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Public Involvement Report: Learning the Narratives and Expectations of Health and Care Needs for Older LGBTQ+ People

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Abstract

Older LGBTQ+ adults face persistent inequalities in health and social care, often shaped by historical trauma and systemic exclusion, raising critical questions about how ageing can be supported equitably. This public involvement project explored the narratives and expectations of older LGBTQ+ individuals regarding ageing, health, and social care. Public involvement events were organised and facilitated by an interdisciplinary group of academics between January and April 2025 in Cardiff, Exeter, and Bristol, locations chosen for their rural, coastal, and urban contexts. Creative participatory methods were used to engage LGBTQ+ individuals, aged 50 years old and over, in discussion and sharing narratives. The work found attendees wanting to talk about themes of isolation and invisibility in society, and within LGBTQ+ spaces, the need for inclusive spaces, as well as concerns about discrimination in healthcare settings. Throughout the three events, there was a clear desire among attendees for future research and advocacy, alongside the emergence of a strong community network committed to inclusive and affirming care. These insights can help guide future research projects and initiatives aimed at improving support for LGBTQ+ ageing.

Keywords: LGBTQ+ studies; ageing; care of the older person; knowledge exchange; social inequalities

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1. Introduction

Population ageing is now recognised globally as a major demographic and social shift, with the United Nations Decade of Healthy Ageing (2021–2030) calling for coordinated action to ensure that older people are supported in ways that promote equity and inclusion (United Nations General Assembly 2020). Similarly, the World Health Organization emphasises that longer lives will reshape health and social care systems and that structural discrimination can significantly influence older adults' wellbeing and access to services

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(World Health Organization 2021). Effectively responding to the complexities of an ageing society demands a deliberate focus on minority ageing and an appreciation of the varied needs and experiences that different groups of older adults bring.

Research into the experiences of older LGBTQ+ individuals in the UK has grown in recent years (Westwood et al. 2020; Hafford-Letchfield and Roberts 2023; Adley et al. 2025). Throughout their lives, LGBTQ+ people often face significant inequalities in accessing health and social care. Much of the existing literature highlights these persistent inequalities, which are compounded by historical discrimination and a lack of inclusive service design (McDermott et al. 2021). These inequalities include higher rates of mental health issues, discrimination in healthcare settings, and avoidance of medical services due to fear of mistreatment (Löf and Olaison 2020; Wolff et al. 2023). According to Stonewall's LGBT in Britain—Health report (2018), one in seven LGBTQ+ individuals avoid seeking healthcare due to fear of discrimination, and nearly one in four have witnessed negative or discriminatory remarks from healthcare staff. Since Stonewall's (2018) report, several more recent UK-based reports have expanded and updated the evidence on LGBTQ+ health inequalities. These include LGBT Foundation's (2023) *Hidden Figures*, the ongoing NHS *England LGBT+ Health Evidence Review* (NHS England 2025), and the peer-reviewed policy analysis *The Inclusion of LGBTQ+ People Within UK Health Policy* (Braybrook et al. 2025). These newer sources confirm that significant inequalities persist, particularly for trans and older LGBTQ+ people.

Older adults frequently report a lack of confidence in approaching services provided by the NHS, religious organisations, or the state, institutions that have historically marginalised LGBTQ+ communities (Age UK 2019; Janssen and Scheepers 2019; Mendos et al. 2020; Cousins et al. 2021). This historical trauma represents the cumulative emotional and psychological wounding experienced across generations due to systemic oppression, criminalisation, stigma, and state-sanctioned discrimination, a pattern similarly observed in other marginalised groups such as ethnic minorities, Indigenous communities, and migrants, whose collective memories of discrimination shape health inequalities across the life course (Chan et al. 2025). It contributes to deep-rooted mistrust, particularly among those who lived through periods of criminalisation, institutional abuse, or social exclusion (Marchi et al. 2023). The shared experiences of stigma and resilience among LGBTQ+ individuals lead community formation by developing chosen families and support networks that shape wellbeing and care-seeking behaviours (Peel et al. 2023).

