Equalities Monitoring Guidance

Guidance and recommended questions for NHS Scotland
We are happy to consider requests for translations in alternative languages and formats. Please contact our publications team at alternativeformats@health.scot.nhs.uk or telephone 0131 536 5500.
What is equalities monitoring and profiling and what are the benefits?

Equalities monitoring

Definition
Equalities monitoring is the collection and analysis of information on people’s age, disability, gender (including transgender status), ethnic group, religion or belief, and sexual orientation for the purpose of monitoring at group level. Equalities monitoring involves aggregating data to better understand differences between the six equality groups defined above in terms of:

- access to and use of health services
- prevalence of different health conditions and different risk factors
- health outcomes.

Why monitor people by equality strand?
The Equality Duties, together with the then Scottish Executive’s Fair for All policy(1), require the NHS to record equality data for all patients. This will aid a better understanding of health related to specific groups, as well as promote equality and help examine underlying causes of inequalities in health. It will also play a major role when planning services. Without equalities monitoring NHS Boards are unable to assess whether or not equality policies are working, or to demonstrate progress in promoting equality as required under current legislation.
Equalities profiling

Definition
Equalities profiling is focused on the individual patient with the aim of understanding their specific and unique needs. It goes beyond data on equality strands to capture more detailed information – e.g. a patient’s needs with regard to spiritual care, dietary requirements, language, communication or other support.

Why profile patients from different equality groups?
Equalities profiling allows the NHS to put services, support or adjustments in place to meet patients’ needs. Responding to patient needs will not only improve patients’ experience of care but will lessen the workload of NHS staff by removing the necessity for them to respond reactively to a patient’s need for support or adjustments. Aggregated data from profiling also allows NHS Boards to plan effectively to meet the projected future demand for reasonable adjustments or services.

Information with respect to methods of monitoring and profiling for each of the equality strands can be found on the following pages.

Recommended questions
The recommended questions for equalities monitoring in this guidance have been approved for use by the Scottish Government for large social surveys. Questions for age, gender, ethnicity, religion and sexual orientation have been agreed, and a disability question will shortly be finalised. It is extremely likely that the disability questions on pages 09 and 10 of this guidance will be adopted. No questions for transgender have been agreed by Scottish Government as yet.

Please make use of all the questions for equalities monitoring in this guidance.

The Happy to Ask, Happy to Tell training resource provides further support around asking these recommended questions and is available at www.isdscotland.org/equalityhappytoaskdvd

04
Age

Why should the NHS in Scotland routinely collect information on age?

Legislative and policy background
The NHS Reform (Scotland) Act 2004 (2) extends a duty to encourage equality of opportunity to all equality areas, including age. In Scotland, this is supported by the government’s Fair for All (1) policy, which sets out the obligations of NHS Boards. The forthcoming Single Equality Act (3) will place a Duty on public bodies to promote equality between people of different ages. It will also protect people aged over 18 from discrimination in the provision of goods and services on the grounds of their age. Therefore, the NHS will not be able to refuse treatment to older people. With this in mind, in order to demonstrate that they are treating people of all ages equally, NHS Boards need complete and accurate information about the age of those who use NHS services. Such data could be used, for example, to demonstrate that people of all ages in Scotland have similar waiting times for operations or cancer treatment, or that indicators of quality of care are similar.

Understanding the needs and health issues for different groups of patients
Cancer, heart disease, stroke, respiratory disease and injuries account for over 80% of all deaths in people aged 65 and over and therefore many older people have regular contact with health services. A Help the Aged study showed that 27% of those aged over 65 believed that older people are treated worse with respect to health care. Barriers faced by young people to accessing health services include lack of provision for young people – for example young people being placed in adult mental health services – opening times only during school hours, and concerns about confidentiality and anonymity.

Routine data is collected on age by the NHS in the form of the patients’ Community Health Index (CHI) number. Harnessing this data would allow the NHS to monitor progress towards reducing these inequalities. Routine data could be used at national or regional level to monitor inequalities or could be used locally, for example in practice audits, to monitor the equity of care.
Improving individual care
Routine collection of information on age could contribute towards better care for the individual by identifying specific needs. These could include the increased risk of cancer or heart disease due in part to age but mainly attributed to poor access to health services. However, in order to improve care, other data items related to age – such as additional staff support or appointment times outwith school hours – would also be useful. These items could be included as part of a referral process, for example, to ensure that nursing staff are available and able to assist older people with eating meals in hospital, or that young people are referred to a service designed for adolescents.

