

# Inequalities and measurement issues in researching older LGBT people's health and care needs in the UK

## Scoping Review Protocol

Dylan Kneale<sup>1\*</sup> ([D.Kneale@ucl.ac.uk](mailto:D.Kneale@ucl.ac.uk))

Robert French<sup>2</sup> ([FrenchR3@cardiff.ac.uk](mailto:FrenchR3@cardiff.ac.uk))

Josie Henley<sup>2</sup> ([HenleyJ@cardiff.ac.uk](mailto:HenleyJ@cardiff.ac.uk))

James Thomas<sup>1</sup> ([James.Thomas@ucl.ac.uk](mailto:James.Thomas@ucl.ac.uk))

<sup>1</sup>Evidence for Policy and Practice Information and Coordinating Centre, UCL Institute of Education, University College London, 20 Bedford Way, London, WC1H 0AL, United Kingdom

<sup>2</sup>School of Medicine, UHW Main Building, Cardiff University, Cardiff, CF14 4XN, United Kingdom

This protocol should be cited as:

Kneale D, French R, Henley J, Thomas J (2018) Inequalities and measurement issues in researching older LGBT people's health and care needs

London: EPPI-Centre, Social Science Research Unit, UCL Institute of Education, University College London.

For further details, please contact:

Dylan Kneale, Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre), Social Science Research Unit (SSRU), UCL Institute of Education, University College London, 20 Bedford Way, London, WC1H 0AL, United Kingdom

tel: 0207 612 6020

email: [D.Kneale@ucl.ac.uk](mailto:D.Kneale@ucl.ac.uk)

<http://eppi.ioe.ac.uk/>

## 1. Background

This protocol describes a systematic scoping review that will be carried with the purpose of:

- (i) Informing later quantitative stages of the study through identifying where inequalities in health and care in later life have been hypothesised to exist among LGB&T people based on quantitative and qualitative research literature
- (ii) Reviewing different strategies of identification of LGBT people in survey research and considering the suitability of their application with particular reference to older LGBT people

### (i) Older LGBT health and care needs

Many aspects of LGBT life course histories have been historically underexplored, and consequently, it is unclear the extent to which LGBT life course transitions fit into the normative patterns of transitions to older age. Biological markers of ageing can be pronounced and revolve around the extent of diminution of functional capability (Kuh and NDAP Network, 2007). The social markers of transitions to older age are less defined but may include retirement (Kim and Moen, 2002), assumptions of caring responsibilities (Hughes et al., 2007, Utz et al., 2002), changes in marital status (and particularly experiences of widowhood) (Chudacoff and Hareven, 1979) as well as experiences of serious ill-health or infirmity and the development of care needs (Settersten Jr and Mayer, 1997). The literature exploring if, how and why LGB ageing patterns differ from non-LGB is underdeveloped. Where LGB experiences of older age have been considered, many suggest that older LGBT people's experience of ageing is marred by some of the same discrimination observed in younger years (Addis et al., 2009). Greater contact with care providers through institutional or domiciliary care can be particularly stressful for older LGBT people who may come into contact with heteronormative or homophobic attitudes and behaviours among care providers or other care recipients (Addis et al., 2009, Phillips and Marks, 2008, Musingarimi, 2008). Other sources have indicated that LGBT ageing patterns are marked by greater provision of unpaid care (Kneale and French, 2018). Little robust evidence exists to ascertain whether LGBT people's lives are characterised by inequalities health or (unmet) care needs; similarly we hold little robust evidence on whether LGBT lives are marked by advantages in any domain in terms of health and care needs. This has led to older LGB people being characterised as societally invisible, and consequently being underserved by formal systems of support (Fredriksen-Goldsen and Muraco, 2010). Health and care needs of particular LGBT groups may be poorly understood

by healthcare providers, for example long-term impacts of hormone use and the understanding of hormone requirements in later life among transgender older people. While the evidence base is characterised as underdeveloped, with particular underrepresentation from quantitative studies, the purpose of this scoping review is to understand where researchers have identified inequalities, or the potential for inequalities to develop, in the health and care needs of older LGBT people in order to prioritise indicators for exploration in later stages of a larger research project (<https://eppi.ioe.ac.uk/cms/Default.aspx?tabid=3691>).

