Measuring use of health services by equality group.
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Summary

Reducing health inequalities is a major national priority for Scotland. Inequalities can affect a wide range of groups, including people of different age, gender, ethnicity, religion, sexual orientation, gender identity and level of disability. Without good data on inequalities in health it is impossible to plan and prioritise effective action or to monitor progress towards a more equal society.

This report describes the current availability of equality data in routine national administrative health datasets in Scotland that are used for a number of secondary uses such as planning, performance monitoring, benchmarking and research. It provides information about what data are collected and how complete they are, discusses possible data quality issues and gives examples of how routine health service data can be used to measure differences between equality groups. It also highlights and explains the gaps in equality data and explores ways in which these could be addressed. Where possible, we have also drawn upon evidence from other sources.

The key findings of this report are:

- Data on age and sex are routinely collected in national administrative health datasets and are of a high quality. They are widely used, but there is still scope to develop their use in routine ISD releases.
- Data on ethnicity are routinely collected in national administrative health datasets, but are of mixed quality and completeness. Use of these data has therefore been limited to date, but there are ways in which the existing data could be augmented and used, and ways in which recording could be improved.
- Data on religion, sexual orientation, gender identity and disability are not usually routinely collected in national administrative health datasets. There are a number of challenges around the collection of these data, including sensitivities around asking for (and providing) information about sexual orientation and gender identity and difficulties defining disability in a consistent and meaningful way. Data on religion however is likely to be collected at point of care for a number of services and could potentially be sourced from local NHS Board systems.

Alongside the report, we have published a new web-based ISD Equality Evidence Finder\(^1\) which is intended to complement the broader Scottish Government Equality Evidence Finder\(^2\) and make it easier for users to establish what equality data are available for routine health datasets and how they can be accessed.

We hope that this report, the evidence finder, and further work ISD aims to undertake to build upon the work presented in this report are useful for a range of stakeholders.
1. Introduction

1.1 Report purpose and scope

The purpose of this report is to:

- Set the scene in terms of the availability, completeness and suitability for analysis of equality data in administrative health datasets;
- Provide comparisons of health service use by equality groups where suitable data are available (referencing existing work and presenting new analysis);
- Outline the next steps to develop and improve access to and use of equality data in routine health datasets.

This report focuses on the following equality groups: age; disability; ethnicity/race; gender/sex; religion and belief; sexual orientation; and gender identity. It is primarily concerned with measuring use of health services at Scotland level using routine administrative health datasets held by ISD.

We recognise that use of services is a mixed measure, influenced by variations in “need” (due to different risk or prevalence of health conditions in equality groups), “demand”, “access” and “supply” (possibly influenced by many factors, including for example differences in willingness to engage with some services, the availability of suitable services for some equality groups or other challenges such as language barriers). It is beyond the scope of this report to present a comprehensive assessment of need or demand for, access to and supply of multiple health services by multiple equality groups, but we hope that the information we present will be helpful for those wishing to carry out this kind of work.

We also recognise that there are numerous local collections of equality data of varying scope and scale collected for a variety of purposes by different organisations, but this report is focussed on national level data collection and analysis.

Alongside this report, ISD is releasing a new ISD Equality Evidence Finder\textsuperscript{1} to provide information about what equality data are available in routine administrative health datasets and how they can be used. This is intended to complement the Scottish Government Equality Evidence Finder\textsuperscript{2}.

1.2 Background

There is a need to collect equality data both to directly improve the care and experience of individual service users and to provide aggregated evidence about groups of patients with the same or similar characteristics. This aggregated evidence is necessary to focus on particular groups, to compare different groups, to assess and monitor inequality and for needs assessments to inform service improvement and service planning.
The UK Equality Act 2010³ includes an Equality Duty for public sector organisations to collect equality data and to provide evidence against agreed equality outcomes. This means that as well as collecting equality data to improve the individual care of patients, there is also a legislative requirement for NHS Boards to collect and use equality data about their service users. In order to help NHS Boards achieve this, the Scottish Government has published Equality Monitoring Guidance (2012)⁴.

The role of ISD in this context is to provide meaningful equality information for health datasets at national level, both by supporting and improving the collection of consistent data by NHS Boards and by reporting and interpreting the data available. ISD reports aggregated (grouped) data, which does not identify individuals. Small numbers of people in a particular group are not included in reporting, to protect the confidentiality of individual service users. ISD continues to strive to include relevant and meaningful analysis of, or reference to, equality and health inequality in routine publications. In 2016/17, this was achieved for over 45% of ISD’s releases.

A range of organisations and networks have undertaken national level work on equality groups and health. In particular, the Scottish Public Health Observatory (ScotPHO)⁵ maintains information about equality groups, which highlights a range of differences. More information about this is available in Appendix A.

### 1.3 Availability and completeness of equality data

ISD sources national standardised datasets from NHS administrative systems to reduce the burden of data collection and analysis on the territorial NHS Boards and to enable consistent national reporting and comparison across Scotland. The availability, completeness and quality of equality data in routine health datasets are very variable.

Good quality data on age and sex/gender have been widely available since the inception of the routine health datasets in the 1960s and they are extensively used.

Collection of data on ethnic group in health datasets has increased considerably in recent years and this report explores approaches that could enable more routine use and reporting of these data.

There remains a dearth of data in routine health datasets on disability, sexual orientation, gender identity and religion/belief. In most cases, these data are not currently included at all in the submissions of data made by NHS Boards to ISD, although a more recently established data collection scheme such as the Accident and Emergency (A&E) dataset does contain fields for religion and sexual orientation and completeness of the information submitted for these equality groups is slowly starting to increase. This report explores whether data on some equality groups (for example religion) could be sourced from NHS Board patient management systems and collated centrally.

More detailed information about what is collected for each equality group is presented in sections 2–6 of this report and is also available in the ISD Equality Evidence Finder¹.
1.4 Challenges around collecting and using equality data

There are a number of challenges around the collection of equality data in administrative health datasets. The data are usually entered by staff on behalf of the service user and staff may be reluctant to ask for details about potentially sensitive personal characteristics. This might mean that they either do not enter any data or, in some cases, it may mean that the data entered are based on assumptions about the service user or that groups of what appear to be “similar” service users are all automatically coded in the same way. Where service users are directly providing the data, some may be unwilling to share potentially sensitive personal information about themselves. These issues are further exacerbated if it is not clear why the NHS is collecting this information and how it will be used, particularly where the data relate to relatively small numbers of people in minority groups.

Evidence\(^6,7\) suggests that missing or incomplete data are likely to be disproportionately higher for some equality groups. This could mean that comparisons between groups are inaccurate or misleading unless they are adjusted to take this into account. It is however difficult to quantify and adjust for this. A number of approaches have been used to deal with missing data, but all have limitations. This is discussed in more detail for ethnicity data in Section 3.1 of this report.

Another point worth noting is that focusing on particular equality groups in isolation risks over-simplifying classification or stereotyping people with apparently similar characteristics, without taking into account the influences of other characteristics of the people in these groups. In this report we have tried to address this in part by using age-sex standardised rates when comparing ethnic groups, so that the different age and sex profiles of each ethnic group are taken into account. However, there are still likely to be other differences between and within the groups being compared. A full multi-factorial analysis is the best way to assess which factors or characteristics are most strongly related to health outcomes, but this is not something that was within the scope of the work for this report.

It is also worth remembering that the number of people recorded for some minority groups are, or would be, very small and that this limits meaningful and robust comparisons based on these groups. Universal collection of data in administrative datasets may not always be the best approach for some minority groups. It may sometimes be more appropriate and beneficial to undertake bespoke, targeted work focusing on the issues or services relevant to the population of interest.

Finally, it is often difficult to source accurate and timely population counts (denominators) for equality groups, which means that it can be difficult to calculate robust rates to be used for comparisons or benchmarking.

