

# Inequalities in older LGBT people's health and care needs in the UK: Protocol for an Individual Participant Data Meta-Analysis

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## 1. Background

This protocol describes an individual participant meta-analysis that will be carried with the purpose of:

- (i) Measuring inequalities in health and care needs between older lesbian, gay, bisexual and transgender (LGBT) people and non-LGBT people in the UK
- (ii) Establishing how inequalities vary across the LGBT spectrum
- (iii) Understanding the extent to which differences in measurement explain heterogeneity in effect sizes
- (iv) **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, and greater exposure to traumatic events earlier in life, which could impact upon later life health (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. Much of the evidence base is therefore characterised as underdeveloped, with particular underrepresentation from quantitative studies.

(v) [Data on \(older\) 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).

This protocol builds on both of these deficiencies. Firstly, through pooling estimates of health inequalities, using an approach that aims to harmonise differences in the estimates of inequalities (IPD meta-analysis), this research aims to address the issue of sample size and particularly in the understanding of different health needs in later life within the LGBT spectrum. It also aims to ensure that the estimates of inequalities are based on representative population level data. Secondly, through building on an earlier scoping review (Kneale et al., 2018a), this research aims to ensure that indicators and health statuses pertinent to LGBT life course histories are a focus of the research, and that differences in measurement approaches are explored fully.

### Aims

This IPD meta-analysis aims to:

- a. Measure inequalities in health and care needs between older lesbian, gay, bisexual and transgender (LGBT) people and non-LGBT people in the UK
- b. Establish how inequalities vary across the LGBT spectrum
- c. Understand the extent to which differences in measurement explain heterogeneity in effect sizes

## 2. Methods

### 2.1 Identification of evidence

This review aims to create representative population level estimates of health and care inequalities among older LGBT people in the UK through Individual Participant Data Meta-Analysis. Because of the focus on data that are representative of the UK (or regions within the UK), the searching will mainly be confined to the UK's largest repository of individual data, hosted by the UK Data Service. The UK Data Service provides access to over 6,000 sources of population, social and economic data and since 2012 has assumed all functions of the ESRC's Census Programme, Economic and Social Data Service (ESDS) and Secure Data Service (SDS). While multidisciplinary in nature, the repository hosts several well-known data sources focussed on health (for example the annual Scottish and English Health Surveys) and ageing (for example the English Longitudinal Study of Ageing).

The following terms will be used to search within the repository: "sexual identity", "sexual orientation", "same sex", "gender identity", "lesbian", "gay", "bisexual", "transgender", "transsexual", "transvestite", "queer", "LGBT", "LGB", "homosexuality", "sexual attraction", "sexual experience", "sexual desire". A search will be undertaken for each term separately, given limitations in the source's search facility.

Each record will then be screened based on information contained within the abstract initially (equivalent to title and abstract screening), and where appropriate the study documentation including the original questionnaire to establish relevance (equivalent to full-text screening). Because the repository does not allow for data set records to be exported out of the system in order to (i) facilitate screening, (ii) identify duplicate records across searches; or (iii) attach additional information to records (e.g. published studies that use the data); the search instead will be conducted following the principles laid out by Stansfield et al. (2016) on conducting website searching. These principles include (i) detailing the rationale for the search and the selected website(s); (ii) utilising the resources in a consistent way; and (iii) recordkeeping of executing the searches using the templates suggested (Stansfield et al., 2016). One of our limitations of this approach to identifying evidence is that, unlike when screening for published studies, a fewer details outlining the flow of studies through a review can be understood and recorded, as recommended in the 'Preferred reporting items for systematic reviews and meta-analyses' (PRISMA statement) (Moher et al., 2009, Stewart et al., 2015).

Additional sources from outside the UK Data Archive may be identified through the accompanying scoping review (Kneale et al., 2018a) and other sources including through contact with researchers.

## 2.2 Assessment of eligibility

Data sources will be included in the individual participant models if they meet the following criteria.

