IMPROVING DATA AND EVIDENCE ON ETHNIC INEQUALITIES IN HEALTH: INITIAL ADVICE AND RECOMMENDATIONS FROM THE EXPERT REFERENCE GROUP ON ETHNICITY AND COVID-19

Purpose

1.   The Expert Reference Group (ERG) was asked to provide advice and recommendations by the Scottish Government in relation to data, evidence, risk and systemic issues. This paper deals with the recommendations looking at data and evidence:

- What are the priorities for action on health data in relation to COVID-19 and race? What should be done to improve the accuracy and completeness of data on ethnicity within our health system?
- Is there a case for making the collection of health data on ethnicity mandatory? What are the pros and cons of doing this?

Background

2.   International evidence suggests COVID-19 has affected minority ethnic groups disproportionately. In England, there is consistent evidence of increased risks among many minority ethnic groups.[1] In Scotland, data has been slow to emerge on the risks for minority ethnic groups and initial analyses were contradictory. Since the ERG was first established, more recent analyses by Public Health Scotland (PHS) and National Records of Scotland (NRS) has confirmed increased risks associated with COVID-19 in South Asians but robust analyses are still unavailable for several minority ethnic groups.[2,3]

3.   The monitoring of how policy and public services meets the needs of different groups of people as defined by protected characteristics is enshrined in law under the Equality Act 2010. Of particular relevance, the Act includes the need to monitor outcomes by "race" which includes colour, nationality, ethnic or national origins. This duty applies to Scottish Government as well as other public sector organisations but at present there is limited accountability for this and there is limited consideration within the National Performance Framework.

4.   The Equality and Human Rights commission advise that,

"On 6 April 2011, a new Public Sector Equality Duty (PSED) came into force under the authority of the Equality Act (2010). The Commission's guidance on the duty[4] does not make detailed suggestions about what information public

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[1] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/908434/Disparities_in_the_risk_and_outcomes_of_COVID_August_2020_update.pdf

[2] https://publichealthscotland.scot/news/updated-analysis-of-covid-19-outcomes-by-ethnic-group/

[3] https://www.nrscotland.gov.uk/files/statistics/covid19/ethnicity-deceased-covid-19-june20.pdf

[4] http://www.equalityhumanrights.com/uploaded_files/EqualityAct/PSED/essential_guide_guidance.pdf

authorities should gather. The onus is on them to decide in light of the relevance of their functions to equality".

5.   The COVID-19 pandemic has highlighted the lack of adequate data to monitor the needs of different minority ethnic groups, particularly in relation to the health consequences of the pandemic. However, a lack of ongoing monitoring of ethnic inequalities in health within Scotland has been longstanding.

6.   Data on ethnicity has been recorded in many NHS Scotland administrative systems for some time, but levels of recording and data quality have often been too poor to allow meaningful analysis. There have been previous occasions when concerted efforts have been made to improve ethnicity recording by individual health boards, but these have often not led to sustained improvements in data collection that have been maintained. However, these experiences do provide lessons for how improvements in ethnicity recording could be achieved.

Principles for analysing ethnicity data

7.   Analysing data for different minority ethnic groups can be challenging for a number of reasons: often small numbers of minority ethnic groups may limit analyses (with statistical disclosure control requirements and particularly small numbers within surveys etc.), potential inconsistent recording of ethnicity across datasets, and potential for greater population movement (e.g. in-migration and out-migration) making denominators difficult to ascertain and often rapidly outdated. Small numbers of some minority ethnic groups may preclude analysis, even if 100% coding achieved. There can also be legal and confidentiality requirements when dealing with ethnicity data and small numbers as General Data Protections Regulation includes requirements on dealing with personal data and Special Category Data[5] (the latter of which includes ethnicity). However, this should not act as a barrier to appropriate analysis in the public interest since the non-use of data may itself result in harms.

8.   Concerns have also been expressed that data is not always analysed by official statistical agencies in the most appropriate way, with some ethnic groups not being reported. For example, Irish community groups expressed concern that National Records of Scotland did not report COVID-19 mortality risk for the White Irish group. While it is not within the remit of the ERG to adjudicate on the appropriateness of specific analyses, we note the concerns that have been expressed. As such, The ERG acknowledges that "White Minority Ethnic Communities", such as the Irish, Polish and Gypsy Travellers, are Minority Ethnic communities and should be considered as such in data collation, interpretation and disaggregation.

