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Ethnicity coding in English health service datasets

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This report uses Hospital Episode Statistics (HES) data (year range 2010/11 to 2019/20). Copyright © 2020, re-used with permission. A data-sharing agreement with NHS Digital (DARS-NIC-226261-M2T0Q) governed access to and use of HES data for this project.

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Key points

- The Covid-19 pandemic has highlighted the extent and impact of ethnic disparities in health to communities, health services and government. However, poor data about ethnicity has obscured the true extent of ethnic disparities in the impact of the pandemic.

- Many health related datasets do not routinely include ethnicity. Ethnicity recorded within hospital records is used instead, but mis-coding in hospital data mean that estimates of Covid-19 infections, hospitalisations and deaths could be over or under counted in minority ethnic and White groups.

- Our analysis of the quality of ethnicity coding in hospital datasets found data quality problems including:

    - incomplete coding and inconsistent use of codes

    - an excessive and growing proportion of patients have ethnicity recorded as “not known”, “not stated” or “other” which impedes reliable analyses of ethnic differences, and

    - systematic biases in data quality - for example, data quality is worse in London, in adults of working age, and for patients with short hospital stays.

- Importantly, data quality problems affect records for minority ethnic patients disproportionately.

- The lack of comprehensive, high quality data on health and mortality by ethnicity is a significant obstacle to understanding ethnic inequalities in health, and therefore how the diverse health needs of different ethnic groups can be addressed.

- Action is needed to improve data quality at source by developing and implementing up to date guidance on ethnicity coding for health service providers and GPs.

- In the meantime, users of data need to be aware of problems with ethnicity coding, and analysis and reporting of ethnicity data quality issues is essential.

1 Summary

Introduction

The Covid-19 pandemic has highlighted the extent and impact of ethnic disparities in health to communities, health services and government.

The pandemic has also demonstrated that the limited availability of ethnicity data and the quality of the data are reducing understanding of, ethnic inequalities, and the ability to identify effective responses. Current challenges range from the absence of ethnicity data in essential data sources such as death registrations (from which mortality statistics are derived), to poor coverage in primary care data, outdated ethnicity codes used within the NHS compared with those used in the 2011 and 2021 censuses, and systematic differences in ethnicity coding between White and minority ethnic groups.

Effectively using currently available ethnicity data and improving the quality of the data are vital for identifying and addressing ethnic disparities in health.

For this report we have analysed the quality and consistency of ethnicity coding within widely used health datasets, in order to inform users of ethnicity data and identify the actions needed to improve the quality of the underlying data.

Along with providing insights for data users, the report sets out recommendations for policy-makers and organisations that generate and regulate health data.

Approach

We conducted a descriptive analysis of ethnicity category coding in English NHS hospital datasets and the Community Services Data Set (CSDS). We assessed the completeness, validity and consistency of ethnic category coding, and explored variations in coding between different groups of patients and services. We also compared the distribution of people from ethnic groups in health care datasets by age group with population estimates from the Office for National Statistics (ONS).

We analysed data from 2010/11 to 2019/20 on inpatients, outpatients, accident and emergency (A&E) attendances – including using the new Emergency Care Data Set (ECDS) – and community services referrals. These five datasets use the ethnicity codes used in the 2001 census.

Our analysis complements work by Public Health England and the ONS on how to address data quality problems with ethnicity data in producing health statistics[1].

Key findings

We found that, overall, the proportion of health records containing the patient's ethnicity code was high, with 87% of the over 17 million inpatient spells having a valid ethnic group recorded in 2019/20, a slightly higher proportion than for outpatient attendances (83% of over 96 million) and A&E attendances (86% of over 19 million). In addition, 8.5% of inpatient records had a code of 'not stated', which, although a permitted code, is not useful for analysis purposes. However, 8.8% of inpatient spells had an 'other' ethnic group coded. These proportions have increased since 2010/11, from 6.1% (not stated) and 7.2% ('other' ethnic groups).

Importantly, records without ethnicity codes were not distributed evenly between ethnic groups. For most ages, specific minority ethnic groups were under-represented in health data when compared with national population estimates by ethnic group, while 'other' ethnicity codes were over-represented. Further, analysis of the consistency of coding for the same individual indicated that records of patients from minority ethnic groups were less likely to be recorded consistently over time or have a specific code. 'Other','

[1] Nuffield Trust (2021) 'Nuffield Trust and NHS Race and Health Observatory workshop on ethnicity coding'. www.nuffieldtrust.org.uk/files/2021-04/workshop-on-ethnicity-coding-20210330-notes.pdf.

not stated', 'not known' and invalid codes were not uniformly distributed between ethnic groups. Excluding these missing ethnicity data from analysis is likely to introduce bias in the results, and impacts most on minority ethnic patients' records.

There were differences in coding according to patient and service characteristics, which indicate that there are systemic factors that impact on data quality. For example:

- the proportion of inpatient spells with ethnicity not stated was highest for men aged 16–64 (at over 10%) and lowest for the over-80s (6.5%) and babies and children under five (at 5.8%)

- coding of ethnicity was more complete for patients who died in hospital compared with those discharged (3.2% of records for the former were recorded as ethnicity not known versus 4.0% for the latter, and 6.5% of records for the former were recorded as ethnicity not stated versus 8.6% for the latter)

- coding of ethnicity in London showed more patients with ethnicity not stated (14%), or recorded in one of the 'other' categories (24%), compared with 8.5% not stated and 8.8% 'other' across England

- data quality for independent health care providers was worse than for NHS providers, with only 62% of records having a known, stated ethnicity category.

Almost a half of inpatients had more than one inpatient record over a three-year period (2017/18 to 2019/20), and overall, almost three-quarters of patients had more than one contact (as an inpatient, outpatient or A&E attendee) over the three years. A third of patients with multiple contacts had inconsistent ethnicity codes.

Inconsistent codes disproportionately impacted on minority ethnic groups:

- Patients who were White Irish, 'other White', 'other Mixed' or from 'any other ethnic group' were inconsistently coded as White British.
- 'Other' impacted on the coding of Asian and Black ethnic groups – for example in the A&E dataset, 7.5% of Indian patients also had a code of 'other Asian', and 9.1% of Black Caribbean patients and 7.6% of Black African patients also had a code of 'other Black'.
- Up to 40% of 'any other ethnic group' patients also had an alternative ethnic group code, with minority ethnic groups comprising two-thirds of patients impacted.

Conclusions

The Covid-19 pandemic has highlighted significant health inequalities between minority ethnic and White groups, and between different minority ethnic groups. The diversity of health patterns between different ethnic groups, and the need for a differentiated response, are now widely recognised. However, the lack of comprehensive, high-quality data on health and mortality by ethnicity is a significant obstacle to understanding ethnic inequalities in health, and therefore how the diverse health needs of different ethnic groups can be addressed.

Accurate ethnicity coding to the most granular code possible is crucial, because of significant differences between ethnic groups in terms of health outcomes, experiences of health services, health risk factors and wider determinants of health such as deprivation. The proportion of records coded as 'other Asian', 'other Black' and 'other White' is higher in health records than in other sources, indicating miscoding. This is unsatisfactory given differences in health risks within broad groups, for example between Pakistani, Bangladeshi and Indian groups, and between Black Caribbean and Black African groups.

Our findings have two important implications:

- **Making the best use of available data**. Analysis using ethnicity data as released will overcount some categories of patients (particularly 'other' ethnic categories) and therefore undercount activity for specific minority ethnic groups. Understanding and reporting on the quality of ethnicity data is essential.

- **Looking ahead, improving the underlying quality of data**. Urgent action is required to address poor-quality ethnicity coding data at source – when NHS organisations and general practitioners (GPs) collect and record data from patients.

These improvements are essential for enabling ethnic disparities in health to be understood and addressed in the future.

From our analysis we have set out areas for further research, to enable data quality issues to be understood and addressed.

Recommendations

Responsibility for the coding and quality of ethnicity data in health records is dispersed across a number of organisations, national and local, including the Department of Health and Social Care, NHS England and NHS Improvement, NHS Digital, NHS organisations and GPs. All have a role to play in improving the quality of the ethnicity data available for analysing and addressing ethnic inequalities in health.

Our recommendations relate to:

- improving the analytical potential of currently available data, notwithstanding the associated data quality problems (short term)

- improving the quality of the underlying source data (medium term).

