

Review of equality health data needs in Scotland

NHS Health Scotland
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NHS Health Scotland is a WHO Collaborating Centre for Health Promotion and Public Health Development.

‘NHSScotland is committed to understanding the needs of different communities, eliminating discrimination, reducing inequality, protecting human rights and building good relations by breaking down barriers that may be preventing people from accessing the care and services that they need.’

(The Healthcare Quality Strategy for NHSScotland, 2010)

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Summary

Background

A Ministerial Task Force on Health Inequalities was established to identify and prioritise practical actions to reduce the most significant and widening health inequalities in Scotland. *Equally Well: Report of the Ministerial Task Force on Health Inequalities*,¹ was published in June 2008 and laid out a number of recommendations for change in policy, practice and delivery. This data review is in response to Recommendation 74:

‘The Government should commission a review of health data needs which covers gender, ethnicity, age, disability, religion and belief, sexual orientation and transgender identity. The review should be published and include a plan of action with milestones to fill information gaps identified.’

Pregnancy/maternity, marriage and civil partnership have since been introduced as protected characteristics through the Equality Act 2010, but are not within the scope of this report as they were introduced following the commission of the review. The recommendation to review health data needs follows on from a UK Review of Equality Data led by the Office for National Statistics,² which recommended that the Department of Health, the Scottish Government and the Welsh Assembly Government should undertake an audit of health data needs.

This summary provides some background to equality data and why they are needed, along with the key messages from the review and the key recommendations for data development.

What are equality data and why do they matter?

This is about describing individuals

Everyone in Scotland can describe themselves in terms of their age, disability status, ethnicity, gender/sex, religion/belief, sexual orientation, and transgender identity. Understanding the characteristics of an individual can help to improve health and health care in two ways:

1. **To directly improve individual care at the point of service delivery:** capturing information on an individual’s needs or values can assist directly when assessing a person’s requirements for care and support (e.g. action required to assist someone with physical access). Such information should ideally be collected by NHSScotland and shared, when relevant and appropriate, across health services **in advance** of the patient using each service.
2. **Through aggregate analyses:** combining information for people with the same protected characteristics can help to identify patterns in prevalence, access, experience and outcomes for different groups of the population (e.g.

experiences of inpatient care for young people). Such information can be gathered at a point in time **after** the patient has used NHS services.

'Equality data' can be defined as:

Any information relating to the protected characteristics of: age, disability, ethnicity, gender, religion and belief, sexual orientation and transgender identity. This information can take the form of broad categories used to describe a characteristic directly, e.g. religious group, disability impairment; or more detailed information on individual needs and preferences related to a protected characteristic, e.g. dietary requirements or use of a hearing loop.

For example:

Equality characteristic	Data for analysis of groups	Data for individual care
Disability	Learning disability	Makaton interpreter required

Why does it matter?

Evidence to help reduce inequalities

There is some evidence to suggest how a person's protected characteristics can be associated with their health and care. Links are seen across all aspects of health and care, e.g. prevalence of health conditions, how people access care and how people experience health care. Below are some of the things we already know:

- People from minority ethnic groups generally have lower mortality than the general population in Scotland.³
- There is a higher prevalence of heart disease and diabetes among those in the South Asian population.³
- Self-reported poor health and limiting long-term illness appear to be consistently higher among people whose religion is Muslim, Sikh or Roman Catholic.³
- Women, younger people, and disabled people report some less positive experiences of inpatient care in Scotland in 2010, although it is not clear whether the variations in experience reported by these groups reflect real inter-group differences in the quality of services received, or inter-group differences in subjective factors such as expectations, perceptions or the way questions are answered, or some combination of these factors.⁴
- The needs of people with transgender identity may require gender-specific services to change their practice (for example, NHS Tayside has produced guidance for women's services on the inclusion of transgender women).⁵

We have a good understanding of how a person's age and gender is associated with certain health conditions. For other protected characteristics, we either do not know if inequalities occur or, where we have some evidence to suggest inequalities, we cannot tailor our services easily to eliminate these as we do not record information about a patient's characteristics.

Evidence to demonstrate compliance with current legislation

The UK Government's Equality Act 2010⁶ includes a new public sector Equality Duty which requires public authorities to be active in promoting equality, eliminating unlawful conduct and fostering good relations. The new Duty came into force on 6 April 2011 and provides a single, consistent framework covering age, disability status, ethnicity, gender/sex, marriage and civil partnership, pregnancy and maternity, religion/belief, sexual orientation, and transgender identity. A public sector duty to provide evidence of compliance with this legislation and to set and report on equality outcomes came into force in Scotland in May 2012. Health Boards in Scotland will require good quality equality information to demonstrate that they are meeting the new public sector equality duty and to measure progress on meeting agreed equality outcomes. The improvements to data will support the public sector equality duties required, especially the setting and monitoring of equality outcomes.

Evidence to support Scottish Government policy

NHSScotland has an ongoing commitment to equality of experience and outcomes – to everyone in Scotland, no matter who they are, or where they live.⁷ We cannot meet this commitment unless we embed in services the ability to assess variations in experience and outcomes for different groups in the population and to measure our progress in eliminating them. The NHSScotland Quality Strategy⁷ has suggested a programme of action to ensure that people's equality needs are gathered, shared and responded to across health services in order to improve quality of service provision for all. The Christie Commission Report²⁸ proposed that public sector organisations prioritise prevention, reducing inequalities and promoting equality, but we need to improve quality and consistency of equality data in order to measure our progress towards this ambition.

Improving efficiency and effectiveness of health care

Shorter waiting times in NHSScotland mean that good communication with patients is more important than ever.⁸ If patients fail to attend appointments they may be referred back to the end of the waiting list or to their GP, which will lead to a delay in treatment; and at an average cost of £115 for an outpatient appointment,⁹ missed appointments present a considerable cost to NHSScotland. Poor communication will only be one of a number of reasons why patients do not attend appointments; however, it is one of the areas we can do something about. Patients may also have a delay in treatment if their consultation cannot go ahead as planned because the support they need is not in place (e.g. an interpreter).

About this review

This review aimed to: detail the current availability of equality health data in Scotland for routinely collected data sources; assess equality data needs; and identify national priorities for data development.

Information on data needs was gathered through extensive engagement with: Health Boards; voluntary organisations; academic and government data users. An audit was undertaken to identify what data, for each protected characteristic, were currently being gathered through all routine, national, health data sources.

Details of the review objectives and scope, along with membership of the review project group are given in [Annex A](#).

This report provides in Part 1 some background to equality data and why they are needed, and then considers national priorities for data development in Parts 2–4:

Part 2 The need for equality data to directly improve individual care.

Part 3 The need for equality data for aggregate analyses.

Part 4 What further support is necessary to develop equality data in Scotland.

Below is a summary of the key messages from the review along with the key recommendations.

Key messages

- Equality data are defined in this report as: any information relating to the protected characteristics of: age, disability, ethnicity, gender, religion and belief, sexual orientation and transgender identity
- Better information on peoples' protected characteristics is required in Scotland to:
 - provide evidence to: reduce inequalities; demonstrate compliance with current equality legislation; and support Scottish Government policy
 - help NHSScotland, and its community planning partners to: predict and meet the changing demands for health care brought about by demographic change in Scotland; and to provide efficient and effective services.

Information to improve individual care at the point of service delivery

- The review identified strong support for recording and sharing equality information to directly improve individual care at the point of service delivery
- Information for this purpose will usually be more detailed than the broad categories used to record protected characteristics, as these data must alert staff to **specific actions or provisions** necessary to meet a person's **individual needs and preferences**
- Key to this development is effective sharing of data between primary and secondary care

Information for aggregate analysis

- The audit of data sources identified large variations in the level of data currently collected for different protected characteristics.
 - **Age and gender:** most data sources hold information on age and gender; however it is most likely to be biological sex that is recorded rather than gender.
 - **Ethnicity:** routine data sources are beginning to hold some information on ethnicity; however, of the sources that did include ethnicity, less than half could provide analysable data.
 - **Disability and sexual orientation:** only a handful of data sources collected disability or sexual orientation. These related to a specific disability condition or sexually transmitted infections respectively.
 - **Religion and belief and transgender identity:** no routine data sources collected data on transgender identity or religion and belief.