Collecting patient information
Capturing age data is embedded in most NHS data collection, Better Together patient experience programme surveys and social care. This data is captured in the form of an age question or CHI. The Scottish Government has published guidance on asking the age question\(^4\).

Collection of patients' age is unlikely to be a problem. However, staff will need to be comfortable in asking and defending why the question is being asked, while patients should be comfortable in giving their age and in understanding why the question is being asked.

Status of the question
The recommended question is a harmonised question and no changes are planned.

Recommended question

<table>
<thead>
<tr>
<th>What was your age last birthday?</th>
</tr>
</thead>
<tbody>
<tr>
<td>If more detail is required then the recommended question for collecting date of birth is:</td>
</tr>
<tr>
<td>What is your date of birth?</td>
</tr>
</tbody>
</table>
Why should the NHS in Scotland routinely collect information on disability?

Legislative and policy background
The Disability Discrimination Act\(^{(5)}\) introduced the Disability Equality Duty (2006)\(^{(6)}\), which places a Duty on public bodies to promote equality between disabled and non-disabled people. In Scotland, this is supported by the government’s Fair for All\(^{(1)}\) policy, which sets out the obligations of NHS Boards. In order to demonstrate that they are treating disabled and non-disabled people equally, NHS Boards need complete and accurate information about the impairment status of those who use NHS services. Such data could be used, for example, to demonstrate that disabled and non-disabled people in Scotland have similar waiting times for operations or cancer treatment, or that indicators of quality of care are similar.

Understanding the needs and health issues for different groups of patients
There is a wealth of evidence that identifies that disabled people face discrimination in accessing health services. People experiencing learning disabilities or mental health problems are most disadvantaged: there is evidence that these groups of people have much lower rates of cervical screening, mammography and other routine tests than other people (Disability Rights Commission, 2006)\(^{(7)}\), resulting in them being at an increased risk of developing diseases such as cancer.

Inequalities in access to health care also exist for other groups, with 24% of deaf people missing a GP appointment and 19% missing five or more appointments (RNID, 2006), due to inaccessible communication. Routine data would allow the NHS to monitor progress towards reducing these inequalities. This data could be used at national or regional level to monitor inequalities or could be used locally, for example in practice audits, to monitor the equity of care.
Improving individual care
Routine collection of information on disability could contribute towards better care for the individual by identifying specific needs, such as increased risk of cervical or breast cancer due to poor access to health services. It is important for disabled people to have the same access to services as anybody else. This is covered under legislation\(^5,6\). In order to improve care, other data items related to disability, such as physical and communication support, would also be useful. These items could be included as part of a referral process, for example, to ensure that a British Sign Language interpreter is available; to indicate the need for consultations to take place on the ground floor; or for nursing staff to provide additional support and assistance.

Collecting patient information
A question on disability was present in the 2001 Census\(^8\) and a revised extended disability question has been proposed by The General Register Office for Scotland (GROS) for inclusion in the 2011 Census\(^9\). A form of the extended disability question has been used in the NHS complaints form. Definitions for impairment and national clinical data standards for disability exist in the ISD Data Dictionary under Disability Needs and Personal Requirements\(^10\).

Currently, the disability question is being cognitively tested by the Better Together Programme with the aim of having the disability question consistent across all of NHS Scotland.

Since disability and impairment status is self-assigned and can change, these should not be presumed by care professionals. Therefore, staff involved in asking the question will need to be comfortable in asking and defending why the question is being asked, while patients should be comfortable in giving information about their disability and in understanding why the question is being asked.

Status of the question
This question is under review and may be changed. This information will be updated should any future changes to the question be made.
### Recommended questions

Do you have any of the following? Tick all that apply.