(ii) **Evolution of identification strategies of LGBT people in large surveys**  
Population level studies have, historically, rarely asked about same sex behaviour, attraction or identity. One of the first comprehensive exercises in the UK was through the National Survey of Sexual Attitudes and Lifestyles (see Wellings et al., 1994), which was able to estimate the number of LGB people, but offered limited insight into broader life course trajectories. Since then a number of studies have started to collect data on same sex identify and behaviour that can be linked to examine other domains. This started through being able to identify same sex cohabiting couples in large datasets such as the NCDS (for example Kneale et al., 2014) and the census, although was restricted with partnership being a pre-requisite for identification. Few studies appear to have been based on identifying those in civil partnerships (which since 2014 has operated alongside same sex marriage as a legal partnership). Since then, data collection has progressed to examining sexual identity in large household studies such as the Integrated Household Survey (Joloza et al., 2010) and UK Household Longitudinal Study (Uhrig, 2015), as well as studies focussed on particular life course stages such as the Next Steps study (Henderson, 2015); meanwhile same sex attraction and behaviour has also been collected in other smaller studies such as the English Longitudinal Study of Ageing (ELSA) (Kneale, 2016) and the Adult Psychiatric Morbidity Survey (Hayes et al., 2012). Many of these data that allow for the identification of LGB people have been made available only within the past decade, meaning that opportunities for life course researchers to redress the balance and explore transitions among sexual minorities are only now emerging (Meier and Allen, 2008, Furstenberg, 2010). However, data sources that are rich in the breadth of data collected are otherwise compromised by the small sample of LGB people that are identifiable. For example, although an impressive 1,300 non-heterosexual adults (aged 16+) were identified in Uhrig's (2015) analyses of the UKHLS, this number quickly dissipates once other intersectional factors such as age and gender become a joint focus of study.

Not only is LGB life course research compromised by the ability to identify LGB people, it may also be compromised by the suitability of indicators. Hammack and Cohler (2011), for

example, in their study of memoirs highlight the importance of (sexual) identity construction and ‘coming out’ (self-identification as LGB) as developmental milestone for LGBT people, one that shape later life health and care trajectories. Among older LGB people this experience of identify formation will hold different significance between those age cohorts experiencing transitions to adulthood before and after an era of gay liberation and increasing gay rights (Fredriksen-Goldsen and Muraco, 2010). Broader contextual factors, for example HIV/AIDS related experiences in the case of gay men, may also have added significant for the health and care needs of LGBT people (Muraco and Fredriksen-Goldsen, 2016).

There has been little systematic attempt to draw together researchers’ understandings of the opportunities and limitations of using different identification approaches and their particular application to identifying older LGBT health and care inequalities. Similarly, while the heteronormative nature of indicators contained within large scale surveys has been identified as potentially problematic in earlier work by members of the team (Kneale, in press), there has been little systematic discussion as to whether this is a concern shared across the literature. This aspect of the scoping review will summarise how researchers working with UK survey data have set about identifying LGBT people and the limitations of their analytical strategies.

### Aims

This scoping review seeks to address two research questions; the second being addressed through synthesising a subset of studies examined as part of the first.

- i. Where are the main differences in the health status and care needs of older LGBT people in the UK?
  - a. How do these differ across the spectrum of the LGBT acronym?
  - b. How do these differ across different domains of health e.g. physical vs mental health vs health determinants?
- ii. What approaches have been taken to identify LGBT adults in large UK-based population-level surveys?
  - a. How have strategies for the identification of LGBT people in large surveys evolved?
  - b. What are the limitations of adopting differing identification strategies?
  - c. How do strategies for the identification of LGBT people in general population surveys differ from specialist surveys (not population-level)?
  - d. What are the limitations of other design features of general population surveys in conducting research on (older) LGBT people?

## 2. Methods

### 2.1 Identification of evidence

Because of the focus on health and care outcomes, searches will be conducted on PubMed, Scopus, and PsychInfo. Supplementary searches will also be conducted on Google Scholar and specialist journals focussed on LGBT studies. All relevant titles and abstracts will be exported into EPPI-Reviewer 4 (specialist systematic review software) and will be screened independently by reviewers after an initial pilot screening phase.

Included abstracts will subsequently be rescreened on full text. See appendix for example search strings to be operationalised on Scopus.

### 2.2 Assessment of eligibility

Titles and abstracts of the documents retrieved in the searches will be independently screened by two reviewers (JH/DK) to determine eligibility. Included studies will be UK-based studies that focus on lesbian, gay, bisexual, transgender, queer or intersex older people. Older people are notionally defined as aged 50+, and studies focussed on older people (or with a comparative focus) are identified through terms included in the. Studies fulfilling the inclusion criteria will be selected for full text assessment, after which a new independent assessment will be performed. Disagreements will be resolved through discussion between the reviewers and will be referred to RF/JT if necessary. A subset of studies focussed on quantitative survey-based data will be analysed to examine measurement strategies taken to identify older LGBT people in the UK.