To improve the analysis of ethnicity using existing health data, we recommend the following:

- NHS Digital regularly publishes data on the quality of ethnicity coding within the Data Quality Maturity Index and this should also include the proportion of records coded as not known, not stated, an 'other' group and 'any other ethnic group'.
  Action: NHS Digital

- The UK Statistics Authority should review the quality of ethnicity coding within health statistics, in order to identify and make recommendations for improving the quality and consistency of data.
  Action: UK Statistics Authority

- Analyses of health care activity should routinely include the ethnic dimension, and consider and report on the quality of coding.
  Action: Data analysts and users

- Analysis methods to address data quality issues in analysis of ethnic differences should be clearly described and, where appropriate and feasible, the methodology developed by Public Health England for reassigning ethnicity in health records should be used.
  Action: Data analysts and users

To improve the quality of source data on ethnicity in the future, we recommend the following:

- The Health Inequalities Improvement Programme at NHS England and NHS Improvement should work with NHS Digital and the NHS Race and Health Observatory on developing and implementing guidance for ethnicity coding in the NHS, in keeping with priority 3 of the NHS England and NHS Improvement operational guidance[2]. Guidance needs to cover NHS-funded care, wherever this is provided, and include protocols for

[2] NHS England and NHS Improvement (2021) 2021/22 Priorities and Operational Planning Guidance. NHS England and NHS Improvement. www.england.nhs.uk/wp-content/uploads/2021/03/B0468-nhs-operational-planning-and-contracting-guidance.pdf.

asking patients their ethnicity and recording it in health records, using the updated 2021 census categories.
Action: NHS England and NHS Improvement

- Integrated care system leaders should use their role to reduce inequalities to improve the quality of ethnicity coding in health records, ensuring that the updated guidance on ethnicity coding is implemented, and learning from local partners and spreading best practice in data quality and analysis.
Action: Integrated care system leaders

- Boards and leaders of NHS providers and commissioners, and GP practices, should take ownership of the quality of ethnicity coding for their patients, ensure that the updated guidance is implemented, routinely monitor the quality of coding, identify how it can be improved, and put in place actions to achieve this. Once guidance on ethnicity coding is available, all health care providers should endeavour to record/update/correct ethnicity coding in all patient records.
Action: All NHS providers and commissioners, and GP practices

- The Care Quality Commission should incorporate the assessment of the quality of ethnicity coding in its inspections and ratings, and address independent providers' poor-quality coding, taking action where the data suggest possible shortfalls and a failure to implement the updated guidance.
Action: Care Quality Commission

2 Context

Why the coding of ethnicity matters

The Covid-19 pandemic has brought the extent and impact of ethnic disparities in health to the forefront for communities, health services and government. Several studies and reports[3] have shown that the risk of Covid-19 infection, severe disease and mortality is significantly higher among people from minority ethnic communities than in the White population. Differences in health outcomes between ethnic groups are not unique to Covid-19,[4,5] but the pandemic has drawn attention to them, and this focus provides a potential opportunity to address long-standing inequalities in health care.

The pandemic has also demonstrated that limited and poor-quality ethnicity data are reducing understanding of, ethnic inequalities, and the ability to identify effective responses. Comprehensive and high-quality ethnicity data are essential for improving the health and wellbeing of people from minority ethnic communities. They play a vital role in:

- supporting needs assessments and service planning
- enabling the monitoring of equity of access and outcomes
- informing clinical practice
- improving the evidence on inequalities in population-based risks and outcomes

[3] The Independent Scientific Advisory Group for Emergencies (SAGE) (2020) *Disparities in the Impact of COVID-19 in Black and Minority Ethnic Populations: Review of the evidence and recommendations for action*. The Independent SAGE Report 6. The Independent SAGE. www.independentsage.org/wp-content/uploads/2020/07/Independent-SAGE-BME-Report_02July_FINAL.pdf.

[4] Public Health England (2017) *Public Health Outcomes Framework: Health equity report: Focus on ethnicity*. Public Health England. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/733093/PHOF_Health_Equity_Report.pdf.

[5] Raleigh V and Holmes J (2021) 'The health of people from ethnic minority groups in England'. www.kingsfund.org.uk/publications/health-people-ethnic-minority-groups-england. Accessed 11 May 2021.

- supporting high-quality research.

Ethnicity data from hospital datasets are widely used in analysis of other health related data, including mortality, amplifying the impact of data quality issues further.[6]

What is already known about the quality of ethnicity coding?

Current challenges in terms of ethnicity coding range from the absence of ethnicity data in essential data sources such as death registrations (from which mortality statistics are derived), to poor coverage in primary care data,[7] outdated ethnicity codes used within the NHS compared with the 2011 and 2021 censuses, and systematic differences in coding between White and minority ethnic groups.

Raleigh and Goldblatt[8] set out evidence of the poor quality of ethnicity coding across a range of health datasets, including:

- weak agreement between ethnicity coding in hospital data compared with self-reported ethnicity as captured in the 2010 Cancer Patient Experience Survey in England,[9] with routine hospital data miscoding between 20% and 35% of patients from major ethnic groups (Indian, Pakistani, Bangladeshi,

[6] Public Health England (2020) *Disparities in the risk and outcomes of COVID-19*. Public Health England. 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. Accessed 18 May 2021.

[7] Mathur R, Rentsch CT, Morton CE, Hulme WJ, Schultze A and others (2021) 'Ethnic differences in SARS-CoV-2 infection and COVID-19-related hospitalisation, intensive care unit admission, and death in 17 million adults in England: an observational cohort study using the OpenSAFELY platform', *The Lancet* 397(10286), 1711–24. https://doi.org/10.1016/S0140-6736(21)00634-6. Accessed 11 May 2021.

[8] Raleigh V and Goldblatt P (2020) *Ethnicity Coding in Health Records*. The King's Fund. www.kingsfund.org.uk/publications/ethnicity-coding-health-records.

[9] Saunders CL, Abel GA, El Turabi A and Lyratzopoulos G (2013) 'Accuracy of routinely recorded ethnic group information compared with self-reported ethnicity: evidence from the English Cancer Patient Experience survey', *BMJ Open* 3(6). https://bmjopen.bmj.com/content/3/6/e002882. Accessed 11 May 2021.

Chinese, Black Caribbean and Black African)

- very poor agreement between the ethnicity coding of minority ethnic groups in primary care and hospital records – for patients of South Asian ethnicity, the agreement was only 50%, and weaker still for other ethnic groups, while there was high concordance for the White group[10]

- evidence from a qualitative study of substantial variations in data classification, and practical challenges in data collection and usage, which undermine the integrity of the data collected[11]

- the over-representation of 'other' codes in NHS datasets, including 'any other ethnic group', 'other Black', 'other Asian' and 'other White', which has led to disproportionately high rates of Covid-19 infections and mortality being recorded for the 'other' groups, and has been identified in other contexts, including mental health services[12] and detentions under the Mental Health Act 1983[13] – overuse of the 'other' categories inevitably means that ethnicity is not being recorded correctly for every ethnic group, including the White group.

The legal framework and policy context

Reducing inequalities in health is a moral imperative. It is also enshrined in legislation. The Health and Social Care Act 2012 introduced specific legal duties for health bodies in England to have regard to inequalities in the

[10] Mathur R, Bhaskaran K, Chaturvedi N, Leon DA, vanStaa T, Grundy E and Smeeth L (2014) 'Completeness and usability of ethnicity data in UK-based primary care and hospital databases', *Journal of Public Health (Oxford, England)* 36(4), 684–92, doi: 10.1093/pubmed/fdt116.

[11] Morrison Z, Fernando B, Kalra D, Cresswell K, Robertson A and Sheikh A (2014) 'The collection and utilisation of patient ethnicity data in general practices and hospitals in the United Kingdom: a qualitative case study', *Informatics in Primary Care* 21(3), 118–31.

[12] Cabinet Office (2017, revised 2018) *Race Disparity Audit*. Cabinet Office. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/686071/Revised_RDA_report_March_2018.pdf.

[13] UK Government (2021) 'Detentions under the Mental Health Act'. www.ethnicity-facts-figures.service.gov.uk/health/mental-health/detentions-under-the-mental-health-act/latest#:~:text=. Black people were most likely to be the detained ethnic group – 232.8 detentions for every 100,000 people.

provision of health services and the outcomes achieved. The Race Relations Amendment Act 2000 built on previous legislation (the Race Relations Act 1976) designed to ban discrimination on grounds of race and requires public authorities to promote race equality. And the Equality Act 2010 extended anti-discrimination legislation to cover nine protected characteristics, including race.

Within the NHS, the requirement to address inequalities has been embedded within successive strategic plans[14] and operational guidance, most recently in the planning guidance for 2020/21.[2] The latest guidance builds on the 31 July 2020 letter from NHS England and NHS Improvement to the NHS about the third phase of the NHS response to Covid-19,[15] requiring the NHS and GPs to comprehensively record ethnicity. Integrated care systems are now required to:

> Ensure datasets are complete and timely: systems are asked to continue to improve the collection and recording of ethnicity data across primary care, outpatients, A&E, mental health, community services, and specialised commissioning… Systems should also implement mandatory ethnicity data reporting in primary care, to enable demographic data to be linked with other datasets and support an integrated approach to performance monitoring for improvement.[16]

The renewed focus on recording ethnicity in health records is welcome. However, without complementary action to improve data quality, it will not be sufficient to allow valid analyses of ethnic disparities. Accurate recording of ethnicity using specific ethnicity codes is essential for meaningful analysis.

How should ethnicity be coded in health care records and what are the challenges?

[14] NHS England (2019) *The NHS Long Term Plan*. NHS England. www.longtermplan.nhs.uk/publication/nhs-long-term-plan. Accessed 11 May 2021.

[15] NHS England and NHS Improvement (2020) 'Important – for action – third phase of NHS response to Covid-19'. Letter. www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/07/20200731-Phase-3-letter-final-1.pdf.

[16] NHS England and NHS Improvement (2021) 2021/22 *Priorities and Operational Planning Guidance: Implementation guidance*, p. 12. NHS England and NHS Improvement. www.england.nhs.uk/wp-content/uploads/2021/03/B0468-implementation-guidance-21-22-priorities-and-operational-planning-guidance.pdf.