A major contributing factor is that health and care services are often designed around heteronormative assumptions, failing to account for the diverse identities and needs of LGBTQ+ individuals (National LGBT Partnership 2017; Thomas and Sladen 2023). For example, older LGBTQ+ people may face challenges in residential care settings where assumptions about heterosexuality and cisgender identity are embedded in daily routines and policies. This can lead to feelings of invisibility, isolation, and the need to conceal one's identity in later life (Taylor et al. 2021; Victor and Rippon 2023). Many reported feeling forced to 'go back into the closet' when accessing care services due to fears of discrimination or misunderstanding (Almack 2018; Willis et al. 2016; Moriarty and Willis 2024). Concerns about future care are also present among younger LGBTQ+ individuals. In the CILIA-LGBTQI+ project (2021), participants under 40 expressed hopes that growing awareness and acceptance would lead to more inclusive care in later life. While some were optimistic, citing recent progress in LGBTQ+ equality, others remained uncertain about whether meaningful improvements in care provision would materialise. Despite increasing visibility of LGBTQ+ issues in public discourse, older LGBTQ+ adults remain underrepresented in research (Westwood et al. 2020; Crowe et al. 2021). As the ageing population faces multiple co-morbidities, it is essential that public services become more inclusive, equitable, and responsive to the full spectrum of communities they serve. Although older LGBTQ+ adults share many of the same age-related needs as the wider population, intersectional factors—such as historical discrimination, minority stress, and reduced access to familial support—create additional layers of vulnerability that must be recognised to ensure equitable care.

Addressing inequalities experienced by older population and ageing LGBTQ+ individuals is not only a matter of social justice but also a public health imperative.

This article offers a report on the "making of" and reflections from a community knowledge exchange project designed to elicit the experiences, perceptions, and expectations of LGBTQ+ people regarding ageing and related health and social care needs. Central to this initiative was a commitment to centring the voices of older LGBTQ+ individuals and surfacing their priorities. As a public involvement project, the purpose was not to produce research findings but rather to lay groundwork needed to inform future research by helping academics focus on topics most relevant to the community. Through knowledge exchange activities, the group ensured that any future research would be shaped by the community from the outset, living up to the principle of "nothing about us without us."

2. Methods

The public involvement events were designed to inform future research. The events themselves did not comprise academic research. Accordingly, our approach was exploratory; we did not set out to test specific hypotheses or pursue pre-specified objectives with guiding questions. In constructing the events, we drew on participatory approaches (Chevalier 2019), to foreground the voices and lived experiences of LGBTQ+ older people as co-creators of knowledge (Terkelsen et al. 2022). In-person community events were chosen as the engagement method to foster inclusive dialogue, build trust, and create spaces where narratives around ageing, health, and care could emerge organically. This approach aligns with theories of co-production and empowerment in to identify themes and priorities that may otherwise remain unexplored in traditional research settings (UK Research and Innovation 2025). This project was designed by an interdisciplinary team comprised academics from Nursing, Medicine, Health Psychology, Epidemiology, Architecture, Law, and Geospatial Sciences. The group reflected the different perspectives and complexity of the topic of social inequalities, and was a group representing different ethnicities, nationalities, ages, genders and sexual orientations, with a shared commitment to social justice. Their approach was shaped by an ethos of respectful presence, aiming to create spaces where participants felt seen, heard, and cared for, without intrusion or appropriation. Through listening to lived experiences, the team enacted a form of "caring about", a reflective practice aimed at noticing and revealing unmet care needs and emergent themes (Tronto 1993). This was conceptualised as a potential act of care, which begins with recognition of others' experiences as a first step towards and eliciting a help response to engage in positive change. This real-world, problem-solving work drew widely on the epistemological and methodological richness of the interdisciplinary team, embracing pluralistic ways of knowing and valuing the lived experiences of everyone involved. Such an approach resonates with social justice-oriented qualitative inquiry, which encourages open inquiry, responsive, and attuned to the relational dynamics of care and knowledge production (Johnson and Parry 2022). In practical terms, the experiences shared during the public involvement events were synthesised using a methodology inspired by the thematic analysis approach (Clark et al. 2021), which involved identifying recurring themes through iterative reading and group reflections on the event materials. The purpose of this work is to represent all points of view, including contradictory ones, which are highlighted here but require further exploration in future work.

