

Implementation Guidance Fundamental Standard for Sexual Orientation Monitoring

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| Description | This Guidance supports the implementation of the Information Standard for Sexual Orientation Monitoring; the standard provides the mechanism for recording the sexual orientation of all patients/service users aged 16 years and over across all health services and Local Authorities with responsibilities for Adult social care in England where it may be relevant to record this information |
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Implementation Guidance

Fundamental Standard for Sexual Orientation Monitoring

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Data Coordination Board

This information standard (DCB2094) has been approved for publication by the Department of Health under [section 250 of the Health and Social Care Act 2012](#).

Assurance that this information standard meets the requirements of the Act and is appropriate for the use specified in the specification document has been provided by the Data Coordination Board (DCB), a sub-group of the Digital Delivery Board.

This information standard comprises the following documents:

- Specification
- Implementation Guidance.

An Information Standards Notice (DCB2094 Amd 51/2015) has been issued as a notification of use and implementation timescales. Please read this alongside the documents for the standard.

The controlled versions of these documents can be found on the [NHS Digital website](#). Any copies held outside of that area, in whatever format (e.g. paper, email attachment), are considered to have passed out of control and should be checked for currency and validity.

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Contents

| | | |
|---|---|---|
| 1 | Introduction..... | 5 |
| 2 | Scope | 5 |
| 3 | Consultation | 5 |
| 4 | Implementation..... | 5 |
| 5 | Implementation Task and Finish Group..... | 7 |
| | Appendix A: SNOMED CT mapping..... | 9 |

1 Introduction

We would expect data sets and organisations implementing this standard to be consistent. This document sets out how the standard is to be implemented.

2 Scope

This is a fundamental information standard that provides the mechanism for recording the sexual orientation of all patients/service users aged 16 years and over across all health services and Local Authorities with responsibilities for Adult social care in England in all service areas where it may be relevant to record this data. In settings and circumstances where data set owners and health and social care organisations decide to record patient/service user sexual orientation, the data should be recorded as per this standard. If the record does not capture in this way, it must be able to be matched to produce the outputs required. The scope applies to Local Authorities with responsibilities for Adult social care but may be used more widely by local authorities.

3 Consultation

Consultation took place with the owners of the three data sets which already collect this data (GUMCAD [Public Health England], IAPT and DoLS [NHS Digital]) and with organisations in the healthcare system which routinely monitor sexual orientation to learn how sexual orientation monitoring had been implemented.

This found that data set owners and organisations had taken a phased approach to implementation. Any necessary changes to IT systems were made as part of broader system updates. Training was incorporated into organisational training plans and budgets. In this way, the costs of implementation were absorbed into other costs and did not bring any additional financial burden. We therefore anticipate that any implementation costs for data sets and organisations adopting this standard will be absorbed in the same way when data sets are routinely uplifted.

4 Implementation

The standard is intended to outline how users will map data, rather than how they should record it; it describes the output rather than the input. In settings and circumstances where data set owners and health and social care organisations decide to record patient/service user sexual orientation, the data should be recorded as per this standard.

There may be collections which are sensitive as a result of recording sexual orientation, so organisations should review their internal Privacy Impact Assessments (PIA) and associated action plans and guidance.

The table at Appendix A shows how the codes for this standard map to those used by SNOMED CT.

Based on the consultation described above, we recommend the following for implementation:

- Data should be collected using the same recording and reporting method for other equalities data (such as age, gender, etc.) for example, in the IAPT data set.

- Organisations should take a phased approach to implementation and make any necessary changes to IT systems as part of broader system updates. Our consultation found that organisations implementing equalities monitoring had incorporated the cost of implementation into existing data collection requirements and made necessary changes to IT systems when other systems updates were due, therefore reducing the costs of implementation.
- Training costs should be incorporated into the routine costs of updating monitoring and performance systems.
- Health and social care organisations should review their role-based access arrangements in light of collecting this personally-identifiable sensitive data in the relevant settings. Providers are reminded that information about sexual orientation is sensitive personal data for the purposes of the Data Protection Act 1998 and therefore providers must have consent or an alternative legal basis for processing such data.
- Health and social care organisations should update their privacy impact assessments in light of collecting this personally-identifiable sensitive data in the relevant settings.
- Providers will be aware that the General Data Protection Regulation is due to come into force on 25 May 2018. Consequently, providers will need to carry out a further review of their basis for processing this data before that time to ensure compliance with that Regulation.

The Implementation Task and Finish group (see 5 below) will be advising on each of the above points.

We recommend that sexual orientation monitoring occurs at every face to face contact with the patient, where no record of this data already exists. Demographic data should be periodically reviewed by the organisation collecting it i.e. once recorded, entries will need to be verified with the patient (similar to periodic reviews of data such as address). The patient will retain the right not to disclose this information, but this response will become part of the record (similar to that which is done with recording ethnicity).