- **Population surveys:** surveys such as patient experience surveys and the Scottish Health Survey (SHeS) collect information on all protected characteristics apart from transgender identity.
- Understanding of the associations between ethnicity, sexual orientation, transgender identity, religion and belief and health or care was very limited among NHS staff, beyond those working directly in the area of equality.
- The last few years have seen a substantial increase in the number of Scottish Morbidity Records that include the patient's ethnicity for some Health Board areas; however, this pattern is not consistent across Scotland. There has also been an increase in recording of ethnicity for people registered with general practices; this has been driven by QOF targets
- The Scottish Care Information (SCI) Gateway exists as a formal mechanism to share ethnicity information between primary care and secondary care. The SCI Gateway is a national system that integrates primary and secondary care systems.^a
- Although the long-term aim is for routine collection of information on all protected characteristics to meet legislative requirements, the next steps for data development must reflect the current position of data collection for each protected characteristic.

^a www.sci.scot.nhs.uk/products/gateway/gateway_main.htm

All recommendations

Preliminary recommendation

Information Services Division (ISD) in consultation with Scottish Government (SG) should:

1. Maintain a clear process of change control for any diversity related standards maintained and published by ISD (see box 1) to minimise the impact of any changes on Health Boards.

Information to improve individual care at the point of service delivery

NHS Health Scotland (NHS HS) and ISD should (in consultation with GPs and Health Boards):

2. Support Health Boards by developing consistent standards, data definitions and coding for equality information necessary to improve individual care at the point of service delivery.

NHS 24 should:

3. Consider what equality information is necessary to improve individual care at the point of call to NHS 24 and at referral from NHS 24 to accident & emergency and out-of-hours services.

Scottish Government (SG) should:

4. Consider whether collection and transfer of a minimum set of information to improve individual care should be made mandatory for the following points on the patient pathway: referral from GP to hospital; accident & emergency attendance; transfer within hospital; and discharge from hospital.

e-Health should:

5. Support collaborative work across NHS Boards to use technology to enable data to support individualised patient care to be:

- **Recorded consistently** e.g. through an agreed e-Form which can be implemented in key applications such as GP IT, Patient management systems (PMS), Multidisciplinary Information Systems (MiDIS).
- **Accessible at the point of care**, e.g. through GP IT, PMS, clinical portal, patient/citizen portal.
- **Shared at key transitions in care**, such as referral, admission, discharge.
- **Extracted to support monitoring and reporting** upon equality, e.g. using Ensemble, MiG.

Information for aggregate analysis

ISD and NHS HS should:

6. Develop further equality analysis of age and gender data and provide a central resource for access to key equality evidence for age and gender.

NHS HS and NHS Education for Scotland (NES) should:

7. Deliver a programme for staff and patients that increases awareness of the relevance of ethnicity, sexual orientation, religion and belief to health and care.

Health Boards should:

8. Demonstrate clear progress to increase the completeness of ethnic group recording in national Scottish Morbidity Records (SMR).
9. Develop processes to share ethnicity data between Primary Care and Secondary Care at the point of referral and discharge.
10. Ensure that procurement of all new IT systems for use within NHSScotland includes an equality impact assessment of the system to ensure that it has, or can be easily amended to have, fields to hold information on current and future protected characteristics (as shown in [Annex B](#)).

SG should:

11. Ensure that the assessment of patient experience in Scotland continues to collect information by **all** protected characteristics, whether through national surveys or local qualitative work.
12. Continue to look for opportunities to incentivise the recording of ethnicity in primary care.
13. Ensure that the development of every national performance target for health includes an assessment of the likely impact on people with different protected characteristics; and, where a target may impact differently, ensure methods to monitor this are in place.

Information for improving culture and infrastructure

NHS HS and NES should:

14. Work with Health Boards to pull together consistent and practical resources to support staff with the collection and analysis of equality data; and in the longer term integrate staff training on equality data into equality and diversity training for NHS staff.

ISD, Health Protection Scotland (HPS), and SG should:

15. Maintain, and make available annually, a record of whether or not fields exist within routine national health data sources to hold equality data, and (subject to availability of resources to do this) report on whether the data within these are sufficient for equality analysis

Further recommendations arising from consultation on this report

SG and NHS HS should:

16. Explore the relationship between socioeconomic status and protected characteristics and explore whether it is possible to collect individual measures of socioeconomic status in routine health data collection systems.
17. Explore the potential for streamlining equality data collection processes for collection, analysis and application across the public sector.

Part 1: What are equality data and why do they matter?

- 1.1 There are many things that contribute and interact to determine an individual's health, these include:
- the social and economic environment,
 - the physical environment, and
 - the person's individual characteristics and behaviours.
- 1.2 This review is focused on the last of these: the person's individual characteristics and behaviours. Although we know that personal characteristics and behaviours interact with socioeconomic and environmental factors in determining health; this report focuses on how we can better use data on protected characteristics to improve the health and care of people in Scotland.

This is about describing individuals

- 1.3 Everyone in Scotland can describe themselves in terms of their age, gender, disability status, ethnicity, sexual orientation, religion, belief or transgender identity. Understanding the characteristics of an individual can help to improve health and health care in two ways:
1. **To directly improve individual care at the point of service delivery:** capturing information on an individual's needs or values can assist directly when assessing a person's requirements for care and support (e.g. action required to assist someone with physical access). Such information should ideally be collected by NHSScotland and shared, when relevant and appropriate, across health services **in advance** of the patient using each service.
 2. **Through aggregate analyses:** combining information for people with the same protected characteristics can help to identify patterns in prevalence, access, experience and outcomes for different groups of the population (e.g. experiences of inpatient care for young people). Such information can be gathered at a point in time **after** the patient has used NHS services.
- 1.4 'Equality data' can be defined as:
- Any information relating to the protected characteristics of: age, disability, ethnicity, gender, religion and belief, sexual orientation and transgender identity. This information can take the form of broad categories used to describe a characteristic directly, e.g. religious group, disability impairment; or more detailed information on individual needs and preferences related to a protected characteristic, e.g. dietary requirements or use of a hearing loop.

1.5 For example:

Equality characteristic	Data for analysis of groups	Data for individual care
Disability	Learning disability	Makaton interpreter required

Box 1 - Classification of protected characteristics

As with any framework to group individuals, broad categories to describe protected characteristics are unlikely to be ideal – particularly for very complex concepts such as ethnicity. However, the effectiveness of using information to pick out patterns in health and care requires clear definitions to be used consistently across the NHS. This is particularly important for analysis of information relating to minority groups in the population, where it may be necessary to combine data from a number of Health Boards for robust analysis. For the purpose of aggregate analysis it is recommended that the questions in [Annex B](#) are used to record people’s protected characteristics for health and health care in Scotland. Much work has gone into the development of these questions and response categories and these are being promoted for use across the wider public sector in Scotland¹⁰ and within key Scottish population surveys. As Scotland’s society continues to change it may be necessary to review and revise the questions used to gather equality data; however, it is recommended that the Scottish Government, in consultation with other relevant organisations implement a clear process of change control for equality questions. A change control process would aim to ensure any changes to the wording of questions seeking to categorise protected characteristics or the answer categories defined for them are centrally logged and an up-to-date list of recommended questions is maintained. Note: there is as yet no agreed question for asking people about their transgender identity.

Patient Privacy and consent

1.6 Whenever a patient is being asked a question about their protected characteristics they should always be given the option to respond ‘Prefer not to answer’. This report makes recommendations for what information should be requested from the patient, should they wish to disclose it, and as shown in [Annex B](#) ‘Prefer not to answer’ is a valid response to each equality question. Where recommendations are made to share equality data within the NHS, procedures for patient consent should also be established. As with any personal data, NHSScotland confidentiality guidelines should be adhered to when managing equality data.

Why does it matter?