2.1. Recruitment and Settings

The recruitment strategy implied the use of multiple approaches. First, we drew on the positionality of several authors as LGBTQ+ community members to recruit through existing contacts within the community, which helped contribute to a sense of trust in the group. Second, we conducted tailored recruitment through social media and physical flyers in community spaces to reach LGBTQ+ individuals more broadly. In communications with interested individuals, we made clear that the purpose was to create a space for dialogue and listening, not to collect data for a research study. Invitations to attend each of the three workshops were posted on widely used social media platforms. In addition to digital promotion, posters and institutional contacts, we focused on engaging local LGBTQ+ communities (e.g., choirs, sports groups, academic networks) and third-sector organisations to ensure inclusivity. The team aimed to include a spectrum of LGBTQ+ identities alongside demographic diversity. Members of the public were reimbursed for their time and contributions in line with National Institute for Health and Care Research guidance (National Institute for Health and Care Research 2022).

The team chose to include individuals aged 50 and over to allow for the views of those closer to pivotal transition points in life as well as those currently experiencing the ageing journey. This decision aligns with the existing research that highlights the unique health and care inequalities faced by LGBTQ+ people aged 50+, including increased risks of long-term illness, mental health challenges, and social isolation (Kneale et al. 2020). The events were held between January and April 2025 in three centres across the Southwest of the UK (Cardiff, Exeter and Bristol) selected for their diverse locations (urban centres of varying size and rural hinterlands), different health and social care systems, including funding and policy landscapes (Welsh and UK governments and different regional service providers), the high percentage of LGBTQ+ populations and their proximity to the universities of the project team. The team was mindful that interest in or attendance at the event could be disclosive; accordingly, communications with attendees was via secure university email.

2.2. The Workshops

Each workshop was designed for up to 10 attendees and lasted two hours, held in the evening from 17:00 to 19:00 to accommodate schedules of attendees who were working as well as those who were retired. Sessions began with a general introduction outlining the structure and purpose of the event, followed by a brief presentation of the team of academic facilitators. Attendees were reminded of the sensitivity of the topic and that the event was for community involvement and not research. The team clarified that no audio or video recordings would be made; instead, the team would take notes to help synthesise emerging topics and document key reflections. In each workshop, two team members took paper notes from which no individuals could be identified; these were later typed up and stored on secure university servers, with the paper notes destroyed. Attendees were encouraged to take breaks and share only what they felt comfortable disclosing. Afterward, they introduced themselves and reflected on how ageing and care related to their own experiences. To spark discussion, each attendee received a small, coloured slip of paper to jot down words or thoughts associated with the prompt "*Care and Health in Ageing*." These responses were collected to identify initial themes. In the final workshop, a table displaying preliminary key topics from the two earlier sessions served as a conversation starter and helped share insights from previous groups. Attendees were divided into smaller groups to discuss scenarios related to health and social care expectations, rights to care, and spaces for engagement as people age. Photos depicting diverse aspects of ageing and life, such as landscapes, hospital settings, homes, and weddings, served as visual prompts to inspire discussion. Topics emerged organically, allowing attendees to guide the conversation.

After the small group discussions, all attendees reconvened for a final plenary, where the team presented a thematic poster created from the initial paper notes. To close the session, attendees shared a word or phrase related to the topic, and contact details were collected from those interested in future research involvement.