Ethnicity is a complex, multidimensional concept, often defined by features such as a shared history, common cultural traditions and common geographical origin, language and literature.[8] It is therefore a highly subjective classification, but one which an individual is required to articulate within a simple data item structure. As such, the only true meaningful categorisation is self-definition.

The principle that ethnic group should be self-identified, rather than ascribed by someone else, underpins ONS guidance for the collection and classification of ethnic group, national identity and religion data in the UK.[17] Although the guidance relates to how questions should be asked in social surveys, the general principles also apply to recording ethnicity in health records. The ONS recommends that the ethnic group question should be asked in a way that allows the respondent to see all possible response options before making their decision, recognising that categories are not exclusive in all cases. Individuals may change their self-identified ethnicity over time and dependent on circumstances: for example, while more than 90% of White, Chinese and South Asian people self-identified with the same ethnicity between the 1991 and 2001 censuses, almost one in four (23%) Black African and Black Caribbean people did so.[18]

Guidance for the NHS on the recording of ethnicity dates back to 2001, when a Data Set Coding Notice (DSC Notice: 02/2001)[19] was issued to NHS organisations after the passing of the Race Relations Amendment Act 2000. This enshrined the principle of self-identification, and required the NHS to use the 17 ethnic categories included in the 2001 census. In addition to issuing the Data Set Coding Notice, the Health and Social Care Information Centre held a

[17] Office for National Statistics (2016) 'Measuring equality: a guide for the collection and classification of ethnic group, national identity and religion data in the UK'. www.ons.gov.uk/methodology/classificationsandstandards/measuringequality/ethnicgroupnationalidentityandreligion. Accessed 11 May 2021.

[18] Platt L, Simpson L and Akinwale B (2005) 'Stability and change in ethnic groups in England and Wales', *Population Trends* (121), 35–46. www.researchgate.net/profile/Bola-Akinwale-2/publication/7516932_Stability_and_change_in_ethnic_groups_in_England_and_Wales/links/54de12700cf22a26721e4f98/Stability-and-change-in-ethnic-groups-in-England-and-Wales.pdf.

[19] NHS Digital (2017) 'Information Standards Notices and Data Set Change Notices'. https://nhs-prod.global.ssl.fastly.net/binaries/content/assets/legacy/excel/m/0/isns-and-dscns-archive.xlsx. Accessed 11 May 2021.

series of events with NHS organisations to introduce the ethnic category code changes and discuss the implications with key staff, and training materials for use nationally were developed and provided to the NHS.

It is unclear the extent to which NHS organisations are following the principle of self-identification, or whether health workers understand the need for high-quality data on ethnicity.[20] Asking patients to complete a form asking for their ethnicity can undoubtedly present challenges in a clinical setting when staff may be under pressure and patients are unwell or lack capacity. Hence, it is possible that this requirement is not always followed. It may also occur if staff are simply unaware that self-reporting is the required procedure or, for example, if there is uncertainty about whether staff are required to ask for ethnicity again if it is already recorded for an earlier episode of care. Further, the response options available in NHS systems may not be consistent across different organisations and care settings.

[20] Morrison Z, Fernando B, Kalra D, Cresswell K, Robertson A and Sheikh A (2014) 'The collection and utilisation of patient ethnicity data in general practices and hospitals in the United Kingdom: a qualitative case study', *Informatics in Primary* Care 21(3), 118–31. https://hijournal.bcs.org/index.php/jhi/article/view/63/103. Accessed 11 May 2021.

Importantly, guidance for the NHS has not been updated since 2001. The categories used within the NHS are no longer in line with the census categories for 2011 or 2021. This presents a specific challenge in comparing health data with population estimates: patients are not being presented with the same response options as the data sources used for denominators to calculate population rates. Further, data collection systems within NHS organisations use a variety of coding systems, which may not map directly onto the categories identified in the NHS Data Dictionary.

Epidemiological analyses require linkage across different datasets, and population denominators to calculate rates, for example for mortality or hospital admissions. Ensuring that ethnicity is self-reported in the NHS using a consistent set of codes to other population and health data is essential if discrepancies and biases in the data are to be avoided. The ONS and Public Health England (PHE) are taking measures to ensure their analyses are as robust as possible.[21] However, it is unclear whether data quality issues are widely known and taken into account by users of NHS data across the NHS, within academia and among policy-makers.

Incomplete or inaccurate ethnicity data mean that we cannot reliably assess the health needs of, and access and outcomes for, different ethnic groups. Furthermore, analyses may actually be misleading if particular ethnic groups are over-coded or under-coded.

This report

Our analysis in this report of the quality of ethnicity coding within widely used English hospital and community services datasets provides a thorough assessment of the quality of ethnicity coding, and identifies significant data quality issues. This will inform data users about the issues, so they can take account of them in their analyses. We also identify actions that need to be taken to improve the underlying quality of data on ethnicity.

[21] Nuffield Trust (2021) 'Nuffield Trust and NHS Race and Health Observatory workshop on ethnicity coding'. www.nuffieldtrust.org.uk/files/2021-04/workshop-on-ethnicity-coding-20210330-notes.pdf.

3 Data and methods

Data

We analysed ethnicity coding using Hospital Episodes Statistics (HES) on inpatients, outpatients and A&E (see Table 1), along with data for 2019/20 from the Emergency Care Data Set (ECDS) and the Community Services Data Set (CSDS) (see Appendix 1). We did not have access to any primary care data for this project.

The volume of data recorded in each HES dataset has increased over time. While this reflects increased activity in many cases (for example, emergency admissions), it may in part reflect changes in what activity data providers have submitted. For example, in recent years, more activity from minor injury units has been recorded in the A&E dataset, and there has been more non-consultant-led activity in the outpatient dataset.

Table 1: Data included from Hospital Episodes Statistics (millions)

Financial year	Inpatients[a]		Outpatients[b]		A&E	
	Patients	Spells	Patients	Spells	Patients	Attendances
2010/11	8.7	14.8	18.2	70.3	10.8	16.2
2011/12	8.8	14.9	18.5	72.6	11.5	17.6
2012/13	8.8	15.1	19.1	75.5	11.9	18.3
2013/14	8.9	15.4	20.5	82.1	11.9	18.5
2014/15	9.1	15.8	20.5	85.6	12.6	19.6
2015/16	9.2	16.2	20.8	89.4	13.0	20.5
2016/17	9.4	16.5	21.2	93.9	13.1	20.9
2017/18	9.4	16.5	21.4	93.5	13.2	21.3
2018/19	9.6	17.1	22.0	96.4	13.8	22.4
2019/20	9.5	17.1	23.6	96.4	12.4[c]	19.4[c]

Notes:

a Inpatient activity was grouped into spells, and regular day and night attendances were excluded.

b Only attended outpatient appointments were included.

c A&E data cover April 2019 to January 2020 due to the change from A&E HES to the ECDS.

We undertook more detailed analysis using inpatient data, because they were more complete in terms of ethnicity. For most of the analysis we focused on A&E HES records, rather than the ECDS, given the longer time series for the former, and did not carry out detailed analysis of the community services dataset, given the low proportion of records with an ethnic group code.

Ethnicity groups in NHS datasets

The ethnic group codes used in NHS datasets relate to the ethnicity codes used in the 2001 census (see Table 2). Codes A to S represent different ethnic groups, with code S being a catch-all for 'any other ethnic group'. In addition, a code of 'not stated' (Z) is intended to be used when an individual chooses not to give their ethnicity. The 'not known' group (99, or X before 2013) is intended to be used for people who were not asked their ethnicity, for people who were unable to answer, and for any missing or other values not in the NHS Data Dictionary. It should be noted that ONS codes for the 2011 census include additional codes that are not available in NHS datasets: a separate code for people from an Arab background and separate codes within the White group for people from a Roma background and people from a Gypsy or Irish Traveller background.

Table 2: Ethnicity categories in NHS datasets

	Code	Ethnic category description	Other?
Valid ethnic group	A	British (White)	
	B	Irish (White)	
	C	Any other White background	Other
	D	White and Black Caribbean (Mixed)	
	E	White and Black African (Mixed)	
	F	White and Asian (Mixed)	
	G	Any other Mixed background	Other
	H	Indian (Asian or Asian British)	
	J	Pakistani (Asian or Asian British)	
	K	Bangladeshi (Asian or Asian British)	
	L	Any other Asian background	Other
	M	Caribbean (Black or Black British)	
	N	African (Black or Black British)	
	P	Any other Black background	Other
	R	Chinese (other ethnic group)	
	S	Any other ethnic group	Other
Not stated	Z	Not stated	
Not known	X	Not known (before 2013)	
	99	Not known (since 2013)	
	?	Missing or values not in the NHS Data Dictionary	

Population data by ethnic group

In our analysis we used the 2018 population estimates by ethnic group derived from the census and migration data.[22] These are available by age and sex, and so enabled us to compare coding within age groups.

Limitations with currently available population estimates by ethnic group, alternative sources and trends over time in the ethnic composition of the population are discussed in Appendix 2.

Research questions and methods

In this section we set out our three research questions, along with the methods we used to answer them.

Research question 1: How does ethnic coding in NHS datasets compare with the ethnic composition of the general population?