<table>
<thead>
<tr>
<th>Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deafness or severe hearing impairment</td>
</tr>
<tr>
<td>Blindness or severe vision impairment</td>
</tr>
<tr>
<td>A physical disability (a condition that substantially limits one or more basic physical activities, such as walking, climbing stairs, lifting or carrying)</td>
</tr>
<tr>
<td>A learning disability, such as Down’s syndrome</td>
</tr>
<tr>
<td>A learning difficulty, such as dyslexia or dyspraxia</td>
</tr>
<tr>
<td>A mental health condition, such as depression or schizophrenia</td>
</tr>
<tr>
<td>A long term condition, such as cancer, HIV, diabetes, heart disease or epilepsy</td>
</tr>
<tr>
<td>Other condition</td>
</tr>
<tr>
<td>No</td>
</tr>
</tbody>
</table>
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 problems related to old age)?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, limited a lot</td>
<td></td>
</tr>
<tr>
<td>Yes, limited a little</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>
Gender

Why should the NHS in Scotland routinely collect information on gender?

Legislative and policy background
The Equality Act 2006 \(^{(11)}\) introduced the Gender Equality Duty 2007 \(^{(12)}\) that places a Duty on public bodies to promote equality between men and women and protects transgender people from discrimination in the provision of goods and services. In Scotland, this is supported by the government’s Fair for All \(^{(1)}\) policy, which sets out the obligations of NHS Boards. In order to demonstrate that they are treating men and women equally, NHS Boards need complete and accurate information about the gender of those who use NHS services. Such data could be used, for example, to demonstrate that women and men in Scotland have similar waiting times for operations or cancer treatment, or that indicators of quality of care are similar.

Understanding the needs and health issues for different groups of patients
While it is known that rates of coronary heart disease vary by gender – 54% of heart attacks in women go undiagnosed compared with 33% in men – there is a lack of evidence available as to the differential health experiences of men and women. Fair for All – Gender (2006) cites that men are more reluctant to seek health services generally, whereas women are more likely to report practical problems in accessing services.

Women, particularly older women, face barriers to primary care. This is a result of many being unpaid carers who don’t own private transport and rely upon public transport, which is often not integrated with the location of health centres.

Routine data on males and females is collected by the NHS. If the NHS harnessed this data for monitoring purposes NHS Boards could monitor progress towards reducing gender inequalities. Such monitoring could occur at a national or regional level, or the data could be used locally – for example in practice audits – to monitor the equity of care.
**Improving individual care**
Routine collection of information on gender could contribute towards better care for the individual by identifying specific needs such as increased risk of coronary heart disease due to poor access to health services. However, in order to improve care, other data items related to gender – such as specific appointment times benefiting those with caring or childcare responsibilities, or primary care services delivered in the home or community – would also be useful. These items could be included as part of a referral process, for example, to ensure that a community or home visit is available.

**Collecting patient information**
Currently, the predominant collection is based on the biological sex of the person at birth (male, female) and is embedded in NHS and social care data collection so is unlikely to be a problem if the biological question is being asked. The Scottish Government has published guidance on asking the gender question.

Since gender is self-assigned and can change, it should not be presumed by care professionals. Therefore, staff involved in asking the question will need to be comfortable in asking and defending why the question is being asked, while patients should be comfortable in giving their gender – as per the new definition – as well as understanding why the question is being asked.

The new definition of gender is concerned with the person’s self-identity rather than their physical characteristics. Gender includes men, women and transgender people and it is for this reason that gender questions often include an ‘other’ option.

**Status of the question**
This is a harmonised question and no changes are planned.

**Recommended question**

<table>
<thead>
<tr>
<th>Are you male or female?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
</tbody>
</table>
Why should the NHS in Scotland routinely collect information on ethnicity?

Legislative and policy background
The Race Relations Amendment Act 2000 (14) introduced the Race Equality Duty, which places a Duty on public bodies to promote racial equality. In Scotland, this is supported by the government’s Fair for All (1) policy which sets out the obligations of NHS Boards. In order to demonstrate that they are treating all ethnic groups equally, NHS Boards need complete and accurate information about the ethnic group of people who use NHS services. Such data could be used, for example, to demonstrate that all ethnic groups in Scotland have similar waiting times for operations or cancer treatment, or that indicators of quality of care are similar.