1.5 Structure of this report

This report has been structured around each of the selected equality groups. In each section, we provide an overview of the availability of equality data in routine administrative health datasets, give information about the equality group in the underlying population and provide commentary about what analysis is possible and any issues that may impact on the accuracy
or reliability of analysis. Where data are available, we have included some interesting examples based on existing evidence and new analysis, but this is not intended to be a comprehensive review of all the existing evidence.
2. Age and Sex/Gender

2.1 Data availability and completeness

Data on age and sex are routinely collected in administrative health datasets. The quality and completeness of the data are high, with almost all records in most administrative health datasets including a valid date of birth and biological sex.

The availability of full date of birth means that analysis is possible for multiple types of age groupings.

Most administrative datasets will hold a record of biological sex, as assigned by health professionals, usually at the time of birth. A person’s perception of their gender (their gender identity) may not match the biological sex they were assigned at birth, but this will not always be captured in an administrative health record. In administrative health datasets, there is also currently no way of recording the gender of people who identify in a way other than male or female (that is, non-binary people). Where gender, rather than biological sex assigned at birth, has been recorded, it is worth noting that this may not always reflect the gender identity of trans patients. This may depend on number of factors, including whether gender has been entered by the health professional or by the service user, and on whether a trans service user feels able to be open about their gender identity with the relevant health professional.

Age and sex have been consistently collected since the inception of most administrative health datasets, so robust trend data are usually available.

2.2 Notes on underlying population profile

- Scotland’s population is ageing (Chart 1).

- The number of people aged over 40 years has increased year on year for the past twenty years whilst the number of people aged under 40 years has fallen and then plateaued (Chart 2).

- There have been consistently higher numbers of elderly women than men aged 70+ years, but the number of men in these age groups is increasing more steeply over time than it is for women of the same age (Charts 2 and 3). This reflects the considerable improvements in life expectancy for males over the past twenty years.

- The overall population of Scotland is projected to rise over the next twenty years. These projected increases are driven partly by a higher number of projected births than deaths, but mainly by assuming continued net migration into Scotland. The number of people of pensionable age is projected to decrease slightly in the short term and then increase fairly consistently during this period.
Chart 1 - Change in population age profile over time - Scotland 1996 vs 2015

Source: NRS population estimates

Chart 2 - Trends in population, by age and gender - Scotland 1996 to 2015

Source: NRS population estimates
2.3 Who is using health services?

Statistics using age and sex are routinely included in ISD publications and a wide range of information is available. Below is a selection of key points for some of the main types of health services about which ISD holds administrative data and releases routine statistics.

- A range of different types of breakdowns by age and sex are available in routine ISD releases of data on hospital inpatient and day case activity and outpatient activity. For example:
  - The highest rates of outpatient attendance are for people aged 75-84 years; and the highest rates of people not attending appointments ("did not attend", DNA) are for young people aged 16-24 years, particularly young men.
  - The highest rates of admission to hospital are for people aged 85+ years.
  - Emergency admissions for older people have been increasing in the long term, but this appears to have stabilised in recent years.
  - Admissions of children are increasing over time, driven mainly by an increase in emergency admissions and transfers. Boys are more often admitted as an emergency than girls, which is likely to reflect their greater risk of unintentional injury.
  - Alcohol-related hospital admissions are around three times more common in males compared to females. Alcohol-related admission rates increase with age, tailing off in those aged 65 years (due to the lower life expectancy of people with alcohol dependency or addiction).
Measuring use of health services by equality group.

- **Drug-related hospital admissions** are around two times more common in males compared to females. Currently, drug related admission rates are highest in people aged 35-39 years.

- **Hospital admissions for heart disease** are around two times more common in males compared to females. In the past ten years, the rate of admissions has, in relative terms, decreased more for females than it has for males; and, in relative terms, decreased more for those aged under 75 years than for those aged 75+ years.

- **Hospital admission rates for stroke** are slightly higher for males compared to females and the rate for males has increased more steeply over the past 10 years than the rate for females. Considerably higher numbers of elderly females are however admitted because there are more elderly females in the population.

- ISD statistics on **who uses Emergency Departments in Scotland** show that the very young and the very elderly are the most likely to attend and that men have higher rates of attendance than women.

- In general, the number of people with cancer increases with age. This is because the risks of developing cancer increase with age, elderly people with cancer tend to survive for longer than in the past and there are increasing numbers of elderly people in the underlying population. The impact of age and sex on development of cancers, treatment and survival is dependent on the type of cancer concerned. **Cancer statistics** released by ISD include information for all cancers combined and for each of the most common types of cancer.

- The mean (average) age of patients admitted to hospital with a **mental health or behavioural diagnosis** is 52 years (psychiatric specialties) and 60 years (non-psychiatric specialties). This mean age is driven both by variations in risk in different age groups and the number of people in each age group. Over the past twenty years, there has been an increase in young people aged 25-39 years admitted to psychiatric specialties with a diagnosis relating to use of psychoactive substances, schizophrenia or mood disorders. The majority of admissions for people aged 75+ years are for dementia and most are admitted to non-psychiatric specialties.

- ISD **maternity statistics** show that the average age of women giving birth is increasing: the number of babies born to women aged over 35 years has increased threefold over the past forty years. Meanwhile, teenage pregnancies are decreasing over time.

- According to ISD statistics on **GP consultations**, a higher rate and number of females visit their GP practice, except in the very youngest and oldest age groups where the rate for males is slightly higher. This seems to have been a consistent pattern over time.

In the following sections, we present new analysis, focussing on the age-sex profiles of people admitted to hospital as inpatients or day cases and people having outpatient appointments over the past twenty years. We also present new analysis focussing on the age-sex profiles of people with heart disease and dementia over the past 20 years.
2.4 Focus: Hospital Inpatients/Day Cases and Outpatients 1996-2015

The average age of people attending hospital as inpatients or day cases and as outpatients has increased considerably over the past twenty years (Chart 4). This is likely to reflect higher use of health services by older people in an ageing population. On average, women being admitted to hospital as inpatients or day cases have been consistently older than males, although this gap is narrowing over time. The average age of males having outpatient appointments has now overtaken that of women. This may be partly driven by increasing numbers of younger women having outpatient appointments (Charts 5 and 6).

Chart 4 - Average age of patients admitted to hospital and having outpatient appointments – Scotland 1996 to 2015

Source: SMR01 (all episodes) and SMR00 (all appointments)

We calculated rates per unit population of outpatient appointments and hospital admissions for each sex and age group in each year so that we could assess changes over time, over and above the changes caused by the ageing population.
Chart 5 shows that over the past twenty years, rates of recorded outpatient appointments have increased considerably for all age groups. Some of these increases are likely to be due to improvements and changes in recording and submission of data by NHS Boards however, so they should not be entirely attributed to increased use of services. Rates of outpatient appointments have increased most dramatically for elderly people aged 70-89 years. Rates of outpatient appointments have generally increased to a similar extent for males and females in each age group, except for young women aged 25-39 years (for whom larger increases are observed than for men of the same age) and for elderly people (for whom slightly larger increases are observed for men than for women). Further analysis confirms that these have been consistent long term increases, but the reasons for these differences are unclear.

