



# **Monitoring Equality and Health Inequalities: A Position Paper**

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## 1 Introduction

This purpose of this paper is to:

- present the current commonly used questions and codes for the collection of equality and health inequalities data in health and social care; and
- provide an update on the programme of work to develop equality data collection information standards for health and care

This paper does not represent formal guidance nor a mandate for data collections. It provides examples of how the NHS and other organisations currently collect equality and health inequalities data about local patients, service users, communities and the workforce. It has been produced for the interim period until equality data monitoring information standards are developed and rolled-out to the health and social care system. It may also be useful for other health and social care providers that are commissioned to provide services for the public sector.

For the monitoring of equality, the paper focuses upon the nine characteristics given protection under the Equality Act 2010, plus 'carer status'. For health inequalities it focuses on 'postcode of residence', 'socio-economic factors' and 'educational attainment'.

The questions and categories given in this paper are best suited to monitoring purposes only and are not designed to contribute towards clinical decision-making.

If required, the categories for some equality characteristic can be disaggregated to reflect the make-up of local populations, to provide data that are more meaningful. However, this should be done with the ability to re-aggregate data back to the main categories to enable comparisons with national figures and populations in other areas.

It should also be noted that existing mandated data sets and mandated collections (including age, ethnicity, sexual orientation and disability) should continue to be collected as they currently are.

There is a level of sensitivity around some of the data collected. Everyone working in the NHS setting has a legal duty to maintain the highest level of confidentiality. All staff members are trained on information governance and handling patient and staff confidential data. It is critical that information governance standards for confidential data are followed at all times. Organisations should refer to the Data Protection Act 1998 and related guidance for a full understanding of data protection principles<sup>1</sup>.

This paper will help to inform the development of information standards for approval through the Standardisation Committee for Care Information processes.

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<sup>1</sup> <http://www.legislation.gov.uk/UKPGA/1998/29/contents>

## 2 Why equality and health inequalities matter?

### 2.1 Drivers for equality and health inequalities data collections

There are important drivers in the health and care system that require the collection and effective use of good equality and health inequalities data. The drivers include, but are not limited to, the following:

- the NHS Constitution;
- the Equality Act 2010 and the Public Sector Equality Duty;
- the health inequalities duties under the NHS Act 2006 as amended by the Health and Social Care Act 2012;
- the Equality Delivery System for the NHS – *EDS2*;
- the Workforce Race Equality Standard;
- the effective commissioning and provision of NHS and care services that are capable of delivering high quality care for all individuals and communities;
- Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies;
- the standards required by the Care Quality Commission under the Health and Social Care Act regulations

### 2.2 Equality

NHS organisations are public bodies that must operate within equality law. The Equality Act 2010<sup>2</sup> rationalises and brings together previous equality legislation and applies to every individual and organisation in the country. At the heart of the Equality Act are provisions to outlaw direct and indirect discrimination, harassment and victimisation with regard to the nine protected characteristics.

The Equality Act offers protection to people possessing a minimum of one of the nine characteristics (see below). All characteristics will have some impact on all people, whether it is only by “not having” a specific characteristic.

- Age;
- Disability;
- Race including ethnicity and national identity;
- Sex;
- Gender re-assignment;
- Marriage and civil partnership;
- Pregnancy and maternity;
- Religion or belief, including lack of belief;
- Sexual orientation

Within the Equality Act, there is a framework for public sector organisations to use when responding to the Act. This is called the Public Sector Equality Duty (PSED) – sometimes called the general duty. It requires public bodies to have due regard to the need to:

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<sup>2</sup> [www.homeoffice.gov.uk/equalities/equality-act/](http://www.homeoffice.gov.uk/equalities/equality-act/)

- Eliminate discrimination, harassment, victimisation and other conduct prohibited by the Act
- Advance equality of opportunity between persons who share a relevant protected characteristic and those who do not share it
- Foster good relations between persons who share a relevant protected characteristic and persons who do not share it

Specific duties, set out in regulations to the Equality Act, help public bodies to meet the general duty and require them to:

- Publish information to demonstrate compliance with the public sector Equality Duty, annually. The information must be published in such a manner that it is accessible to the public, either in a separate document or within another published document.
- Prepare and publish equality objectives at least every four years. All such objectives must be specific and measurable.

Equality data and other evidence will help NHS organisations to monitor patients, service users and staff against the protected characteristics, this will be essential in responding well to the PSED of the Equality Act 2010.

'Carer status' is a characteristic that has not been assigned protection under the Equality Act 2010. However, it is increasingly recognised, particularly for workforce management purposes, that people with caring responsibilities may need specific support. This paper therefore contains the suggested question and response categories for monitoring this status.

Indeed, there are fundamental considerations that should be undertaken with regard to staff working in the NHS. While there is a job to be done, employers should strive to make recruitment, selection, progression and retention processes fair, inclusive and transparent, so that the workforce becomes representative of the communities that are served, within all occupations and grades.

## 2.3 Health Inequalities

The World Health Organisation (WHO) defines health inequalities as "Differences in health status or in the distribution of health determinants between different population groups"<sup>3</sup>. Reducing health inequalities can improve average life expectancy and reduce illness and disability across the social gradient. Tackling health inequalities is therefore core to improving access to services, health outcomes, improving the quality of services and the experiences of people. It is also core to the NHS Constitution and the values and purpose of the NHS.

Avoidable health inequalities are – by definition - unfair and socially unjust. A person's chance of enjoying good health and a longer life is influenced by the social and economic conditions in which they are born, grow, work, live and age. These conditions also affect the way in which people look after their own health and use services throughout their life. Addressing such avoidable inequalities and moving

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<sup>3</sup> <http://www.who.int/hia/about/glos/en/index1.html>

towards a fairer distribution of good health therefore requires a life course approach and action to be taken across the whole of society.