Understanding the needs and health issues for different groups of patients
There is a wealth of evidence that shows that health problems vary by ethnic group. Although they have lower overall mortality, South Asians in Scotland have a higher risk of coronary heart disease and diabetes. Chinese people have very low levels of coronary heart disease but increased risk of certain cancers.

Routine data would allow the NHS to monitor progress towards reducing inequalities related to modifiable risk factors or issues with access to health services. Routine data could be used at national or regional level to monitor inequalities. It could also be used locally, for example in practice audits, to monitor the equity of care.

Improving individual care
Routine collection of information on ethnic groups could contribute towards better care for the individual by identifying specific needs, such as increased risk of coronary heart disease or diabetes. However, in order to improve care, other data items related to ethnicity would also be useful, such as language, dietary preferences and spiritual needs. These items could be included as part of a referral process, for example, to ensure that an interpreter is available; to indicate the need for a particular diet; or to indicate particular spiritual needs.
Collecting patient information

Standard classifications of ethnic group are available and have been used in the 1991 and 2001 Census\(^{(8)}\) in Scotland, as well as in routine health data collection. Additionally, the proposed questions published by GROS for the forthcoming 2011 Census include a question on language. Ethnic group is defined in the ISD Data Dictionary\(^{(15)}\). Collection of ethnicity in primary care settings is likely to increase considerably due to the Directly Enhanced Service indicator\(^{(16)}\) of the Quality Outcomes Framework for GPs, which tasks them with collecting ethnic data from patients. The Scottish Government has published guidance on asking the question about ethnicity\(^{(17)}\).

A question on ethnicity has been cognitively tested in the Better Together survey.

While the ethnicity question has been standard for some time, it may, on occasion, still be asked. Since ethnicity is self-assigned, a patient’s ethnic group should not be presumed by care professionals. Therefore, staff involved in asking the question will need to be comfortable in asking and defending why the question is being asked, while patients should be comfortable in giving their ethnic group and in understanding why the question is being asked.

Status of the question

The recommended question has been harmonised and no changes are planned.
What is your ethnic group? Choose ONE section from A to E, and then tick ONE box that best describes your ethnic group or background.

<table>
<thead>
<tr>
<th>A. White</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scottish</td>
</tr>
<tr>
<td>English</td>
</tr>
<tr>
<td>Welsh</td>
</tr>
<tr>
<td>Northern Irish</td>
</tr>
<tr>
<td>British</td>
</tr>
<tr>
<td>Irish</td>
</tr>
<tr>
<td>Gypsy/traveller</td>
</tr>
<tr>
<td>Polish</td>
</tr>
<tr>
<td>Other white ethnic group, please write in:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>B. Mixed or multiple ethnic groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any mixed or multiple ethnic groups, please write in:</td>
</tr>
<tr>
<td>____________________________________</td>
</tr>
</tbody>
</table>


### C. Asian, Asian Scottish or Asian British

- Pakistani, Pakistani Scottish or Pakistani British
- Indian, Indian Scottish or Indian British
- Bangladeshi, Bangladeshi Scottish or Bangladeshi British
- Chinese, Chinese Scottish or Chinese British
- Other, please write in:

### D. African, Caribbean or Black

- African, African Scottish or African British
- Caribbean, Caribbean Scottish or Caribbean British
- Black, Black Scottish or Black British
- Other, please write in:

### E. Other ethnic group

- Arab
- Other, please write in:

_________________________________________________________________________________
Religion and belief

Why should the NHS in Scotland routinely collect information on religion and belief?

Legislative and policy background
The Equality Act 2006 Part II (1) protects individuals from direct or indirect discrimination on grounds of religion and belief in the provision of goods, facilities and services. In Scotland, this is supported by the government’s Fair for All (1) policy, which sets out the obligations of NHS Boards. The forthcoming Single Equality Act (3) will place a Duty on public bodies to promote equality for different groups with religious beliefs, as well as those who hold no religious beliefs. In order to demonstrate that they are providing equitable treatment, NHS Boards need complete and accurate information about the religious status of those who use NHS services. Such data could be used, for example, to demonstrate that people of different religions, or of no religion, in Scotland have similar waiting times for operations or cancer treatment, or that indicators of quality or experience of care are similar.