The question for health care professionals to use is as follows:

Sexual orientation:

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 asked and does not know or is not sure
- Z. Not stated (person asked but declined to provide a response)
9. Not known (not recorded)

Classifications 1-3 are those which people are most likely to be familiar with, and are intended to simplify the question and answer. Classification 2 is 'gay or lesbian' as this category will include some women who identify as gay rather than lesbian.

Classification 4 allows patients to identify as other than heterosexual/straight or lesbian, gay or bisexual (LGB), including but not limited to asexual or queer¹ (estimated to be a small minority of non-heterosexuals).²

Classification U allows recording where a patient does not know or is not sure, consistent with terminology in the Data Dictionary.

Classification Z allows for the patient choosing not to disclose this information, as is their right.

Classification 9 is not intended to be visible to the patient or healthcare professional but is needed to account for missing data in analysis, i.e. where there is no record of sexual orientation.

It should be noted that the question requires self-declaration. In situations where this would not be possible (e.g. patients requiring care under the Mental Capacity Act, where they are not able to give consent and therefore would not be able to declare their sexual orientation) only classification 9 could be recorded.

It should further be noted that implementation and use of this fundamental standard has potential to have an impact on Clinical Safety. System suppliers and organisations implementing and adhering to this standard must ensure that they update their clinical safety case reports to accept this potential impact and set out steps to manage it.

5 Implementation Task and Finish Group

A cross-system task and finish group has been set up to support implementation of this fundamental standard following publication. Membership consists of senior representatives from:

- British Medical Association
- Department of Health
- Equality and Human Rights Commission
- Gay and Lesbian Association of Doctors and Dentists (GLADD)
- Government Equalities Office
- Health Education England
- LGBT Foundation
- Local Government Association

¹ Queer is an umbrella term, used in the LGB community. As a sexual orientation it can be used to describe a complex set of sexual behaviours and desires, or to make a statement against categories such as lesbian, gay, bisexual or straight. Queer is an in-group term, and can be considered offensive in certain contexts and settings.

² Office for National Statistics. 'Sexual identity in the UK' *Part of Integrated Household Survey, January to December 2012 Release*. ONS, 2014. <http://www.ons.gov.uk/ons/rel/integrated-household-survey/integrated-household-survey/january-to-december-2012/info-sexual-identity.html>

- National LGB&T Partnership
- NHS Digital
- NHS Employers
- NHS England
- Nottingham CCG
- Oxleas NHS Foundation Trust
- Public Health England
- Royal College of Nursing
- Stonewall
- UNISON
- Warrington Council

The cross-system task and finish group facilitates strategic engagement with system leaders, representatives of professional bodies, the LGBT sector, and those responsible for educating and training the workforce. This multi-agency approach aims to prepare the system for implementation by identifying barriers and solutions and using system levers. The work of the cross-system task and finish group focuses on IT systems, workforce development, and communication to the health system and wider public.

The cross-system task and finish group's action plan includes the following activities:

- Early adopters of the fundamental standard from across 12 sites nationally to test the standard, facilitated by NHS Employers. The sites held their first meeting on 02/11/16 and agreed to focus their pilot through four key areas: leadership; IT systems; workforce training and development; and communication to patients.
- Early adopters of the fundamental standard across social care to test the standard with support from colleagues on the Task and Finish Group.
- Development of an e-learning package to be rolled out across health and social organisations (owned by Health Education England).
- A communications strategy for the health and social care system.
- A maintenance plan for this fundamental standard.

Appendix A: SNOMED CT mapping

| SNOMED CT ID | Fully Specified Name | Synonym | DD ID | Data Dictionary | READ2 ID | Term Code | Read2 Term | CTV3 ID | Term ID2 | CTV3 Term |
|------------------|---|----------|-------|--|----------|-----------|------------------------------|---------|----------|---|
| 20430005 | Heterosexual (finding) | Straight | 1 | Heterosexual or straight | 1b1.. | 0 | Heterosexual | X766q | Y7DFa | Heterosexual |
| 89217008 | Female Homosexual (finding) | Lesbian | 2 | Gay or Lesbian | 1b20. | 0 | Lesbian | E2201 | Y7DFf | Female homosexual |
| 76102007 | Male Homosexual (finding) | Gay | 2 | Gay or Lesbian | 1b21. | 0 | Male homosexual | E2200 | Y7DFe | Male homosexual |
| 42035005 | Bisexual (finding) | | 3 | Bisexual | 1b0.. | 0 | Bisexual | X666r | Y7DFh | Bisexual |
| 472985009 | Sexually attracted to neither gender (finding) | | 4 | Other sexual orientation not listed | | | | | | |
| 440583007 | Sexual Orientation unknown (finding) | | 9 | Not known (not recorded) | 1b3.. | 0 | Sexual orientation unknown | XaPO2 | Yas53 | Sexual orientation unknown |
| 1064711000000108 | Sexual Orientation undecided (finding) | | U | PERSON asked and does not or is not sure | | | | | | |
| 729951000000104 | Sexual orientation not given- patient refused (finding) | | Z | Not stated (PERSON asked but declined) | 1b4.. | 0 | Sexual orientation not given | XaWSA | YatrF | Sexual orientation not given- patient refused |