Evidence to help reduce inequalities

1.7 There is some evidence to suggest how a person's protected characteristics can be associated with their health and care. Links are seen across all aspects of health and care, e.g. prevalence of health conditions, how people access care and how people experience health care. Below are some of the things we already know:

- People from minority ethnic groups generally have lower mortality than the general population in Scotland.³
- There is a higher prevalence of heart disease and diabetes among those in the South Asian population.³
- Self-reported poor health and limiting long-term illness appear to be consistently higher among people whose religion is Muslim, Sikh or Roman Catholic.³
- Women, younger people, and disabled people had less positive experiences of inpatient care in Scotland in 2010.⁴
- The needs of people with transgender identity may require gender-specific services to change their practice (for example, NHS Tayside has produced guidance for women's services on the inclusion of transgender women).⁵
- The experience of people with different disabilities varied.^{2,4}

1.8 We have a good understanding of how a person's age and gender is associated with certain health conditions and we are learning more about how it influences people's likelihood to access health care and respond to treatment. For other protected characteristics, we either do not know if inequalities occur or, where we have some evidence to suggest inequalities, we cannot tailor our services easily to eliminate these as we do not record information about a patient's characteristics.

Demographic change in Scotland

1.9 Scotland's population is diverse, and it is changing (see Box 2 over the page). There are some aspects of the Scottish population we still know very little about, e.g. how religion and belief interact with health. At the same time, the make-up of the population is changing and presenting new challenges for our health service. An ageing population will mean that more people in Scotland will be living with long-term illness and disability, a trend which is set to continue in the coming decades. Recent changes in the population have also placed immediate demands on the NHS for additional services, e.g. an increase in the demand for maternity services for the recent European migrant population was seen in some areas of Scotland. The NHS in Scotland needs better information about people's characteristics in order to plan for future demands and to help staff to respond effectively to the individual in front of them.

Box 2 - Scotland's population

The population of Scotland is ageing and this trend is expected to continue.^{11, 12} By the year 2031, the number of children under 16 is projected to decrease by 7%, while the number of people aged 65 and over is expected to rise by around 62%.¹³ With more people reaching old age and older people living longer, more people in Scotland will be living with long-term illness and disability. Four in ten adults reported having a long-standing physical or mental condition or disability in 2009.

Around 2% of the population in Scotland is from non-white ethnic minority backgrounds and recent years have also seen a net migration of workers to Scotland, with the single largest group coming from Poland.

Although the number of transgender people in Scotland is unknown, UK research would suggest it could lie between 50,000 and 250,000.

In 2001, people in Scotland reported their current religion as Church of Scotland (42%), none (28%), Roman Catholic (16%) and other Christian (7%). Muslims were the largest non-Christian faith group in Scotland – 0.8% of the population.

Adapted from: Dimensions of Diversity, January 2010³

Evidence to demonstrate compliance with current legislation

- 1.10 The UK Government's Equality Act 2010 simplifies, strengthens and where possible harmonises previous equality legislation. The Act also includes a new public sector Equality Duty which requires public authorities to be active in promoting equality, eliminating unlawful conduct, foster good relations, and, under the specific duty, provide evidence of compliance and set and report on equality outcomes. The new duty brings together three separate equality duties, covering race, disability and gender; replacing them with a single, consistent framework covering age, disability status, ethnicity, gender/sex, marriage and civil partnership, pregnancy and maternity, religion/belief, sexual orientation, and transgender identity. It came into force on 6 April 2011. Health Boards in Scotland will require information on the above protected characteristics for their patients to demonstrate that they are meeting the new public sector equality duty, and for measuring progress on agreed equality outcomes. The lack of information in the public sector was highlighted in a recent Equality and Human Rights Commission report: 'It is impossible to tell whether public services are treating a group fairly if that group is, to all intents and purposes, invisible.'¹⁴

Evidence to support Scottish Government policy

Box 3 - What is equity in health care?

Equity in health care is not about providing everyone in Scotland with exactly the same services. It is about providing people with the support and services that they need to give everyone in Scotland the best health experience and the best opportunity for successful health outcomes. NHSScotland has an ongoing commitment to equality of experience and outcomes – to everyone in Scotland, no matter who they are, or where they live.⁷

- 1.11 We cannot meet this commitment unless we have data to capture variations in experience and outcomes for different groups in the population and to measure our progress in eliminating them. The Christie Commission Report proposed that public sector organisations prioritise prevention, reducing inequalities and promoting equality and the Quality Strategy is developing a programme of action to ensure that people's equality needs are gathered, shared and responded to across health services.

Improving efficiency and effectiveness of health care

- 1.12 Shorter waiting times in NHSScotland mean that good communication with patients is more important than ever.⁸ If patients fail to attend or cancel appointments they may be referred back to the end of the waiting list or to their GP, which will lead to a delay in treatment. This does not apply to cancellations by the service. At an average cost of £115 for an outpatient appointment,⁹ missed appointments present a considerable cost to NHSScotland. Poor communication will only be one of a number of reasons why patients do not attend appointments; however, it is one of the areas we can do something about. Patients may also have a delay in treatment if their consultation cannot go ahead as planned because the support they need is not in place (e.g. an interpreter). More generally, a lack of knowledge about the health risks for different groups in the population and their access and response to treatment, screening and health promotion interventions, may mean that NHSScotland is not making the best use of its resources nor providing the most effective care to particular groups of the population.
- 1.13 The remainder of this report is presented in three parts:
- Part 2** assesses the need for equality data to directly improve individual care.
 - Part 3** assesses the need for equality data for aggregate analyses.
 - Part 4** considers what further support is necessary to develop equality data in Scotland.

Key messages from Part 1

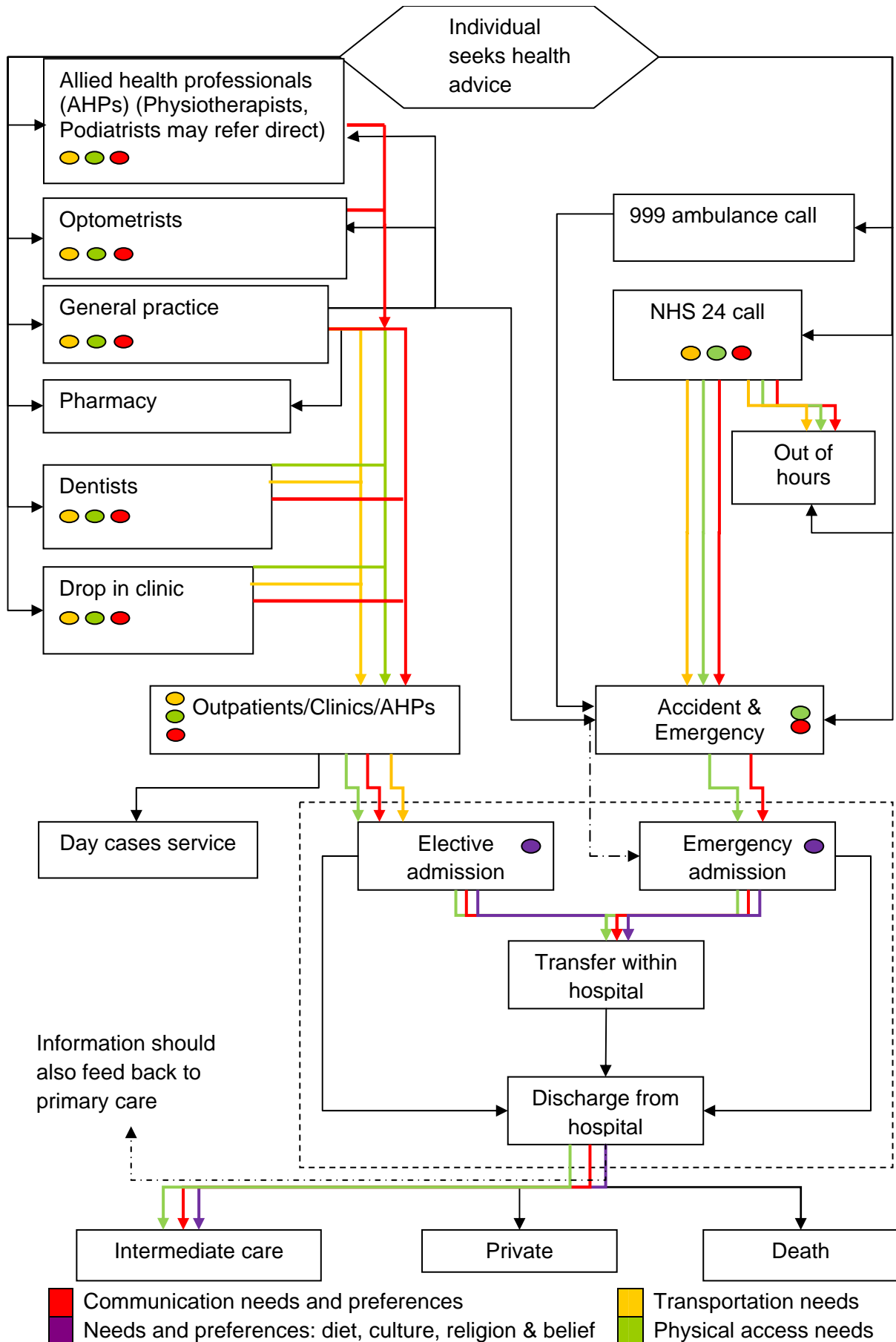
- A person’s individual protected characteristics are some of the many things that contribute and act together to determine their health and how they interact with health care.
- Understanding the protected characteristics of an individual can help to improve health and health care in two ways: to directly improve individual care at the point of service delivery; and through aggregate analyses to help identify patterns in prevalence, access, experience and outcomes for different groups of the population.
- Equality data are defined in this report as: any information relating to the protected characteristics of age, disability, ethnicity, gender, religion and belief, sexual orientation and transgender identity.
- Better information on people’s protected characteristics is required in Scotland to:
 - provide evidence to: reduce inequalities; demonstrate compliance with current equality legislation; and support Scottish Government policy
 - help NHSScotland and its community planning partners to: predict and meet the changing demands for health care brought about by demographic change in Scotland; and to provide efficient and effective services.