### 2.2.1 Type of data

Data sources are included if they collect information that distinguishes between the health and care status of older LGBT people and non-LGBT people at a population level. Studies should record this information quantitatively; studies collecting qualitative data only are not eligible for further analysis. Data sources that do not seek to represent specific defined populations, for example data sources that do not collect data from representative samples or have defined parameters (e.g. tracking the health status of a specific cohort of people), but are based on convenience samples or other non-robust methods where further inference cannot be easily made, are excluded. Data should be

available from the UK Data Service for download and further analysis; this may sometimes be available through the UK Data Service Secure Lab only (see <https://www.ukdataservice.ac.uk/use-data/secure-lab>), and further applications will be made where appropriate.

### 2.2.1 Type of participants

Data sources that allow for the identification of people aged 50+ as Lesbian, Gay, Bisexual or Transgender are eligible in this study. While participants aged 50 are not considered to be 'older' in a conventional sense, this cut off point mirrors that used in major studies exploring population ageing (e.g. ELSA) as a point to monitor ageing trajectories.

Eligible data sources may have adopted a variety of strategies in order to identify participants as LGBT, including through collecting data on (i) sexual identity/orientation; (ii) sexual desire/attraction; or (iii) sexual behaviour. Data specifically on transgender individuals will be sought through exploring reports of gender identity and specifically whether participants' gender identity is the same as ascribed at birth. Data will be included if they allow for a full understanding of differences across the LGBT spectrum through distinguishing between, for example, lesbian and bisexual women's health, or allow for understanding LGBT health inequalities where LGBT treated as a single group.

Where these data (above) are unavailable, separate models may also be constructed in order to compare inequalities among those with same sex cohabiting partnership histories with those whose partnership histories do not include same sex cohabitation (see Kneale et al., 2014 for an example in practice); these latter data represent a subset of the population but will further our understanding of health inequalities. However, in order to facilitate the analysis, data sources collecting information on same sex partnership histories will only be selected where there is a derived indicator of same sex partnership history or where same sex partnership is drawn out as a specific variable/category. This latter stipulation is, in part, in order to ensure that data on partnership histories that have already been cleaned are used for analysis; data cleaning and constructing partnership histories for every data set potentially eligible for analysis is beyond the scope of this analysis, given the substantial undertaking involved in deriving and interpreting just one set of partnership histories in a large data set (for example Goldstein et al., 2002).

### 2.2.2 Type of intervention/exposure

In this study, being LGBT is the 'exposure' of interest, and in order to estimate inequalities, all data sources must also collect information on non-LGBT people in order to be eligible for inclusion. This means that surveys of LGBT people that do not offer a comparison will not be included in this review. Reports of being LGBT can reflect same sex

identity occurring at any point during the life course. Data sources that only collect attitudes to LGBT people but not data about health inequalities will not be eligible for further analyses. IPD-data from intervention studies are not eligible for inclusion in this study, as the focus of interest is on estimating inequality in the general population.

In order to account for potential differences between LGBT and non-LGBT people which may confound the observed relationship between sexuality and health, a standard set of controls will be used in adjusted estimates that include age group, gender (where appropriate), an indicator of social class, retirement status, and marital status.

### 2.2.3 Type of outcome

Primary outcomes: Four primary outcomes of interest are identified for this review. These reflect indicators of general and physical health status. These include:

#### Physical Health

- (i) Self-rated health
- (ii) Long-term illness (and limiting long-term illness)

#### Mental Health

- (iii) Quality of Life
- (iv) Life Satisfaction

Secondary outcomes: A number of secondary outcomes are also considered in this review that reflect the preliminary findings of the scoping review. These findings suggested where further inequalities in older LGBT health may lie (Kneale et al., 2018a) including:

- (i) Loneliness
- (ii) Provision of care
- (iii) Suicide and suicidal ideation
- (iv) Alcohol consumption (as a proxy for substance misuse)
- (v) Osteoporosis (particularly among transgender individuals)

### 2.3 Study selection and data extraction

After a pilot phase where both reviewers run a search independently and discuss their screening decisions, reviewers will independently screen records on the Data Archive. Reviewers will record details of the search and the results according to ways suggested by Stansfield et al. (2016).

