The NHS England Fundamental Information Standard for Monitoring Sexual Orientation

INTRODUCTION

In October 2017 NHS England launched the Fundamental Information Standard for Monitoring the Sexual Orientation of patients/service users (aged ≥16 years) in all health services and local authorities with responsibilities for adult social care. This acts as a pilot for a unified information standard and is being shared with other UK home nations.[1]

This announcement has been misreported in the media and prompted objections from the Family Doctor Association, but extensive research has shown that negative reactions are typically based on uncontextualised assumptions about the process and feasibility of monitoring patient sexual orientation (Box 1).[2–4]

This article contextualises the introduction of the information standard and reports unpublished data from a survey exploring the attitudes of general practice staff in England towards monitoring sexual orientation.

CONTEXT AND RATIONALE FOR MONITORING SEXUAL ORIENTATION

News coverage has reported challenges to the value and purpose of such monitoring, but it has been consistently shown that significant and unaddressed health inequities exist among lesbian, gay, and bisexual (LGB) people compared with the general population, including: self-harm and suicide, smoking, alcohol and drug use, eating disorders, domestic abuse, some cancers, and increased isolation/vulnerability in old age, as well as men's sexual health.[5–7] UK research has also shown lower rates of LGB access to health services, avoidance of screening programmes, and higher rates of service dissatisfaction.[8,9]

Explanations for these health inequities include LGB people's use of maladaptive coping strategies to deal with stigma and 'minority stress' (for example, substance use or self-harm); the avoidance of healthcare services due to vulnerability to hostile judgement and assumptions of heterosexuality; and consequently elevated confidentiality concerns.[5,10,11]

Public Health England (PHE) reported in 2017 that between 1.2 and 3.2 million of the English population (aged ≥16 years) identify as LGB in surveys. However, PHE acknowledges that these estimates are likely to underrepresent actual figures, as marginalisation, stigma, and negative experiences are barriers to disclosure.

In 2010 the UK Equality Act introduced the Public Sector Equality Duty (PSED), obliging all public bodies (and contracted services) to consider the equitable treatment of service users and requires due regard to the 'protected characteristics': age, disability, pregnancy and maternity, race, religion or belief, sex, sexual orientation, and gender reassignment. Knowing how individuals do, or do not, interact with services is a vital first step towards meeting these obligations. In 2012 the NHS mandate stated the need to:

'... tackle ingrained inequalities and consider the needs to LGB&T communities ... it is vital the NHS Commissioning Board consider how best to address this lack of research and data'.[12]

POLICY VERSUS PRACTICE: THE CHALLENGES OF MONITORING

Despite the increased morbidity of LGB people and extensive policy commitment to address inequities, data collection that could help identify and address these inequities remains inadequate in health services. In the first report on the PSED from the Equality and Human Rights Commission (EHRC), health commissioners and primary care services were among the three worst-performing sectors:

'Data collectors are not committed to collecting the data and, when they do, the practice is inconsistent. This is partly because they do not see the case for doing this, are reluctant to do so, or believe that some LGB people are reluctant to report their sexual orientation. This then leads to public bodies claiming they lack evidence and so do not see the case for taking action on LGB issues, meaning that action to tackle inequalities is weak or non-existent.'[13]

In *Beyond Tolerance: Making Sexual Orientation a Public Matter* (2009), the EHRC found that LGB organisations advocated monitoring, while objections to monitoring most frequently lay with staff in services.[4] In addition, the Office for National Statistics found that the vast majority of the general public considered sexual orientation questions both understandable and acceptable, but, despite this:

'... some interviewers were nervous asking the question [and] *if individual interviewers are concerned about this question, this may be passed onto respondents'.*[4]

Box 1. Standardised monitoring question, response items, and coding[1]

Which of the following options best describes how you think of yourself?

1. Heterosexual or straight
2. Gay or lesbian
3. Bisexual
4. Other sexual orientation not listed

   U. Person was asked and does not know or is not sure

   Z. Not stated (person was asked but declined to provide a response)
5. Not known (not recorded)

LGB ENGAGEMENT WITH MONITORING

LGB community groups have supported sexual orientation monitoring and produced comprehensive guides and campaigns advocating LGB participation in monitoring. The LGBT Foundation found that 80% of LGBT patients would be willing to disclose sexual orientation on a GP registration form, and 78% of LGB and 65% of trans people who would not currently disclose would be encouraged to do so if they had trust in practices' confidentiality and/or that the data would be used to improve services.[14]

In partnership with the Royal College of General Practitioners and NHS North West, the LGBT Foundation developed the 'Pride in Practice' toolkit that supported monitoring; and LGB lobby group Stonewall was commissioned by the Department of Health to develop primary care guides on monitoring.[15] A recent systematic review found that monitoring questions are a welcome facilitator of LGB disclosure and are typically interpreted as indicating affirmative practices, which increase trust in services.[9]

WHAT WE FOUND

Despite official policy, extensive research, and the support of LGB groups, health service staff have continued to express objections to the introduction of sexual orientation monitoring. In order to explore these barriers in general practice we surveyed GP practice staff in clinical commissioning groups (CCGs) across Kent, Surrey, and Sussex (615 practices), assessing knowledge levels

about LGB health inequities, and attitudes and comfort levels with administering sexual orientation monitoring at new-patient registration.

This survey is the first to explore the attitudes towards sexual orientation monitoring among a wide range of general practice staff (especially reception/administration who typically carry out monitoring).

Staff from 133 GP practices (from 19 of 20 CCGs) responded: 39% receptionists/administrators; 30% practice managers; 8% practice nurses; 7% GPs; 16% other. We found that of the nine protected characteristics, sexual orientation was the least likely to be monitored, with only 14 practices (11%) systematically recording. Responders did not generally recognise an association between LGB sexual orientation and poorer health or barriers to services. Staff perception of patients' comfort with sexual orientation monitoring was dramatically lower than comfort levels reported in research.[2–4] And staff discomfort with explaining sexual orientation questions almost exactly mirrored their assumption of patient discomfort with answering such questions, suggesting that staff may be projecting their anxieties about monitoring onto patients.

Practices in areas with smaller LGB populations were least likely to have implemented sexual orientation monitoring, resulting in the health needs of the most marginalised LGB populations being least likely to be recognised.

CONCLUSION

The legacy of prejudice and ongoing social stigma towards non-heterosexual people has contributed to significant health inequities and low levels of awareness about these inequities. Reactions to the new information standard indicate a continuing lack of engagement with these issues, and a reluctance to amend monitoring forms, which could inform future awareness.

Our findings on the attitudes of practice staff towards conducting these monitoring questions differ significantly from substantial research reporting the public's more relaxed attitude towards answering the questions,[2–4] which suggests staff have exaggerated anxieties about monitoring sexual orientation.

The new NHS England information standard presents an opportunity to recognise and improve understanding of LGB health inequities, develop health data, and equitably address the needs of all patients. The administration of monitoring may benefit if staff in all roles recognise the existence of LGB health inequities, understand the purpose and value of monitoring, and avoid projecting untested assumptions onto patients' comfort with tick-box monitoring questions.

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