Preliminary recommendation	Responsibility for implementation
1. Maintain a clear process of change control for any diversity related standards maintained and published by ISD (see Box 1 on page 16) to minimise the impact of any changes on Health Boards.	ISD in consultation with the SG

Part 2: Information to improve individual care

- 2.1 Equality data can be used directly, at the point of service delivery, to improve individual care. Part 2 of this report considers priorities for data development in this area.
- 2.2 The review identified strong support for recording and sharing equality information to directly improve individual care at the point of service delivery. Information for this purpose will usually be more detailed than the broad categories used to record protected characteristics, as these data must alert staff to **specific actions or provisions** necessary to meet a person's **individual needs and preferences**.
- 2.3 Broadly, this type of information can be grouped into four areas:
- Communication needs and preferences
 - Transportation needs
 - Physical access needs
 - Needs and preferences relating to diet, culture, religion and belief
- 2.4 Examples of the type of information that should be shared include: 'Book Makaton interpreter'; 'Requires Bariatric transport/equipment'; 'Prefers male/female consultant'. In addition to detailed needs, a limited number of broader categories that alert staff to a particular set of complex needs, e.g. 'Learning Disability', should also be included within this information.
- 2.5 The primary purpose of this information is to alert NHS staff to the appropriate actions and provisions to support each patient and as such this information should ideally be collected and shared, where appropriate, across the relevant health services **in advance** of the patient using each service. Once processes are in place to collect and share this information it can also be extracted retrospectively to provide evidence for local planning of services and to monitor equality of access, patient experience and outcomes for those with different needs or preferences.
- 2.6 Collection and sharing of this type of information does take place, often informally, within Health Boards; however, this is not done consistently and processes vary across boards and specialities. A recent report on waiting times by Audit Scotland⁸ found that Health Boards were not consistently recording information about people's additional needs and that only a third of people requesting support had their needs addressed. In May 2010 the Chief Executive of NHSScotland wrote to Health Boards to ask them to conduct a review of current local processes to ensure that information on additional needs and the necessary support services are recorded and transmitted throughout services. Although local systems and processes may vary, national agreement is needed on: what information should be collected where in the patient pathway and when these data should be shared. Where possible, Health Boards should also share knowledge on how this can be implemented locally (see Box 4 on page 23).

Figure 1: Possible collection and sharing of information to improve individual care at point of delivery



2.7 Figure 1 provides an illustration of where this type information might be collected and shared across a high level patient pathway. NHSScotland's Healthcare Quality Strategy states:

'We want confidence for patients that their NHS is amongst the best in the world – safe, effective and responsive to their needs, every time and all of the time.'⁷

2.8 Ultimately, NHSScotland should aim to accommodate all of a person's needs and preferences where possible. In order to prioritise the work necessary to reach this aim, it is recommended that the development of processes to collect and share information that may impact directly on the success of a person's treatment or their health outcomes should be taken forward in the first instance.

2.9 Key to this development is effective sharing of data between primary and secondary care. Staff working in primary care often develop a detailed knowledge of the people within their practice and therefore may not require structured systems to record people's individual needs or preferences. However, when a patient enters secondary care, staff are unlikely to know their individual needs. Many GPs will be providing some information on needs through the referral system. Common processes for this are required to ensure consistency of care for patients across Scotland, to make information transfer clearer and to incorporate processes into electronic systems. This is arguably the biggest gap in health equality data for Scotland. Procedures should also be implemented to transfer relevant information from secondary care back to primary care, when appropriate.

Box 4 – Embedding equality data into systems and processes

Embedding the collection and sharing of this type of data into existing systems and processes is a very complex task. NHS Lothian has recently considered some areas of patient needs, and scoped out specification of requirement for patient administration systems (PAS), in the hope that this could be tested with their system. Recommendations made in the resulting report covered:

- the potential needs of patients within each of the areas considered, with priority needs identified
- who needs to know about these additional needs, and at what point in the patient journey
- how to ensure that this information is communicated within the system.

NHS Lothian is currently working with its system suppliers and it is anticipated that this work will help inform Scotland-wide requirements for e-Health, training, communication and service redesign in this area.

Key messages about individual care from Part 2

- The review identified strong support for recording and sharing equality information to directly improve individual care at the point of service delivery.
- Information for this purpose will usually be more detailed than the broad categories used to record protected characteristics, as these data must alert staff to **specific actions or provisions** necessary to meet a person's **individual needs and preferences**.
- Key to this development is effective sharing of data between primary and secondary care.

Recommendations for improving individual care	Responsibility for implementation
2. Support Health Boards by developing consistent standards, data definitions and coding for equality information necessary to improve individual care at the point of service delivery.	NHS Health Scotland (NHS HS) and the Information Services Division (ISD) – in consultation with GPs and Health Boards
3. Consider what equality information is necessary to improve individual care at the point of call to NHS 24 and at referral from NHS 24 to Accident & Emergency and out-of-hours services.	NHS 24
4. Consider whether collection and transfer of a minimum set of information to improve individual care should be made mandatory for the following points on the patient pathway: referral from GP to hospital; Accident & Emergency attendance; transfer within hospital; and discharge from hospital.	Scottish Government (SG)
<p>5. Support collaborative work across NHS Boards to use technology to enable data to support individualised patient care to be:</p> <ul style="list-style-type: none"> • Recorded consistently, e.g. through an agreed e-Form which can be implemented in key applications such as GP IT, PMS, MiDIS • Accessible at the point of care, e.g. through GP IT, PMS, clinical portal, patient/citizen portal • Shared at key transitions in care, such as referral, admission, discharge • Extracted to support monitoring and reporting upon equality, e.g. using Ensemble, MiG 	e-Health

Part 3: Information for aggregate analysis

- 3.1 Information for aggregate analysis uses standard categories to identify patterns in health and care based on people's protected characteristics. Combining information for people with the same protected characteristics can help to identify patterns in prevalence, access, experience and outcomes for different groups of the population. Like the information outlined in Part 2, these data should also improve individual care, with findings from aggregate analyses being fed back to inform future care and services. These data can be gathered at a point in time **after** the patient has used an NHS service. Part 3 of this report considers the data priorities for aggregate analysis.

The review focused on four main uses of aggregate equality data:

1. Patient monitoring
2. Measuring patient experience
3. Performance management
4. Understanding population health

Patient monitoring

Patient monitoring involves embedding information on protected characteristics into health services to help identify patterns in:

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

Why monitor patients by protected characteristics?