Understanding the needs and health issues for different groups of patients
Both the positive and negative experiences of those from various religious and faith groups are captured in the Fair for All – Religion and Belief (2007) document, ‘Religion and Belief Matter – An Information Resource for Healthcare Staff’ (18). This guidance also advocates the beneficial contribution that the provision of spiritual care can make to improving the health of patients recovering from illness.

It is understood that the Data Protection Act (19) prevents healthcare staff from informing spiritual care providers about patients. Thus, unless patients are asked whether they have any religious or spiritual care needs upon arriving at hospital, then any spiritual care needs they have may not be met. Failing to provide spiritual care to all groups could be considered discrimination, which is unlawful.

Routine data could be used at national or regional level to monitor health inequalities or could be used locally, for example in practice audits, to monitor the equity of care.
Improving individual care
Routine collection of information on religion and belief could contribute towards better care for the individual by identifying specific needs. In order to improve the patient’s experience of care, other data items – such as dietary requirements, access to the spiritual care lead or praying practices – should be included as part of a referral process.

Collecting patient information
The 2001 Census (8) allowed for analysis by religion and showed that Christians and then Muslims were the largest religious groups. Additionally, a substantial proportion of respondents stated they were of no religion. The proposed questions for the 2011 Census (9) include a question on religion.

The religion question has been cognitively tested in the Better Together survey and no problems have been reported.

In the past, it was common for patients going into hospital to be asked for their religion and most patient administration systems in hospitals and GP practices (using Read Codes) are still able to support this data collection. Some NHS Boards are collecting statistics under ‘religion/faith/belief or none’ as part of their collection of ethnicity and to help interpret the needs of their population. The Scottish Government has published guidance about asking the religion question (20).

Therefore, both staff and patients should be familiar with the religion question. Since religion is self-assigned and can change, it should not be presumed by care professionals. Therefore, staff involved in asking the question will need to be comfortable in asking and defending why the question is being asked, while patients should be comfortable in giving their religion and in understanding why the question is being asked.

Status of the question
The recommended question has been harmonised and no changes are planned.
### Recommended question

**What religion, religious denomination or body do you belong to?**

<table>
<thead>
<tr>
<th>Option</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
</tr>
<tr>
<td>Church of Scotland</td>
</tr>
<tr>
<td>Roman Catholic</td>
</tr>
<tr>
<td>Other Christian</td>
</tr>
<tr>
<td>Muslim</td>
</tr>
<tr>
<td>Buddhist</td>
</tr>
<tr>
<td>Sikh</td>
</tr>
<tr>
<td>Jewish</td>
</tr>
<tr>
<td>Hindu</td>
</tr>
<tr>
<td>Pagan</td>
</tr>
<tr>
<td>Another religion, please write in:</td>
</tr>
</tbody>
</table>

---

19
Sexual orientation

Why should the NHS in Scotland routinely collect information on sexual orientation?

Legislative and policy background
The Equality Act (Sexual Orientation) Regulations 2007 (21) protects individuals from direct or indirect discrimination on grounds of sexual orientation in the provision of goods facilities and services. In Scotland, this is supported by the government’s Fair for All (1) policy, which sets out the obligations of NHS Boards. The forthcoming Single Equality Act (3) will place a Duty on public bodies to promote equality for people of all sexual orientations. In order to demonstrate that they are providing non-discriminatory equitable services to people of different sexual orientations, NHS Boards need complete and accurate information about the sexual orientation of those who use NHS services. Such data could be used, for example, to demonstrate that people of different sexual orientations in Scotland have similar waiting times for operations or cancer treatment, or that indicators of quality or experience of care are similar across groups of people of different sexual orientations.

Understanding the needs and health issues for different groups of patients
There is a wealth of research evidence that demonstrates people who are lesbian, gay and bisexual face discrimination in accessing health services and experience health inequalities. For example, a recent Scottish survey of lesbian and bisexual women (22) showed that of those respondents eligible for a smear test – 15% had never had one, compared to 7% of the eligible general population – with one in fifty being refused a test. The same study showed that 20% of the respondents had self-harmed in the previous year, compared to 0.4% of the general population.