*Table 1: Exclusion criteria*

<ul style="list-style-type: none"><li>• <b>Exclude 1 - Duplicate</b></li><li>• <b>Exclude 2 - Not about UK</b></li></ul> <p><i>Does not focus on setting(s) in any part of the UK</i></p> <ul style="list-style-type: none"><li>• <b>Exclude 3 - Not about LGBTQ</b></li></ul> <p><i>Does not include Lesbian, Gay, Bisexual or Transgender people as a focus or comparative focus</i></p> <ul style="list-style-type: none"><li>• <b>Exclude 4 - Not older LGBT</b></li></ul> <p><i>Does not include older people aged 50+ as a focus or comparative focus</i></p> <ul style="list-style-type: none"><li>• <b>Exclude 5 - Not about health or care</b></li></ul> <p><i>Does not include a focus on health or care needs of older LGBT people</i></p> <ul style="list-style-type: none"><li>• <b>Exclude 6 - Not empirical or is a case study of individual</b></li></ul>
---

*Is not empirical (e.g. a theoretical study)*

- **Exclude 7 - Exclude on Publication Type**

*Not a primary study: is a review piece, systematic review, letter or commentary*

- **Exclude 8 - Not English**

*Is not available in English*

- **Query**
- **Include for Full Text**

### 2.3 Data extraction

After piloting, we will extract information from all included studies on study background, study design, setting, sample, data collection methods, and findings.

We will not undertake formal quality assessment of the studies since the aim of the review is to map the literature in this area and to lay the groundwork for further research and more detailed synthesis (if supported by the data).

### 2.4 Synthesis of the results

Our methods of synthesising the data will be aligned with a narrative, configurative approach (Gough et al., 2012). We will follow five stages: (a) initial coding the text by producing preliminary textual descriptions of studies and their findings in a tabular format; (b) further inductive coding of the textual summaries and identifying key preliminary themes and their recurrence across studies; (c) developing a framework for arranging groupings and clusters of studies according to the themes and exploration of these within and between the studies; (d) further generation of analytical themes through attempting to develop a common rubric to describe these findings; (e) consideration of the completeness and applicability of evidence, the robustness of the analysis methods and the quality of evidence in terms of its relevance to the research question (Snilstveit et al., 2012).

### 3. References

- ADDIS, S., DAVIES, M., GREENE, G., MACBRIDE-STEWART, S. & SHEPHERD, M. 2009. The health, social care and housing needs of lesbian, gay, bisexual and transgender older people: A review of the literature. *Health & social care in the community*, 17, 647-658.
- CHUDACOFF, H. P. & HAREVEN, T. K. 1979. From the empty nest to family dissolution: Life course transitions into old age. *Journal of Family History*, 4, 69.
- FREDRIKSEN-GOLDSSEN, K. I. & MURACO, A. 2010. Aging and sexual orientation: A 25-year review of the literature. *Research on Aging*, 32, 372-413.
- FURSTENBERG, F. F. J. 2010. On a new schedule: Transitions to adulthood and family change. *The future of children*, 20, 67-87.
- GOUGH, D., THOMAS, J. & OLIVER, S. 2012. Clarifying differences between review designs and methods. *Systematic reviews*, 1, 1.
- HAMMACK, P. L. & COHLER, B. J. 2011. Narrative, identity, and the politics of exclusion: Social change and the gay and lesbian life course. *Sexuality Research and Social Policy*, 8, 162-182.
- HAYES, J., CHAKRABORTY, A. T., MCMANUS, S., BEBBINGTON, P., BRUGHA, T., NICHOLSON, S. & KING, M. 2012. Prevalence of same-sex behavior and orientation in England: results from a national survey. *Archives of sexual behavior*, 41, 631-639.
- HENDERSON, M. 2015. Understanding Bullying Experiences among Sexual Minority Youths in England. London: Centre for Longitudinal Studies.
- HUGHES, M. E., WAITE, L. J., LAPIERRE, T. A. & LUO, Y. 2007. All in the family: The impact of caring for grandchildren on grandparents' health. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 62, S108-S119.
- JOLOZA, T., EVANS, J., O'BRIEN, R. & POTTER-COLLINS, A. 2010. Measuring sexual identity: an evaluation report. Newport: Office for National Statistics.
- KIM, J. E. & MOEN, P. 2002. Retirement transitions, gender, and psychological well-being a life-course, ecological model. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 57, P212-P222.
- KNEALE, D. 2016. Connected communities? LGB older people and their risk of exclusion from decent housing and neighbourhoods. *Quality in Ageing and Older Adults*, 17, 107-118.
- KNEALE, D. in press. Intergenerationality and LGBT ageing: Assessing the UK evidence base and its implications for policy. In: KING, A., WESTWOOD, S., ALMACK, K. & SUEN, Y. T. (eds.) *Older LGBT People - Minding the Knowledge Gaps*. London: Routledge.
- KNEALE, D. & FRENCH, R. 2018. Examining life course trajectories of LGB people in England – exploring convergence and divergence among a heterogeneous population of older people. *Longitudinal and Life Course Studies*, 9, 226-244.
- KNEALE, D., SHOLL, P., SHERWOOD, C. & FAULKNER, J. 2014. Ageing and lesbian, gay and bisexual relationships. *Working with Older People*, 18, 142-151.
- KUH, D. & NDAP NETWORK 2007. A life course approach to healthy aging, frailty, and capability. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 62, 717-721.
- MEIER, A. & ALLEN, G. 2008. Intimate relationship development during the transition to adulthood: Differences by social class. *New directions for child and adolescent development*, 2008, 25-39.
- MURACO, A. & FREDRIKSEN-GOLDSSEN, K. I. 2016. Turning points in the lives of lesbian and gay adults age 50 and over. *Advances in Life Course Research*.
- MUSINGARIMI, P. 2008. Housing Issues Affecting Older Gay, Lesbian and Bisexual People in the UK: A Policy Brief. London: International Longevity Centre-UK.
- PHILLIPS, J. & MARKS, G. 2008. Ageing lesbians: Marginalising discourses and social exclusion in the aged care industry. *Journal of Gay & Lesbian Social Services*, 20, 187-202.
- SETTERSTEN JR, R. A. & MAYER, K. U. 1997. The measurement of age, age structuring, and the life course. *Annual review of sociology*, 233-261.