Before undertaking the analysis, details about the study will be extracted to consider the comparability of the data. These include information about:

- (i) Provenance and design - Study date, date of collection of the sweep, data collectors, study design (e.g. cross-sectional or longitudinal)
- (ii) Study characteristics - Sample size, geographic and/or population coverage, sampling design (e.g. information about stratification and weighting)
- (iii) Participants -method of identifying participants as LGBT available in the dataset, age distribution of sample, gender, ethnicity, indicator of social class, retirement status, marital/partnership status
- (iv) Data available to support exploring outcomes; data available to support exploring confounders
- (v) Levels of missingness
- (vi) Additional variables (where appropriate) recommended within the strengthening the reporting of observational studies in epidemiology (STROBE) guidelines for reporting observational studies (Von Elm et al., 2007) and the PRISMA-IPD (Stewart et al., 2015).

#### 2.4 Methodological quality assessment

The IPD meta-analyses will be conducted according to criteria set out by (Stewart et al., 2015) and details on study characteristics will be reported according to the STROBE criteria where appropriate (Von Elm et al., 2007). Established criteria for data sources, as opposed to published analyses, are rarer. However, we will also look to criteria included in the National Institute of Health quality assessment tool e.g. around exposure, sample frame, and level of participation, in assessing the risk of bias of individual data sources (NIH, 2014).

#### 2.5 Overall IPD meta-analysis approach

The IPD meta-analysis will adopt a two stage approach to the combining of data in a meta-analysis (Riley et al., 2010). First, effect sizes will be constructed within individual studies before being combined within a meta-analytic dataset. A two-stage approach is preferred in this case because of the difficulty in incorporating elements of each individual study's sample design, which can often be based on complex stratified designs, into a single dataset.

##### 2.5.1 Individual study data collection, checking and management

Raw data from each study will be analysed using STATA v13 (StataCorp, 2013) and combined using the same software. Variables will be derived based on LGBT status/identification will be derived if these have not been pre-constructed within datasets, as well as for health outcomes. An effect size will be calculated for each outcome comparing the value (e.g. odds or standardised mean difference, see below) for

older LGBT people compared to non-LGBT people. Where possible, an estimate will be generated for separately for groups within the LGBT acronym as well as estimates based on broader groupings. An unadjusted estimate of health inequality will be saved for the study within a different dataset, forming a set of effect sizes for subsequent meta-analysis.

A set of common controlling variables will also be derived reflecting marital/partnership status, age group, social class indicator, and retirement status. These controlling variables will be based on a simple binary derivation strategy, in order to maximise comparability between data sources and because the sample size within any single dataset is unlikely to support complex covariates in order to minimise the possibility that estimates within studies are overfitted. Where possible estimates will be generated in as similar way as possible, although it is recognised that the derivation of adjusted effect sizes will differ slightly by dataset dependent on the data collected.

We anticipate that missingness will be an issue in many of the data sources. Although multiple imputation could be a strategy to help correct our estimates for the impact of missing data, we do not plan to adopt this strategy as the reasons for missingness undermines the underlying assumptions. Much of the missingness occurring within sexuality research among older people occurs in the collection of sexuality data itself, and we cannot assume that this missingness occurs at random (Kneale and French, 2018).

#### 2.5.2 Measures of health inequality

We will generate different types of effect size for different outcomes reflecting the underlying data.

**Continuous data:** As set out in the Cochrane Handbook (Higgins and Green, 2011), we will calculate mean differences (MDs) when continuous data were measured by the same scale or unit. When similar outcomes were measured by different scales or units, we will use standardised mean differences (SMDs) (Hedges' (adjusted) g).

**Dichotomous data:** For dichotomous (binary) data, we will calculate odds ratios (ORs), and when appropriate, we will combine results from different studies.

**Ordinal data:** As set out in the Cochrane Handbook, we will analyse ordinal outcomes (such as quality of life scales) as continuous variables, or when appropriate thresholds are identified, we will analyse them as dichotomous variables.