Under the Health and Social Care Act 2012 amendments to the National Health Service Act 2006, NHS England and Clinical Commissioning Groups (CCGs) must, in the exercise of their functions, have regard to the need to (a) reduce inequalities between patients with respect to their ability to access health services, and (b) reduce inequalities between patients with respect to the outcomes achieved for them by the provision of health services.

The Act does not define a list of groups impacted by the duties. Any group experiencing health inequalities is covered. The duties therefore take a whole population approach. This means that CCGs and NHS England must consider the whole of the population for which they are responsible, and identify inequalities within that population group.

Health inequalities are known to exist across some of the protected characteristics (such as age, sex and ethnicity) but data is less clear for others. In addition, there are some important dimensions of health inequalities, such as deprivation, employment, income and educational attainment that are not protected characteristics under the Equality Act 2010. Therefore the collection of equality data and questions related to some of the main dimensions of health inequalities will support meeting these duties.

The NHS Five year Forward View sets out the need to address the health and wellbeing gap, preventing any further widening of, and working towards a reduction, in health inequalities. To do so requires a move towards a proportionately greater investment in health and health care where the level of deprivation is higher.

The following data categories are useful to support further analysis across some important dimensions of health inequalities:

- Postcode of residence which can be linked to the Index of Multiple Deprivation;
- Socio-economic factors: Profession / Occupational status; and
- Educational attainment

Health care services should be built around the diverse, individual needs of patients and service users, rather than those individuals fitting into the services on offer. NHS organisations should therefore - within reason and within the law - be prepared to make adjustments to their services, and how people access them, depending on the needs, circumstances and protected characteristics of individual patients and service users.

### **3 Data monitoring and information standards update**

Work on equality data monitoring information standards is being led by NHS England, in partnership with key stakeholder organisations through the national Equality and Diversity Council. The Council has endorsed the ongoing work on



sexual orientation monitoring including work to develop a sexual orientation data monitoring information standard.

Going forward, the Council will look towards ratifying and timetabling the combination of data monitoring information standards related to the other characteristics given protection under the Equality Act 2010.

## 4 Questions and categories for equality collections

This section presents the questions and response categories for monitoring equality, which are commonly used across the health and care sector and beyond. Where applicable, the source of the questions and categories is provided. Questions and response categories for monitoring the workforce have been taken from the National Workforce Dataset (NWD) and/or the Electronic Staff Record (ESR) system.

Under each of the protected characteristics, those questions that are currently mandated to the system are presented first; other commonly used questions follow thereafter. It should be stressed that the questions and response categories cited in this position paper are not to inform clinical care.

This paper should help NHS organisations to:

- review and refine current categories that they may use locally in addition to national data sets, and;
- improve the ways by which they conduct local equality monitoring.

If organisations wish to use more detailed breakdowns than those given in the Census or an alternative source, they are advised to ensure, for consistency across data sets, that their disaggregation can be aggregated back up to the Census or other source categories.

### 4.1 Age

For monitoring purposes, it is normally sufficient to collect a person's age by using the question 'What is your date of birth?' Where more detailed information is required, collecting the full date of birth allows the resulting data to be used or manipulated in any way appropriate, including categorisation into age-bands. The Office for National Statistics (ONS) provides guidance on this matter in their 'Harmonised Concepts and Questions for Social Data Sources' document<sup>4</sup>.

In some circumstances, a person may have different dates of birth recorded on documentations. In such circumstances it may be best to verify the accurate date of birth with the person. However, where date of birth is not known or available, the person's age should be collected.

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<sup>4</sup> <http://www.ons.gov.uk/ons/guide-method/harmonisation/primary-set-of-harmonised-concepts-and-questions/index.html>

To obtain accurate “live” data on age, date of birth should be collected in the dd/mm/yyyy format. However, it should be noted that there are international variations in the order in which date and month are presented.

Patient monitoring question	Workforce monitoring question
<p><b>ONS 2011 Census questionnaire for England:</b></p> <p>What is your date of birth?</p> <p>dd/mm/yyyy</p>	<p><b>National Workforce Dataset (NWD) / Electronic Staff Record (ESR) system:</b></p> <p>Date of birth</p> <p>Format not specified in NWD. ESR date format is DD-MMM-YYYY but can be reformatted in report outputs as required.</p>

## 4.2 Disability

The Equality Act 2010 defines disability as a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities. The Act defines ‘substantial’ as being more than minor or trivial – e.g. if it takes much longer than it usually would to complete a daily task like getting dressed. ‘Long-term’ is defined as lasting for a period of 12 months or more – e.g. a breathing condition that develops as a result of a lung infection<sup>5</sup>.

The 2011 ONS Census question on disability allows comparison with national and other data sources. Other common sources of questions and codes for monitoring disability include the Health and Social Care Information Centre NHS Data Model and Dictionary<sup>6</sup>, the Family Resources Survey<sup>7</sup> and the Integrated Household Survey<sup>8</sup>/Health Survey for England<sup>9</sup>.

Following the 2007 Equalities Review<sup>10</sup>, the Office for National Statistics (ONS) has worked with other Government departments to produce a harmonised suite of disability questions for use in Government surveys<sup>11</sup>.

Should your organisation wish to use a follow-up question to understand more about your service users, the follow-up question (taken from the Harmonised Suite of questions) is presented in the table overleaf.