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[5] https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/special-category-data/

9.   In analyses of ethnic minority inequalities, we recommend:

- Monitoring of inequalities by 'race' in line with the Equality Act 2010 should routinely occur and clear lines of accountability should exist for ensuring appropriate monitoring and reporting takes place.
- Intersectionality is important and consideration should be given to reporting social characteristics separately and in combination, whenever possible. For example, this would include also considering religious groups, migrant status, gender and the multiple dimensions of socio-economic position.
- Consideration should be given to reporting related characteristics in addition, whenever possible. Ethno–religious communities, such as Jewish and Sikh communities, should be better identified and responded to by enabling a religious indicator in data collation. This may also be useful for identifying inequalities in other minority faith groups.[6]
- Clear explanations will be needed when not reporting analyses by ethnicity or when not reporting specific ethnic groups. These may be warranted (e.g. when the number of people available for analysis is too small for meaningful analysis) but explanations should be provided about this in as transparent a way as possible.

Current challenges in collecting ethnicity data

10.   The ERG notes that a major barrier for the analysis of ethnicity data has been the lack of adequate data available for analysis. While this paper focuses on health data, given the immediate responsibility of the NHS in responding to the pandemic, our expectations are that other sectors should be taking equivalent measures to produce robust data by ethnicity as a matter of priority.

11.   Ethnicity data is collected on a number of key health service datasets that are collated by PHS. Further details and levels of completeness are presented on the PHS website.[7]
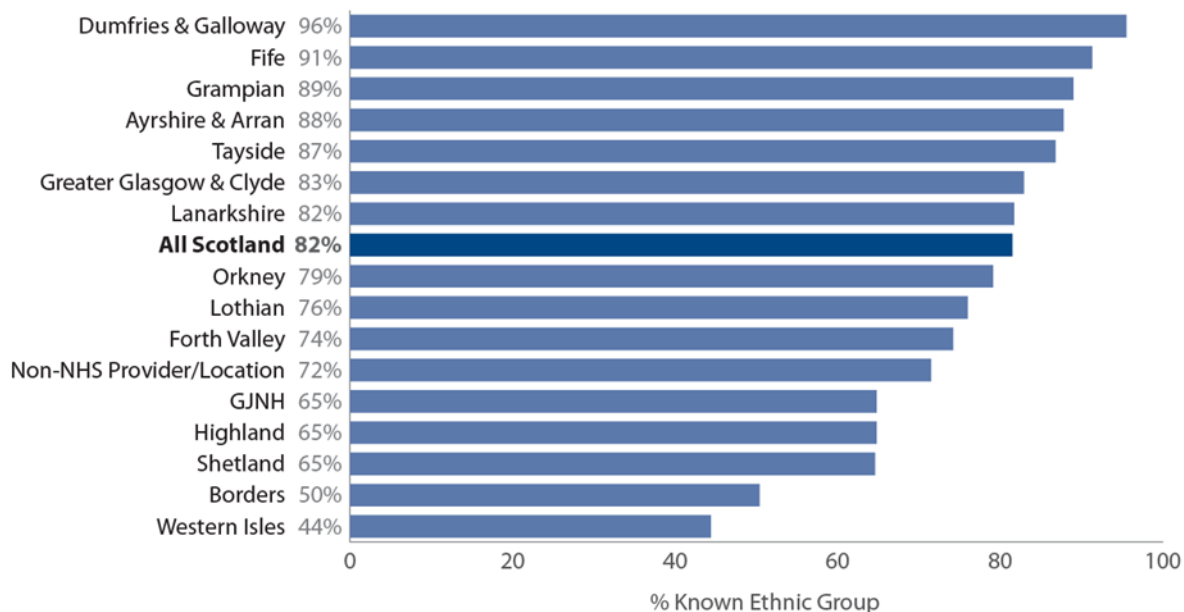
12.   The current level of ethnicity coding and trends over time are reported by Public Health Scotland on an annual basis. The latest figures for hospital inpatients and outpatients show that there is wide variation across Scotland. This variation is evident in not only the level of completeness but also the proportion coded as 'refused/not known'. This considerable variation is suggestive of differences in how the data are collected and recorded, suggesting that mandating the collection of ethnicity information will not be a panacea. Further improvement of data quality is necessary and this is likely to require leadership within the individual health boards that provide the data.