Routine data could be used at national or regional level to monitor health inequalities, or could be used locally in practice audits, for example, to monitor the equity of care.
Improving individual care
Routine collection of information on sexual orientation could contribute towards better care for the individual by identifying specific needs, such as increased risk of cervical or breast cancer due to poor access to health services. It is important for lesbian, gay and bisexual people that same-sex partners are treated in the same way as opposite sex partners, which would be covered under legislation (21). Therefore, collecting other data items, such as partner gender, could also be useful to improve care. Recording the gender of their partner sensitively under ‘marital status’ or ‘nearest relative’, and including these in the referral process, would result in gay, lesbian or bisexual patients admitted to hospital being confident that their partners will be given the same information and treated in the same way as opposite sex partners are. Limiting the assumptions being made about patients’ personal circumstances and being sensitive, and responsive to these, would also contribute to improved individual care.

Collecting patient information
A question on sexual orientation was trialled in part of the Census Test (2006), although there is no question on sexual orientation recommended for the 2011 Census (9). Despite this, analysis of responses to the 2011 Census questions relating to gender, as well as relationship status to others in the household, will derive data on the number of same-sex couples cohabiting. Additionally, data will be available for the number of those who have registered civil partnerships.

A sexual orientation question has been developed by the Office for National Statistics (ONS).

A version of the Census Test (2006) question is used in the national patient complaints form and in both the Scottish Health Survey and Scottish Crime and Justice Survey.

A question on sexual orientation is included in the Better Together survey and has been cognitively tested with no problems reported. However, the wording of the question differs from that used in the ONS question.

A definition for sexual orientation exists in the ISD Data Dictionary (23), along with national clinical data standards for sexual orientation.
Since sexual orientation is self-assigned and can change, it should not be presumed by care professionals. Therefore, staff involved in asking the question will need to be comfortable in asking and defending why the question is being asked, while patients should be comfortable in giving their sexual orientation and in understanding why the question is being asked.

**Status of the question**
This question has been recommended and no changes are planned.

**Recommended question**

<table>
<thead>
<tr>
<th>Which of the following options best describes how you think of yourself? Please tick one box only</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heterosexual/straight</td>
</tr>
<tr>
<td>Gay/lesbian</td>
</tr>
<tr>
<td>Bisexual</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>
Transgender

Why should the NHS monitor for transgender?

Legislative and policy background
The Sex Discrimination Act 1975 (Amendment) Regulations 2008\(^{24}\) protects only people who intend to undergo, are undergoing or have undergone gender reassignment. It does not protect those transgender people who are not defined as 'under medical supervision'. This means there are some transgender people who may not be protected, so it is important to differentiate between and be specific about who is protected from being discriminated against in the provision of goods, facilities and services. Additionally, the Gender Equality Duty (2007)\(^{12}\) places a Duty on public bodies to promote equality between men and women that includes provisions for transgender people.

The forthcoming Offences (Aggravated by Prejudice) (Scotland) Act 2009\(^ {25}\) protects transgender people from hate crime and this legislation applies to all transgender people, irrespective of whether they have undergone gender reassignment under medical supervision or not. The forthcoming Single Equality Act\(^{3}\) places a Duty on public bodies to promote equality for people who have undergone gender reassignment under medical supervision.

In Scotland, this is supported by the government’s Fair for All\(^{1}\) policy which sets out the obligations of NHS Boards. In order to demonstrate that they are treating transgender people equally, NHS Boards need complete and accurate information about the transgender status of those who use NHS services. Such data could be used, for example, to demonstrate that transgender people and others in Scotland have similar waiting times for operations or cancer treatment, or that indicators of quality of care are similar.
Understanding the needs and health issues for different groups of patients

Little is known about the health of transgender people. However, transgender people have reported discrimination and transphobic attitudes (Equality Review, 2006) in accessing health services. It is likely that some may be alienated from participating in screening services, such as cervical, prostate, or breast screening services, resulting in them being at an increased risk of developing illnesses such as cervical cancer. Additionally, many may have endured transphobic attitudes from general practitioners, or other frontline staff, making them less likely to seek medical advice. Routine data on transgender is not collected by the NHS. In addition to data-handling rules being applicable to all sensitive personal data – this is defined under data protection legislation – disclosure of transgender status without consent is unlawful under the Gender Recognition Act 2004. It is therefore unlawful to pass someone’s transgender status on to another party without consent in a professional capacity: for example, a service provider passing the information on to another service provider, or an employee passing the information to a colleague.