**Chart 5 - Percentage change in rate per 1,000 population of outpatient appointments by age and sex – Scotland 1996 vs 2015**

<table>
<thead>
<tr>
<th>Age group (years)</th>
<th>% change</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;16y</td>
<td></td>
</tr>
<tr>
<td>16-24y</td>
<td></td>
</tr>
<tr>
<td>25-39y</td>
<td></td>
</tr>
<tr>
<td>40-54y</td>
<td></td>
</tr>
<tr>
<td>55-69y</td>
<td></td>
</tr>
<tr>
<td>70-84y</td>
<td></td>
</tr>
<tr>
<td>85y+</td>
<td></td>
</tr>
<tr>
<td>80-84y</td>
<td></td>
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<tr>
<td>85-89y</td>
<td></td>
</tr>
<tr>
<td>90-94y</td>
<td></td>
</tr>
<tr>
<td>95-99y</td>
<td></td>
</tr>
</tbody>
</table>

Source: SMR00 (all appointments)
(1997 used as a reference year for this chart as there were substantial changes in recording and submission of outpatient appointment data during 1996)

*An increase of 100% means that rates have doubled.*

*An increase of 200% means that rates have tripled.*

*A decrease of 50% (~50% on chart) means that rates have halved.*

Additional analysis focussing on new outpatient appointments (and therefore excluding return or follow-up appointments) showed similar patterns, except that the differences between males and females are more pronounced and that rates of new outpatient appointments for men and women aged under 25 years have actually decreased slightly (by 5-10%) during this period.
Over the past twenty years, rates of hospital admissions have increased for all age groups except for people aged 16-39 years, where the largest decreases are observed for young men (Chart 6). Further analysis confirms that these have been steady trends over time. Some of the increases observed may be due to changes in the management of patient stays, as well as changes in recording and submission of data over time. The steepest increases in rates of hospital admissions are observed for elderly people, reflecting the fact that older people tend to have a high number of other illnesses and increasingly complex social care needs that require hospitalisation. Rates of admission to hospital increase steadily with age, except for the most elderly males where a decrease is observed. Rates of hospital admissions have increased more for females than for males in all age groups.

Chart 6 - Percentage change in rate per 1,000 population of admissions to hospital by age and sex – Scotland 1996 vs 2015

Source: SMR01 (all episodes)
Women aged 16-54 years were more likely than men to have an outpatient appointment or to have been admitted to hospital in 2015 (Charts 7 and 8). Further analysis reveals that this gap appears to be widening over time for those aged 16-39 years and stable for those aged 40-69 years. Males aged over 70 years and under 16 years were more likely than females of the same age to have had an outpatient appointment or to have been admitted to hospital in 2015. These gaps appear to have narrowed over the past twenty years, except for the 85+ age group where the gap between men and women appears to be widening.

**Chart 7 - Male:Female ratio of outpatient appointment rates – Scotland 2015**

Source: SMR00 (all appointments)

**Chart 8 - Male:Female ratio of hospital admission rates – Scotland 2015**

Source: SMR01 (all episodes)

A ratio of 1 means that men and women have equivalent rates. A ratio of greater than 1 means that men have higher rates than women. A ratio of less than 1 means that women have higher rates than men.
2.5 Focus: Heart Disease 1996-2015

Men aged 40+ years have higher rates of hospital admission and death from heart disease than women of the same age (Chart 9). The largest difference between men and women is for deaths from heart disease amongst those aged 40-54 years. Further analysis reveals that amongst those aged 40-69 years, the gaps between men and women appear to be narrowing over time for hospital admissions and widening for deaths. Amongst those aged 70+ years, the gaps between men and women appear to be relatively stable.

Chart 9 - Male:Female ratio of heart disease hospital admission and death rates – Scotland 2015

Source: NRS Deaths (registrations) and SMR01 (episodes)

A ratio of 1 means that men and women have equivalent rates.
A ratio of greater than 1 means that men have higher rates than women.
A ratio of less than 1 means that women have higher rates than men.
Deaths from heart disease have decreased considerably for people aged 40+ years over the past twenty years and similar decreases are seen for both men and women (Chart 10). This reflects improved management and treatment of heart disease during this period and reduced exposure to risk factors such as smoking\textsuperscript{20}. Meanwhile, rates of hospital admission for heart disease have increased for elderly people. These increases might be partly due to increased diagnosis as more sensitive tests have become available during this period, but also because older people with heart disease are surviving longer and therefore require more treatment and hospitalisation\textsuperscript{21}.

**Chart 10 - Percentage change in rate per 1,000 population of heart disease deaths and admissions to hospital by age and sex (aged 40+ years) – Scotland 1996 vs 2015**

Source: NRS Deaths (registrations) and SMR01 (episodes)

An increase of 100\% means that rates have doubled.
A decrease of 50\% (-50\% on chart) means that rates have halved.
2.6  Focus: Dementia 1997-2015

The higher number of elderly women in the population mean that there are considerably higher numbers of dementia related hospital admissions and deaths for elderly women than for men. However, men aged 70+ years have slightly higher rates per 1,000 population for dementia related hospital admissions than women of the same age (Chart 11). Further analysis reveals that there has been fluctuation over time, but that the gap in admissions between men and women aged 70-84 years may be widening if the pattern observed in recent years continues. Men and women aged 70-84 years have very similar rates of death from dementia, whilst relatively more women aged 85+ years died from dementia in 2015 than men in the same age group. These differences appear to be stable over time.

Chart 11 - Male:Female ratio of dementia hospital admission and death rates – Scotland 2015

Source: NRS Deaths (registrations) and SMR01/SMR04 (episodes)

A ratio of 1 means that men and women have equivalent rates.
A ratio of greater than 1 means that men have higher rates than women.
A ratio of less than 1 means that women have higher rates than men.
Recorded deaths from dementia have increased considerably for people aged 70+ years over the past twenty years and similar increases are seen for both men and women (Chart 12). Further analysis confirms that these have been steady increases over time. This might be partly due to increased recording of dementia as a cause of death on death registrations. Dementia is more likely to be an underlying, rather than main, cause of death and guidance around recording of diagnoses for additional and underlying causes of deaths has changed over time. It is however also likely to reflect a true increase in prevalence in an ageing population for whom survival from conditions such as heart disease and stroke is increasing over time. Meanwhile rates of dementia related hospital admissions have steadily decreased over the past twenty years, particularly psychiatric admissions and particularly for females. This may be partly due to the fact that the number of elderly people in the underlying population is increasing, masking increases in the absolute numbers of people admitted with dementia. It also possibly reflects changing approaches to services, where elderly people with dementia are increasingly treated in the community (such as in specialist care homes) rather than in psychiatric hospitals.

**Chart 12 - Percentage change in rate per 1,000 population of dementia related deaths and admissions to hospital by age and sex (aged 70+ years) – Scotland 1997 vs 2015**

Source: NRS Deaths (registrations) and SMR01/SMR04 (episodes) (1997 used as a reference year for this chart, because recording of dementia diagnoses pre 1997 is not consistent with current practices)

An increase of 100% means that rates have doubled.
A decrease of 50% (-50% on chart) means that rates have halved.
3. Ethnicity/Race

3.1 Data availability and completeness

The completeness of data on ethnicity in many of the hospital-based administrative health datasets has increased considerably in recent years, following sustained effort to improve and increase recording by NHS Boards, ISD and Health Scotland. The aim is to have a valid recording of ethnicity for every patient.

Since 2010, ISD has released an update every six months showing progress of ethnicity recording for hospital inpatient and day case admissions and for outpatient activity by each NHS Board area.22 While the increases in completeness are positive, they have not been seen across all NHS Board areas and this means that robust analysis at national level is still not always possible for these (and other) health datasets.

Ethnicity is not a fixed characteristic, nor is it necessarily consistently defined. It could relate to a variety of factors including nationality, culture, heritage and skin colour; and people’s perception of their ethnicity may be influenced by a range of social and political circumstances, which may change in different contexts and over time. This complicates efforts to assess the accuracy of ethnicity data and to interpret comparisons between data sources.

The quality and reliability of ethnicity recording in Scottish administrative health datasets is untested. Some parts of Scotland appear to have disproportionately high rates of particular ethnic groups (usually “White Scottish”, “White British” or “Other Ethnic Group”) or higher than average rates of “refusals” (where the patient is recorded as having refused to provide their ethnicity). These types of inconsistencies between NHS Board areas and even between services within NHS Board areas suggest underlying data quality issues, but this has not been fully explored. The extent to which missing or invalid ethnicity recording is an issue varies by NHS Board and dataset. Appendix C includes a breakdown of missing/invalid recording of ethnicity for hospital admissions, outpatient appointments and A&E attendances, by NHS Board area.

For some services, there is a particular focus on collecting ethnicity data. For example, Health Protection Scotland23 follow up with diagnosing clinicians to ensure that ethnicity is accurately recorded for patients with human immunodeficiency virus (HIV). These data have been used for internal monitoring to-date, but there is potential to use them in published reporting in future.

