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Raising the equality flag

Health inequalities among older LGBT people in the UK

Health and care
Carers
Community
NHS
Care homes
Connections
Inequalities
Retirement
Social care

Summary

New data analysis shows that LGBT men and women aged 50+ have poorer self-rated health and are more likely to have other conditions that impact their health and wellbeing. This analysis has, for the first time, demonstrated strongly that these differences persist even after accounting for other factors.

This builds on previous evidence which shows that older LGBT people have worse outcomes across different aspects of their lives including physical health, loneliness, social isolation, mental health, and experiences of violence.

Action is needed to address these health inequalities for older LGBT people through improving the inclusivity of mainstream health and care provision, strengthening the training of health and care staff – potentially through the creation of a national standard or quality framework – and enhancing data collection around older LGBT people and their health and care needs.

About this report

This report highlights new findings from a recent project conducted by researchers at University College London (UCL), Cardiff University, and ILC, funded by the Wellcome Trust [207986/Z/17/Z]. This work included three parts:

- A review of available evidence around various outcomes related to health and wellbeing among the LGBT community aged 50+;
- A meta-analysis using a range of existing datasets to identify disparities in such outcomes;
- A roundtable bringing together a group of expert stakeholders from the civil service, health and care provision, the third sector, and academia.

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Acknowledgements: We are extremely grateful to the members of our stakeholder group and to our research partners, especially Dr Dylan Kneale (UCL) and Dr Robert French (Cardiff University), for their contributions to this report. We are also grateful to have received funding for the project from the Wellcome Trust [207986/Z/17/Z].

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LGBT people and health: What is known?

When we look at older members of the LGBT community, it is important to recognise the legal framework that has evolved throughout their lives. Despite progress in recent years towards equality, most older LGBT people were born when being gay was effectively illegal in the UK, and this could have had a variety of influences on LGBT people as they age and approach later life.

For example, some people may have hidden their LGBT identity; from a health perspective, this could have led them to hide aspects of their own health for fear of "outing" themselves. For others, it could have fostered a reluctance to engage with health services for fear of discriminatory attitudes by health care providers.

Our knowledge of the extent to which earlier hostile treatment has influenced health and care outcomes among older LGBT people is incomplete, however, which has motivated the current study. Much of the existing evidence has come from qualitative research, and while there has been some quantitative work in this area, there are a number of issues that impact this work. The small proportion of LGBT people in most UK survey data (where LGBT identity is included) means that findings have low generalisability to the entire LGBT population. In addition, we must recognise that the LGBT community itself is diverse, and many quantitative studies do not have sufficient numbers to allow us to differentiate in a statistically meaningful way between gay men and lesbians, for example.

Addressing the unknown: Theories relevant for LGBT ageing

There are three theoretical concepts that shape our understanding of the differences in health outcomes among older LGBT people: minority stress theory, life course theory, and intersectionality.

Minority stress theory relates to the idea that people from disadvantaged or marginalised backgrounds experience long-term stress as a result of factors associated with such an identity. In the context of LGBT ageing, the idea is that poorer health outcomes stem from the negative social climate that they can experience or may have experienced in the past. In other words, the consequences of prejudice and stigma have an impact that manifests in worse physical and mental health.

For LGBT people reaching later life, such experiences could have occurred across several years. There may have also been periods where such experiences were more common than they are today or where the nature or intensity of prejudice/stigma was different. This connects to theories in the literature around the **life course**, where later life experiences are shaped by the **accumulation of advantages and disadvantages** over time. In other words, a negative experience or instance of adversity will have a more detrimental impact on an individual if it has been preceded by several similar negative instances.

The nature of such negative instances can vary greatly between different individuals. Moreover, they may be characterised by factors that relate to other aspects of an individual's identity. This highlights the importance of **intersectionality** as we explore ageing in the LGBT community. Intersectionality describes how multiple identities contribute to a person's sense of self and how these different aspects are themselves potentially subject to forms of discrimination and marginalisation. Moreover, it underscores the notion that marginalisation on the basis of multiple identities is more multiplicative than additive, i.e. the interconnectedness of these identities means they are best understood or examined together.

These theoretical perspectives help to frame and contextualise research like ours. They also help us understand how best to formulate and develop recommendations for policy and services.

Our research: What was discovered?

The research in this project was conducted across two phases: a scoping review of existing evidence and a new analysis drawing on several existing UK datasets.

Scoping review results

The scoping review was designed to cover the evidence around if and how the health and care needs of older LGBT differ from those of non-LGBT people. After searching four databases, 4,574 unique abstracts were screened, which resulted in 49 papers from 42 distinct studies being analysed in the review. A majority of these studies were qualitative in their methodology (23), with the rest being mixed methods (11) or quantitative (8).