Comparison with the ethnic composition of the general population provides context for interpreting coding by ethnic group within health datasets.

We compared population estimates by ethnic category from the ONS for each age group, with the distribution of ethnicity codes in inpatient data for 2019/20, to examine how different groups were represented in health care datasets. Differences between ethnic groups, even with age groups, could indicate differential need or access to services, as well as differences in the completeness or validity of ethnicity coding.

[22] Office for National Statistics (2018) 'Population denominators by ethnic group, regions and countries: England and Wales, 2011 to 2018'. www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/adhocs/008780populationdenominatorsbyethnicgroupregionsandcountriesenglandandwales2011to2017. Accessed 11 May 2021.

Research question 2: To what extent is ethnicity coding complete and valid and how does this vary between groups of patients?

We analysed the completeness and validity of ethnic category coding across NHS datasets. As a result of previously identified issues with the over-representation of 'other' groups, we also examined the proportion of 'other' codes within the datasets, combining all of the 'other' categories.

Using these measures (see Box 1 for definitions), we examined:

- what proportion of records have an ethnic group coded in the most recent year for all five datasets, including the Emergency Care Data Set (ECDS) and the Community Services Data Set (CSDS)
- how coding has changed over time, from 2010/11 to 2019/20, in HES data
- how data quality varies between sub-groups of patients and across the patient pathway, focusing on data from 2019/20.

Our scope in this project was to describe ethnicity coding quality and variation, to highlight these to users of ethnicity data. We did not undertake a multivariate analysis to explore the relationship between factors.

Box 1: Definitions of the measures of data quality used

Completeness, indicated by the proportion of not known codes: the percentage of records with a not known code (X or 99), a missing value or any other value apart from A to S or Z.

Not stated: the percentage of records with not stated code (Z) – while this is a permitted code, it does not provide data that are useable for the analysis of ethnicity.

Valid ethnic group: the percentage of records with codes A to S, and subsets of this:

'Other' groups: the percentage of records recorded as an 'other White' (C), 'other Mixed' (G), 'other Asian' (L) or 'other Black' (P), or 'any other ethnic group' (S).

Any other group: the percentage of records with code 'Any other ethnic group' (S)

Research question 3: How consistently is ethnicity coded, for patients who have multiple health records?

Finally, we assessed the consistency of ethnic category coding for individuals over time, across multiple contacts with hospitals. We constructed a patient index for any patient who appeared in the inpatient, outpatient and A&E data in 2017/18, 2018/19 or 2019/20. This index enabled us to track patients with multiple contacts across these services. We then examined the extent to which people's ethnicity records were consistent over time, and whether this varied between ethnic groups.

4 Findings

Comparison with population estimates

We compared the ethnicity of inpatients with national estimates of ethnicity in the general population, by age group. Despite limitations with currently available population data (see Appendix 2), a comparison of the ethnic distribution of inpatients and population estimates provides additional insights into potential systemic problems in ethnicity recording in health datasets.

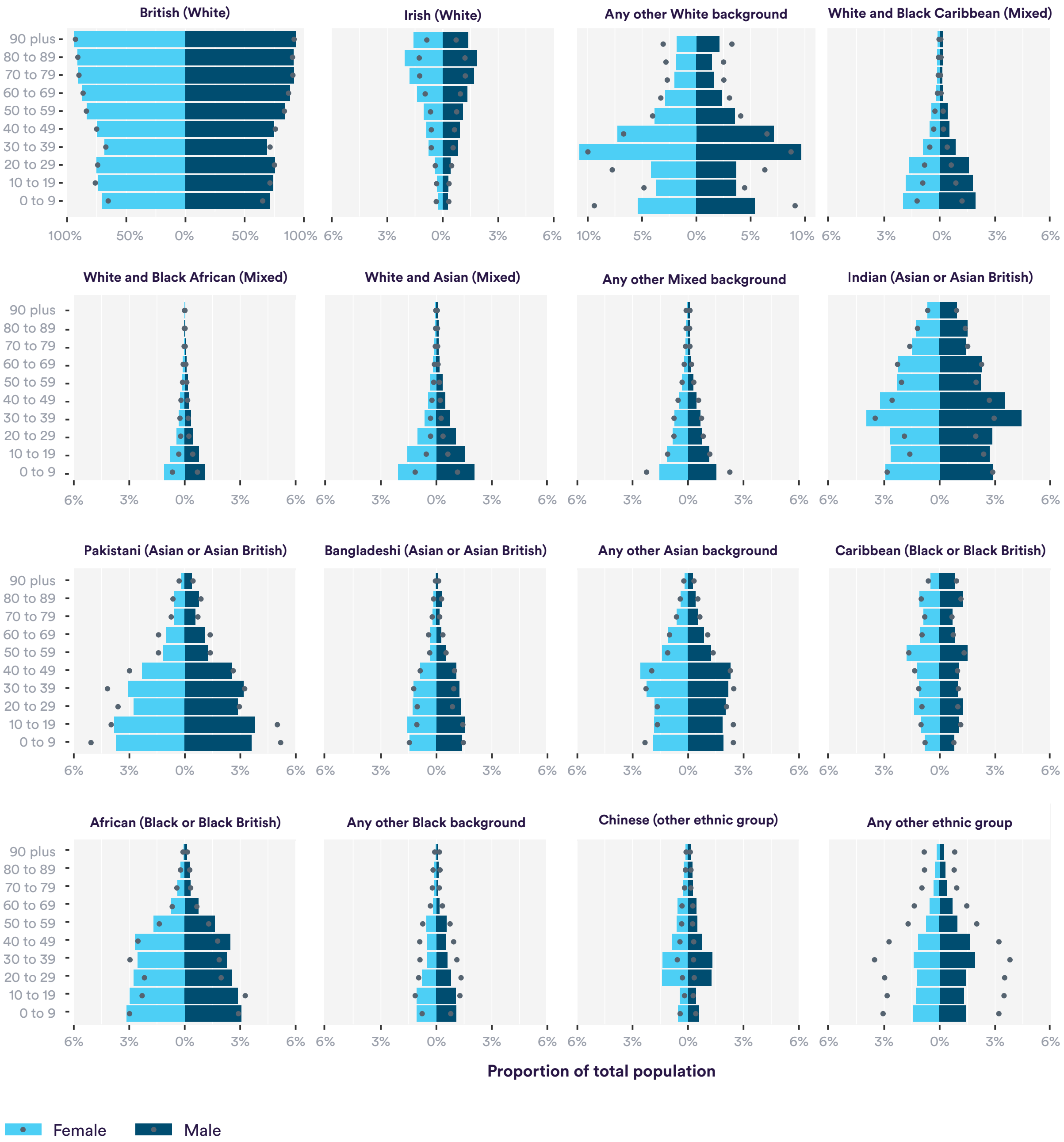
Figure 1 shows age/sex population pyramids by ethnicity for mid-2018 ONS population estimates.[22] Percentages are used to allow comparison between ethnic groups, for which the population count is very different. The distribution based on inpatient records is overlaid (using dots).

This shows that, in most cases, hospital records over-represent 'other' categories while under-representing Mixed ethnic groups, and some specific ethnic groups. For example, among the population, 1.1% of women in their 40s are recorded as being from 'any other ethnic group', but this represents 2.7% of records in the inpatient dataset. For boys under the age of 10, the population estimates indicate that around 2% of them are 'White and Asian (Mixed)', but only 1.1% of records indicate that they are in this ethnic group.

While differences in the ethnic distribution between inpatients and the general population could reflect differential access or need, the differences for 'other' groups are striking. When 2021 census data are available (expected during 2022), it will be possible to undertake a more detailed comparison against that gold standard, including analysis at the regional level.

Figure 1: Ethnicity coding in ONS population estimates and HES inpatient records

Bars represent population estimates, dots represent HES inpatient spells in 2018/19.



Notes: Our analysis was for hospital spells rather than individuals, because not all individuals have a consistent ethnicity code. However, this could mean that ethnic groups with more inpatient spells per person would account for a higher proportion of hospital records. We excluded regular day and night attendances from the analysis.

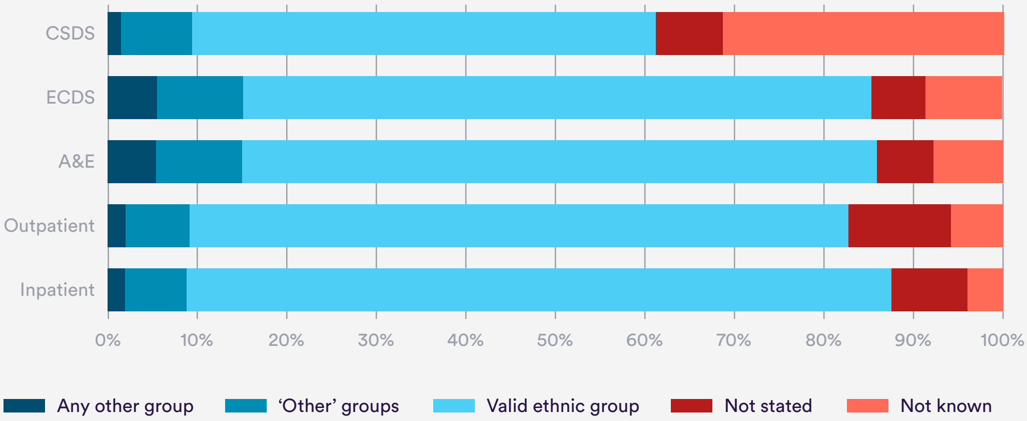
What proportion of NHS records had an ethnic group coded?