<sup>5</sup><https://www.gov.uk/definition-of-disability-under-equality-act-2010>

<sup>6</sup><http://www.datadictionary.nhs.uk/index.asp>

<sup>7</sup><https://www.gov.uk/government/statistics/family-resources-survey-2012-to-2013>

<sup>8</sup><https://www.gov.uk/government/statistics/integrated-household-survey-january-to-december-2013>

<sup>9</sup><http://healthsurvey.hscic.gov.uk/support-guidance/public-health/health-survey-for-england.aspx>

<sup>10</sup><http://webarchive.nationalarchives.gov.uk/20100807034701/http://archive.cabinetoffice.gov.uk/equalities-review/>

<sup>11</sup><http://www.ons.gov.uk/ons/guide-method/harmonisation/primary-set-of-harmonised-concepts-and-questions/long-lasting-health-conditions-and-illnesses--impairments-and-disability.pdf>

Patient monitoring question	Workforce monitoring question
<p><b>NHS Data Model and Dictionary approved National Codes for disability:</b></p> <p>This could be where:</p> <ul style="list-style-type: none"> <li>• the person has been diagnosed as disabled or</li> <li>• the person considers themselves to be disabled</li> </ul> <p>National Codes:</p> <p>01. Behaviour and Emotional  02. Hearing  03. Manual Dexterity  04. Memory or ability to concentrate, learn or understand (Learning Disability)  05. Mobility and Gross Motor  06. Perception of Physical Danger  07. Personal, Self-Care and Continence  08. Progressive Conditions and Physical Health (such as HIV, cancer, multiple sclerosis, fits etc.)  09. Sight  10. Speech  XX. Other  NN. No disability  ZZ. Not Stated (person asked but declined to provide a response)</p>	<p><b>National Workforce Dataset (NWD) / Electronic Staff Record (ESR) system:</b></p> <p>Disability Category:</p> <ul style="list-style-type: none"> <li>• Yes*</li> <li>• No</li> </ul> <p>In addition ESR enables the recording of the nature of the disability:</p> <ul style="list-style-type: none"> <li>• Learning disability/difficulty</li> <li>• Long-standing illness</li> <li>• Mental Health Condition</li> <li>• Not declared</li> <li>• Other</li> <li>• Physical Impairment</li> <li>• Sensory Impairment</li> </ul> <p>* i.e. In ESR this equates to 'Yes (category not specified)'</p>

Patient monitoring question	Workforce monitoring question
<p><b>ONS 2011 Census questionnaire for England:</b></p> <p>Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? (include any issues problems related to old age)</p> <ul style="list-style-type: none"> <li>• Yes, limited a lot</li> <li>• Yes, limited a little</li> <li>• No</li> <li>• Prefer not to say</li> </ul>	
<p><b>ONS harmonised suite of disability follow-up questions:</b></p> <p>If ticked “Yes” to the above, please indicate your disability:</p> <ul style="list-style-type: none"> <li>• Vision (e.g. due to blindness or partial sight)</li> <li>• Hearing (e.g. due to deafness or partial hearing)</li> <li>• Mobility, such as difficulty walking short distances, climbing stairs, lifting and carrying objects</li> <li>• Learning or concentrating or remembering</li> <li>• Mental Health</li> <li>• Stamina or breathing difficulty</li> <li>• Social or behavioural issues (e.g. due to neuro diverse conditions such as Autism, Attention Deficit Disorder or Asperger’s Syndrome)</li> <li>• Other impairment</li> </ul>	

Patient monitoring question	Workforce monitoring question
<p><b>The Family Resources Survey 2012/13 disability question:</b></p> <p>Does this physical or mental illness or disability (Do any of these physical or mental illnesses or disabilities) limit your activities in any way?</p> <ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul> <p>Does this/ Do these health problem(s) or disability(ies) mean that you have substantial difficulties with any of these areas of your life?</p> <ul style="list-style-type: none"> <li>• Moving - Mobility (moving about)</li> <li>• Lifting - Lifting, carrying or moving objects</li> <li>• Hands - Manual dexterity (using your hands to carry out everyday tasks)</li> <li>• Bladder - Continence (bladder and bowel control)</li> <li>• Speech - Communication (speech, hearing or eyesight)</li> <li>• Learn - Memory or ability to concentrate, learn or understand</li> <li>• Danger - Recognising when you are in physical danger</li> <li>• Balance - Your physical co-ordination (eg: balance)</li> <li>• Other - Other health problem or disability</li> <li>• None - None of these</li> </ul>	
<p><b>The Integrated Household Survey 2013 / Health Survey for England 2012 question:</b></p> <p>Does this illness or disability (Do any of these illnesses or disabilities) limit your activities in any way?</p> <ul style="list-style-type: none"> <li>• Yes</li> <li>• No</li> </ul> <p>Would you say your activities are limited or strongly limited?</p> <ul style="list-style-type: none"> <li>• Limited</li> <li>• Strongly limited</li> </ul>	

### 4.3 Ethnicity

Collecting data on ethnic group, and national identity, can be complex because of the subjective and multifaceted nature of the concepts. Membership to each of the concepts is something that is self-defined and subjectively meaningful to an individual.

NHS organisations are mandated to use ethnic monitoring questions and response codes that are based on the ONS 10 yearly Censuses. The NHS currently utilises the ethnic category codes from the 2001 Census. ONS introduced two new sub-categories into the ethnicity question for the 2011 Census, namely 'Gypsy or Irish Traveller' under the 'White' category and 'Arab' under the 'Other ethnic group' category. Another change since the 2001 Census question on ethnicity is that 'Chinese' has moved into the 'Asian or Asian British' category.

Additional codes can be included as appropriate at a local level to reflect the demographic make-up of the local population. This allows local monitoring to take place in a way that supports service planning and decision-making and key processes such as the Joint Strategic Needs Assessments, but allows national comparisons to be made at the level of the sections A-E.