Transgender monitoring could be used at a national or regional level, or the data could be used locally, for example in practice audits, to monitor the equity of care. It is imperative though that local monitoring in smaller NHS Boards is conducted with great care so to not inadvertently identify transgender people due to the low numbers of transgender people in these areas. Routine monitoring may not be able to provide evidence around equity of care due to the small number of patients involved. Where this is the case, NHS Boards should consider alternative approaches to understanding the potential access and patient experience issues for transgender people – e.g. focus groups.
Improving individual care
Routine collection of information on transgender could contribute towards better care for the individual by identifying specific needs, such as increased risk of cancer due to poor access to health services. However, in order to improve care, other data items related to transgender would also be useful. These could include ensuring that the individual is placed on a ward that matches their present gender identity, or that the patient is to receive prostate cancer screening even though they have transitioned to being female. These items could be included as part of a referral process, for example, to ensure that a female-to-male transgender patient is placed on a male ward even if he has not undergone any gender reassignment surgery.

Collecting patient information
While there is no harmonised question nor even a commonly agreed one, Strategic Workforce Information Systems Scotland (SWISS) and the Scottish Government NHS complaints monitoring form have tried a few questions. The Scottish Health Survey has also cognitively tested some questions, but these, ultimately, were not included in the survey. The Scottish Transgender Alliance has recently published guidance (28).

Status of the question
There is no harmonised question.

Recommended question
While there are various questions that can be used no recommended question currently exists.
1. Fair For All – NHS (HDL) 2002 51

2. NHS Reform (Scotland) Act 2004
   www.opsi.gov.uk/legislation/scotland/acts2004/asp_20040007_en_1

3. Single Equality Act
   http://services.parliament.uk/bills/2008-09/equality.html

4. Scottish Government guidance on the age question

5. Disability Discrimination Act 2005
   www.opsi.gov.uk/Acts/acts2005/ukpga_20050013_en_1

   www.dotheduty.org/

7. Formal Investigation, Disability Rights Commission 2006

8. General Register Office for Scotland – 2001 Census
   www.gro-scotland.gov.uk/census/censushm/index.html

9. Recommended questions for 2011 Census

10. ISD Data Dictionary – Disability Needs and Personal Requirements
    National Clinical Data Standards (under review)
    www.datadictionaryadmin.scot.nhs.uk/isddd/29572.html


    www.scotland.gov.uk/Topics/People/Equality/18500/20506

13. Scottish Government guidance on the gender question
14. Race Relations Amendment Act 2000
www.opsi.gov.uk/acts/acts2000/ukpga_20000034_en_1

15. ISD Data Dictionary – Ethnicity (will change to reflect 2001 Census)
www.datadictionaryadmin.scot.nhs.uk/isddd/1781.html


17. Scottish Government guidance on the ethnicity question

18. ‘Religion and Belief Matter – An Information Resource For Healthcare Staff’, Fair For All – Religion and Belief 2007
www.scottishinterfaithcouncil.org/resources/Religion+and+Belief.pdf


20. Scottish Government guidance on the religion question

www.opsi.gov.uk/si/si2007/uksi_20071263_en_1

22. Prescription for Change Stonewall 2008
www.stonewall.org.uk/what_we_do/research_and_policy/3101.asp

23. ISD Data Dictionary – Sexual Orientation
www.datadictionaryadmin.scot.nhs.uk/isddd/11177.html

www.opsi.gov.uk/si/si2008/uksi_20080656_en_1

25. The Offences (Aggravation by Prejudice) (Scotland) Act 2009

http://archive.cabinetoffice.gov.uk/equalitiesreview/upload/assets/www.theequalitiesreview.org.uk/equalities_review_-_fairness_and_freedom.doc

27. Gender Recognition Act 2004
www.opsi.gov.uk/acts/acts2004/ukpga_20040007_en_1

28. Scottish Transgender Alliance guidance 2009
www.scottishtrans.org/Page/Equality_Monitoring.aspx