In 2019/20, 87% of inpatient, 86% of A&E, and 85% of Emergency Care Data Set (ECDS), records had a known ethnic category recorded and 83% of outpatient records had one (see Figure 2). In contrast, only 61% of Community Services Data Set (CSDS) records had ethnicity recorded; this is a new dataset with significant coverage and data quality issues.

In addition to records with a valid ethnic group, 8.5% of inpatient and 11% of outpatient records were recorded as not stated.

The proportion of records with an ethnicity code of 'any other group' and those with 'other' ethnic group codes was highest for the A&E dataset and the related ECDS.

Figure 2: Completeness and validity of ethnicity coding across NHS datasets, 2019/20



How has coding changed over time?

The quality of ethnicity coding in the outpatient and A&E datasets improved dramatically between 2010/11 and 2012/13 (see Figure 3). This was linked to wider improvements in data quality over this period. The proportion of inpatient records that have a valid ethnic group has been declining slowly since 2010. Meanwhile there has been an increase in the proportion of records where ethnic group is not stated (see Figure 4).

Figure 3: Proportion of records with a valid ethnic group code, 2010/11 to 2019/20

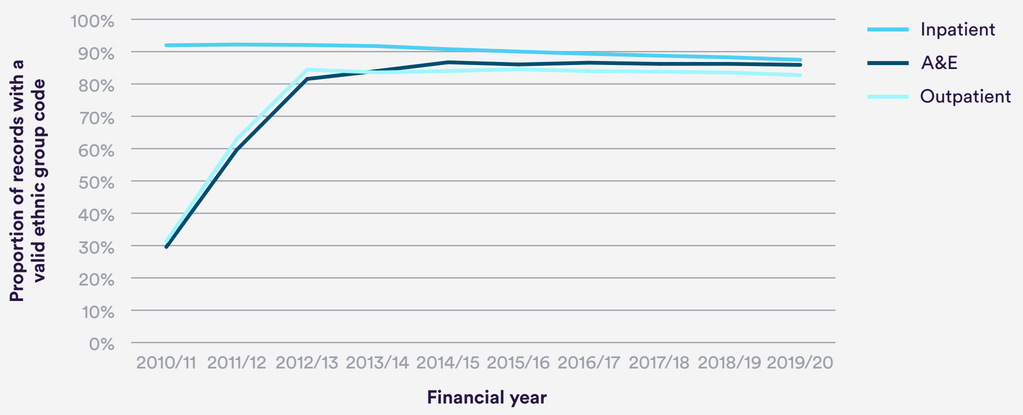
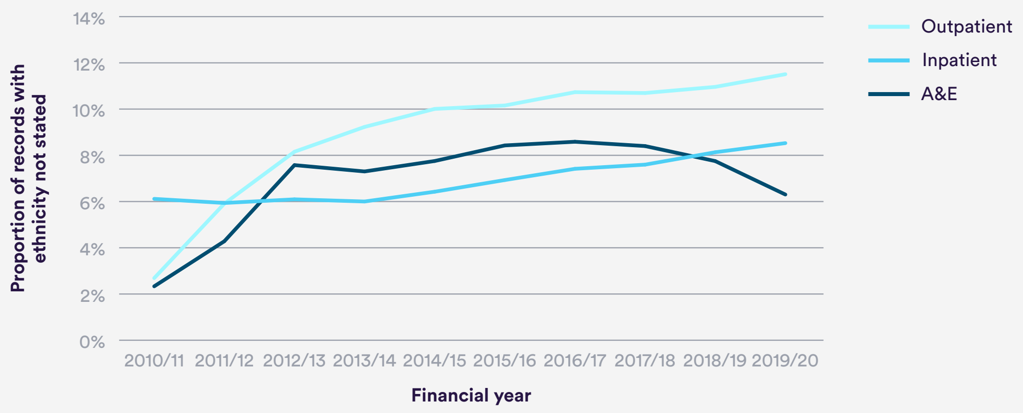


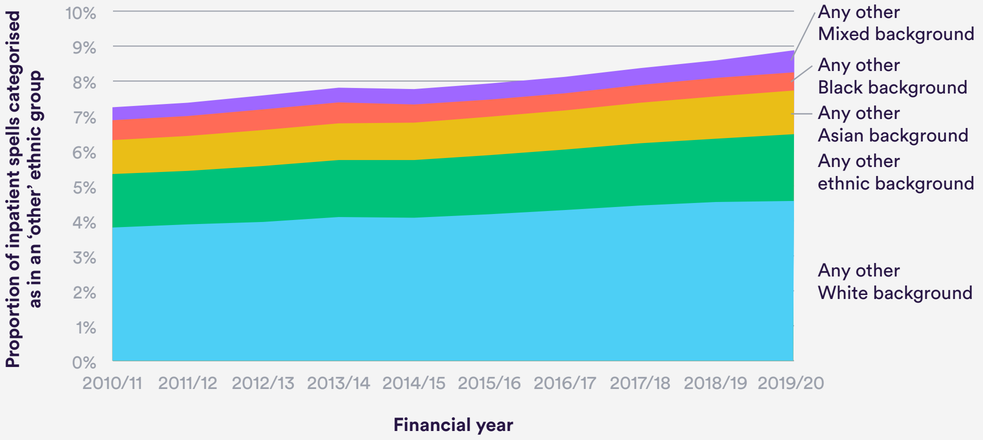
Figure 4: Proportion of records with ethnicity not stated, 2010/11 to 2019/20



In addition, there was also an increase in the proportion of records that were in an 'other' ethnic group category. For inpatient records it rose from 7.2% to 8.8% between 2010/11 and 2019/20 (see Figure 5). The proportion of 'any other ethnic group' records specifically increased from 1.5% to 2.1%.

There are a number of potential explanations for this. A similar increase in 'other' and Mixed ethnic group categories can be seen in population estimates by ethnic group (see Appendix 2). Over this time period there was significant inward migration of European migrants, which may have contributed to the increase in the 'other White' category. There may also be a generational shift in how individuals record their ethnic group, with people in second- or third-generation ethnic groups changing how they ascribe their ethnicity.[18]

Figure 5: Proportion of inpatient spells categorised as in an 'other' ethnic group, 2010/11 to 2019/20



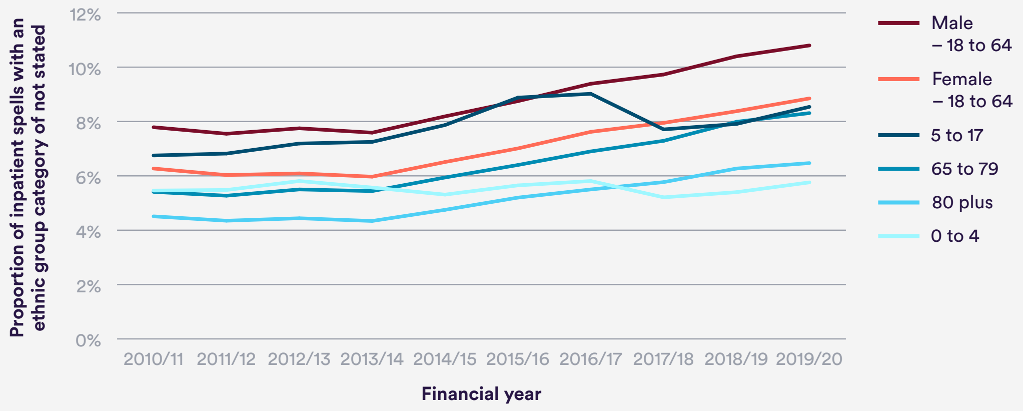
Variations in data quality between sub-groups of patients and population groups

We examined how the quality of ethnicity coding varied for different groups of patients or activity types. For brevity, in this section the comparisons are discussed primarily for inpatient data, and only where there were substantial differences in coding between sub-groups or over time.

Age and gender

There was variation in ethnicity coding by age and, for working-age patients, by gender. For example, records for working-age men were almost twice as likely to have an ethnicity code of not stated as records for people over the age of 80 and children under five (see Figure 6). We also found that older people and women were less likely to have not known codes. Differences in terms of age and gender could reflect the frequency of contacts, with working-age men having fewer admissions than other age–gender combinations. The increasing proportion of records with a not stated ethnicity code between 2010/11 and 2019/20 was apparent across all age groups apart from children.