The NHS Data Model and Dictionary approved National Codes for ethnicity are also presented in the table below. The NHS Data Model and Dictionary also allows for the value '99' for 'Not Known' (i.e. where the person hasn't been asked), and value 'Z' for 'Not Stated'. Regarding these, the NHS Data Model and Dictionary states that the National Code 'Z' should be used where the person has been given the opportunity to state their ethnic category but chose not to. Default code '99' should be used where the person's ethnic category is not known.

The NHS Data Model and Dictionary also has optional second character ethnicity codes for local use<sup>12</sup>.

The Department for Education in the School Census 2014 to 2015<sup>13</sup> presents pupil level ethnicity code-sets, including main categories, subcategories and approved extended categories for ethnic monitoring<sup>14</sup>. These are also presented in the table overleaf.

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<sup>12</sup>[http://www.datadictionary.nhs.uk/data\\_dictionary/data\\_field\\_notes/p/pds/pds\\_ethnic\\_category\\_code\\_d\\_e.asp?shownav=1](http://www.datadictionary.nhs.uk/data_dictionary/data_field_notes/p/pds/pds_ethnic_category_code_d_e.asp?shownav=1)

<sup>13</sup><https://www.gov.uk/government/publications/school-census-2014-to-2015-collect-guide-for-academies>

<sup>14</sup>[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/376100/2014\\_to\\_2015\\_School\\_Census\\_Guide\\_V\\_1\\_7.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/376100/2014_to_2015_School_Census_Guide_V_1_7.pdf)

Patient monitoring question	Workforce monitoring question
<p><b>The NHS Data Model and Dictionary approved National Codes for ethnicity:</b></p> <p>National Codes:</p> <p>White</p> <p>A. British</p> <p>B. Irish</p> <p>C. Any other White background</p> <p>Mixed</p> <p>D. White and Black Caribbean</p> <p>E. White and Black African</p> <p>F. White and Asian</p> <p>G. Any other mixed background</p> <p>Asian or Asian British</p> <p>H. Indian</p> <p>J. Pakistani</p> <p>K. Bangladeshi</p> <p>L. Any other Asian background</p> <p>Black or Black British</p> <p>M. Caribbean</p> <p>N. African</p> <p>P. Any other Black background</p> <p>Other Ethnic Groups</p> <p>R. Chinese</p> <p>S. Any other, please write in</p> <p>99. Not known</p> <p>Z. Not stated</p>	<p><b>National Workforce Dataset (NWD) / Electronic Staff Record (ESR) system:</b></p> <p>NWD: Ethnic Category / ESR: Ethnic Origin</p> <p>A White British</p> <p>B White Irish</p> <p>C White - Any other White background</p> <p>D Mixed - White &amp; Black Caribbean</p> <p>E Mixed - White &amp; Black African</p> <p>F Mixed - White &amp; Asian</p> <p>G Mixed - Any other mixed background</p> <p>H Asian or Asian British - Indian</p> <p>J Asian or Asian British - Pakistani</p> <p>K Asian or Asian British - Bangladeshi</p> <p>L Asian or Asian British - Any other Asian background</p> <p>M Black or Black British - Caribbean</p> <p>N Black or Black British - African</p> <p>P Black or Black British - Any other Black background</p> <p>R Chinese</p> <p>S Any Other Ethnic Group</p> <p>Z Not Stated</p> <p>(ESR also enables use of the optional sub-categories as set out in DSCN 2/2001)</p>

Patient monitoring question	Workforce monitoring question
<p><b>ONS 2001 Census questionnaire for England:</b></p> <p>What is your ethnic group?</p> <p>Choose ONE section from A to E, then tick the appropriate box to indicate your ethnic group.</p> <p>A : White</p> <ul style="list-style-type: none"> <li>• White British</li> <li>• White Irish</li> <li>• Other White</li> </ul> <p>B : Mixed</p> <ul style="list-style-type: none"> <li>• White and Black Caribbean</li> <li>• White and Black African</li> <li>• White and Asian</li> <li>• Other Mixed</li> </ul> <p>C : Asian or Asian British</p> <ul style="list-style-type: none"> <li>• Indian</li> <li>• Pakistani</li> <li>• Bangladeshi</li> <li>• Other Asian</li> </ul> <p>D : Black or Black British</p> <ul style="list-style-type: none"> <li>• Caribbean</li> <li>• African</li> <li>• Other Black</li> </ul> <p>E : Chinese or Other Ethnic Group</p> <ul style="list-style-type: none"> <li>• Chinese</li> <li>• Other Ethnic Group</li> </ul>	



Patient monitoring question	Workforce monitoring question
<p><b>Ethnicity question from the ONS 2011 Census questionnaire for England:</b></p> <p>What is your ethnic group?</p> <p>Choose ONE section from A to E, then tick the appropriate box to indicate your ethnic group.</p> <p>A : White</p> <ul style="list-style-type: none"> <li>• Welsh / English / Scottish / Northern Irish / British</li> <li>• Irish</li> <li>• Gypsy or Irish Traveller</li> <li>• Any other White background (please write in)</li> </ul> <p>B : Mixed</p> <ul style="list-style-type: none"> <li>• White and Black Caribbean</li> <li>• White and Black African</li> <li>• White and Asian</li> <li>• Any other mixed background (please write in)</li> </ul> <p>C : Asian or Asian British</p> <ul style="list-style-type: none"> <li>• Indian</li> <li>• Pakistani</li> <li>• Bangladeshi</li> <li>• Chinese</li> <li>• Any other Asian background (please write in)</li> </ul> <p>D : Black or Black British</p> <ul style="list-style-type: none"> <li>• Caribbean</li> <li>• African</li> <li>• Any other Black background (please write in)</li> </ul> <p>E : Other ethnic group</p> <ul style="list-style-type: none"> <li>• Arab</li> <li>• Any other, please write in:</li> </ul>	