#### 2.5.3 Combining the estimates of sexuality-based health inequality

Data from different studies will be combined in a meta-analysis using STATA. For dichotomous variables (such as presence of a limiting long-term illness), we will combine

data with a random-effects odds ratio (OR) and 95% confidence intervals. For continuous data variables (such as (potentially) quality of life), we will combine data with a random-effects mean difference and 95% confidence intervals. When substantial statistical heterogeneity is detected, we will explore potential sources and will consider using a random-effects model. Separate models will be constructed for adjusted and unadjusted estimates of health inequality (effect sizes) as well as for different definitions of LGBT and health outcome.

#### 2.5.4 Assessing heterogeneity across estimates of health inequality with a meta-analysis

We will assess statistical heterogeneity by using the  $I^2$  measure (Higgins et al., 2003). We will explore possible sources of variation when the  $I^2$  value exceeds 25% by thoroughly conducting pre-specified sensitivity and subgroup analyses and performing meta-regression analysis. We will construct random-effects meta-regression models using STATA, and will aim to construct multi-variate models that allow us to model the impact of different covariates simultaneously, after first exploring the impact of these potential effect size study-level moderators in univariate models. We will assess model fit by examining changes in  $\tau^2$  and changes in the value of adjusted R-squared.

#### 2.5.5 Subgroup analysis and investigation of heterogeneity

We will conduct a statistical test for heterogeneity across subgroups using an  $I^2$  statistic. When data allow, our aim will be to construct a multi-variate meta-regression model based on our results for different outcomes.

We will undertake pre-specified analyses to investigate heterogeneity on the basis of the following characteristics:

- Geographic reach: Does the study present estimates for the national level (UK), individual constituent country (Wales vs Scotland vs England vs N Ireland), sub-regional level
- Year of collection: Was the data collected within 5 years, 10 years etc
- Age range/groups of study members: which age groups are represented within the individual studies
- Study design: Is the estimate from a cohort study, household panel or cross-sectional survey design

#### 2.5.6 Sensitivity analyses

We will undertake sensitivity analyses on the basis of the following.

- Risk of bias assessment: We will include all studies in the primary analysis and explore the impact of potential sources of bias with respect to: adequacy of the sampling strategy;

levels of missingness; adequacy of controlling for confounding in adjusted estimates; adequacy of LGBT identification.

- Fixed-effect modelling.

#### 2.5.7 Alternative synthesis approaches

If the data are not suitable for meta-analysis, we will consider trialling alternative synthesis approaches; for example Qualitative Comparative Analysis (QCA (Thomas et al., 2014)) or narrative synthesis (Snilstveit et al., 2012) to examine how inequalities vary both within studies and between studies.

### 3. Discussion

This protocol describes an IPD meta-analysis of observational studies to provide evidence of the way in which sexuality drives health inequalities in later life. Individual Participant Data (IPD) meta-analysis involves the application of meta-analysis methods to participant-level data and allows more flexible, complex statistical analysis of study data and can enhance the range of robustness of the evidence generated (see (Riley et al., 2010)). Despite the strength of the approach, some caveats will remain. Firstly, because of the source of the estimates, attributing a causal relationship between sexuality and health will be challenging, and if attempted, will necessitate drawing on different causal accounts (Kneale et al., 2018b). Secondly, differences across data source may require the combining estimates of LGBT status based on identity, attraction and/or experience; these different methods of estimating sexual orientation are known to lead to different results (Geary et al., 2018), although it is hoped that this work will lead to an improved understanding of the implications of using different measurement approaches. Thirdly, while this work is concerned with synthesising representative data sources (not based on convenience samples), we do anticipate issues in securing data represented of all older people as, for example, data on older people in care settings is known to be lacking (Kneale et al., 2016), although it is known that these are settings where inequalities can arise (Musingarimi, 2008). Despite these caveats, we expect this research to lead to an improved understanding of LGBT health and care needs in later life, and form the basis of further research and policy recommendations (see <https://epi.ioe.ac.uk/cms/Default.aspx?tabid=3691> for further updates).

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