Figure 6: Proportion of inpatient spells with an ethnic group category of not stated, by age and gender, 2010/11 to 2019/20



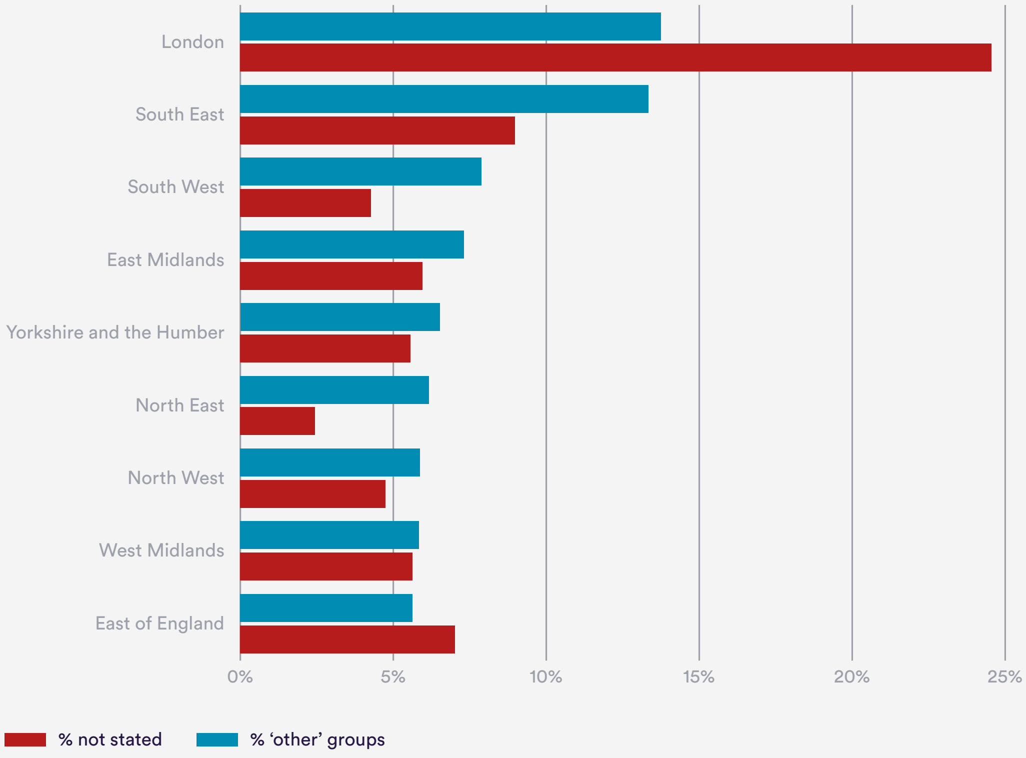
Note: Gender differences were only noted for working-age inpatients, so the split is not shown for other age groups.

Region

There were substantial differences in ethnicity coding between regions, with almost double the proportion of spells being recorded as not stated in London and the South East than in other regions, accounting for more than one in eight records in these regions (see Figure 7).

London had three times as many spells recorded as an ‘other’ category than other regions, with 6.5% recorded as ‘any other ethnic group’. Higher proportions of ‘other’ groups were in line with population estimates of ‘other’ ethnic groups in London, although nearly a fifth (18%) of records did not have a valid ethnic group, hindering direct comparison with population estimates.

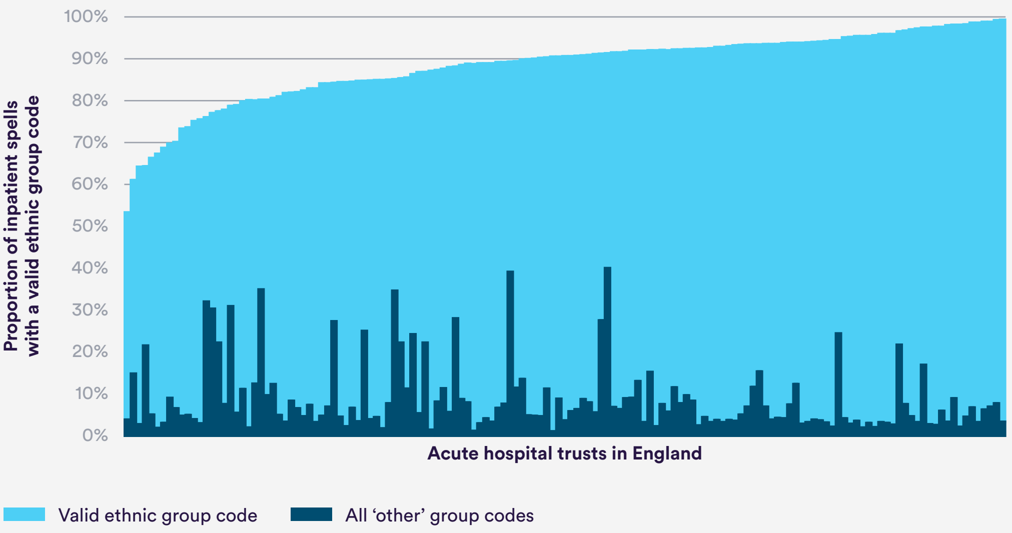
Figure 7: Regional differences in the proportion of inpatient spells recorded as not stated or an 'other' category, 2019/20



Variation between providers

The proportion of records with a valid ethnic group varied markedly between providers, from 53% to almost 100% (see Figure 8). This range suggests there is significant potential for providers to learn from best practice, and for very high levels of data quality to be achieved. In some cases, a very high percentage of valid ethnicity codes includes a large proportion of records – up to 40% – being recorded in one of the 'other' ethnic groups, and this coding has been found to be over-used in the NHS[8].

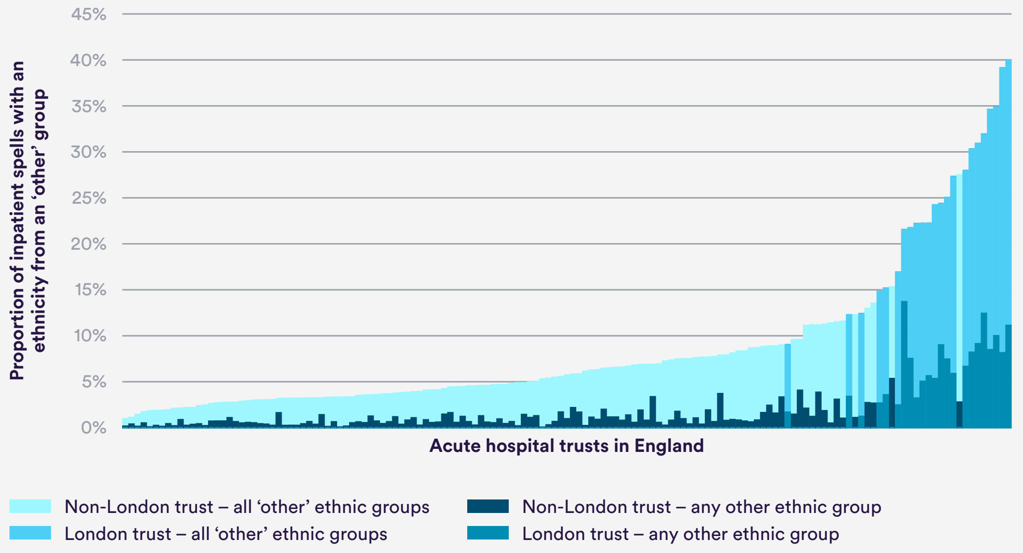
Figure 8: Percentage of inpatient spells with a valid ethnic group code, 2019/20



Note: Acute NHS providers only.

As noted above, a much higher proportion of inpatient records was recorded with an 'other' ethnic group category in London than in other regions. This was reflected at individual trust level, where London trusts made up the majority of providers doing so, with a quarter or more of records recorded with an 'other' ethnic group category (see Figure 9).

Figure 9: Percentage of inpatient spells with an ethnicity from an 'other' group recorded, 2019/20



Note: Acute NHS providers only.

Deprivation

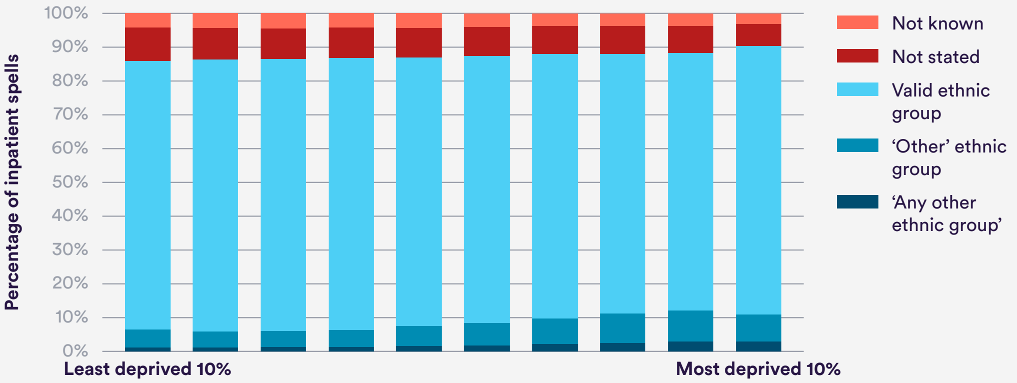
We compared ethnicity coding for inpatient spells of patients within each decile of deprivation, based on the small area (Lower-layer Super Output Area) of residence of the patient (see Figure 10).

Patients in the least deprived decile were the least likely to have a valid ethnic group, with 10% of spells being coded as not stated, compared with 6% for the most deprived decile.

In contrast, the proportion of patients with an 'other' ethnic group increased with deprivation. This is consistent with more deprived areas having more diverse populations.[23]

[23] UK Government (2020) 'People living in deprived neighbourhoods'. www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/demographics/people-living-in-deprived-neighbourhoods/latest. Accessed 11 May 2020.