Patient monitoring can assist in designing and planning services, and equality monitoring can help to examine underlying causes of inequalities in health, and to promote equality. Without patient monitoring Health Boards are unable to assess whether or not equality policies are working or to demonstrate progress in promoting equality as required under current legislation.⁶

- 3.2 Although the long-term aim is for routine collection of information on all protected characteristics, it is necessary to take account of the current position when making recommendations for data development. The review identified three stages of equality data development:

1. **Initiation:** the right climate for data collection is created; data collection is initiated and processes are developed to support this. (Having the right climate, i.e. staff and service users know why the information is being asked and what it will be used for, is particularly important when starting to collect personal data.)
2. **Collection:** data of sufficient quality, i.e. coverage, completeness and accuracy, is routinely collected in appropriate systems and processes.

3. **Use:** effective analysis of data to inform policy, plan services and monitor health equality needs and trends over time is provided.

The review gathered information to assess the current status of equality monitoring data routinely available in Scotland for each equality characteristic (summarised in Figure 2). The results of the Data Audit may be requested from ScotPHO, and are available at: www.scotpho.org.uk/equalityhealthdataneeds, or, alternatively available on the Health Scotland Equalities website at: nshs.com/documents/6046.aspx

Figure 2: Current status of patient monitoring data in Scotland

Age	Initiation	Collection	Use
<p>Data audit: Most data sources held information on age.</p> <p>Needs and climate: There was a clear understanding of the associations between age and health and care, and the benefits of collecting age data were widely understood. The review identified no real demand for additional data collection; however, some demand for improved access to and analysis of age data was expressed.</p>			
Disability	Initiation	Collection	Use
<p>Data audit: Only a handful of data sources collected disability information and each data source was directly related to a specific disability condition (e.g. New Referrals to Prosthetic Services). There was no routine collection of information on disability that used the standard disability categories, as given in Annex B (apart from Patient Experience surveys and Scottish Health Survey).</p> <p>Needs and climate: There was a clear understanding of the associations between disability and health and care. It was recognised that better information on disability was needed to assist with planning and delivering services in the future with the demographic changes taking place in Scotland. The usefulness of disability categories for this purpose was questioned given the heterogeneity of people who may classify themselves within the same category, e.g. two people may classify themselves as having a 'physical impairment' - for one this may impact significantly on their health and care needs, while for the other it may have little impact. Other categories (e.g. 'Learning disability') that describe people with similar health and care needs are therefore considered more useful.</p>			
Ethnicity	Initiation	Collection	Use
<p>Data audit: Routine data sources were beginning to hold some information on ethnicity; however, of the sources that did include ethnicity, less than half could provide analysable data.</p> <p>Needs and climate: Understanding of the associations between ethnicity and health and care varied considerably across the NHS. The main demand for ethnicity data was to baseline the population served by Health Boards to assist with planning services and making them accessible - ethnicity data from the Census being considered too out-of-date for this purpose. There was less awareness of the potential use of ethnicity for monitoring equality in health care or outcomes.</p>			

Figure 2: Current status of patient monitoring data in Scotland (cont.)

Gender	Initiation	Collection	Use
<p>Data audit: Most data sources held information on gender; however, it was most likely to be biological sex that was recorded rather than self defined gender (gender identity refers to a person’s internal, deeply felt sense of being male or female, or something other in between. Because gender identity is internal and personally defined, it is not visible to others).¹⁵</p> <p>Needs and climate: There was a clear understanding of the associations between biological sex and health and care, and the benefits of collecting biological sex data were widely understood; less was understood about the benefits of collecting data on self assigned gender. The review identified no real demand for additional data collection; however there was a demand for improved access to and analysis of data.</p>			
Religion and belief	Initiation	Collection	Use
<p>Data audit: No routine data sources collected data on religion or belief (apart from Patient Experience surveys & SHeS). Information about a person’s religion and belief was often ascertained informally without formal data gathering by NHS staff during inpatient care, but in one Health Board using the TRAK system there was evidence of valid religious belief codes in around half of patient records.</p> <p>Needs and climate: Beyond those working directly in equality, understanding of the associations between religion and belief and health and care was limited. This meant that there was little demand expressed for data on religion and belief. Many NHS staff also raised concern about the public reaction to being asked about their religion & belief.</p>			
Sexual orientation	Initiation	Collection	Use
<p>Data audit: Only a handful of data sources had fields to record sexual orientation – all were data sources relating to sexually transmitted infections (except Patient Experience surveys and SHeS).</p> <p>Needs and climate: Beyond those working directly in equality, understanding of the associations between sexual orientation and health and care was very limited and a number of misconceptions around health behaviours and risks were evident. Suggestion of routinely collecting information on sexual orientation was often considered inappropriate, unnecessary or invasive. The main demand for data on sexual orientation was to create a baseline of the population served by Health Boards to assist with planning services (unlike the other main protected characteristics, information on sexual orientation for Scotland’s population is not provided through the Census).</p>			
Transgender identity	Initiation	Collection	Use
<p>Data audit: No routine data sources collected data on transgender identity</p> <p>Needs and climate: There was some understanding of the associations between transgender identity and health and care. There was a general consensus that routinely recording transgender identity data may not be appropriate or effective. Privacy laws are in place to protect the identity of people who have undergone gender re-assignment in the UK.¹⁶ With low numbers and an emphasis on privacy it is unlikely that robust analysis can be undertaken through routine collection of transgender identity data.</p>			

Next steps for Patient Monitoring

3.4 Based on the assessment in Figure 2, the next steps to develop data for patient monitoring are outlined below.

Age and gender

Use: Further develop analysis, presentation and use of age and gender data to monitor equality.

The collection of age and gender data has become so routine that it is often overlooked when considering how data should be analysed and what questions could be examined using age and gender data. Routine standardisation by age and gender, and the tendency to disregard age and gender breakdowns beyond the headline figures may mask inequalities that could be elucidated through more detailed analyses, e.g. better analyses of access to services or of those who did not attend appointments by age and gender could provide useful information to improve equality. Analyses should look beyond the biological affects of age and sex to provide evidence of variations in access, experience and outcomes of health for different groups in the population. A central resource should be provided to present key equality evidence for age and gender and provide links to relevant data and research. This should assist data users and service providers in accessing evidence and should provide a template for future dissemination of analyses for other protected characteristics.

Religion and belief; sexual orientation

Initiation: Further work is needed to improve understanding of the relevance of religion and belief and sexual orientation to health and care.

It is difficult to assess the needs for data development when many data users are not aware of the associations between religion and belief or sexual orientation and health and care. Many NHS staff have not given any consideration as to how such information could be used to improve services. The NHS needs to develop a wider awareness of the relevance of religion and belief and sexual orientation to health and care and dispel some of the misconceptions around health risks and behaviours and the public willingness to disclose personal information on their religion, belief or sexual orientation.

Transgender identity

Routine data collection is NOT recommended at present

Engagement with the transgender community should continue to take place through qualitative work to assess health needs and experience and to inform service improvement.

Ethnicity

Initiation: Further work is needed to disseminate what we already know about the links between ethnicity and health and care and why this is relevant in Scotland.

Although collection of ethnicity data is starting to take place across NHSScotland, how ethnicity relates to health and care still remains unclear for some staff.

Data collection: Increase completeness of ethnic group recording on Scottish Morbidity Records (SMRs)

Looking at ethnicity in Scotland involves minority populations and therefore the numbers for analysis can often be small (e.g. around 2% of the population is from non-white minority ethnic background). We need to obtain ethnicity information on a high enough proportion of patients to identify how health and care relates to ethnic group in Scotland. The last few years have seen a substantial increase in the number of Scottish Morbidity Records (SMRs) that include the patient's ethnicity for some Health Board areas. This pattern is not consistent across Scotland (Figures 3 and 4). Boards should continue work to increase the completeness of ethnic group recording in national SMRs.

Data collection: Increase completeness of ethnic group recording in general practice

In addition to collection of ethnicity in secondary care, there has also been an increase in recording of ethnicity for people registered with General Practices in Scotland. This has been driven by incentives in the Quality Outcomes Framework (QOF) (collection of ethnicity for all new patients registering with the practice) and a Directed Enhanced Service¹⁵ (collection of ethnicity for all patients in the practice). The incentivisation through the QOF was removed recently through a UK negotiation process but Scotland will continue to look for opportunity to incentivise the recording of ethnicity in Scotland through the GP contract.