Patient monitoring question	Workforce monitoring question
<p><b>The Department for Education School Census 2014 to 2015 ethnicity codes:</b></p> <p>A : White</p> <ul style="list-style-type: none"> <li>• British</li> <li>• Irish</li> <li>• Traveller of Irish heritage</li> <li>• Any other White background</li> <li>• Gypsy / Roma</li> </ul> <p>B : Mixed / Dual background</p> <ul style="list-style-type: none"> <li>• White and Black Caribbean</li> <li>• White and Black African</li> <li>• White and Asian</li> <li>• Any other mixed background</li> </ul> <p>C : Asian or Asian British</p> <ul style="list-style-type: none"> <li>• Indian</li> <li>• Pakistani</li> <li>• Bangladeshi</li> <li>• Any other Asian background</li> </ul> <p>D : Black or Black British</p> <ul style="list-style-type: none"> <li>• Black - Caribbean</li> <li>• Black - African</li> <li>• Any other Black background</li> </ul> <p>E : Chinese</p> <p>F : Any other ethnic group</p> <p>G: Any other, please write in</p>	

#### 4.4 Sex

It should be noted that “sex”, “sexual orientation” and “gender re-assignment” are three separate and distinct matters, and that good equality systems will keep them separate, e.g. Trans people, as anyone else, may be bisexual, lesbian, gay or heterosexual.

For monitoring purposes, and in line with the definition cited in the Equality Act 2010, the sex of an individual refers to whether they regard themselves as a man or a woman. Within the NHS Data Model and Dictionary, this category is referred to as ‘person gender’.

It should be noted that the NHS Data Model and Dictionary are moving from one definition of ‘gender’ to another. The original, ‘person gender code’, focuses upon ‘what someone looks like’ as opposed to ‘what they state they are’. The NHS Data Model and Dictionary are currently introducing ‘person stated gender code’<sup>15</sup> and ‘person phenotypic sex’<sup>16</sup> classification to correct and differentiate between the two. The new items are being changed in national data sets on a rolling basis; however it is possible to map between ‘person gender code’ and ‘person stated gender code’ values.

There is an argument put forward by the Gender Identity Research and Education Society (GIRES)<sup>17</sup>, that as a section of the population has one of the twenty or so intersex conditions, people with these conditions may not be comfortable to be offered only "male", "female" or "prefer not to say" in any monitoring form because this denies them the opportunity to self-identify, accurately, as "intersex", if that is what they prefer.

Patient monitoring question	Workforce monitoring question
<p><b>The NHS Data Model and Dictionary approved National Codes for person stated gender:</b></p> <ol style="list-style-type: none"> <li>1. Male</li> <li>2. Female</li> <li>9. Indeterminate (unable to be classified as either male or female)</li> <li>X. Not known (not recorded)</li> </ol>	<p><b>National Workforce Dataset (NWD) / Electronic Staff Record (ESR) system:</b></p> <p>Gender</p> <ul style="list-style-type: none"> <li>• Male</li> <li>• Female</li> </ul>
<p><b>The Gender Identity Research and Education Society (GIRES) recommend the following question and response codes to the monitoring question on ‘Sex’:</b></p> <p>What is your sex?</p> <ul style="list-style-type: none"> <li>• Male</li> <li>• Female</li> <li>• Intersex</li> </ul> <p>Prefer not to say</p>	

<sup>15</sup>[http://www.datadictionary.nhs.uk/data\\_dictionary/attributes/p/person/person\\_stated\\_gender\\_code\\_de.asp?shownav=1](http://www.datadictionary.nhs.uk/data_dictionary/attributes/p/person/person_stated_gender_code_de.asp?shownav=1)

<sup>16</sup>[http://www.datadictionary.nhs.uk/data\\_dictionary/attributes/p/person/person\\_phenotypic\\_sex\\_classification\\_de.asp?shownav=1](http://www.datadictionary.nhs.uk/data_dictionary/attributes/p/person/person_phenotypic_sex_classification_de.asp?shownav=1)

<sup>17</sup> <http://www.gires.org.uk/>

## 4.5 Gender reassignment

At the time this guide was published, there was no standard approach to asking questions or collecting data on gender reassignment. In line with the Equality Act 2010, the question proposed aims to collect data on the number of people that are at some stage of their reassignment 'journey'.

NHS organisations are reminded of the sensitivity surrounding data collection for this equality characteristic, and should be made aware of the need (and legal requirement) to refrain from revealing people's previous gender history. As with the collection of information for all equality characteristics, it is recommended that the intended purpose for the collection of data and the way in which the security of the information will be ensured, is made apparent during the collection process.

The Gender Identity Research and Educations Society (GIREs) acknowledge that the general shape and length of the question informed by the work carried out by the Equality & Human Rights Commission (EHRC), in the table below, is appropriate, in that the intention of the question appears to have been understood by those responding. However, GIREs state that there is an incorrect conflation of "sex" (male or female) and "gender identity" (man, woman, other) within the EHRC informed question.

GIREs state that this error is replicated across much governmental and legal documentation. For a medical institution to continue this mistake would be considered inappropriate. Moreover, GIREs argue that it may constitute indirect discrimination in undermining the position of people who have, or are perceived to have, the gender reassignment protected characteristic. Though this has not been considered in Court.

