

Sexual identity data collection and access in UK population-based studies



Sexual minority research in the UK has been underfunded and frequently stigmatised.¹ Nonetheless, researchers have identified multiple health inequities, including in mental health and chronic disease, with the National Health Service England calling for the development of this evidence base since 2018.²⁻⁴

One potential route for closing this evidence gap is the use of existing data. The UK is a leader in the curation and design of population-based survey data that cover multiple disciplines and domains of human health and wellbeing.⁵ However, many of these resources do not collect sexuality data (eg, the 1958 National Child Development Study and post-2013 British Social Attitudes Surveys). This omission is increasingly hard to justify with the substantial legal and attitudinal shift observed in the UK in the past 50 years, and with the availability of widely tested survey questions on participant sexual identity, such as those included in the 2021 Census.^{6,7} As such, continuing to exclude what is usually a single question, is increasingly hard to justify.

Even when questions on sexuality are asked, the information is not always accessible to researchers. For example, the UK Household Longitudinal Study (UKHLS) includes one of the largest samples of sexual minority participants in a UK general population study. In 2020, the UK Data Service removed the sexuality variables from the standard dataset available for research use.⁸ As a result, researchers now have to apply for special access to UKHLS data on sexual identity, a process that can take months.

Such processes might be justified on the basis that sexuality is considered sensitive special category data under General Data Protection Regulation and interest in the data is deemed low. However, other special category data such as ethnicity, religion, and disability data are accessible to researchers under a standard license; singling out sexuality data for restricted access without clear rationale regarding differing sensitivity or risk to participant anonymity and wellbeing. Additionally, it is unclear how participant choice to share their data is considered, if at all, in such data management decisions. Participants carefully and consciously chose to disclose data for research and might reasonably expect their data

to be used to elucidate the health and other disparities they experience, rather than being inaccessible.

We believe a vicious cycle is perpetuated by these barriers to data access and research. Sexuality-based health inequalities have been underfunded and under-researched and consequently researchers, particularly marginalised scholars and those on short-term or insecure contracts, have little resources to conduct this important research. Also, researchers can face additional barriers in accessing data and publishing findings that feeds back into perceptions of low interest, and lower funding and resource allocations. Removing the barriers to data access is an essential step to ensure sexuality-based health inequalities can be delineated, understood, and prevented.

Addressing these issues should be a priority. First, the notion that decisions are made to create additional barriers to accessing sexuality data without consultation highlights the power imbalances between survey participants and decision makers, and a narrow view of what is meaningful and safe research. Across health research more broadly, there has been welcome progress to incorporate patient and public involvement and co-production into research,⁹ which specifically seek to change power dynamics between researchers and research participants.¹⁰ Individuals curating large social surveys should explore the value of co-production, incorporating equality and diversity, and opening up research processes to constructive challenge. Second, in cases where access might be restricted due to concerns around perceived sensitivity of sexuality data, disclosure of participant identities, and a perceived lack of research and policy interest; the clear recourse to address these concerns is not to make it harder to use these data, but to inform researchers that these data exist and how best to use them. Third, an increasing array of sexuality data needs to be matched by a step-change in investment to ensure capacity building and infrastructures for LGBTQ+ research.

Social and scientific theory supports increasingly complex health inequalities research (eg, intersectionality). However, the points raised in this Comment underscore that there is continued othering (a process

by which groups or persons are marginalised and marked as lesser) of sexuality data. There is a need for greater inclusion of sexuality data and better access to these data, supported by principles of co-production, to address sexuality-based health inequalities.

We declare no competing interests.

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