Ethnic group has been collected on death registration records since 2012 and the completeness of valid ethnicity recording is high (around 95% for registrations made during 2015 and 2016). However, there are some concerns about the quality of recording, due at least in part to the fact that the ethnicity recorded on death registrations is provided by a third party. Comparison with self-reported census records7 revealed higher instances of mis-matches between the ethnicity recorded in the census and ethnicity recorded on the death registration.
for non-“White Scottish” people and that there are higher proportions of missing ethnicities in death registrations for people from non-"White Scottish" groups. This is consistent with what has been observed during analysis of ethnicity recording in the English Cancer Registry\textsuperscript{6}.

Death registration data are linked routinely to hospital activity data in ISD. As part of the work for this report, we carried out analysis comparing the ethnicity recorded on death registrations with ethnicity recorded on hospital activity records. This showed that around two thirds of death registrations did not have exactly the same ethnicity recording in hospital activity data. The mis-matches were mainly related or similar ethnicities, but there were also some more unexpected differences. The results of this analysis are presented in Appendix D.

A number of approaches can be used to deal with missing records\textsuperscript{6}: randomly assigning cases with missing ethnicity according to the distribution of valid ethnicities observed in the dataset or in a reference dataset; assigning all cases with missing ethnicity to the largest group (“White”); or randomly assigning cases with missing ethnicity according to a distribution that favours minority ethnic groups. All of these approaches have limitations. In particular, none of these approaches accurately adjusts for what is likely to be an uneven distribution in missing values across ethnic groups\textsuperscript{6,7}. Further work needs to be done to accurately quantify the impact of this and adjust analysis accordingly.

Some research studies have used surname recognition software, such as Onolytics\textsuperscript{24} (previously known as Onomap) or Nam Pehchan\textsuperscript{25} to assign ethnic group or religion. Onolytics has also been used by Health Protection Scotland\textsuperscript{23} to try to differentiate between “British” and “non-British” patients with blood borne viruses\textsuperscript{26}. This sort of approach has limitations, for example: for people of mixed ethnicity; people who may identify as an ethnicity different from their heritage such as non-recent immigrants; and for women who have changed their name after marriage. There is also evidence that these approaches work better for names associated with some ethnic groups than others\textsuperscript{27}. They should, however, be able to assign most ethnicities more accurately than a random allocation and their more routine use is worthy of further exploration.

In future, it may be possible to source ethnicity recording for primary care patients from the Scottish Primary Care Information Resource (SPIRE)\textsuperscript{28}, which is being rolled out across Scotland from May 2017. Analysis of SPIRE test data in early 2017 revealed that some pilot practices are recording a valid ethnicity for the majority of their patients, while there is very low recording of ethnicity in other pilot practices. This is likely to reflect local use of the data and the ethnic diversity of the population the practices serve.

### 3.2 Notes on underlying population profile

- According to 2011 census\textsuperscript{29}, 84% of Scotland’s population was “White Scottish” and a further 8% was “White British”.

- In 2011, 4% of people responding to the census reported themselves as being from minority ethnic groups, compared with 2% in 2001. In census reporting, minority ethnic groups were defined as all “non-white” groups.
• The largest minority ethnic group in Scotland was “Asian”, (141,000; 3% of the population), around a third of whom were “Pakistani”. In the Scottish Census, recording for minority ethnic groups includes Scottish and British, for example: “Pakistani” includes “Pakistani/Pakistani Scottish/Pakistani British”.

• “African”, “Caribbean” or “Black” groups made up 1% of the population of Scotland in 2011; mixed or multiple ethnic groups represented 0.4% (20,000) and other ethnic groups 0.3% (14,000) of the total population.

• Glasgow City Council Area had the highest proportion of minority ethnic groups (12% of the population), followed by the City of Edinburgh and Aberdeen City (both 8%) and Dundee City (6%).

Note: The census is the best source of data we have on the distribution of ethnicities in the Scottish population and we use census data to calculate rates for each ethnic group. Whilst the quality of the census data is high, it is only available every ten years and Scotland’s population is changing. This means that as we move further away from the last census, information about the ethnicities of Scotland’s population may no longer reflect the current demographic and rates may become inaccurate or misleading, particularly for minority groups involving small numbers of people.

3.3 Who is using health services?

To date, the main source of information about ethnic groups and health in Scotland has been from the Scottish Health and Ethnicity Linkage Study (SHELS)\textsuperscript{30}. This has linked census data on ethnicity to health datasets and produced a range of academic papers. For example, studies from SHELS have shown that:

• Males and females in most of the larger ethnic minority groups in Scotland have longer life expectancies than the majority White Scottish population\textsuperscript{31};

• Compared to White Scottish men and women, Indian, Pakistani, Other South Asian, African, and Chinese groups all had lower rates of hospitalisation or death from cancer as a whole\textsuperscript{32};

• Pakistani men and women had the highest rates of hospitalisation and death due to heart attack\textsuperscript{33};

• Chinese men and women, Other South Asian men and Pakistani women have substantially higher rate of hospitalisation for liver disease\textsuperscript{34}; and

• Compared to the White Scottish population, the highest rates of hospital admission for respiratory conditions were in Pakistani males and females and Indian males. The lowest rates were seen in Chinese males and females\textsuperscript{35}.

The Scottish Migrant and Ethnic Health Research Group (SMEHRS)\textsuperscript{36} is a strategic group that encourages and promotes high quality research that will help to improve the health and wellbeing of all ethnic groups living in Scotland. Members of this group have been involved
in initiating and carrying out a range of work, including analysis to compare ethnicity recorded in routine hospital admissions data with census recording of ethnicity\textsuperscript{37}, analysis to assess whether or not ethnicity recording in routine hospital admissions data can be increased sufficiently to allow robust comparison between ethnic groups\textsuperscript{38} and assessment of the accuracy of ethnicity recording in death registrations\textsuperscript{7}.

Previous work\textsuperscript{39} has reviewed evidence from studies across the United Kingdom and explored why some conditions are more common in particular ethnic groups (for example: relatively high rates of coronary heart disease and low rates of cancer in South Asian people; high rates of hypertension amongst people of Afro-Caribbean descent; high rates of stroke amongst people of Bangladeshi descent; and high rates of lung cancer amongst people of white Scottish descent).
3.4 Focus: Augmenting ethnicity recording in administrative health datasets

In this section we present information about ISD work that “pooled” data to improve ethnicity recording and enable analysis of administrative health data by ethnic group.

During 2016, ISD carried out some exploratory work using hospital admissions data, to assess whether the completeness of valid ethnic group could be increased sufficiently to allow robust analysis. The method looked back over all admissions between 2009 and 2015 and sourced the most recent valid recording of ethnic group for each patient. This approach increased the completeness of ethnicity recording for episodes in 2013 from 76% to 85%.

Similar exploratory analysis was done using waiting times data and looking back over inpatient/day case and new outpatient waiting lists during 2015. The result was that the completeness of valid ethnic group was increased from 78% to 82% for inpatients/day waiting list cases and from 72% to 76% for new outpatient waiting list cases in 2015. Appendix B shows comparisons of waiting times by ethnic group, produced using this method.

For this report, ISD has taken this kind of approach a step further and assessed whether pooling data from across different datasets could be used to increase the level of ethnicity recording and therefore enable more robust analysis. This was done by creating a reference file based on the most recent valid recording of ethnicity from hospital inpatient/day case admissions and hospital outpatient appointments during the period 2009-2015 and National Records of Scotland (NRS) death registration data during 2015-2016. This reference file was used to “fill in the gaps” where a valid recording of ethnicity was not available in another dataset.

Table 1 shows that using this approach can increase the completeness of ethnicity recording in a range of national administrative health datasets.