### Patient question

**The question below is informed by the work carried out by the Equality & Human Rights Commission (EHRC) and guided by the requirements of the Equality Act 2010:**

Have you gone through any part of a process, or do you intend to (including thoughts or actions) to change from the physical sexual appearance you had at birth to the gender you now identify with? (This could include changing your name, your appearance and the way you dress, taking hormones or having gender confirming surgery)

- Yes
- No
- Prefer not to say

**Patient question****GIRES present an amendment to above the question:**

Have you gone through any part of a process, or do you intend to (including thoughts or actions) to bring your physical sex appearance, and/or your gender role, more in line with your gender identity? (This could include changing your name, your appearance and the way you dress, taking hormones or having gender confirming surgery)

- Yes
- No
- Prefer not to say

There is currently no item in the NHS Data Dictionary, nor in National Workforce Dataset (NWD) / Electronic Staff Record (ESR) system, on gender reassignment.

**4.6 Marriage and civil partnership**

The question and categories below are taken from the *Civil Service 'Best practice guidance on monitoring equality and diversity in the workplace'*. This characteristic has been given protection under the Equality Act 2010. It is included in this paper for the purposes of monitoring the workforce. Patients should not be asked about their status in relation to this characteristic.

Legislation in this area aims to ensure that there is no difference between the treatment of married people/civil partners in the workplace compared to those who are not. As a result, this question does not need to be asked when monitoring access or service provision, nor should people be asked about what type of single person they are, for example, never married, widowed, or divorced.

**Workforce monitoring question****The NHS Data Model and Dictionary approved National Codes for legal marital status:**

- S Single
- M Married/Civil Partner
- D Divorced/Person whose Civil Partnership has been dissolved
- W Widowed/Surviving Civil Partner
- P Separated
- N Not disclosed

### Workforce monitoring question

#### Electronic Staff Record (ESR) system:

- Civil Partnership
- Divorced
- Legally Separated
- Married
- Single
- Widowed
- Unknown

#### Marital / same sex civil partnership question from the ONS 2011 Census questionnaire for England:

What is your legal marital or same-sex civil partnership status?

- Never married and never registered a same-sex civil partnership
- Married
- In a registered same-sex civil partnership
- Separated, but still legally married
- Separated, but still in a registered same-sex civil partnership
- Divorced
- Formally in a registered same-sex civil partnership which is now dissolved
- Widowed
- Surviving partner from a registered same-sex civil partnership

There is currently no item on marriage and civil partnership in the National Workforce Dataset (NWD).

## 4.7 Pregnancy and maternity

Currently there is no standard approach to asking questions or collecting data on pregnancy and maternity. As cited in the Equality Act 2010, this question should be asked in relation to employment and Human Resources issues. However, it is important for organisations to give due regard to the importance of asking questions on pregnancy and maternity with respect to issues relating to patients as well as for the workforce.

In the non-work context, protection against maternity discrimination is for 26 weeks after giving birth, compared to the applicable time period for protection against maternity discrimination for employment purposes which is up to a year. This includes avoiding treating a woman unfavourably because she is breastfeeding.

Currently, the NHS Data Model and Dictionary only carries a 'pregnancy indicator for HIV', used in the HIV and AIDS Related Data Set only; this is not the same as the

Equality Act 2010 definition. However, the Health and Social Care Information Centre are currently introducing a 'pregnancy status indicator', this will be a patient-orientated code that will indicate whether the patient is currently pregnant, and will not include any time after the outcome of the pregnancy such as birth, miscarriage etc.

There is currently no item on pregnancy and maternity in the National Workforce Dataset (NWD). ESR enables the recording of Maternity Leave, Reason for Moving CCST (Maternity) and Assignment Change Reason (Pregnancy). These are instigated by the employee declaring that they are pregnant.

#### Workforce monitoring question

##### Data collection category (for workforce) may take the form of:

Are you pregnant, on maternity leave or returning from maternity leave?

- Yes
- No
- Prefer not to say

If ticked "Yes" to the above, please answer the following question:

- Pregnant
- On maternity leave
- Returning from maternity leave

##### Data collection category (for patients) may take the form of:

Are you pregnant or have you given birth in the last 26 weeks?

- Yes
- No
- Prefer not to say

## 4.8 Religion or belief

There are many different concepts of religion or belief that can be measured. A question on religion or belief appears in the 2011 Census. ONS have carried out extensive testing on the question and response categories for religion or belief. Testing has found that the question "What is your religion?" best met the requirements of collecting good quality data on religious affiliation.

Testing has also found that using the names given to the followers of that religion (i.e. Muslim, Christian etc.) was generally what respondents expected to find in answer to the question. As these labels can also be taken to mean "the Muslim

religion" etc. a decision was made to use the names given to the followers of the religions rather than the names of the religions themselves.

It should be noted that the 2011 Census question is recommended by ONS for use in England only. Different wording in the definition of Christian is used in Scotland, Wales and Northern Ireland<sup>18</sup>.

It should also be highlighted that the NHS Data Model and Dictionary focuses upon the religious or other belief system affiliation of a person, as specified by the individual person<sup>19</sup>. The national main religious or other belief system affiliations as cited in the NHS Data Model and Dictionary are presented below. The NHS Data Model and Dictionary also has an extensive list of subdivisions to these codes<sup>20</sup>.