Data collection: Better sharing of ethnicity data between primary and secondary care

The above drives to increase recording of ethnicity in Scotland are functioning relatively independently of one another, with no mechanisms for information collected in primary care to inform secondary care or vice versa. Health Boards should develop processes to share ethnicity data between primary care and secondary care at the point of referral and discharge.

Use: Examples of how ethnicity data can be used should be developed and shared across Health Boards

As the completeness of ethnicity data on Scottish Morbidity Records increases, there will be more opportunities for ethnicity analysis at board and Scotland level.

Disability

Initiation: Further consideration should be given to the most appropriate way of categorising information relating to disability for the analysis of equality in health and health care.

The definition of disability is so wide that careful consideration has to be given to what is being collected and what it can be used for, particularly at an aggregate level. Not all people with a disability receive disability living allowance (DLA) and although data are collected on people who fall into strictly defined impairment categories for the purpose of welfare benefits, more detailed information may be required for planning of health services and assessment of inequalities. Part 2 of this report moves away from describing people in terms of their 'impairment category' and instead proposes that information is collected on what the NHS can do to assist the patient, i.e. their needs. The section below proposes that this information should be used for aggregate analysis. Further consideration should be given to the most appropriate way of categorising information relating to disability for the analysis of equality in health and health care.

Data collection: The information described in Part 2 that relates to physical access and communication needs should be aggregated for analysis

These data will provide useful information for future planning of services and could be used to explore patterns of health and care for people with different needs, e.g. do patients who require assistance with communication receive treatment to the same timescales as those who did not require assistance?

Figure 3: Percentage of discharge episode records (SMR01) with a valid ethnic group by Health Board of Treatment; quarter ending 31st March 2012

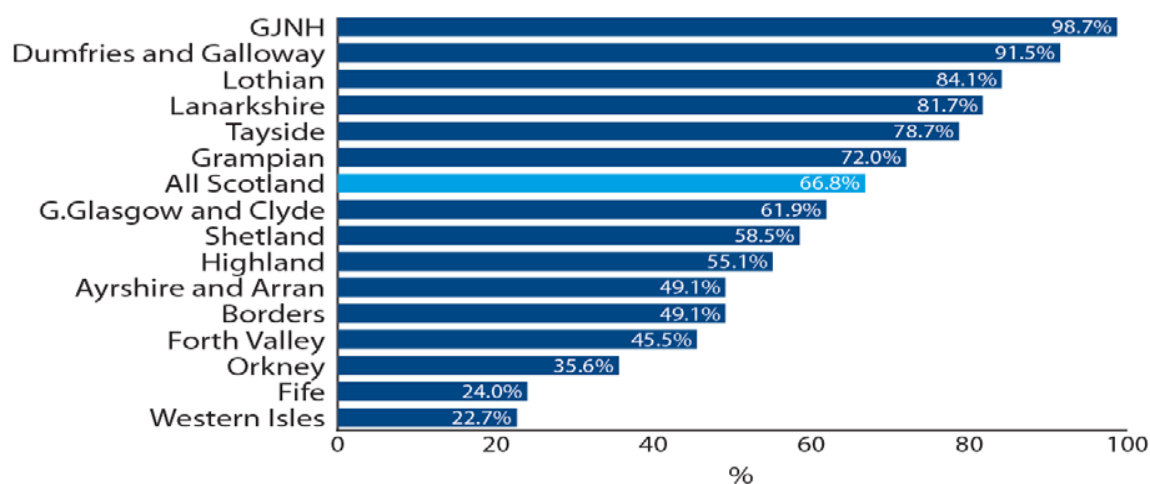
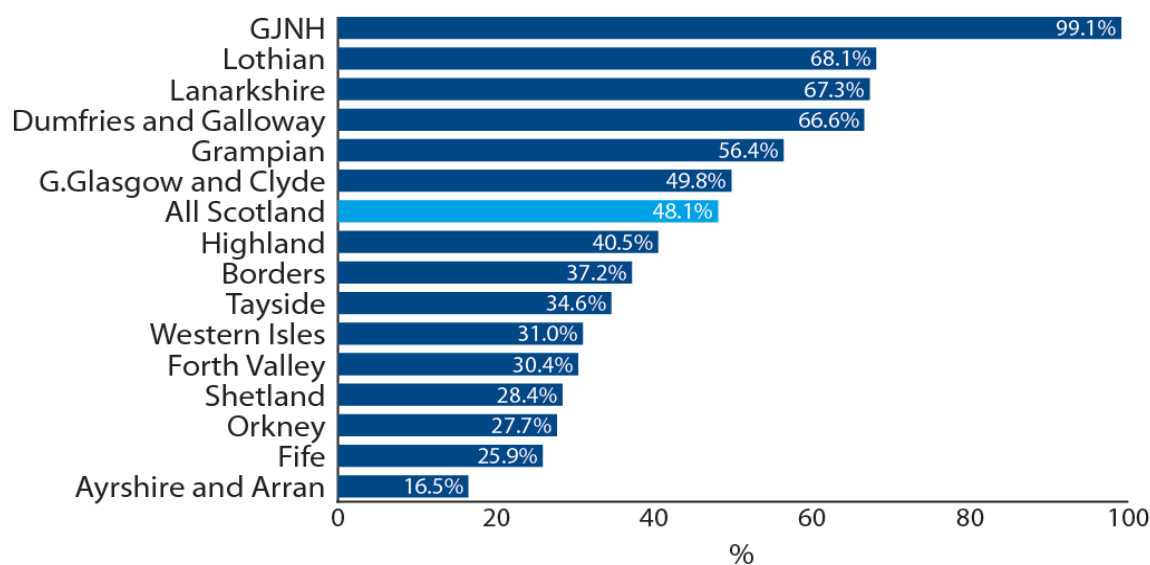


Figure 4: Percentage of new outpatient appointment records (SMR00) with a valid ethnic group by Health Board of Treatment; quarter ending 31st March 2012



Note: A new patient management system (PMS) is currently being implemented in a phased approach across five NHS Boards. There has been a noticeable impact on the submission of SMR returns. Data should therefore be interpreted with caution. Figures include as 'complete' those who declined to state their ethnic group.^b Updated figures are published twice a year.^c GJNH is the Golden Jubilee National Hospital.

^b www.isdscotland.org/Health-Topics/Equality-and-Diversity/Publications/2012-08-28/2012-08-28-EDIP-Report.pdf?77343386412

^c www.isdscotland.org/Health-Topics/Equality-and-Diversity/Publications/

Patient experience

Patient experience is assessed nationally through two main surveys in Scotland: the Scottish GP Patient Experience Survey¹⁸ and the Scottish Inpatient Patient Experience Survey.⁴

Why assess patient experience by protected characteristics?

Different groups in the population will vary in their needs, expectations and concerns for health care. It is therefore necessary to capture patient experience information by equality groups so that we can ensure that all people in Scotland are empowered to work in partnership with the NHS to plan their care and improve services.

- 3.5 The Better Together Patient Experience surveys^{4, 18, 25, 29, 30} capture information on protected characteristics, apart from transgender identity.
- 3.6 Variations in inpatient experience were examined in a further analysis of the 2010 inpatient survey²⁴ for different groups of the population. This showed that, in general, women and younger people report more negative experiences. For other protected characteristics there were mixed results, and for some the numbers responding in each category make it difficult to draw firm conclusions (particularly ethnicity and sexual orientation). Lesbian, gay and bisexual (LGB) people tended to report more negatively around arrangements for leaving hospital but similarly on most aspects of care. In general, where differences were seen, people identifying as Christian reported more positive experiences than those with other religion, agnostic or no religion.
- 3.7 Overall, people whose day-to-day activities are limited a lot because of a health problem or disability were less likely to report a positive experience, as were people who said they had translation, interpretation or communication support needs. Detailed analysis of questions by disability are also available in the report, and provide some interesting insights.
- 3.8 Where there were differences found between groups, it is not clear whether any variations in experience reflect real inter-group differences in the quality of services received, or inter-group differences in subjective factors such as expectations, perceptions or the way questions are answered, or some combination of these factors
- 3.9 These surveys provide an example of the way in which equality information can be embedded into national surveys to provide evidence for service improvement. The assessment of patient experience in Scotland should continue to collect information by all protected characteristics, whether through national surveys or local qualitative work.