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[6] https://www.scotsman.com/news/politics/catholics-muslims-and-polish-people-more-likely-experience-deprivation-304911
[7] https://www.isdscotland.org/Health-Topics/Equality-and-Diversity/Equality-Evidence-Finder/

Percentage of acute inpatient and day case records with a known ethnic group
by NHS Board of treatment: quarter ending 30 September 2019

NHS Board	%
Dumfries & Galloway	96%
Fife	91%
Grampian	89%
Ayrshire & Arran	88%
Tayside	87%
Greater Glasgow & Clyde	83%
Lanarkshire	82%
All Scotland	**82%**
Orkney	79%
Lothian	76%
Forth Valley	74%
Non-NHS Provider/Location	72%
GJNH	65%
Highland	65%
Shetland	65%
Borders	50%
Western Isles	44%

% Known Ethnic Group

Reference: https://www.isdscotland.org/products-and-Services/Data-Support-and-Monitoring/SMR-Ethnic-Group-Recording

13.   Further information on how this information can be used is detailed in Chapter 3 of the NHS NSS Report on Measuring the Use of Health Services by Equality Group[8]. This also covers data on religion which is rarely recorded. It is important that the full range of minority ethnic groups are included whenever possible within statistical analysis.

14.   An ongoing concern is that data is not readily available for analysis when dealing with events such as COVID-19. The length of time required and governance barriers to conduct data linkage, such as to reliable ethnicity data within the census, has meant timely and robust analyses have not been available. Furthermore, timeliness of national returns of patient data for key datasets such as inpatient and outpatients is a challenge for many Boards especially meeting the 6 week target for submission from patient discharge. While not always a problem for larger longer scale epidemiological analyses of data, it is problematic for analysis of infection outbreaks over the most recent days and weeks.

15.   The NHS Scotland data standard is based on the same ethnic groups as defined in the Scottish Census classification[9]. It will be important to consider how best to maintain ethnicity recording within computer systems in a way that is comparable over time, especially over the long-term.

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[8] https://www.isdscotland.org/Health-Topics/Equality-and-Diversity/Publications/2017-06-27/2017-06-27-Measuring-Use-of-Health-Services-by-Equality-Group-Report.pdf
[9] https://www.ndc.scot.nhs.uk/Data-Dictionary/SMR-Datasets/SMR-Validation-Section/Appendices/Appendix-2/Patient-Identification-Section.asp

16.   Addressing the challenges in ethnicity data collection will require improvements to data collection at source. It is important to note that patient reluctance is usually not a problem, but not being asked and how people are asked is.

Recent initiatives

17.   On 23 June 2020 a letter from the Interim NHS Scotland Chief Executive went to all Health Boards. The letter highlighted two immediate issues that needed more action: ethnicity data and risk assessments for ethnic minority staff.

18.   The letter emphasised the importance data completion and encouraged efforts to be made to explain the reasons for collection of personal data, including ethnicity.

19.   It is also important to learn lessons from approaches that have worked in the past, notably the improvements in ethnicity recording made in many Boards in Scotland since 2008. A study by Davidson et al (in press) showed that NHS Lothian improved ethnicity recording from 3%-90% in three years. It should be noted that this was a temporary improvement, including in Lothian, and there is a need for commitment, leadership and good governance to ensure any improvements are made permanent.

20.   Boards that have made significant progress in ethnicity coding have cited a number of actions that have contributed to improvements. According to work done by the Equality & Diversity programme in NHS Information Services Division (now part of PHS) these include:

- A commitment by senior managers to introduce ethnicity monitoring
- Training of identified staff who ask patients about their ethnic group
- Mandatory data collection by asking all service users the question and recording their answers. (Note that refusal to provide ethnicity by a person being asked should always be permissible).