Patient monitoring question	Workforce monitoring question
<p><b>The NHS Data Model and Dictionary approved National Codes for religious or other belief system affiliations:</b></p> <p>National Codes:</p> <ul style="list-style-type: none"> <li>• Baha'i</li> <li>• Buddhist</li> <li>• Christian</li> <li>• Hindu</li> <li>• Jain</li> <li>• Jewish</li> <li>• Muslim</li> <li>• Pagan</li> <li>• Sikh</li> <li>• Zoroastrian</li> <li>• Other</li> <li>• None</li> <li>• Declines to disclose</li> <li>• Unknown</li> </ul>	<p><b>Electronic Staff Record (ESR) system:</b></p> <p>Religious Belief</p> <ul style="list-style-type: none"> <li>• Atheism</li> <li>• Christianity</li> <li>• Buddhism</li> <li>• Hinduism</li> <li>• Judaism</li> <li>• Islam</li> <li>• Sikhism</li> <li>• Other</li> <li>• I do not wish to disclose my religion/belief</li> <li>• Jainism</li> </ul>

<sup>18</sup> <http://www.ons.gov.uk/ons/guide-method/measuring-equality/equality/ethnic-nat-identity-religion/religion/index.html> provides further details and guidance on the questions to be used in other parts of the UK and points to be taken into account when comparing.

<sup>19</sup> [http://www.datadictionary.nhs.uk/data\\_dictionary/attributes/r/red/religious\\_or\\_other\\_belief\\_system\\_affiliation\\_group\\_code\\_de.asp?shownav=1](http://www.datadictionary.nhs.uk/data_dictionary/attributes/r/red/religious_or_other_belief_system_affiliation_group_code_de.asp?shownav=1)

<sup>20</sup> [http://www.datadictionary.nhs.uk/data\\_dictionary/attributes/r/red/religious\\_or\\_other\\_belief\\_system\\_affiliation\\_code\\_de.asp?shownav=1](http://www.datadictionary.nhs.uk/data_dictionary/attributes/r/red/religious_or_other_belief_system_affiliation_code_de.asp?shownav=1)



Patient monitoring question	Workforce monitoring question
<p><b>Religion question taken from the ONS 2011 Census questionnaire for England:</b></p> <p>What is your religion?</p> <ul style="list-style-type: none"> <li>• No religion</li> <li>• Christian (including Church of England, Catholic, Protestant and all other Christian denominations)</li> <li>• Buddhist</li> <li>• Hindu</li> <li>• Jewish</li> <li>• Muslim</li> <li>• Sikh</li> <li>• Any other religion, please write in</li> <li>• Prefer not to say</li> </ul>	

There is currently no item on religion or belief in the National Workforce Dataset (NWD).

## 4.9 Sexual orientation

The protected characteristic under the Equality Act 2010 in this area is ‘sexual orientation towards’. The initial question below is informed by the research carried out by ONS as part of the Government response to the Equalities Data review. Though this research concluded that ‘sexual identity’ was the right question to use in household surveys, sexual orientation is a more appropriate concept in health related settings.

The ONS Integrated Household Survey (IHS) question on ‘sexual identity’ (below) was developed and tested on a number of surveys in 2008 and was added to the IHS in 2009. While the Equality Act 2010 and relevant legislation in the past refers to sexual orientation, ONS has focused on collecting data on sexual identity. The sexual identity question measures how people see themselves and not how others see them.

The question and the categories below are similar to those used by ONS in the Integrated Household Survey, but in line with the Equality Act 2010, it uses the concept of ‘sexual orientation’ rather than ‘sexual identity’.

The NHS Data Model and Dictionary refers to the “sexual orientation” of a patient<sup>21</sup>.

<sup>21</sup>

[http://www.datadictionary.nhs.uk/data\\_dictionary/attributes/s/ses/sexual\\_orientation\\_code\\_de.asp?shownav=1](http://www.datadictionary.nhs.uk/data_dictionary/attributes/s/ses/sexual_orientation_code_de.asp?shownav=1)

Patient monitoring question	Workforce monitoring question
<p><b>The NHS Data Model and Dictionary approved National Codes for sexual orientation:</b></p> <p>What is your sexual orientation?</p> <ul style="list-style-type: none"> <li>• Heterosexual</li> <li>• Gay / Lesbian</li> <li>• Bi-sexual</li> <li>• Person asked and does not know or is not sure</li> <li>• Not Stated (person asked but declined to provide a response)</li> </ul>	<p><b>National Workforce Dataset (NWD) / Electronic Staff Record (ESR) system:</b></p> <p>Sexual Orientation</p> <ul style="list-style-type: none"> <li>• Heterosexual</li> <li>• Gay</li> <li>• Lesbian</li> <li>• Bisexual</li> <li>• I do not wish to disclose my sexual orientation</li> </ul>
<p><b>Question informed by the research carried out by ONS:</b></p> <p>Which of the following options best describes how you think of yourself?</p> <ul style="list-style-type: none"> <li>• Heterosexual / straight</li> <li>• Gay / Lesbian</li> <li>• Bisexual</li> <li>• Other</li> <li>• Prefer not to say</li> </ul>	
<p><b>The ONS Integrated Household Survey (IHS) question on ‘sexual identity’:</b></p> <p>Which of the following options best describes your sexual orientation?</p> <ul style="list-style-type: none"> <li>• Heterosexual / straight</li> <li>• Lesbian</li> <li>• Gay</li> <li>• Bisexual</li> <li>• Other</li> <li>• Prefer not to say</li> </ul>	

## 4.10 Carer status

Carer status is a characteristic that has not been assigned protection under the Equality Act 2010. However, NHS organisations will benefit from the collection and use of data about patients, service users, communities and staff with regard to this additional characteristic.

Although at present there is no expectation that organisations should record this data, it is increasingly recognised, particularly for workforce management purposes, that people with caring responsibilities may need specific support. The Equality Act 2010 introduced the protection of ‘discrimination by association’ and ‘carers’ are one of the groups that have benefited from the protection. Therefore, it will be advantageous for service providers and workforce managers within the NHS to include a monitoring question on whether an individual is a carer or not.