Table 1: Percentage records with valid ethnic group pre- and post-matching to the ethnicity reference file

<table>
<thead>
<tr>
<th></th>
<th>Outpatient appointments</th>
<th>Inpatient and day case admissions</th>
<th>A&amp;E attendances</th>
<th>Cancer registrations</th>
<th>Maternity hospital episodes</th>
<th>Psychiatric hospital admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before: Baseline data</td>
<td>75%</td>
<td>82%</td>
<td>58%</td>
<td>54%</td>
<td>81%</td>
<td>78%</td>
</tr>
<tr>
<td>for 2015</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>After: Following</td>
<td>84%</td>
<td>90%</td>
<td>83%</td>
<td>87%</td>
<td>85%</td>
<td>89%</td>
</tr>
<tr>
<td>matching to the</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ethnicity reference</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>file</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix C includes a breakdown of the extent to which matching to the ethnicity reference file increased completeness of hospital admissions, outpatient appointments and A&E attendance data for each NHS Board.

A breakdown of the ethnicities recorded and sourced from the reference file for each dataset is available in supplementary table S8.

Although this approach increases the completeness of ethnicity recording to some extent, there remains a notable proportion of records that do not have a valid ethnic group. If these records are simply excluded from analysis, calculated disease or activity rates may be misleading. Before calculating rates, we therefore randomly assigned records without a valid ethnicity to an ethnic group, based on the age-sex distributions for ethnic groups observed in results from the 2011 census. A breakdown of how ethnicities were assigned for each dataset is available in supplementary table S9. Alternative approaches for dealing with missing or invalid ethnicity recordings are discussed in section 3.1.

Charts 13-18 compare age-standardised rates for ethnic groups, based on the approach used to augment ethnicity recording and randomly allocation of cases with a missing ethnicity described above. Alongside each chart, we have provided commentary about what the chart is showing and issues that should be considered when interpreting the results.

The calculated rates for “other ethnic group” have not been included in these charts because they are exceptionally high, which suggests that there is over-recording of people as “other ethnic group” in administrative health datasets compared to the prevalence of people self-reporting as “other ethnic group” in the census. The absolute numbers involved are small, so even a small amount of over-recording of “other ethnic group” in administrative health datasets skews the rates considerably. To a lesser extent, there may be similar issues with recording of other more generic ethnicities, such as “Asian other” or “White other” because rates for these groups in some of the charts appear disproportionately high compared to the rates for related ethnic groups.

Conversely, rates per 1,000 population for some ethnic groups (for example, “White Irish”, “White Gypsy/Traveller”) seem consistently low, which is possibly partly due to under-recording of these ethnicities compared to the prevalence of people self-reporting as these ethnic groups in the census. Low rates may however also relate to challenges around accessing services for some groups (for example, people in the “White Gypsy/Traveller” group).

Cautious comparison of ethnic groups based on these charts is recommended as it is difficult to unpick the impacts of these (and potentially other) recording issues from real differences between ethnic groups.

Charts 13-18 highlight some interesting points, both in terms of potential differences in service use and also possible issues with data quality. Further work is needed to explore and explain the differences observed. We hope that the release of this analysis will ultimately drive improvements in the recording and use of these data.
Rates of outpatient appointments are higher for females than males in all ethnic groups apart from the “Asian Other” group where males have slightly higher rates. This is despite evidence that males more frequently miss outpatient appointments than females in Scotland\textsuperscript{40} and evidence that this is particularly the case for some ethnic groups\textsuperscript{41}, which would be expected to increase the male rate (missed appointments resulting in multiple repeat appointments being made).

Low rates of outpatient appointments for males and females in the “White Irish”, “White Gypsy/Traveller”, “Chinese”, and “Arab” groups. This is possibly partly due to under-recording of these ethnicities compared to the proportions reported in census records and used to calculate rates. For some of these groups, it may also reflect issues with access.

We are not aware of any other work that has compared outpatient appointment rates by ethnicity in Scotland.
Measuring use of health services by equality group.

Chart 14: Hospital admissions EASR per 1,000 population, by ethnic group and sex - Scotland 2015

- Relatively high rates of hospital admissions for the “White Other British” and “White Other” groups, particularly for males in the “White Other” group.

- Low rates of hospital admissions for males and females in the “White Irish”, “White Gypsy/Traveller”, “Arab” and “Chinese” groups. This is possibly partly due to under-recording of some of these ethnicities compared to the proportions reported in census records and used to calculate rates. For some of these groups, it may also reflect issues with access.

- Relatively high rates of hospital admission for females in the “Pakistani”, “Bangladeshi” and “Black/Caribbean” groups, compared to males in these ethnic groups. The underlying numbers for the latter two of these groups are relatively small, which may skew rates, but this does not explain these observations entirely.

- Much higher rates for males in the “Asian Other” group than females in the same ethnic group.

Previous work from the Scottish Health and Ethnicity Linkage Study (SHELS)\(^{30}\) showed variations in hospitalisation rates of different ethnic groups for specific conditions. The observation that people in the “Chinese” ethnic group appear to have lower rates of hospital admission overall seems to tally with several of these research studies. Previous exploratory work\(^{38}\) using augmented ethnicity recording in hospital admissions data from 2013 shows similar patterns.
Measuring use of health services by equality group.

Chart 15: A&E attendances EASR per 1,000 population, by ethnic group and sex - Scotland 2015

- Relatively high rates of A&E attendance for people in the “White Other British” group, especially males. This could be related to differences in classification between “British” and “Scottish” in the data compared with people’s self-reported ethnicity in census results.

- Relatively high rates of A&E attendances for males in the “White Other” and “Mixed/Multiple” groups. This is possibly partly due to over-recording of these ethnic groups instead of recording more specific ethnic groups.

- Relatively low rates of hospital admissions for males and females in the “White Irish”, “White Gypsy/Traveller” and “Arab” groups. This is possibly partly due to under-recording of these ethnicities compared to the proportions reported in census records and used to calculate rates.

- Relatively high rates of A&E attendance for males and females in the “Black/Caribbean” and “Pakistani” groups.

- Relatively low rates of A&E attendance for males and females in the “Arab” group.

- Males have higher rates of attendance than females for all ethnic groups apart from “White Gypsy/Traveller” and “Pakistani”. This is consistent with ISD statistics showing that generally men have higher rates of A&E attendance than women\(^{15}\).

We are not aware of any other work that has compared A&E attendance rates by ethnicity in Scotland.
Measuring use of health services by equality group.

Chart 16: Cancer registrations EASR per 1,000 population, by ethnic group and sex - Scotland 2015

European Age Standardised Rate per 1,000 population

- Relatively high rates of cancer registration for males and females in the “White Other British” group. These rates are much higher than rates for males and females in the “White Scottish” group. This could be related to differences in classification between “British” and “Scottish” in the data compared with people’s self-reported ethnicity in census results.

- High rates of cancer registration for males in the “White Other” group. This is possibly partly due to over-recording of this ethnic group instead of recording more specific ethnic groups, but that does not explain the differences observed between males and females in this group.

- Relatively low rates of cancer registration for males and females in the “White Irish”, “White Gypsy/Traveller” and “Arab” groups. This is possibly partly due to under-recording of these ethnicities compared to the proportions reported in census records and used to calculate rates.

- Relatively high rates of cancer registration for males in the “African” group, especially compared to females in the same ethnic group.

Scottish Health and Ethnicity Linkage Study (SHELS) research concluded that compared to White Scottish men and women, Indian, Pakistani, Other South Asian, African, and Chinese groups all had lower rates of hospitalisation or death from cancer as a whole, which seems to be broadly similar to these findings. SHELS research has also shown evidence of lower uptake of screening amongst some groups (for example: low rates of South Asian women having breast screening), which could reduce the rates of cancer detection in these groups.
Chart 17:  Maternity hospital admissions EASR per 1,000 population; Females, Scotland 2015

- Relatively high rates of maternity admissions for females in the “White British/Irish” group. This rate might be partly boosted by the amalgamation of “White Other British” and “White Irish” groups here, but this could also be related to differences in classification between “British” and “Scottish” in the data compared with people's self-reported ethnicity in census results.