Figure 10: Ethnicity coding by deprivation decile, inpatient data, 2019/20



Variations in data quality across patient pathways

Inpatient pathway

We examined differences in data quality in the inpatient pathway by type of admission, type of provider, length of stay and whether the patient died in hospital or was discharged.

Elective (planned) activity was less likely than emergency admissions to be coded with a valid ethnic group, and more likely to be not stated or not known (see Table 3). The direction of this difference is counter-intuitive, as recording ethnicity before planned care should be easier than in an emergency. One potential explanation is that hospitals are using previous records to populate ethnicity data, rather than asking patients. Patients admitted as an emergency are more likely to be in poorer health, with more frequent previous contacts, and so have a more complete recording of ethnic group than elective patients.

Table 3: Ethnicity coding in HES inpatient spells in 2019/20, by broad admission group

Admission method	% not known	% not stated	% with valid ethnic group	% with 'other' ethnic group	% with 'any other ethnic group'
Elective	4.7%	10%	85%	7.0%	1.6%
Emergency	3.2%	6.4%	91%	8.9%	2.0%
Maternity	3.5%	7.3%	89%	17%	3.6%
Other	3.8%	5.9%	90%	17%	2.3%

Independent elective care

Independent providers' recording of ethnicity was poor, with 10% of records not known and 27% not stated (see Table 4). The volume of activity in the independent sector comprised 7% of elective activity overall, with volumes being more significant for some types of activity.

Table 4: Ethnicity coding for elective inpatient care delivered in independent and NHS providers, 2019/20

Provider type	% not known	% not stated	% with valid ethnic group	% with 'other' ethnic group	% with 'any other ethnic group'
Independent	10%	27%	62%	2.8%	0.5%
NHS	4.3%	9.2%	86%	7.3%	1.7%

Length of stay in hospital

Shorter hospital stays were least likely to have a valid ethnic group recorded, with 4.4% of spells recorded as not known and a further 9.4% as not stated (see Table 5). This partly reflects shorter stays being more likely to be elective admissions – as we saw earlier, elective admissions were less likely to have a valid ethnic group. In addition, spells of one day and two to seven days were more likely to have an 'other' ethnic group category than other lengths of stay.

Table 5: Ethnicity codes recorded for different lengths of stay in hospital, 2019/20

Length of stay	% not known	% not stated	% with valid ethnic group	% with 'other' ethnic group	% with 'any other ethnic group'
0 days	4.4%	9.4%	86%	8.2%	1.8%
1 day	3.6%	7.4%	89%	11%	2.3%
2–7 days	3.4%	7.2%	89%	9.9%	2.1%
8–14 days	3.0%	6.4%	91%	6.7%	1.5%
15 or more days	3.3%	6.5%	90%	6.6%	1.4%

Deaths in hospital

Ethnicity coding was more complete for patients who died in hospital (see Table 6), which corresponds with more complete coding for older patients. This is an important finding if death certificates are to make use of hospital records for ethnicity coding.

Table 6: Ethnicity coding for patients who died in hospital compared with all patients, 2019/20

	% not known	% not stated	% with valid ethnic group	% with 'other' ethnic group	% with 'any other ethnic group'
Patient discharged or transferred	4.0%	8.6%	87%	8.8%	2.0%
Patient died in hospital	3.2%	6.5%	90%	5.0%	1.1%

Outpatient attendances

Ethnicity coding was better for follow-up than first outpatient appointments, with fewer not known and not stated codes (see Table 7).

Table 7: Ethnicity recording for first and follow-up outpatient appointments, 2019/20

Appointment	% not known	% not stated	% with valid ethnic group	% with 'other' ethnic group	% with 'any other ethnic group'
First	7.3%	13%	80%	9.6%	2.2%
Follow-up	5.0%	11%	84%	8.9%	2.0%

Coding quality differed according to the referral route, suggesting that hospital administrative processes impact on data recorded (see Table 8). For example, patients referred from another specialty had a higher proportion of not stated codes than GP referrals, referrals from A&E and self-referrals. The characteristics of patients following different referral pathways may also be a factor, particularly for patients referred via A&E, for whom there was a higher proportion of 'other' ethnic group coding.

Table 8: Ethnicity recording by the top four referral routes for outpatient appointments, 2019/20

	% not known	% not stated	% with valid ethnic group	% with 'other' ethnic group	% with 'any other ethnic group'
GP referral (n = 38.8 million)	4.4%	11%	80%	9.1%	2.1%
Consultant referral, excluding A&E (n = 25.8 million)	6.5%	14%	84%	8.5%	1.9%
Self-referral (n = 4.1 million)	3.6%	7.3%	84%	11.%	2.8%
Referral from an A&E department (n = 3.5 million)	6.9%	9.1%	89%	14%	2.9%

Note: These four referral sources accounted for 75% of outpatient appointments.

A&E attendances

Patients arriving at A&E by ambulance were more likely than patients arriving via another route to have a valid ethnic group coded, and less likely to be recorded in an 'other' group (see Table 9). Patients admitted to hospital from A&E were similarly more likely to have a valid ethnic group than patients discharged from A&E (see Table 10). Both these differences are consistent with these patients being older and more acutely unwell.

Patients whose disposition from A&E was not known also had a high proportion of not known ethnicity coding recorded, suggesting overall poor data quality with these records.

One in six patients discharged without follow-up had an 'other' ethnic group, while the proportion was more than one in four for patients discharged with GP follow-up. These higher proportions could reflect demographic differences in patients using these services, as well as differences in the recording of ethnicity in different service settings, for example between minor and major A&E departments.

Table 9: Ethnicity coding by mode of arrival for A&E attendances, 2019/20

	% not known	% not stated	% with valid ethnic group	% with 'other' ethnic group	% with 'any other ethnic group'
Ambulance	4.7%	6.3%	89%	8.5%	2.1%
Other	8.0%	6.1%	86%	16%	5.2%

Table 10: Ethnicity coding by the top four disposition routes from A&E attendances, 2019/20

	% not known	% not stated	% with valid ethnic group	% with 'other' ethnic group	% with 'any other ethnic group'
Discharged – no follow-up (n = 8.8 million)	7.3%	6.4%	86%	15%	5.0%
Admitted (n = 2.8 million)	3.7%	5.7%	91%	9.1%	2.1%
Discharged – GP (n = 2.4 million)	7.5%	5.9%	86%	23%	9.2%
Not known (n = 2.8 million)	14%	7.5%	78%	13%	3.5%

Note: These four disposition routes accounted for 87% of A&E attendances.

How consistently is ethnicity recorded for patients with multiple episodes of care?

We examined consistency of ethnicity coding for patients with multiple contacts with health services across three years: 2017/18 to 2019/20 (see Table 11). Multiple ethnicity codes occur when a different ethnicity is recorded for the same person on different occasions, either as a result of the individual giving a different response when asked, or because of staff assigning a different code for the patient. Understanding how consistent ethnic codes are for individuals provides insights into variation in data quality between ethnic groups, and can inform analysis methods to address data quality problems.[24]

[24] Public Health England, 2021, Outputs by ethnic group in PHE's COVID-19 Health Inequalities Monitoring for England (CHIME) tool. Assigning ethnicity to records of deaths and hospital admissions [Accessed 25 May 2021] https://fingertips.phe.org.uk/documents/Outputs%20by%20ethnic%20group%20in%20CHIME.pdf

Just over half of inpatients and A&E attendees, and a quarter of outpatients attendees, had only one contact with services over the three-year period, so only one ethnicity code was recorded. Overall, almost three quarters of patients had more than one contact.

Among inpatients with more than one contact, 84% had the same ethnicity code across all hospital spells in the three years. The proportion of outpatient and A&E attendees with consistent codes was lower, and across all datasets, 65% of patients had the same ethnicity code for all their contacts. These levels of consistency were lower than between census returns for the same individual, but in line with a comparison between NHS and other data sources.[9]

In almost over a quarter of cases where patients had multiple codes, these included multiple codes that contained only one valid ethnic group code (ranging from 12% of inpatients to 22% of outpatients). More than one valid code was recorded for between 3.6% (inpatients) and 8.6% (A&E) of patients who had multiple valid codes.

Table 11: Consistency of ethnicity codes for the same individual within three years of activity data (2017/18 to 2019/20), within individual datasets and across datasets (percentage of individuals)

	Inpatient (n = 21.0 million)	Outpatient (n = 39.1 million)	A&E (n = 28.7 million)	Combined (n = 50.0 million)
Patients with one contact only	54%	24%	53%	27%
Patients with multiple contacts, of which:	46%	76%	47%	73%
Multiple contacts and always the same code	84%	72%	75%	65%
Multiple codes and 1 valid ethnic group code	12%	22%	15%	26%
Multiple valid ethnic group codes	3.6%	4.2%	8.6%	7.5%
Multiple codes and never a valid ethnic group code	0.4%	1.4%	0.9%	2.2%
Sub-total	100%	100%	100%	100%

We examined in more detail the records where patients had two valid ethnic group codes, to understand which ethnic groups were most impacted by inconsistent coding. While the percentages of patients affected overall may be small, millions of individuals are impacted, and further we found there was a disproportionate effect on minority ethnic groups.