Patient / workforce monitoring question
<p><b>The NHS Data Model and Dictionary approved National Codes for young carer:</b></p> <p>Y Yes            N No            Z Not Stated (Person asked but declined to provide a response)</p>
<p><b>Carer status question taken from the ONS 2011 Census questionnaire for England:</b></p> <p>Do you look after, or give any help or support to family members, friends, neighbours or others because of either:</p> <ul style="list-style-type: none"> <li>➤ Long-term physical or mental ill-health / disability</li> <li>➤ Problems related to old age</li> </ul> <ul style="list-style-type: none"> <li>• No</li> <li>• Yes, 1-19 hours a week</li> <li>• Yes, 20-49 hours a week</li> <li>• Yes, 50 or more hours a week</li> </ul>

It should be noted that the NHS Data Dictionary only has an item on young carer status. There is currently no item on carer status in the National Workforce Dataset (NWD) / Electronic Staff Record (ESR) system.

## 5 Questions and categories for health inequality proxy collections

The measurement of inequalities in health is complex and multifaceted, with an array of evidence based methods and indicators available. Health inequalities are widely considered to be differences in health status or outcomes between geographical areas of deprivation and/or between socio-economic groups. For example, those included in the ‘inclusion health’ groups, such as homeless people, experience some of the poorest health outcomes in England. In addition, it should be recognised that health inequalities also exist across the protected characteristics covered by the Equality Act 2010.

### 5.1 Postcode of residence

Postcode of residence (along with other markers) is often used to determine the Index of Multiple Deprivation – a marker that determines area deprivation<sup>22</sup>.

#### Monitoring question

##### Data collection question to determine Index of Multiple Deprivation:

What is your postcode of residence?

The NHS Data Model and Dictionary primarily uses ‘postcode of usual address’. For national data flows this includes main permanent and other permanent residence<sup>23</sup>. However, it should be recognised that not all individuals have a fixed abode and an option to collect this information should be included.

### 5.2 Socio Economic Factors

Socio-economic status is a measure of an individual’s or family’s social and economic position, compared to others, based on their occupation, income or education. It is thus often determined by a combination of factors that look at an individuals’ profession, employment status or level of education.

The National Statistic Socio-economic Classification (NS-SEC) developed by the ONS, is a widely used coding tool in social surveys in the UK for determining socio-economic status. This measures employment relations and the conditions of occupation. Here we have also included educational attainment as it is another important attribute which can affect health status.

<sup>22</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/6320/1870718.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/6320/1870718.pdf)

<sup>23</sup> [http://www.datadictionary.nhs.uk/data\\_dictionary/data\\_field\\_notes/p/po/postcode\\_of\\_usual\\_address\\_d\\_e.asp?shownav=1](http://www.datadictionary.nhs.uk/data_dictionary/data_field_notes/p/po/postcode_of_usual_address_d_e.asp?shownav=1)

### Monitoring questions

#### The NHS Data Model and Dictionary approved National Codes for employment status:

##### *National Codes:*

- 01 Employed
- 02 Unemployed and seeking work
- 03 Students who are undertaking full (at least 16 hours per week) or part-time (less than 16 hours per week) education or training and who are not working or actively seeking work
- 04 Long-term sick or disabled, those who are receiving Incapacity Benefit, Income Support or both; or Employment and Support Allowance
- 05 Homemaker looking after the family or home and who are not working or actively seeking work
- 06 Not receiving benefits and who are not working or actively seeking work
- 07 Unpaid voluntary work who are not working or actively seeking work
- 08 Retired
- ZZ. Not Stated (person asked but declined to provide a response)

#### The following question on the individuals' profession has been taken from the 2011 ONS Census for England:

What is your full and specific job title?

For example, primary school teacher, car mechanic, district nurse, structural engineer.

Briefly describe what you do in your main job: \_\_\_\_\_

#### The following question on the individuals' employment status has been taken from the 2011 ONS Census:

Last week (include any paid work, including casual or temporary work, even if only for one hour) were you:

- Working as an employee?
- On a government sponsored training scheme?
- Self-employed or freelance?
- Working paid or unpaid for your own or your family's business?
- Away from work ill, on maternity leave, on holiday or temporarily laid off?
- Doing any other kind of paid work?
- None of the above

### 5.3 Educational attainment:

#### Monitoring questions

**The following question on educational attainment has been taken from the 2011 ONS Census for England:**

Which of these qualifications do you have?

Tick every box that applies if you have any of the qualifications listed

If your UK qualification is not listed, tick the box that contains its nearest equivalent. If you have qualifications gained outside the UK, tick the 'Foreign qualifications' box and the nearest UK equivalents (if known)

- 1 - 4 O levels / CSEs / GCSEs (any grades), Entry Level, Foundation Diploma
- NVQ Level 1, Foundation GNVQ, Basic Skills
- 5+ O levels (passes) / CSEs (grade 1) / GCSEs (grades A\* - C), School Certificate, 1 A level / 2 - 3 AS levels / VCEs, Higher Diploma
- NVQ Level 2, Intermediate GNVQ, City and Guilds Craft, BTEC First / General Diploma, RSA Diploma
- Apprenticeship
- 2+ A levels / VCEs, 4+ AS levels, Higher School Certificate, Progression / Advanced Diploma
- NVQ Level 3, Advanced GNVQ, City and Guilds Advanced Craft, ONC, OND, BTEC National, RSA Advanced Diploma
- Degree (for example BA, BSc), Higher degree (for example MA, PhD, PGCE)
- NVQ Level 4 - 5, HNC, HND, RSA Higher Diploma, BTEC Higher Level
- Professional qualifications (for example teaching, nursing, accountancy)
- Other vocational / work-related qualifications
- Foreign qualifications
- No qualifications

## 6 Further information and queries

For further information/comments, please contact: [england.eandhi@nhs.net](mailto:england.eandhi@nhs.net)