- Relatively low rates of maternity admissions for females in the “White Gypsy/Traveller” group. This is possibly partly due to under-recording of this ethnicity compared to the proportions reported in census records and used to calculate rates. It might also be related to higher rates of home births amongst this ethnic group.

- Relatively high rates of maternity admissions for females in the “Bangladeshi”, “African” and “Pakistani” groups. This might be related to larger average family size in these ethnic groups.

This analysis was based on all maternity admissions. Some women may have had multiple admissions: while they were pregnant, for the birth itself and after the birth. In older women, multiple admissions may be common as pregnancies are likely to be more complex and high risk. Maternal age may vary by ethnic group. The rates above are age adjusted, but higher numbers of admissions for older women may increase the overall rate for some ethnic groups where average maternal age is higher.
Chart 18: Psychiatric hospital admissions EASR per 1,000 population, by sex - Scotland 2015

- Very high rates of psychiatric admission for males in the “Black/Caribbean” group, compared to females in this group and also compared to all other ethnic groups. Note however that this rate is based on a relatively small number of people.

- Relatively high rates of psychiatric admission for males in the “African”, “Asian Other” and “Arab” groups, compared to females in the same ethnic groups.

- Relatively high rates of psychiatric admission for females in the “White Gypsy/Traveller”, “White Polish” and “Mixed/Multiple” groups, compared to males in the same ethnic groups.

- Relatively low rates of psychiatric admission for people in all of the Asian groups, apart from “Asian Other” (the latter possibly due to over-recording of this ethnic group compared to the proportions reported in census records and used to calculate rates).

- Relatively high rates of psychiatric admission for the “White Other British” group, compared to the other “white” ethnic groups. This could be related to differences in classification between “British” and “Scottish” in the data compared with people’s self-reported ethnicity in census results.

Relatively low rates of psychiatric admission for males and females in all of the South Asian and “Chinese” ethnic groups is consistent with Scottish Health and Ethnicity Linkage Study (SHELS) research, which showed that people from these groups were particularly likely to delay or avoid accessing mental health services.

Source: SMR04 dataset, augmented with the ethnicity reference file (excludes rates for “other ethnic group” as these are not thought to be reliable)
4. Religion and Belief

4.1 Data availability and completeness

Records on the religion or belief of patients are not submitted for most centrally collated administrative health datasets. A more recently established data collection such as the Accident and Emergency (A&E) dataset does contain a field for religion and completeness of the information submitted is slowly starting to increase (28% of records having a valid record of religion in 2016).

Information about patient’s religion and beliefs is likely to be collected by health professionals at the point of care where relevant for care or treatment, but it is not centrally collated. Some data on religion may be held in local patient management systems in NHS Boards. ISD asked one NHS Board with relatively high recording of other equality information in routine submissions to check the completeness of valid recording of religion on their local patient management system. For a snapshot of activity during a single month in late 2016, a valid recording of religion was available for around 50% of inpatient/day case episodes and around 40% of attendances at emergency departments. The distribution of religions recorded broadly matched that observed in census data. Further exploration of this is needed to determine whether religion is recorded consistently enough elsewhere for local, and possibly in the future regional or national, analysis.

There is some correlation between particular ethnic groups and religions and, as for ethnicity, the use of surname recognition software can sometimes be used to assign religion where a record does not exist.

Like ethnicity, religion is not a fixed characteristic and people’s religion and beliefs may change over time. There may also be differences between the religion and belief people report being brought up in and their current practice or belief. This complicates efforts to assess the accuracy of data on religion and to interpret comparisons between data sources.

4.2 Underlying population profile

- According to the 2011 census, 54% of Scotland’s population said that they were one of the “Christian” religions”, a drop from 65% in the 2001 census. Of these, 32% said that they belonged to the “Church of Scotland” and 16% said that they were “Roman Catholic”.
- The proportion stating that they had no religion increased between the 2001 census (28%) and the 2011 census (37%). This equates to around 1.7 million people in 2011.
- In 2011, 1.4% stated that they were “Muslim”, an increase from 0.6% in 2001.
- The number of “Buddhists”, “Hindus” and “Sikhs” combined accounted for 0.7% of the population and all had increased since 2001.
- The number of “Jewish” people declined slightly between 2001 and 2011, with around 6,000 in 2011 (approximately 0.1% of the population).
4.3 Who is using health services?

Data are not available in national administrative datasets to compare health service use by people belonging to different religious groups.

A number of research studies have shown that people of Irish Catholic descent in Scotland have significantly higher rates of physical and mental illness compared to the rest of the population, even when socio-economic factors, age and sex are taken into account\textsuperscript{42, 43, 44, 45, 46, 47}.

According to responses to the Scottish Health Survey\textsuperscript{48}, Hindus have the best self-reported health status and the most positive mental health scores – and people who said they were Catholic were significantly less likely to rate their health as “good” or “very good” than other respondents. The same survey also reported that people with no religious affiliation were significantly more likely to drink alcohol at hazardous or harmful levels. Note however that although this analysis was age-standardised, it did not take account of the influence of other factors. This may mean that apparent differences between ethnic groups are actually driven by other differences between people in these groups, such as deprivation.
5. Sexual Orientation and Gender Identity

5.1 Data availability and completeness

Records on the sexual orientation of patients are not submitted for most centrally collated administrative health datasets. Data on gender identity are also not routinely collated centrally (as outlined in section 2.1). Some services, such as sexual health services, are more focussed on providing care and support to Lesbian, Gay, Bisexual and Trans (LGBT) people. These services usually gather good information on the sexual behaviour of their users, but this may not necessarily include data on how service users identify themselves. A more recently established data collection scheme such as the Accident and Emergency (A&E) dataset does contain a field for sexual orientation and completeness of the information submitted is slowly starting to increase (20% of records having a valid record of sexual orientation in 2016).

It is likely to be particularly challenging to collect information about sexual orientation and gender identity in all administrative datasets. Health professionals may be reluctant to ask patients about this – and where patients are asked directly, a relatively high proportion may prefer not to answer, and the proportion declining to respond may be higher than the proportion of patients identifying as non-heterosexual or who identify as trans. A Stonewall patient feedback survey in 2014 reported that more than one in five (22%) of lesbian, gay, bisexual or transgender (LGBT) respondents would feel uncomfortable being open about their sexual orientation or gender identity with NHS staff. Low response to questions on sexual orientation and gender identity is also observed in national surveys (see below).

5.2 Notes on underlying population profile

- According to Scottish Government core survey question results, 1.6% of Scotland’s population identifies as lesbian, gay or bisexual. However, this is likely to be an underestimate as 2.4% of respondents preferred not to answer and 0.4% of respondents identified as “other” than one of the prescribed groups available.

- Stonewall estimates that around 5-7% of the population is lesbian, gay or bisexual. This rate seems to be accepted for government policy and planning, for example: the UK Government analysis of the financial implications of the new Civil Partnerships Act by the Treasury used an estimate of 6% of the population being lesbian, gay or bisexual.

- Scotland’s census does not currently collect data on sexual orientation or gender identity. A pilot study was carried out before the 2011 census to establish whether the census should include questions on sexual orientation. The conclusion was that the census could not gather accurate data on sexual orientation because the rate of missing data (14%) far outweighed the rate of respondents stating a non-heterosexual orientation (around 2%). This is under review and consultation and questions on sexual orientation and gender identity may be included in the 2021 census and beyond.
The Registrar General for Scotland maintains a Gender Recognition Register, which records the birth of any person whose affirmed gender has been legally recognised and their birth certificate updated accordingly. In 2015, this contained 25 entries, an increase from 16 entries in 2014. It is important to note that this figure only reflects a small proportion of people who identify as trans, as many of these people do not have a Gender Recognition Certificate.

The Gender Identity Research and Education Society (GIRES) published a report estimating that in 2007 the UK-wide prevalence of people who had sought medical care for gender identity related conditions was 20 per 100,000. This equates to around 10,000 people in the UK, of whom 6,000 had undergone transition to live as their preferred gender (this may or may not include medical changes such as hormone therapy or surgery, or legal aspects such as changing identity records). More recent commentary from GIRES suggests that these are under-estimates and that prevalence is increasing over time. According to the original GIRES report, 80% were assigned as boys at birth (now trans women) and 20% as girls (now trans men), but more recent commentary suggests that this gap is narrowing over time.