21.   Other information and materials covering the work in improving data quality are available on the PHS website[10].

<u>Improving ethnicity coding through improved data infrastructure – Advice and recommendations</u>

Recommendation 1: Make ethnicity a mandatory field for health databases

22.   This is an immediate action that should be done for one or more systems E.g. primary care databases, Scottish Morbidity Records and others. We recognise that making a field mandatory at the national level is not necessarily a panacea but in our view it is essential to improving the data in the short and longer terms. It means a valid code has to be submitted for each record in Board data submissions. 'Refused' and 'Unknown' are valid codes so even if mandatory

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[10] https://www.isdscotland.org/Health-Topics/Equality-and-Diversity/Publications/

then it does not mean it is available for all patients. At present, data held by PHS does not discriminate between these two concepts and only includes a single code for 'refused'/'unknown', likely including many instances when the patient was never asked. Further work is needed to understand if it is possible to create more refined categories for unknown ethnicity, requiring an improved understanding of the source data within health boards and whether the current computer systems used by health boards allow for more detailed information to be collated.

23. In addition, mandatory does not mean accurate, any code will be accepted, and so data needs to be good quality and this needs data quality monitoring at local and national levels. Given the ownership of much data collection lies with NHS Boards, they should make it mandatory on local systems as well but this would need to go hand in hand with leadership and training initiatives described in the Lothian study and others as described above to ensure quality.

Recommendation 2: Linkage to census

24. The census currently provides the most robust information on ethnicity for the population of Scotland. Data linkage to the census should be immediately pursued by the Scottish Government to monitor the equity of the COVID-19 response in relation to ethnicity. This should not only include the immediate infectious consequences of COVID-19 (such as risks of infection, hospitalisation and death), but also secondary health harms arising from the pandemic response (such as reductions in the use of appropriate healthcare for other health conditions). If a vaccination becomes available, monitoring of its uptake by ethnicity should also be pursued using data linkage.

25. Under the principle of collecting data once but making use of it many times, linkage to the census should be pursued to allow long-term monitoring and research of ethnic inequalities in health. At present, linkage is done for the purposes of a specific project and for this reason such analyses are often not conducted in a timely manner and are resource intensive. The ERG recommends the addition of an ethnicity field derived from the census is added to an appropriate population spine (such as the Community Health Index, CHI) which would be available for routine analyses without requiring approval from multiple organisations. This recommendation should be considered an important priority which could substantially improve data quality and facilitate timely and responsive analysis.

Recommendation 3: Develop a CHI field

26. Allow information to be accessible if provided to any health database only once. This will need maintenance/integration within the Community Health Index (CHI) system and a way for deciding on conflicts in classification between databases and over time. Similarly, some process for updating the information on an occasional basis will likely be necessary. The CHI is due to be substantially revised within the next 1-2 years, providing an opportunity to embed ethnicity within the system. This single change could make a major impact on the potential

for conducting analyses of health data by ethnicity, since this information would then be readily available within many health datasets. There would be considerable synergies if combined with recommendation 2 (para 25 above).

Recommendation 4: Ethnic Group populations

27.   Monitoring of health outcomes by ethnic group should be updated regularly and more frequently than the decennial census as it is difficult to monitor without up to date populations on which to base rates. This is particularly the case in Scotland with the relatively small numbers of many minority ethnic groups and also the fact that many minority ethnic groups have relatively young populations compared to White Scottish/British and so risks can be masked by generally better outcomes in younger people if looking at outcomes at an aggregate level (Note, this was case with recent PHS Ethnicity analysis where the raised risk in South Asians was only apparent after adjustment for underlying age and sex in general population).

28.   Attempts have been made previously by NRS and ONS to look at inter census estimates[11] but appear to have stalled. A group at Leeds University have produced broad population projections for ethnic groups based on a number of assumptions (ETHPOP[12]). Similar work to produce inter census estimates should be taken forward by the Scottish Government and the NRS within the next six months.

Recommendation 5: Social care data

29.   At present, the provision of social care is highly varied across local authorities and data is not collected in a harmonised manner to facilitate robust analysis. There are considerable efforts to improve the quality and harmonisation of data ongoing and the inclusion of ethnicity within such efforts is important. The need for social care provision that is tailored to an ethnically diverse population is likely to increase substantially in coming years, as the proportion of older people who are minority ethnic increases. The Scottish Government and local authorities must make a clear commitment to address data deficits on ethnicity within the social care system.