The findings from these studies broadly fall into four categories: physical health and access to health care; access to social care and end-of-life care; experiences around loneliness, social isolation, and mental health; and experiences of violence. With respect to **physical health and health care**, the literature identifies a range of inequalities, including:

- Older LGBT people are more likely to engage in harmful health behaviours like drug use, frequent alcohol consumption, or smoking, but there are some positive behaviours they are more likely to engage in, such as regular exercise.
- Older LGBT people experience difficulties accessing health care that appropriately deals with their sexual identity; one study found that 18% of older LGBT people would feel uncomfortable disclosing their sexual orientation to their GP.
- Older LGBT people's past experiences of negative interactions with health care providers shape the way they engage with and access health services in later life.
- There is a small body of literature looking specifically at ageing with HIV among gay and bisexual men, identifying e.g. fears about being the first cohort to age on long-term anti-retroviral therapy.

With respect to **social care and end-of-life care**, the review found:

- Nearly all studies on this theme related to homo/transphobia, heteronormativity, invisibility, or a denial of older people's sexuality and identity in social care settings.
- Heteronormativity manifests in different ways, e.g. care staff refusing to acknowledge or miscategorising same-sex relationships, perceptions that expressing LGBT identity were not allowed, or anxiety about concealing or losing their identity.
- Older LGBT people are less able to avoid homo/transphobia in care settings than they are in the general community, reflecting a loss of autonomy.
- Differences in the social networks of older LGBT people compared to non-LGBT people can contribute to a greater need for formal care provision (e.g. due to not having children or being alienated from family members), although there were some examples where complex configurations of social networks enhanced the ability to remain independent.

- With respect to end-of-life care and bereavement, invisibility and denial of identity were discussed, with older LGBT people having the loss of their partner trivialised by care providers and some members of their wider social network.

On the theme of **loneliness, social isolation, and mental health**, the review found:

- Loneliness and social isolation were not universal experiences among older LGBT people, but the risk increased where resources for them to meet and socialise with other members of the community were not available or accessible.
- Older gay men were greatly impacted by the HIV epidemic due to the loss of friends and partners, with commercial safe spaces today seen as youth-oriented or actively ageist.
- Some older LGBT people describe challenges in forming new heterosexual networks, with difficulties finding common ground or feeling unable to present as their authentic selves.
- Mental health issues, particularly around suicide, have been identified among older LGBT people, especially among transgender and bisexual women and those living in rural areas.

The fourth theme, **experiencing violence**, primarily manifested in experiences of aggression and homo/transphobia in daily life, i.e. outside health and social care settings. This has a particular influence on older LGBT people, leading some to conceal their identities, while anxiety around aggression and micro-aggression were acutely felt by transgender people. There were also studies looking at how prior "psychological treatment" of older gay men and transgender women earlier in their lives was characterised by physical and mental violence; this shaped other facets of their later life, including patterns of access to health care.

Individual participant meta-analysis results

While the scoping review identified several important themes and disparities in the experiences of older LGBT people, the few quantitative studies that were found were either too small or employed methods that make it difficult to draw conclusions that would be representative for older LGBT people as a whole. The second phase of the research project sought to address this shortcoming.

For this phase, a technique called individual participant data (IPD) meta-analysis was applied. In simple terms, this approach is similar to a systematic review or other form of meta-analysis, but the information to analyse comes from datasets rather than papers. To our knowledge, this is the first application of this approach to attempt to create robust estimates of differences in LGBT health and care status compared to that of heterosexual older people.

The reason for using this technique is that many existing datasets that include LGBT identity do not have samples large enough to identify statistically significant differences; by combining the samples in a systematic way, we can derive estimates that demonstrate greater confidence.

This analysis included datasets that were representative samples, included older and LGBT people, and measured specific health outcomes. The outcomes of interest covered:

- Physical health: self-rated health, long-term illness, limiting long-term illness, and osteoporosis
- Mental health: life satisfaction, suicidal ideation, and suicide attempts
- Health behaviours: current smoking and (almost) daily drinking
- Providing informal care

We conducted a systematic review of datasets contained within the UK Data Archive and identified other sources manually. We found a total of 29 datasets that collected data on the health or care indicators described above, while the largest model we were able to construct brought together data from 24 datasets.