Performance management

The Scottish Government has a **National Performance Framework**¹⁹ that underpins delivery of the Scottish Government's agenda and **Single Outcome Agreements**²⁰ are used to assess performance towards these at the local level. Health Boards in Scotland are also set HEAT²¹ targets. A measurement framework has been developed for NHSScotland's Healthcare Quality Strategy and this also contains a commitment to streamline the range of performance measures used across NHSScotland.

Why consider performance management by protected characteristics?

Performance management targets drive action in a number of key areas, some of which may be of varying relevance to different groups of the population. Awareness of the status of, and issues for, different groups of the population with respect to each target is necessary to assess the potential impact of such targets on different parts of the population. Differences in service access or take up of a particular initiative by different groups of the population could in fact result in inequalities increasing at the same time as a target is being met.

- 3.10 It is not proposed that every performance indicator needs to be measured separately for all groups of the population; however, the development of future national performance targets for health should include an assessment of the likely impact on people with different protected characteristics; and, where a target may impact differently, methods to monitor this should be put in place.

Understanding population health

Understanding population health **extends beyond those patients that come in contact with the NHS to cover the entire population in Scotland**

Why collect population data by protected characteristics?

Population-wide information, collected by protected characteristics, can provide a picture of health in Scotland for the entire population, not only those who come in contact with the NHS. It also provides Health Boards with a profile of the population they serve. This can assist with planning of services and population-wide health promotion activity.

- 3.11 Data sources in Scotland that provide information relevant to health for the entire population include: the Scottish Health Survey, the Census and vital statistics (e.g. births and deaths). Registrations of births and deaths only include information on age and sex; the Scottish Health Survey currently collects information on all protected characteristics (apart from transgender identity); and the Census includes all characteristics (apart from sexual orientation and transgender identity).

- 3.12 Considerable work has been undertaken in Scotland to combine information from the 2001 Census with Scottish Morbidity Records to investigate associations between ethnicity and health.²² Such data linkage work can be costly and inevitably relies on historic data that may not reflect the current situation in Scotland (e.g. 2001 Census data will not reflect the recent European migrant population in Scotland). Future linkage work with the 2011 Census information is being considered; however it is important that this work is complemented by embedding collection of equality data within health systems so that timely information can be extracted routinely for the improvement of health and care.

Key messages for aggregate analysis from Part 3

- The audit of data sources identified large variations level of data currently collected for different protected characteristics:
 - **Age and gender:** most data sources hold information on age and gender; however, it is most likely to be biological sex that is recorded rather than gender.
 - **Ethnicity:** routine data sources are beginning to hold some information on ethnicity; however, of the sources that did include ethnicity, less than half could provide analysable data.
 - **Disability and sexual orientation:** only a handful of data sources collected disability or sexual orientation. These related to a specific disability condition or sexually transmitted infections respectively.
 - **Religion and belief and transgender identity:** no routine data sources collected data on transgender identity or religion and belief.
 - **Population surveys:** surveys such as patient experience surveys and the Scottish Health Survey collect information on all protected characteristics apart from transgender identity.
- Understanding of the associations between ethnicity, sexual orientation, transgender identity, religion and belief and health and care was very limited among NHS staff, beyond those working directly in the area of equality.
- The last few years have seen a substantial increase in the number of Scottish Morbidity Records that include the patient's ethnicity for some Health Board areas; however, this pattern is not consistent across Scotland. There has also been an increase in recording of ethnicity for people registered with general practices; this has been driven by QOF) targets.
- The Scottish Care Information (SCI) Gateway exists as a formal mechanism to share ethnicity information between primary care and secondary care. SCI Gateway is a national system that integrates primary and secondary care systems.^d
- Although the long-term aim is for routine collection of information on all protected characteristics to meet legislative requirements, the next steps for data development must reflect the current position of data collection for each protected characteristic.

^d www.sci.scot.nhs.uk/products/gateway/gateway_main.htm

Recommendations for aggregate analysis	Responsibility for implementation
6. Develop further equality analysis of age and gender data and provide a central resource for access to key equality evidence for age and gender.	Information Services Division (ISD) and NHS Health Scotland (NHS HS)
7. Deliver a programme for staff and patients that increases awareness of the relevance of ethnicity, sexual orientation, religion and belief to health and care.	NHS HS and NHS Education for Scotland (NES)
<p>8. Demonstrate clear progress to increase the completeness of ethnic group recording in national Scottish Morbidity Records (SMR).</p> <p>9. Develop processes to share ethnicity data between Primary Care and Secondary Care at the point of referral and discharge.</p> <p>10. Ensure that procurement of all new IT systems for use within NHSScotland includes an equality impact assessment of the system to ensure that it has, or can easily be amended to have, fields to hold information on current and future protected characteristics (as shown in Annex B).</p>	Health Boards
<p>11. Ensure that the assessment of patient experience in Scotland continues to collect information by all protected characteristics, whether through national surveys or local qualitative work.</p> <p>12. Continue to look for opportunities to incentivise the recording of ethnicity in primary care.</p> <p>13. Ensure that the development of every national performance target for health includes an assessment of the likely impact on people with different protected characteristics; and, where a target may impact differently, ensure methods to monitor this are in place.</p>	Scottish Government (SG)

Part 4: The culture and infrastructure to support development of equality data

- 4.1 The review identified a number of areas where improvements could be made to support the development of equality data collection. These were:
- better information for staff on why and how to ask about protected characteristics
 - adequate IT systems to support collection and sharing of equality data
 - maintaining information on what equality data is available in Scotland.

Better information for staff

- 4.2 Embedding collection and use of equality data into NHSScotland will require a cultural shift; key to this is developing a clear understanding of the need for and use of protected characteristic data to improve the quality of patients' experience of and outcomes from health care.
- 4.3 Beyond age and gender, there appears to be a lack of understanding as to why NHSScotland should gather information on people's protected characteristics and many staff are uncomfortable with the thought of having to ask patients about such sensitive personal information. Evidence would suggest that patients do not have a problem with being asked about their protected characteristics.²³ However, if staff do not know why they are asking for information and how it will be used then we cannot expect them to: (a) be comfortable asking people to disclose such personal information; (b) give appropriate priority to the collection of accurate information from all patients; and (c) be able to explain to patients why the information is being requested.
- 4.4 In addition to increasing awareness of the relevance of equality data to health and care, information should be developed to answer the questions that NHS staff may have about equality data. Although populations served by each Health Board will vary, the messages about why and how to collect data for each protected characteristic will be consistent and therefore resources should be developed centrally and made available to Health Boards. Some boards already have useful leaflets to provide information for staff and these should be used to develop consistent information. In the longer term, training on equality data should be incorporated into equality and diversity training for NHS staff.

Adequate IT systems

- 4.5 It is beyond the scope of this review to make recommendations about specific changes to IT systems. Although systems will vary between, and sometimes

within Health Boards, general provision should be made to ‘future proof’ IT systems and thus limit any barrier they may pose to future development of equality data. Procurement of new IT systems for use within NHSScotland should include an equality impact assessment of the system to ensure that it has, or can easily be amended to have, fields to hold information on all protected characteristics (as shown in [Annex B](#)).

Keeping stock of equality health data

- 4.6 Many of those consulted as part of the review found it difficult to assess what equality health data were available in Scotland and where to find them. Conducting an audit of equality data takes considerable time and resources and the information only remains current for a very short period of time. The audit undertaken for this review was a repeat of a similar exercise undertaken a few years ago. It is recommended that the main organisations that manage health data in Scotland (i.e. Information Services Division, Health Protection Scotland and the Scottish Government) maintain a record of whether or not fields exist to hold equality data, and whether or not the data within these are sufficient for equality analysis, for all their routine national health data sources. This information should be made available annually and as the number of sources including equality data increases, then appropriate mechanisms for data users to search and locate relevant data should be developed.