The team synthesised the key topics that emerged during the workshops by integrating their reflections and notes, aiming to capture the richness of participants' contributions. Efforts were made to include all voices and comments, and findings were shared with the groups to ensure their views and perceptions were accurately represented. After each workshop, the team met to reflect on the discussions, review notes, identify emerging key topics, and refine potential areas for research development. Following the final workshop, the team continued to share their reflections through collaborative documents and additional meetings. This iterative, collaborative process helped to refine the emergent themes, prioritise topics for future research, and inform grant development.

3. Key Topics of the Narratives

Across the three workshops, there were 24 attendees. Although not formally requested, nor recorded in line with community involvement principles, attendees self-identified across a range of genders and sexual orientations. Attendees also varied by geographic location, representing both urban and rural areas. Consistent with conventions for community involvement events, the team did not collect detailed sociodemographic data beyond what attendees felt comfortable sharing during discussions. Overall, the workshops revealed a strong appetite among attendees to be involved in future research, underscoring the potential for sustained community involvement and co-production. Table 1 outlines the key topics—which present across all three events—and sub-topics pertinent to each.

Table 1. Key topics and subtopics emerged during the three events.

Isolation and Invisibility	Inclusive Venues	Concerns About Care Settings
Social Isolation and Loneliness	Barriers to LGBTQ+ -Affirming Social Spaces	Fear of Loss of Identity and Personhood
Invisibility Within LGBTQ+ Communities	Need for Intergenerational, Accessible, and Affirming Community Spaces	Fear of Homophobia and Discrimination in Care
Disconnection, Distance, and Disruption of Networks	Healthcare as a Venue: The Burden of Education and Exclusion	Lack of Trust in Care Home Quality
Fear of Re-Closeting	Digital Spaces as (Non-)Inclusive Venues	Structural and Systemic Barriers in Health and Social Care
Desire for Care Models That Support Autonomy and Choice (To overcome these fears, groups imagined LGBTQ+ affirming care homes, co-housing or community-based supported living, better care home introductions and open days, intergenerational community structures and environments where they could age safely, openly, and with dignity)		

3.1. Isolation and Invisibility

Attendees described feeling invisible and underrepresented within both mainstream society and LGBTQ+ spaces. This was especially pronounced for those living in rural areas, where opportunities for social connection were limited. A sense of loneliness and a desire for connection led some individuals to relocate from smaller towns to larger cities, although this did not always result in improved social integration. Some attendees also raised concerns about "romance fraud" (a type of scam where someone pretends to have romantic feelings or a relationship with another person to gain their trust and exploit them, usually for financial gain) through online dating platforms, and loneliness was particularly acute among those who were widowed, retired, or on low incomes.

3.2. Inclusive Venues

While some inclusive community spaces were reported, such as LGBTQ+ cafés in Bristol that offer dancing, games, and film nights, these are perceived as rare and were felt to be segregated by age. Despite efforts by LGBTQ+ centres across the cities, many events and activities were seen as primarily targeted at younger generations. Attendees expressed a strong desire for more intergenerational spaces that foster connection, empathy and solidarity across age groups.

3.3. Concerns About Care Settings

Attendees voiced concerns about ageing and the potential need for personal care or assisted living. Many attendees expressed anxiety about planning for future care costs and questioned whether existing services were equipped to support LGBTQ+ individuals, particularly those recovering from surgery or managing chronic illness. There was also uncertainty about how inclusive or affirming these services would be in practice. There were anxieties about whether care providers would be knowledgeable, respectful, and anti-discriminatory. A recurring fear was the need to conceal one's identity when entering care homes or accessing health services. Some reported difficulties integrating into retirement communities. Attendees emphasised that Equality, Diversity, and Inclusion (EDI) assessments in care settings must go beyond box-ticking exercises and include meaningful, private conversations with residents. Transgender individuals shared negative experiences and fears related to accessing hormonal therapy through the NHS and GPs. Conversely, some male gay couples, living in remote areas, reported positive experiences with primary care services.