A key finding from the IPD meta-analysis is that, compared to heterosexual people, **LGBT men and women aged 50+ have poorer self-rated health:**

- Based on data from 24 different surveys, we found that the odds of lesbian, gay, or bisexual (LGB) men and women experiencing poor self-rated health was around 1.2 times higher than for heterosexual people. The estimate was similar in models constructed for men and for women.
- This finding is significant because, in UK studies, poor self-rated health is a strong predictor of future mortality and is also used to determine healthy life expectancy and disability-free life expectancy.
- Furthermore, estimates from individual studies were generally inconclusive in their own right, but the overall impact calculated in meta-analytic estimates suggested that differences in LGB and heterosexual health persisted even after accounting for potential confounding factors and cannot therefore be ignored.

Other results from the IPD meta-analysis also showed that

- Non-heterosexual men are more likely to be living with a **long-term illness** as well as a limiting long-term illness.
- Non-heterosexual men aged 50+ have **lower life satisfaction**.
- Non-heterosexual women aged 50+ are **more likely to smoke**.
- Non-heterosexual men aged 50+ are more likely to **have attempted suicide** in their lifetime.

Exploring the implications for policy and practice

In order to explore the implications for policy and practice of these new insights into health inequalities among older LGBT people, we brought together a group of 14 people from the civil service, health and care provision, the third sector, and academia, with expertise and interest in issues facing the LGBT community.

Members of the LGBT ageing roundtable

Tristan Barber, Royal Free London NHS Foundation Trust
Brian Beach, ILC
Rob French, Cardiff University
Maruska Greenwood, LGBT Health and Wellbeing
Ruthe Isden, Age UK
Kate Jopling, ILC
Andrew King, University of Surrey
Dylan Kneale, UCL
Julia Sweeney, Opening Doors London
James Thomas, UCL
Paul Twocock, Stonewall
Ramses Underhill-Smith, Alternative Care Services
Justin Varney, Birmingham City Council
Paul Willis, Bristol University

There are some key points related to the policy context that are worth highlighting. First, the Health and Social Care Act 2012 established the first legal duties for various bodies to address health inequalities. For example, bodies like Public Health England are now required to work toward reducing health inequalities, while local authorities have seen changes to their functions in public health. In a way, these new obligations strengthen the duty to advance equality established in the Equality Act 2010.

While the Health and Social Care Act placed new responsibilities for public health on local authorities, their duty to improve public health relies on robust information related to the health needs of specific groups. It is unclear the extent to which – if at all – local authorities are collecting such information on older LGBT people. Without such information, the needs of this group may be overlooked.

This need for **better data and information** was echoed during our roundtable with respect to health and care services. For example,

hospitals do not routinely collect data related to patients' sexual orientation, which contributes to the lack of evidence around health outcomes and LGBT people. An information standard for monitoring sexual orientation was commissioned by NHS England, which has been piloted in 25 trusts and is now available to all NHS organisations to use.[1] However, the collection of data using the standard is not compulsory. Also, it was noted in our roundtable that these pilots have not always been successful.

Other issues may also impact the collection of data for this group, such as a fear to openly disclose one's sexual orientation or transgender identity. Such issues make solutions to data collection for the LGBT community more challenging than for other minority groups, e.g. where targeted booster samples in national surveys can offer important insights.

The NHS England pilots and the existence of the monitoring standard do, however, show that there is growing interest around planning and providing services for LGB people in the NHS.[2] This is positive, but it will also be critical to understand what changes are made when particular needs are identified among this community.

In our roundtable discussion we explored the pros and cons of providing specialist services as compared to working with mainstream service providers to support the inclusion of the older LGBT community.

Participants recognised that **specialist or targeted services** rarely exist outside certain cities in which there are higher concentrations of LGBT people than other areas. However, it was noted that, in areas with smaller LGBT communities, it may be significantly more challenging to make the case for specialist services as an effective or efficient use of resources.

"You might be able to train a professional, but you can't change what people in the waiting room or care environment will say."

[1] For more information on the standard, see https://www.england.nhs.uk/about/equality/equality-hub/sexual-orientation-monitoring-information-standard/sexual-orientation-monitoring-frequently-asked-questions/

[2] The monitoring standard does not cover transgender or other non-binary identities; this was done in response to consultation with the trans community. A unified information standard that includes gender identity is under development. https://www.england.nhs.uk/about/equality/equality-hub/sexual-orientation-monitoring-information-standard/sexual-orientation-monitoring-frequently-asked-questions/#q13

This is particularly the case in the absence of clear evidence of demand or need for specialist services.

Overall, there was a sense that the more important focus was on improving the **inclusivity of mainstream service provision**. This suggests a greater focus on identifying where older LGBT people currently access their health and care services and ensuring these are places where they feel comfortable receiving support and, if they wish, disclosing their sexual identity. As a minimum, we need to ensure that such environments feel safe and are free from discrimination, but in our discussions we also considered the need for the commitment to inclusion to be consciously exercised and communicated overtly if the barriers to older LGBT people accessing services are to be reduced.