Recommendation 6: Flexibility in data collection

30.   The analysis of administrative data provides a number of advantages for monitoring ethnic inequalities, including the large size of datasets (which allows minority ethnic groups to be analysed) and its relative efficiency and affordability. However, administrative data will not always be appropriate and there will continue to be a need for bespoke data collection for specific purposes, including monitoring the needs of particularly vulnerable groups or when administrative data does not capture the required information. For example, migrants who have no recourse to public funds are a particularly vulnerable group and specific data collection efforts may be required to respond to their needs. Sufficient resources

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[11] https://www.nrscotland.gov.uk/files/statistics/consultation-groups/pams-10-10-pop-est-ethnic-group.pdf
[12] https://www.ethpop.org/

will need to be made available for data collection for these specific purposes. Furthermore, existing survey datasets often do not include large enough groups of minority ethnic people to allow analyses by ethnicity. Consideration should be given to the need for boosting samples of ethnic minority participants. Often there will be a strong case for collecting qualitative data to supplement the quantitative data that has been the focus of this paper.

Improving ethnicity data collection at source – Advice and Recommendations

Recommendation 7: Co-ordinated Action

31.   A co-ordinated set of initiatives must be put in place by the Scottish Government and NHS Scotland as soon as possible building on the lessons from past successes to improve recording of ethnicity within health databases. The COVID-19 pandemic provides a clear illustration of the importance of collecting this data, so such action has a greater chance of success than in the past. These initiatives cannot be one-off projects but rather a sustained plan of action that embeds the process of ethnicity data collection in the culture of the NHS in Scotland.

Recommendation 8: Primary Care Health Ethnicity Data Collection

32.   Collection of ethnicity information at the time of GP registration provides an opportunity for substantial improvements to health ethnicity data. The current level of completeness is low, so mandating ethnicity data collection within general practice must be taken forward by the Scottish Government. However, the pressures on general practice are considerable at this time, so there is a need to ensure partnership with GPs, the Royal College of General Practitioners and other primary care staff to explore how best to take this work forward.

Recommendation 9: Participation by Minority Ethnic People and Communities

33.   Minority ethnic people and communities must be at the heart of any initiatives to improve ethnicity recording and closely involved in driving forward such initiatives. Minority ethnic communities racialised by the data process need to be involved to make sure it is worthwhile and not just another tick box exercise. This will help ensure the work meets the needs of Scotland's diverse communities and also facilitate success. It should be noted that not being willing to provide ethnicity information is rare when the reason for its collection is appropriately explained.

34.   The perspectives of minority ethnic people and communities should also be brought into the data collection process to ensure greater understanding in relation to the importance of safeguarding data. Caldicott guardians should be supported to understand how racism and racialisation plays out in the systems of data collection and analysis in order to inform their responsibilities regarding the lawful and ethical processing of information. This should include awareness of the risks of both use and non-use of data.

Improving Workforce Data

Recommendation 10: Monitoring workforce data

35.   COVID-19 has highlighted the issue of racism experienced by many of those working in the health and social care sector. While overt racism is relatively uncommon, evidence of institutional discrimination has accumulated. For example, minority ethnic groups have been more likely to report inadequate or needing to re-use personal and protective equipment[13]. More generally and before the COVID-19 pandemic, a special series within the BMJ medical journal highlighted the systemic nature of racism within Medicine, with minority ethnic groups less likely to be promoted and occupy positions of prestige.

36.   Monitoring of the minority ethnic diversity of frontline NHS and social care staff is required urgently by NHS Scotland to be able to appropriately respond to concerns raised by employee representative bodies such as the Unison and STUC Black workers committees. In respect of COVID -19, unions identified that Black workers were disproportionately exposed to COVID risks. The experience of Black workers and others highlights both the legal duty to respond to these minority ethnic workers and also instigate transformative consultations with workers and others to respond to the experience of racialisation in our institutions and systems.

37.   NHS Scotland and public service organisations should put in place effective and sustained systems to record ethnicity of the workforce and analyse workforce data and surveys to show the variation in experience of employment by ethnic group.