- SNILSTVEIT, B., OLIVER, S. & VOJTKOVA, M. 2012. Narrative approaches to systematic review and synthesis of evidence for international development policy and practice. *Journal of development effectiveness*, 4, 409-429.
- UHRIG, S. 2015. Sexual orientation and poverty in the UK: A review and top-line findings from the UK household longitudinal study. *J. Res. Gender Stud.*, 5, 23.
- UTZ, R. L., CARR, D., NESSE, R. & WORTMAN, C. B. 2002. The effect of widowhood on older adults' social participation an evaluation of activity, disengagement, and continuity theories. *The Gerontologist*, 42, 522-533.
- WELLINGS, K., FIELD, J., JOHNSON, A. M., WADSWORTH, J. & BRADSHAW, S. 1994. *Sexual behaviour in Britain: the national survey of sexual attitudes and lifestyles*, Penguin Books.

## Appendix

**Scopus** ( ( ( TITLE-ABS-KEY ( lgbt ) OR TITLE-ABS-KEY ( lesbian ) OR TITLE-ABS-KEY ( gay ) OR TITLE-ABS-KEY ( queer ) OR TITLE-ABS-KEY ( bisexual ) OR TITLE-ABS-KEY ( transgender ) OR TITLE-ABS-KEY ( transsexual ) OR TITLE-ABS-KEY ( homosexual ) OR TITLE-ABS-KEY ( intersex ) ) ) ) AND ( ( TITLE-ABS-KEY ( ageing ) OR TITLE-ABS-KEY ( aging ) OR TITLE-ABS-KEY ( older ) OR TITLE-ABS-KEY ( elder ) OR TITLE-ABS-KEY ( aged ) ) ) AND ( ( ( ( TITLE-ABS-KEY ( uk ) OR TITLE-ABS-KEY ( united AND kingdom ) OR TITLE-ABS-KEY ( england ) OR TITLE-ABS-KEY ( english ) OR TITLE-ABS-KEY ( britain ) OR TITLE-ABS-KEY ( british ) OR TITLE-ABS-KEY ( wales ) OR TITLE-ABS-KEY ( welsh ) OR TITLE-ABS-KEY ( scotland ) OR TITLE-ABS-KEY ( scottish ) OR TITLE-ABS-KEY ( ireland ) OR TITLE-ABS-KEY ( irish ) ) ) ) OR ( ( ( AFFIL ( uk ) OR AFFIL ( united AND kingdom ) OR AFFIL ( england ) OR AFFIL ( english ) OR AFFIL ( britain ) OR AFFIL ( british ) OR AFFIL ( wales ) OR AFFIL ( welsh ) OR AFFIL ( scotland ) OR AFFIL ( scottish ) OR AFFIL ( ireland ) OR AFFIL ( irish ) ) ) ) ) ) )