We included all members of the PPI group (as this was already a representative group) and the additional members were invited from dementia organisations in Ireland. Criteria were the same as for the survey (described in Phase 2).

Comment 18: How were the core needs and recommendations derived from the data before ranking?

Response: Core needs and recommendations were predominantly derived from the themes and subthemes that were developed from the interviews and long-answer survey responses, as well as from the literature on the topic. For instance, where a problem clearly exists in the themes a recommendation to solve that problem was either developed or taken from the participants' recommendations. In some cases, such as the recommendation to provide LGBTQIA+-relevant information leaflets along with other more generalised dementia leaflets, the recommendation was derived directly from an interview source as this recommendation, in particular, was already being conducted in some dementia organisations in the UK but not in Ireland, and we believed this was relevant in relation to the development of international best practice.

Comment 19: This indicates that there may be older people who have not disclosed to anyone at this point that have been excluded from the data. Not clear what this means, how do the authors know this?

Response: This has been removed from the manuscript as it may cause confusion. We had meant that all of our participants had previously disclosed their sexuality or gender identity

to another person at least once. This indicates that our survey did not capture the experiences of any older LGBTQIA+ person who has not “*come out of the closet*”. We have tried not to use this phrase in the manuscript but include it here to help clarify what we had meant.

Comment 20: Did the authors consider adapting the survey to make it shorter?

Response: Yes, we had. We consulted extensively with the PPI group on this and a decision was made to include all items that are currently there but to accept incomplete questionnaires (those with missing data). The survey did use skip logic, which would have shortened the length of time to undertake the survey to an extent.

Comment 21: Looking at the National Survey document – was there an ‘A’ as in LGBTQIA+ ?

Yes, this is correct. Although asexual people are often included in the “+” that was in the survey, this was not explicitly stated. We have changed it accordingly in the results section to avoid confusion. We have not changed throughout the entire manuscript as some of the research presented- including the recommendations and needs explicitly included those who identify as asexual.

We would like to thank you again for your contributions, which we believe have greatly increased the standard and rigor of this article.

Kind regards,

Megan H. Oglesby & Sinéad M. Hynes

Competing Interests: None.