5.3 Who is using health services?

Data are not available in national administrative datasets to compare health service use according to people’s sexual orientation or gender identity.

The Scottish Government patient experience surveys collect data on the sexual orientation of service users. Several analyses of inpatient experience survey responses, have suggested that sexual orientation is less likely to influence rating of experience than factors such as health status, age or gender. They have also highlighted that, in common with other surveys, a relatively high proportion of respondents do not provide their sexual orientation.

Other organisations have undertaken valuable research to explore the experiences of LGBT people using health and social care services:

- Stonewall has undertaken a range of work to explore the experience and treatment of LGBT people using health and social care services in the UK and specifically in Scotland.

- A study commissioned by Marie Curie explored the barriers faced by LGBT people when trying to access palliative care.

- The Scottish Transgender Alliance has commissioned or supported a variety of studies exploring the experiences of trans people accessing gender identity services and mental health services and alcohol and drug services.
6. Disability

6.1 Data availability and completeness

There is no simple definition of disability. According to the UK Equality Act 2010\cite{UKEqualityAct}, disability is defined as a physical or mental impairment that has a substantial and long-term negative effect on a person’s ability to do normal daily activities. In line with this definition, the census and national surveys tend to ask respondents for a subjective assessment of the extent to which their disabilities or long term health conditions limit their day-to-day activities.

Records on the disability status of patients are not submitted for centrally collated administrative health datasets. Administrative health datasets tend to focus on a particular health event requiring treatment and while detailed diagnosis codes will be gathered about that event, little information is gathered about the person’s general health or any underlying health conditions.

Data on disability is likely to be collected by NHS Boards to inform care of individual patients, but this is not usually used for aggregate analysis and the type of information collected will vary depending on who services are targeted at and what disabilities are considered most relevant for effective delivery of that service.

The Scottish Burden of Disease Study\cite{BurdenOfDisease}, has linked various datasets and will produce rates of different disabilities (such as deafness and blindness) for people with a defined set of diseases or injuries. The results of this work are due to be published in July 2017.

Patient Reported Outcome Measures (PROMs) gather data about the impacts of people’s health on their day-to-day activities, but this kind of information tends to be collected as part of research studies in Scotland at present. There is however increasing interest from various quarters in more routinely collecting PROMs type data from a range of different types of patients and this could mean that these data can be more routinely used with information from administrative health datasets in future.

6.2 Notes on underlying population profile

- According to Scottish Government core survey question results\cite{ScottishGovernmentCoreSurvey}, 23% of adults in Scotland had a long-term limiting health condition or disability in 2015.

- The 2011 census\cite{2011Census} reported that 20% of adults in Scotland had a long-term activity-limiting health problem or disability. This was the same as the proportion reported in 2001 census results, despite Scotland’s ageing population. Within this, there was a wide variation according to age: 12% of people aged under 25 years; 72% of people 75 to 84 years; and 87% of people aged 85 years and over.
The Scottish Health Survey\textsuperscript{69} tends to report higher rates of disability, with 32\% of adults reported as having a long-term physical or mental condition or illness in 2015. This difference is thought to be at least in part due to the framing of the questions in a survey focussed on health, compared to other surveys where the question is surrounded by unrelated topics.

6.3 Who is using health services?

Data are not available in national administrative datasets to compare health service according to people’s disability status.

ISD routinely collects and publishes aggregate data on waiting times for audiology services\textsuperscript{70} for people with hearing impairments, but we do not currently hold any patient level data about the people using these services.

ISD also routinely collects and publishes information on NHS General Ophthalmic Service activity in Scotland\textsuperscript{71}, as performed by eye care professionals. This focuses on workload and information about the people using the services or the degree to which their vision is impaired is not collected by ISD.
7. Next steps

ISD aims to build upon the work presented in this report in the following ways:

- **Maintain and develop the ISD equality evidence finder** to ensure that users can find clear and up-to-date information about the availability and quality of equality data in administrative health datasets, preferably in an interactive way.

- **Increase routine reporting of equality groups in ISD releases** by encouraging and monitoring inclusion of analysis of or reference to equality groups, and health inequalities more generally, in ISD releases. This could include reporting some equality information (for example, ethnicity) only for NHS Board areas with high completeness and excluding NHS Board areas with low completeness and possible data quality issues.

- **Build on existing collaborations** with academic groups and organisations such as NHS Health Scotland to develop analysis and reporting of equality data from administrative health datasets. This could include work to undertake more routine linkage to other sources of data (such as surveys or local patient management systems) to source a wider range of equality data for routine use. This could also include further exploration of the use of other approaches such as surname recognition software.

- **Maintain and develop monitoring of ethnicity completeness**, exploring whether this should be extended to a wider range of administrative health datasets and whether or not it could also be extended to include routine reporting of other measures of data quality (for example: rate of “refusals” or rate of recording of possible default codes such as “other ethnic group”). Alongside this, ISD should actively engage with NHS Boards to highlight potential data quality issues.

- **Further explore the value of routinely producing an ethnicity reference file** (based on pooled data from different administrative datasets) could be used to augment completeness where ethnicity has not been recorded in administrative health datasets and therefore increase potential for analysis and reporting (see Section 3.4).

- **Explore future potential to source and routinely use equality data for primary care** from the [Scottish Primary Care Information Resource (SPIRE)](http://www.isdscotland.org/).
Measuring use of health services by equality group.

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Appendix A: Related national equality work and previous recommendations

This appendix provides a summary of equality work undertaken by a range of national organisations and networks.

NHS Health Scotland undertakes a wide range of work on equality groups and protected characteristics. Further information about this work and useful background information is available on the equality pages of the NHS Health Scotland website. In 2012, NHS Health Scotland carried out a review of equality health data needs in Scotland. This review made a number of recommendations for the Scottish Government and different parts of the NHS. It made recommendations for ISD to work in collaboration with others to: improve the consistency of standards, data definitions and coding for equality data; develop use of existing data on age and gender; and improve and maintain information on the availability and suitability for analysis of equality data in routine health datasets. Significant progress has been made in improving the quality and consistency of recording of equality data. There has also been improved collection, use and awareness of the availability of some equality data, most notably ethnicity, but we recognise that more needs to be done in this respect and hope that this report and accompanying evidence finder go some way to addressing this.

The Scottish Public Health Observatory (ScotPHO; a collaboration led by ISD and NHS Health Scotland) also presents useful background information about selected equality groups in the population groups and health, wellbeing and disease sections of their website.

The Scottish Government is planning to release an updated Equality Strategy and a Gender Index for Scotland in summer 2017. The Scottish Government has collaborated with others to produce a range of work on equality including releasing Equality Monitoring Guidance (2012), an equality evidence toolkit for public authorities (2015) and a report on equality outcomes and mainstreaming (2015). The Scottish Government Race Equality Framework (2016) includes a recommendation that ISD collaborate with others to improve approaches to collecting and publishing ethnicity data on health and social care. We hope that the work presented in this report will help to address this.

ISD is also involved in a number of academically focussed collaborations that aim to enable analysis of health data by ethnicity. The Scottish Health and Ethnicity Linkage Study (SHELS) has linked census data on ethnicity to health datasets and produced a range of academic papers. The Scottish Migrant and Ethnic Health Research Group (SMEHRS) encourages and promotes high quality research that will help to improve the health and wellbeing of all ethnic groups living in Scotland.