Recommendations for improving culture and infrastructure	
14. Work with Health Boards to pull together consistent and practical resources to support staff with the collection and analysis of equality data; and in the longer term integrate staff training on equality data into equality and diversity training for NHS staff.	NHS HS, NES
15. Maintain, and make available annually, a record of whether or not fields exist within routine national health data sources to hold equality data, and (subject to availability of resources to do this) report on whether the data within these are sufficient for equality analysis.	ISD, Health Protection Scotland (HPS) and SG

Conclusion

- 5.1 Considerable work has taken place in Scotland to improve the health of different population groups and to incorporate individual needs and preferences into the provision of health care in Scotland. However, progress to develop equality health data in Scotland remains relatively slow. We do not yet have sufficient information to identify where some inequalities may lie or to demonstrate what we are doing to reduce them and to meet our public sector duties. The review of data needs has taken stock of what progress has been made so far and where data gaps remain. This report presents clear national priorities to drive forward equality data development:
1. To directly improve individual care at the point of service delivery
 2. For aggregate analyses to help identify patterns in prevalence, access, experience and outcomes for different groups of the population
- 5.2 This report sets out a number of recommendations for equality data development in Scotland. Progress against these should be reviewed by the Taskforce on Health Inequalities, when new proposals for data development should be considered. A complete list of all the recommendations is provided in the summary of this report.

Addendum: items for further consideration

- 6.1 In comments received on the report draft during a limited consultation, it was suggested that analysis by socioeconomic status (SES) should be explored for equity in access, utilisation and quality of healthcare, and health status.
- 6.2 Although postcode (and the associated Scottish Index of Multiple Deprivation Score) may be a useful proxy for SES at national level, it is an area-based measure which misallocates a large proportion of the population into inappropriate socio-economic groups. Collection of data relating to an individual patient's economic and other social circumstances, including social class, income and education (as determinants of health inequality) is therefore justified as well as data relating to protected characteristics.
- 6.3 Comments also suggested exploring the potential for future partnership working with local authorities and Community Healthcare Partnerships (CHPs) on the potential for development of a public sector equality dataset and combined public sector equality outcomes. This would aim to maximise the limited capacity available for data development in both the NHS and local authorities.

Further recommendations arising from consultation:

Action for the Scottish Government and NHS Health Scotland:

16. Explore the relationship between socioeconomic status and protected characteristics and explore whether it is possible to collect individual measures of socioeconomic status in routine health data collection systems. This would support the implementation of Equally Well recommendation 76: 'The Government, with advice from relevant experts, should work towards better information to describe health inequalities based on socio-economic status, for example looking at low income of individuals, not just at average income of people living in a small area.'
17. Explore the potential for streamlining equality data collection processes for collection, analysis and application across the public sector.

Annex A: Review objectives, scope and management

Review project group membership

Paul Barton	(Programme Manager (formerly Head of Equalities Development), NHS HS)
Andrew Bruce	(Health Improvement & Health Inequalities Policy, Scottish Government)
Pauline Craig	(Head of Equality, NHS HS)
Elaine Drennan	(Senior Statistician, SG) (Chair)
Phyllis Easton	(Health Intelligence Manager, NHS Tayside)
Colin Fischbacher	(Consultant in Public Health Medicine, ISD)
David Gordon	(Former Head of Public Health Observatory, NHS HS)
Lynn Graham	(Equalities Intelligence Manager, NHS HS) (Project Manager)
Joan Jamieson	(Equality and Diversity Information, Programme Manager, ISD)
Gerry McCartney	(Head of Public Health Observatory, NHS HS)
Andrew Millard	(Equalities Intelligence Manager, NHS HS)
Alastair Pringle	(Head of Patient Focus & Equalities, SG)

Review objectives

- to detail the current availability of equality health data in Scotland for routinely collected data sources
- to identify gaps in terms of key uses and to identify the data collection and process changes required to fill these gaps
- to make recommendations about the prioritisation of the identified data gaps
- to assess the feasibility of data collection and process changes in terms of NHS infrastructure and patient/population readiness
- to provide recommendations, with milestones, for equality data development
- to submit a review report to Equally Well and the [successor group to] the Mutuality, Equality and Human Rights Board (MEHRB).

Review scope and exclusions

The review will:

- be limited to covering needs for health data from health data sources only. Although it is acknowledged that data on non-health areas, e.g. education, income and crime, by equality group is necessary to inform our understanding of health inequalities, it is considered too large an undertaking to review all social and health data in Scotland at this time.^e

^e However future partnership work is signposted on equality data improvement across the public sector suggested by comments on this report at the draft stage.

- be limited to the data relating to the protected characteristics of: gender, ethnicity, age, disability, religion and belief, sexual orientation and transgender identity, while acknowledging the impact of socioeconomic inequalities in relation to these.
- utilise existing guidance on definitions and questions, it will not provide new definitions of protected characteristics or new questions for equality assessment.
- focus on NHS and Government data required for both national and local purposes but only that which can be collected through nationwide systems or processes.

Annex B: NHSScotland Equalities Monitoring Form

(These questions follow as far as possible the core and harmonised survey questions²⁶ developed for the NHS by ISD)

Q1. Are you male or female? (Please put X in **one** box only.)

Male

Female

Prefer not to answer

Q2. Do you have a physical or mental health condition or illness lasting or expected to last 12 months or more? (Please put X in **one** box only.)

Yes Don't know

No Prefer not to answer

Q3. If yes, does your condition or illness reduce your ability to carry out day-to-day activities? (Please put X in **one** box only.)

Yes, a lot Yes, a little

No, not at all Prefer not to answer

Q4. Does this condition or illness affect you in any of the following areas? (Please X **all** that apply.)

Vision (for example blindness or partial sight)

Hearing (for example deafness or partial hearing)

Mobility (for example walking short distances or climbing stairs)

NHSScotland: Equalities Monitoring Form (continued)

Dexterity (for example lifting or carrying objects, using a keyboard)

Learning or understanding or concentrating

Memory

Mental health

A long-term illness (such as diabetes, cancer, HIV, heart disease or epilepsy)

Stamina or breathing or fatigue

Socially or behaviourally (for example associated with autism, attention deficit disorder or Asperger's syndrome)

Other – please write in

None of the above

Prefer not to answer

Q5. What is your ethnic group? (Choose **one** section from A to F then **X one** box which best describes your ethnic group or background.)

A. White

Scottish Other British Irish

Gypsy/Traveller Polish

Other white ethnic group, (please write in) _____

B. Mixed or multiple ethnic groups

Any mixed or multiple ethnic groups (please write in)

NHSScotland: Equalities Monitoring Form (continued)

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

- African, African Scottish or African British
- Other, please write in _____

E. Caribbean or Black

- Caribbean, Caribbean Scottish or Caribbean British
- Black, Black Scottish or Black British
- Other (please write in) _____

F. Other ethnic group

- Arab, Arab Scottish or Arab British
- Other (please write in) _____

- Prefer not to answer

Q7. What religion, religious denomination or body do you belong to?
 (Please put X in **one** box only.)

- | | | | | | |
|----------------------|--------------------------|------------------------------|--------------------------|----------------|--------------------------|
| None | <input type="checkbox"/> | Church of Scotland | <input type="checkbox"/> | Roman Catholic | <input type="checkbox"/> |
| Other Christian | <input type="checkbox"/> | Muslim | <input type="checkbox"/> | Buddhist | <input type="checkbox"/> |
| Sikh | <input type="checkbox"/> | Jewish | <input type="checkbox"/> | Hindu | <input type="checkbox"/> |
| Pagan | <input type="checkbox"/> | Other (please specify) _____ | | | |
| Prefer not to answer | <input type="checkbox"/> | | | | |

NHSScotland: Equalities Monitoring Form (continued)

Q8. Which of the following options best describes how you think of yourself? (Please put X in **one** box only)

Heterosexual/straight	<input type="checkbox"/>	Gay/Lesbian	<input type="checkbox"/>
Bisexual	<input type="checkbox"/>	Other	<input type="checkbox"/>
Prefer not to answer	<input type="checkbox"/>		

Q9. What was your age last birthday?

_____ Years

Prefer not to answer

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