To promote environments that are safe and free from discrimination, there is a role for **equality and diversity training**. However, our stakeholder group noted that such training has been required in the NHS for over 20 years, yet we are still discussing how to make care environments fully inclusive. Despite legislation around sexual orientation and gender discrimination making clear that public authorities must not only avoid discrimination but also actively promote equality, there is still a tendency for training to focus on treating all patients the same rather than recognising the divergent needs of different groups, and some equality training remains too generic to address the particular needs of subgroups of the older LGBT community. While commissioners generally require diversity training for services, there is currently no quality assurance or national standard for such training.

In our discussions and through the literature, we also identified particular concerns around the need to ensure that services provided in people's own homes are inclusive and non-discriminatory. This is a particular and growing challenge as a large proportion of social care delivery is provided by private agencies and occurs behind closed doors, making scrutiny of standards very challenging. These challenges will only increase as greater numbers of older LGBT people age and develop care needs. It is therefore crucial that effective strategies are developed now to ensure inclusive personal care in the home is available for older LGBT people. The sector regulator, the Care Quality Commission, recently issued guidance around how adult social care providers should consider people's relationship and sexuality needs, and it

will be important to ensure that this guidance is implemented.[3]

A final theme to emerge in our roundtable was how **ageism and a focus on younger people** influence the discussion. For example, many efforts around public health and prevention target early intervention and thus focus on younger age groups or children, despite the fact that prevention can be an important part of providing robust health and care to older people. Ageism emerges in a variety of ways, including among the LGBT community itself. It also works as a barrier against stimulating in-depth thought about older LGBT people, in the sense that older people are often asexualised, i.e. people assume older people are no longer sexual, and therefore the sexual or gender identity of older LGBT people is ignored.

> *"There are some really deeply imbedded attitudinal issues amongst some of the health and care sector… Growing awareness of LGBT issues amongst health care professionals is really orientated towards younger people."*

What needs to happen

Based on our research, roundtable discussion, and in consultation with our stakeholder group, we have highlighted three main areas for future policy and practice development. We need action to:

- **Ensure mainstream health and care services are inclusive**, i.e. they provide environments where older LGBT people feel safe and comfortable;
- **Develop a national standard or quality assurance framework around equality and diversity training for the needs of older LGBT people;**
- **Improve the collection of data around older LGBT people and their health and care needs.**

The health services that are available to older LGBT people will have an impact on shaping the inequalities this group experiences. While there is value in targeted/specialist services in certain areas of the country, greater effort must be made toward **inclusive services**. One strategy to improve inclusivity could be the

[3] https://www.cqc.org.uk/news/stories/new-guidance-addresses-relationships-sexuality-among-people-using-adult-social-care

availability and promotion of advocates, companions, or voluntary counsellors within health care settings like GP practices. This would help demonstrate that services are inclusive in a conscious and overt way. Fundamentally, however, there will need to be a top-down effort, in that the highest levels of management and senior leadership will need to be on board.

To support inclusion, we need action to improve concerns around inclusive services. More could be done for **equality and diversity training**, specifically around the needs of older LGBT people. Opening Doors London already deliver diversity training endorsed by Skills for Care and have launched a national quality standard for care services, Pride in Care, which is supported by Care England. Such initiatives could inform efforts to improve services for older LGBT people.

Addressing the adequacy of equality and diversity training will be crucially important as greater numbers of people receive services in their own homes. There is a role for statutory regulations in this area, along with a mechanism to resolve disputes over allegations of poor practice.

> *"The NHS have clear statements on inclusion and a clear commitment on training in equality and diversity, and yet that training approach has failed to deliver an inclusive culture. Should we have very specific LGBT inclusion training? This universal respect and inclusion for everything is not detailed enough to deliver culturally competent care."*

Public health services are required to address health inequalities, but they need access to good quality data to do so effectively. There is more that current services could do to **capture data** on older LGBT people, in many cases simply recording if people identify as LGBT.

There is a need for data to be collected at a local level to help local authorities adapt and align their public health and social care responsibilities with the demand and needs of their older LGBT population. There would also be broader benefits from a UK longitudinal study focused on sexual orientation and gender identity. In particular, it could help close the significant gap in knowledge related to transgender people.

Any efforts toward improving data collection must be inclusive and cover the entire spectrum of sexual and gender identities. Indeed, NHS Trusts and local authorities should adopt consistent ways of recording this data and start routinely collecting it for all service users. But it would also help to understand some of the other issues that likely impact older LGBT people differently, such as social isolation, bereavement, and decision-making in care.

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Published in May 2019 © ILC-UK 2019
Registered Charity Number: 1080496.