

## **Monitoring patients' sexual orientation and gender identity: Can we ask? Should we ask? How do we ask?**

There is a growing body of research which evidences that lesbian, gay, bisexual and/or transgender (LGBT+) people experience significant health inequalities [1]. We know that LGBT+ individuals may have encountered accumulative experiences of stigma and discrimination across their lives, which can have a negative impact on their health and even have some bearing on their life expectancy [2]. The fear of stigma and discrimination can also impact on LGBT+ people accessing timely healthcare. Furthermore, there are barriers in our healthcare systems that increase these health inequities [3-5].

Braybrook's<sup>1</sup> paper in this issue of BMJ Quality and Safety makes an important contribution to this work. It adds to a growing literature that addresses the experiences of LGBT+ people (and their significant others) at times of heightened need and vulnerability – facing serious illness and/or in need of palliative or end of life care<sup>2</sup> (see, for example, 6-10). Braybrook's<sup>3</sup> study, performed in the UK, sought to understand from multiple perspectives how to improve the way that sexual orientation, gender identity and gender history are discussed, addressed, and documented in healthcare settings involving LGBT+ patients with serious illness. The study draws on the experiences and perspectives of LGBT+ people with serious illness (N = 34), their significant others (N = 13) and clinicians (N = 27). They provide ten practical recommendations to support clinicians and healthcare organisations to proactively address LGBT+ inclusive care as part of their routine practice. The recommendations are grounded in evidence from the study and are in line with the three main themes from its findings:

- Creating positive first impressions and building rapport
- Enhancing care by actively exploring and explaining the relevance of sexual orientation and gender identity
- Visible and consistent LGBT+ inclusiveness in care systems

This editorial looks more closely at Braybrook's<sup>4</sup> recommendations to develop and improve visible and consistent LGBT+ inclusiveness in care systems. These are: to standardise how LGBT+ related discussions are approached; having LGBT+ inclusive processes and systems in place and visual markers of LGBT+ inclusiveness.

At a broad level, monitoring sexual orientation and gender identity is known to be important [11]. However, to date such monitoring is not consistent; amalgamating evidence relating to LGBT+ patients remains challenging and this is more pronounced for trans identities [12]. Asking LGBT+ related questions consistently to monitor sexual orientation and gender identity of patients will assist the development of more robust data to evidence where there are disparities in health outcomes and health service use. It can also guide resource allocation and intervention development to improve the care and support provided to LGBT+ people. At an individual level, it can signal a commitment to letting LGBT+ patients and their significant others know that their experiences are taken seriously [11, 13, 14]. Braybrook's<sup>5</sup> recommendation regarding visual markers of LGBT+ inclusiveness may also help here. However, putting LGBT+ inclusive policies into practice is not a quick fix solution - as clearly argued by Lecompte et al.'s scoping review of inclusive practice towards LGBT adults in health and social care [15]. Lecompte et al. identify changes that must be made at all levels of organisational structures and a range of competencies that staff need to develop. Acquaviva, who is a US authority on LGBT+ ageing and end of life issues, argued that this does not require special care for LGBT+ people, rather a shift to providing inclusive care to all people that includes LGBT+ people [16].

In monitoring demographics, it is now commonplace to ask routine questions about age, ethnicity, and disability; yet collecting data on sexual orientation and gender identity can still raise sensitivities and questions such as Can we ask? Should we ask? How do we ask? Braybrook's<sup>6</sup> recommendations suggest ways to normalise and routinise talk about questions about sexual orientation, gender identity and pronouns. This is vital to provide inclusive care for LGBT+ people. However, it is also important to pay attention to heterosexual cisgender people who may not comprehend being asked questions or statements such as the examples provided by Braybrook. Could this create a disconnect with elderly cisgender heterosexual people? One might argue they then need to be 'educated' but we rarely see recommendations towards that aim; rather the focus is on overcoming any discomfort that clinicians and other healthcare professionals may have in collecting data on their patients' sexual orientation and gender identity.