Recommendation 11: NHS Workforce Data

38.   NHS Education for Scotland (NES) are responsible for collecting, analysing and publishing NHS workforce data and high level ethnicity data is published annually. NES must address data quality issues and regularly report on progress in achieving equity in relation to NHS workforce issues for minority ethnic staff. This includes information on pay, promotion and recruitment. We would expect NES to monitor the quality and completeness of the data and report regularly on any gaps within that data. We would also expect the Scottish Government to provide oversight of progress on improvement.

Recommendation 12: Social Care Workforce Data

39.   At present, no national workforce data for social care is available for Scotland, with individual local authorities responsible for its provision. Data does not appear to be regularly collated or reported and this may mean that monitoring by ethnicity is not possible within much of Scotland due to the relatively small numbers of minority ethnic people in many individual local authorities. Given the

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[13]   Nguyen LH, Drew DA, Graham MS, et al. Risk of COVID-19 among front-line health-care workers and the general community: a prospective cohort study. The Lancet Public Health 2020.

integration of health and social care, joint work by Scottish Government and local authorities is needed to ensure that minority ethnic workers are treated equitably within social care. This may require data specifications to be included within contracting processes made between commissioners and providers, informed by nationally agreed data standards. This would allow minority ethnic groups to be studied at a national level.

Reporting, Accountability and Governance

Recommendation 13: Reporting data by ethnicity

40.   The COVID-19 pandemic has highlighted the need for ongoing monitoring of health (and other) data by ethnicity. The lack of reporting of datasets that are available by ethnicity can serve to make ethnic inequalities in health hidden and threatens the case for maintaining data quality. It is therefore crucial that data when available and robust enough for analysis are published and disseminated to policymakers, practitioners and communities. We recommend that:

- A dashboard is created by the Scottish Government to report regularly on the impact of decisions made by the public bodies on minority ethnic people and communities during the COVID-19 pandemic, this should also include data from the disruption to health and social care (second-order effects), and financial poverty (third-order effects).
- Public Health Scotland must publish an annual monitoring report on ethnic group health inequalities in Scotland.
- The National Performance Framework must include specific indicators on the impact of racialised inequalities or the impact of systemic racism on minority ethnic people to supplement the current 81 National Indicators.

Recommendation 14: Accountability and Governance

41.   In order to ensure that issues on racism and ethnicity are taken seriously then people within Scottish Government, the NHS, local authorities and other public sector organisations need to be accountable for taking forward this advice and recommendations with speed and commitment. Putting a measurable racism and ethnicity objective in every Scottish Government Health Director and NHS Chief Executive's performance objectives would provide some motivation and personal incentive to drive this forward. The ERG would be happy to discuss what these objectives could be.

42.   Each public body that has duties under the Equality Act should publish its scheme of governance to ensure adequate data recording, analysis and presentation of information to demonstrate their commitment to monitoring and tackling inequalities. Public bodies should do this in the interests of access, experience and outcome for services to minority ethnic groups that it provides, providing specific analysis of conditions of interest such as COVID-19, and the fair employment of staff by ethnic group using agreed indicators.

43.   In line with the reporting recommendation in relation to the National Performance Framework above, actions taken to improve indicators contained

within the National Performance Framework should be publicly reported, with designated Scottish Government leads for responding to each indicator.

Timescale for delivery of recommendations

<u>Immediate action required</u>

Recommendation 1: Make ethnicity a mandatory field for health databases
Recommendation 2: Linkage to census – COVID-19 response
Recommendation 7: Co-ordinated action
Recommendation 9: Participation by Minority Ethnic People and Communities
Recommendation 10: Monitoring workforce data
Recommendation 13: Reporting data by ethnicity - Dashboard

<u>Short-term action required (work started within the next six months, unless other timescale provided in the recommendation text)</u>

Recommendation 2: Linkage to census – monitoring and research
Recommendation 3: Develop a CHI field
Recommendation 4: Ethnic Group populations
Recommendation 5: Social Care Data
Recommendation 8: Primary care health ethnicity data collection
Recommendation 11: NHS Workforce Data
Recommendation 12: Social Care Workforce Data
Recommendation 14: Accountability and Governance
Recommendation 13: Reporting data by ethnicity – National Performance Framework

<u>Longer-term action required</u>

Recommendation 6: Flexibility in data collection
Recommendation 13: Reporting data by ethnicity – Annual Report