There have also been attempts to establish a single record of equality data, which could be matched to other administrative health datasets and remove the need to collect the same information multiple times. The Community health Index (CHI) database is a centrally maintained register of all people in Scotland who are registered with a GP practice. This database contains basic demographic information, including age and sex. Although it has previously been suggested that equality data could be held as part of the CHI database, this option has not been taken forward.
Appendix B: Waiting times activity by ethnic group – exploratory analysis

During 2016, ISD carried out some exploratory work using waiting times data, to assess whether the completeness of valid ethnic group could be increased sufficiently to allow robust analysis. The method looked back over all inpatient/day case and new outpatient waiting lists during 2015. The result was that the completeness of valid ethnic group was increased from 78% to 82% for inpatients/day waiting list cases and from 72% to 76% for new outpatient waiting list cases in 2015.

Charts B-1 and B-2 show the output of this analysis, comparing median waiting times by ethnic group. Note that cases with no valid recording of ethnicity were excluded from this analysis, which may skew medians, particularly for ethnic groups with relatively small populations.

For inpatient/day case waiting times, many of the medians are based on relatively small numbers of people and may therefore be unreliable. In particular, people from the “Arab” and “Bangladeshi” groups may appear to be waiting longer and people from the “Gypsy/Traveller” and “Other African” or “Caribbean” groups may appear to be waiting a shorter time on average than other ethnic groups, but further work is needed to establish whether or not these are real differences.

The higher number of outpatient cases means that there are fewer ethnic groups with small numbers of people in them. However, as for inpatient/day case waiting times, the apparently relatively low median waiting time for people from the “Gypsy/Traveller” group is based on a small number of people and may therefore be unreliable. Otherwise, it appears that people from non-“White” groups may generally be waiting longer for outpatient appointments than people from “White” groups, the exceptions being people from the “White Polish” group (who appear to be waiting longer than other white groups) and people from the “Caribbean” or “Other Caribbean or Black” groups (who appear to be waiting shorter times on average than people from other non-white groups).

Further work is needed to explore and explain the differences observed in these charts.
Chart B-1: Median wait (days) for new inpatients/day cases, by ethnic group - Scotland 2015 (N=318,382)

Source: Waiting times data for inpatients/day cases

Chart B-2: Median wait (days) for new outpatients, by ethnic group - Scotland 2015 (N=1,463,568)

Source: Waiting times data for new outpatients
Appendix C: NHS Board variation in ethnicity recording

The analysis presented in section 3.4 was done at Scotland level. Within this, the completeness of ethnicity recording varied between NHS Boards. As well as varying completeness, there are likely to be variations in data quality due to differences in the ways that NHS Boards, and even different services within the same NHS Board area, are recording and submitting data on ethnicity.

Chart C-1 summarises the impact of augmenting ethnicity recording for inpatient/day case admissions, outpatient appointments and A&E attendances by NHS Board. Note that the A&E dataset is relatively new, which might explain why some NHS Boards had zero or very low completeness of ethnicity recording in the A&E data they submitted for attendances during 2015.

Chart C-2 shows a breakdown of invalid recording of ethnicity and recording of “refusals” (where the patient is recorded as having refused to provide their ethnicity or preferred not to answer). This shows that there is considerable variation between NHS Boards.

Chart C-3 shows recording of “other ethnic group” by NHS Board. The Scotland level analysis highlighted that there appears to over-recording of “other ethnic group” and suggested that this may be used as a “default” code to record a valid ethnicity in some NHS Board areas. Even a relatively small amount of over-recording of this ethnic group can skew rates considerably.

The uneven distribution of missing ethnicity records, coupled with a varied distribution of minority ethnic groups across Scotland further complicates the situation when considering how to adjust for missing ethnicity records.

Further work needs to be done to improve the quality of ethnicity recording, particularly in some NHS Board areas, and to assess how missing data can be assigned in a more accurate way. Further work to compare service use by ethnic group should perhaps focus on NHS Boards with high recording of valid ethnicity.
Chart C-1: Percentage valid ethnicity recording for hospital admissions, outpatient appointments and A&E attendances pre- and post-augmenting of ethnicity recording - by NHS Board, 2015

[baseline: 2015 records before matching to the ethnicity reference file]
[augmented: 2015 records after matching to the ethnicity reference file]

Source: SMR01 (all episodes), SMR00 (all appointments) and A&E datasets (all attendances)

Chart C-2: Breakdown of invalid ethnicity recording (including “blanks”, “not knowns” and “refusals”) for hospital admissions, outpatient appointments and A&E attendances - by NHS Board, 2015

Source: SMR01 (all episodes), SMR00 (all appointments) and A&E datasets (all attendances)
Chart C-3: Breakdown of percentage recording of “other ethnic group” for hospital admissions, outpatient appointments and A&E attendances - by NHS Board, 2015

Source: SMR01 (all episodes), SMR00 (all appointments) and A&E datasets (all attendances)
Appendix D: Comparison of ethnicity recording in NRS death records and hospital admission and outpatient data

ISD compared ethnicities recorded on the National Records of Scotland death registrations (made during 2015 and 2016) with the most recent valid ethnicity recorded in hospital admission or outpatient appointments data (from the period 2009-2015).

- 95% of death registrations made during 2015-2016 included a valid ethnicity recording.
- A valid ethnicity was available from hospital activity data for a further 3.5% of death registrations that did not have an ethnicity recording (potentially increasing completeness to 98%).
- In only 35% of cases was exactly the same ethnic group recorded on the death registration and the hospital activity record. Further analysis reveals a mixture of mismatches between related or similar groups and also some more unexpected combinations (Table D-1). These differences are likely due to the fact that data from both sources is usually recorded by third parties, possible changes in perceived ethnicity over time and also possibly suggest other underlying data quality issues.

Table D-1: Percentage of records with each type of ethnicity recording

<table>
<thead>
<tr>
<th>Ethnicity recorded on death registration</th>
<th>White Scottish (N=94,996)</th>
<th>White British (N=10,583)</th>
<th>Pakistani (N=222)</th>
<th>Indian (N=146)</th>
</tr>
</thead>
<tbody>
<tr>
<td>White Scottish</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>White British</td>
<td>&lt;0.1</td>
<td>34.5</td>
<td>2.3</td>
<td>3.4</td>
</tr>
<tr>
<td>White Irish</td>
<td>&lt;0.1</td>
<td>0.6</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>White Polish</td>
<td>&lt;0.1</td>
<td>0.1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>White Other</td>
<td>0.6</td>
<td>2.4</td>
<td>0.9</td>
<td>2.1</td>
</tr>
<tr>
<td>Mixed</td>
<td>8.0</td>
<td>&lt;0.1</td>
<td>2.7</td>
<td>4.8</td>
</tr>
<tr>
<td>Pakistani</td>
<td>0.7</td>
<td>0.1</td>
<td>54.1</td>
<td>14.4</td>
</tr>
<tr>
<td>Indian</td>
<td>&lt;0.1</td>
<td>&lt;0.1</td>
<td>7.7</td>
<td>39.7</td>
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<tr>
<td>Bangladeshi</td>
<td>&lt;0.1</td>
<td>&lt;0.1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Chinese</td>
<td>&lt;0.1</td>
<td>&lt;0.1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Asian Other</td>
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<td>&lt;0.1</td>
<td>5.0</td>
<td>8.2</td>
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<td>African</td>
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<td>&lt;0.1</td>
<td>0.5</td>
<td>-</td>
</tr>
<tr>
<td>Black</td>
<td>&lt;0.1</td>
<td>&lt;0.1</td>
<td>0.5</td>
<td>-</td>
</tr>
<tr>
<td>Caribbean</td>
<td>&lt;0.1</td>
<td>&lt;0.1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Other ethnic group</td>
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<td>&lt;0.1</td>
<td>-</td>
<td>1.4</td>
</tr>
<tr>
<td>Blank/missing</td>
<td>10.2</td>
<td>11.4</td>
<td>17.1</td>
<td>13.0</td>
</tr>
<tr>
<td>Not known</td>
<td>&lt;0.1</td>
<td>10.0</td>
<td>5.9</td>
<td>6.8</td>
</tr>
<tr>
<td>Refused/not provided</td>
<td>7.8</td>
<td>1.1</td>
<td>0.9</td>
<td>1.4</td>
</tr>
<tr>
<td>TOTAL</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>