In a non-healthcare setting, the Office for National Statistics extensively tested the development of a question about sexual orientation prior to its inclusion in the 2021 UK censuses<sup>7</sup>, illustrative of the perceived sensitivities of asking questions to monitor sexual orientation and gender identity. The question about sexual orientation was included for the first time in the 2021 UK censuses, but as a voluntary rather than a mandated question. Existing research about patients' views on being asked about their sexual orientation and gender identity in healthcare settings is limited, and research that does address this issue is inconclusive. One study surveying UK general practice staff suggests that patients' discomfort mirrors that of staff and that staff may be thus projecting their own anxieties about LGBT+ monitoring onto patients [19]. Bjarnadottir et al., [20] undertook an integrative review to examine LGBT+ and non-LGBT+ patients' perceptions of being asked routine questions about their sexual orientation and gender identity in the healthcare setting. Their review included 21 papers and they found a general willingness to answer such routine questions. However, 17 of these papers only included participants who were LGB. No articles assessing the acceptability of being asked questions about gender identity were identified, and only three of the articles included transgender patients in their studies. This represents a significant gap in the literature. They recommend further research about patient acceptance of these questions would be welcome – across different patient groups (in particular cisgender heterosexual patients) and healthcare settings. This should also include developing greater understandings about disclosure or non-disclosure of sexual orientation and gender identity.

Alongside the need to make monitoring of sexual orientation and gender identity robust and routine, there are also questions about how to use such data to inform service delivery and improve outcomes for LGBT+ people. As noted by the LGBT Foundation's report *"If we're not counted, we don't count: Good practice guide to monitoring sexual orientation and trans status"* [11]; monitoring is only useful if this data is proactively used to improve services. The LGBT Foundation is a national charity based in Manchester which campaigns for a fair and equal society for LGBT+ people. Their report provides an excellent resource to guide the analysis and effective use of data collected on sexual orientation and gender identity. This includes advice on sharing the findings from data collected throughout the organisation with staff and service users; being clear that monitoring is a process to lead to improved outcomes (for example, planning actions which respond to findings). They also caution that initial monitoring may suggest low numbers of LGBT+ people and should not be treated as representative of the population. To date, there is a specific lack of data to understand the extent of inequalities facing different groups within LGBT communities – for example LGBT people from Black, Asian and Minority Ethnic communities. Low response rates may require plans to identify why this might be and develop actions designed to increase response and disclosure rates. Bjarnadottir et al., (20) reported that LGB participants in nine of the studies they reviewed described

hesitations and concerns about disclosing, including fears of being treated poorly, receiving worse care or being met with prejudice.

The importance of work in this field is underlined most recently by discussions about the potential disproportionate impact of the COVID-19 pandemic on the health and well-being of LGBT+ people. Given existing knowledge about health inequalities faced by LGBT+ people which are also indicators of poor prognostic factors for COVID-19, there is a concerning paucity of evidence due to the absence of routinely collected sexual orientation and gender identity data [21]. As a quote from Michael Brady, national adviser for LGBT health at NHS England states [22], it is time to get comfortable with asking about gender identity and sexual orientation as routinely as we do about age, postcodes, ethnicity, and disabilities.

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<sup>1</sup> Braybrook, D, bmjqs-2022-014792 Communication about sexual orientation and gender between clinicians, LGBT+ people facing serious illness and their significant others: a qualitative interview study of experiences, preferences and recommendations

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<sup>3</sup> Braybrook, D, bmjqs-2022-014792 Communication about sexual orientation and gender between clinicians, LGBT+ people facing serious illness and their significant others: a qualitative interview study of experiences, preferences and recommendations

<sup>4</sup> Braybrook, D, bmjqs-2022-014792 Communication about sexual orientation and gender between clinicians, LGBT+ people facing serious illness and their significant others: a qualitative interview study of experiences, preferences and recommendations

<sup>5</sup> Braybrook, D, bmjqs-2022-014792 Communication about sexual orientation and gender between clinicians, LGBT+ people facing serious illness and their significant others: a qualitative interview study of experiences, preferences and recommendations

<sup>6</sup> Braybrook, D, bmjqs-2022-014792 Communication about sexual orientation and gender between clinicians, LGBT+ people facing serious illness and their significant others: a qualitative interview study of experiences, preferences and recommendations

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<sup>7</sup> There are separate censuses in Scotland and Northern Ireland. The questions for England and Wales were developed through close collaboration with National Records of Scotland (NRS) and the Northern Ireland Statistics and Research Agency (NISRA), who are responsible for conducting the censuses in Scotland and Northern Ireland, respectively. The question is voluntary on all censuses in England, Wales, Scotland and Northern Ireland, and there will be no penalty for non-completion

<https://www.ons.gov.uk/census/censustransformationprogramme/questiondevelopment/sexualorientationquestiondevelopmentforcensus2021#annex-2-summary-of-research-undertaken-for-the-sexual-orientation-topic-2016-to-2020>