4. Discussion

This project achieved its primary aim of exploring the experiences, perceptions, and expectations of older LGBTQ+ individuals regarding ageing and health and social care. It also underscored the importance of designing services that are inclusive, affirming, and informed by the lived experiences of this population. Each event attracted different segments of the LGBTQ+ community, enabling the team to capture a broad spectrum of perspectives across gender identity, sexual orientation, and geographic location. However, despite diversity in location and LGBTQ+ identities, the groups were relatively homogenous in ethnicity, reflecting the areas' predominantly White British population and recruitment challenges; a key future priority is to ensure broader representation and address intersecting vulnerabilities across the LGBTQ+ community. Therefore, exploring strategies to reach a wider audience and ensure more diverse voices will be pivotal for future community events and subsequent research. Larger events with more individuals, or a greater number of events, may also be required to adequately capture a fuller range of voices. Given these limitations, we do not claim generalizability of emergent themes to all older LGBTQ+ individuals, nor to all older LGBTQ+ individuals in the Southwest of the UK; rather, we consider findings from these events, and reflections on how we delivered them, as a starting point. It is important to acknowledge that capturing the full breadth of the LGBTQ+ community is inherently challenging, and the term "older LGBTQ+" can risk oversimplifying a complex and diverse group. This term does not denote a single homogeneous entity. Sub-groups—particularly trans and non-binary people—can face distinct barriers, care pathways, and risks, which sector guidance emphasises must be addressed through trans-inclusive, non-cisnormative practice

This aspect also highlights the need for nuanced, intersectional approaches to research in this area. However, this project can be seen as a valuable first step in learning from the narratives of events' participants and "testing the waters" while preparing future studies (Westwood 2020).

The use of participatory methods enabled attendees to articulate complex narratives. The value of co-participation, consistently highlighted throughout the events, fostered trust and mutual exchange, essential for surfacing sensitive issues such as identity concealment in care settings, financial insecurity, and social isolation. The topics emerged align with and reinforce the existing literature on health and care inequalities faced by older LGBTQ+ people in the UK. For instance, the LGBTQ+ Older Adult Social Care Assessment (LOASCA) study (Schaub et al. 2024) found that social care assessments often fail to meaningfully engage with sexual orientation and gender identity, leading to feelings of invisibility and unmet needs. Similarly, a scoping review by Srithumsuk et al. (2024) highlighted persistent inequalities in physical and mental health, access to social care, and exposure to loneliness and violence among older LGBTQ+ adults. These concerns were echoed by attendees, particularly around the fear of identity concealment in care settings and the lack of inclusive, intergenerational community spaces. The topic of uncertainty about future care provision also resonates with broader findings that older LGBTQ+ individuals are more likely to live alone (Kneale et al. 2020), have lower incomes, experience financial insecurity (Age Action Alliance 2025) and lack familial support compared to their heterosexual peers (Westwood 2020; Keemink et al. 2025). Lastly, it is important to note that attendees enjoyed participating in the project. The opportunity to meet others and discuss these topics was described as motivating, affirming, and emotionally meaningful.

5. Future Directions

Insights from the workshops point to several directions for future research aimed at better addressing the needs of older LGBTQ+ communities and improving health and social care systems. Research should examine how identities such as ethnicity, disability, class, and migration status shape ageing experiences, and the need for more inclusive studies that reflect diversity within the LGBTQ+ umbrella. Longitudinal research is also critical to track health and well-being trajectories over time and understand the cumulative effects of discrimination and resilience. Further priorities include evaluating community-based interventions to make care homes and domiciliary services more inclusive, assessing the impact of equality, diversity, and inclusion (EDI) training for care staff, and developing best-practice frameworks. Finally, research should explore how policies are implemented in practice, identify institutional barriers to inclusive care, and design community-led initiatives that reduce isolation and foster intergenerational connection.

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Informed Consent Statement: As this was a public involvement event and not a research study, no data were collected or recorded, and attendees are not identifiable in the article. Therefore, formal informed consent was not required.

Data Availability Statement: The researchers' notes and textual material underlying this report cannot be shared, as they contain confidential information and were generated as part of a public involvement activity rather than a research study.

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