The proportion of White British patients who also had a second valid ethnic group code was 1.4% of inpatients, 2.9% of outpatients and 3.4% of A&E patients. However, these patients constituted a much larger proportion of each minority group (see Table 12), particularly for White Irish, 'other White', 'other Mixed' and 'any other ethnic group' patients. This indicates that these groups were most likely to be miscoded as White British, which would result in activity within each of the more specific ethnic groups being under-represented.

The outpatient dataset was most impacted, as expected given the higher proportions of patients with multiple valid codes. Although the A&E and inpatient datasets contained similar proportions of patients with multiple valid codes, a higher proportion of A&E patients from minority ethnic groups also had a code of White British in comparison with inpatients.

Table 12: Patients with two valid ethnic groups: proportion of each ethnic group also having a code of White British

	Inpatient	Outpatient	A&E
Irish (White)	17%	25%	19%
Any other White background	7.7%	13%	10%
White and Black Caribbean (Mixed)	5.3%	9.6%	8.8%
White and Black African (Mixed)	3.3%	5.9%	6.0%
White and Asian (Mixed)	4.8%	9.1%	7.8%
Any other Mixed background	5.6%	18%	15%
Indian (Asian or Asian British)	0.8%	1.6%	2.2%
Pakistani (Asian or Asian British)	0.6%	1.5%	1.6%
Bangladeshi (Asian or Asian British)	0.6%	1.3%	1.5%
Any other Asian background	1.1%	2.3%	2.2%
Caribbean (Black or Black British)	2.2%	3.9%	4.0%
African (Black or Black British)	1.1%	3.3%	3.8%
Any other Black background	2.0%	3.4%	3.0%
Chinese (other ethnic group)	1.5%	3.0%	1.9%
Any other ethnic group	7.2%	11%	13%

Inconsistency in the use of ‘other’ codes occurred within broad ethnic categories, and particularly impacts on the coding of Asian and Black ethnic groups (see Table 13). In the A&E dataset, 7.5% of Indian, 4.0% of Pakistani and 4.2% of Bangladeshi patients also had a code of ‘other Asian’, and 9.1% of

Black Caribbean and 7.6% of Black African patients also had a code of ‘other Black’. Analysis for specific ethnic groups risks being incorrect if some activity for these groups, for example Indians and Black Africans, is miscoded in other categories.

Table 13: Patients with two valid ethnic group codes: proportion of each ethnic group also having an ‘other’ code within the same broad ethnic category

		Inpatient	Outpatient	A&E
Other White	British	0.7%	1.3%	1.3%
	Irish	1.8%	3.1%	3.8%
Other Mixed	White and Black Caribbean	2.0%	4.1%	4.6%
	White and Black African	1.6%	3.0%	3.9%
	White and Asian	1.4%	2.7%	2.8%
Other Asian	Indian	3.2%	6.0%	7.5%
	Pakistani	2.2%	4.6%	4.0%
	Bangladeshi	2.1%	4.0%	4.2%
Other Black	Black Caribbean	4.4%	7.5%	9.1%
	Black African	3.3%	5.3%	7.6%

The ‘any other ethnic group’ category is a growing proportion of the population. This group is appropriate for the many people in England who do not self-identify with any of the specific or broad categories. However, significant proportions of patients in this group also have an alternative valid ethnic group code, ranging from a fifth of inpatients, to two-fifths of A&E patients (see Table 14). Inconsistent coding in this group indicates over-use of the ‘any other ethnic group’ code within NHS datasets, in line with previous analysis.[8]

Table 14: Patients with two valid ethnic groups: proportion of 'any other ethnic group' patients, by alternative ethnic group category

	Inpatient	Outpatient	A&E
British	7.2%	11%	13%
Irish	0.2%	0.4%	0.4%
Any other White background	4.7%	7.8%	8.8%
White and Black Caribbean	0.2%	0.4%	0.4%
White and Black African	0.2%	0.3%	0.3%
White and Asian	0.3%	0.5%	0.3%
Any other Mixed background	0.8%	1.3%	1.7%
Indian	1.3%	2.1%	2.8%
Pakistani	0.9%	1.5%	1.4%
Bangladeshi	0.3%	0.5%	0.4%
Any other Asian background	2.4%	4.0%	4.8%
Caribbean	0.6%	1.0%	1.1%
African	1.2%	1.9%	2.5%
Any other Black background	0.7%	1.1%	1.9%
Chinese (other ethnic group)	0.3%	0.5%	0.4%
Sub-total (any other ethnic group patients with an alternative valid code)	**21%**	**35%**	**40%**

For health events for which there are multiple records for the same patient, either within the same dataset or other datasets, there are opportunities to use these data to enhance the analysis of ethnicity. This is discussed further in Appendix 3.

5 Discussion and conclusion

Our analysis has identified significant shortcomings in ethnicity coding in widely used health datasets covering hospital inpatients, outpatients and A&E attendances. We found:

- data quality problems, including incomplete ethnicity coding and invalid and inconsistent use of codes, which disproportionately affect the records of minority ethnic patients
- an excessive and growing proportion of patients who have their ethnicity recorded as not known, not stated or 'other'
- systemic biases in data quality – for example, data quality is worse in London, for adults of working age and for patients with short hospital stays.

These, and the other data quality problems identified, will impair the validity of any epidemiological analyses of ethnic differences. Coding biases will feed into the results, leading to systematic underestimation or overestimation of rates for minority ethnic groups. As a result, health issues affecting those communities may be missed, or their severity underestimated.

We found important differences in ethnicity coding between datasets, by age, region and deprivation and along patient pathways. These differences could arise from how different ethnic groups access services. However, unravelling these factors from data quality issues is complex, particularly because there are also limitations in current estimates of the ethnic distribution of the population. Data from the 2021 census, when available, will be vital to understanding the ethnic composition of local populations, and also improve assessments of health data quality.

Our findings have two important implications for the analysis of, and decision-making about, ethnicity and health, and how data can be used as an enabler to identify and reduce inequalities in health:

- **Making the best use of available data**. Given the data quality issues we have identified, users of data need to be aware that analysis using the data as released will overcount some categories of patients (particularly those in 'other' ethnic categories) and therefore undercount activity for those in specific minority ethnic categories. They therefore need to consider data quality when undertaking analysis by ethnic group (see Box 2). Understanding and reporting on the quality of ethnicity data are essential. Analysis should also consider methods to address data quality issues, including using ethnicity codes from other service contacts for the same person.

- **Looking ahead, improving the underlying quality of data**. Urgent action is also required to address poor data quality in terms of ethnicity coding at source – when NHS organisations and GPs collect and record data from patients. This will remove/reduce the need for reassigning ethnicity codes in health records. Moreover, with legislation expected that will introduce ethnicity codes at death registration, there is a window of opportunity to improve coding quality now, which will avoid poor data quality in health records being transferred to mortality records.

These improvements are essential for enabling ethnic disparities in health to be understood and addressed in the future.

Our analysis also points to areas for further research, including:

- understanding the barriers for patients and staff at the point at which ethnic origin is asked of patients, and why 'other' categories are used

- identifying and addressing systemic barriers to how ethnicity data are collected in the NHS, including processes and information systems, learning from differences identified between patient groups

- learning from organisations that have more complete and accurate data, to inform best practice in capturing and using ethnicity data

- investigating data quality issues in other NHS datasets, including those in primary care, mental health and social care
- evaluating options to address data quality issues using linked data, including data from the 2021 census when these are available.

Box 2: Key issues for users of ethnicity data to consider during analysis of the data

1. Completeness of data: check and report on proportions of not stated and ‘other’ categories, as well as missing or not known ethnic group codes.

2. Level of disaggregation: use the most granular ethnic groups possible within your dataset, after taking account of the volume of data. If broad ethnic categories (for example, Black or Asian) are used, discuss the limitations of this approach.

3. ‘Other’ categories: if using specific ethnic groups (for example, Black African, Pakistani), consider the size of the ‘other Black’, ‘other Asian’ and ‘other White’ categories, and whether the miscoding of specific ethnic group categories will distort your analysis.

4. Consider biases in ethnic coding which will affect your results, including age and gender differences, regional differences (especially for London), differences in patient pathways (for example, elective versus emergency pathways) and outcomes, and poor data quality from independent providers.

5. Be cautious in comparing changes over time – as well as increasing proportions of records with not stated and ‘other’ categories, there may have been sudden changes in coding as a result of changes in datasets.

6. Where data for the same individual can be linked (either within or between datasets), investigate the consistency of recording, and whether reassigning ethnicity codes will enhance the analysis (see Appendix 3).

6 Recommendations

Responsibility for the coding and quality of ethnicity data in health records is dispersed across a number of organisations, national and local, including the Department of Health and Social Care, NHS England and NHS Improvement, NHS Digital, NHS organisations and GPs. All have a role to play in improving the quality of the ethnicity data available for analysing and addressing ethnic inequalities in health.

Our recommendations relate to:

- improving the analytical potential of currently available data, notwithstanding the associated data quality problems (short term)
- improving the quality of the underlying source data (medium term).

To improve the analysis of ethnicity using existing health data, we recommend the following:

- NHS Digital regularly publishes data on the quality of ethnicity coding within the Data Quality Maturity Index and this should also include the proportion of records coded as not known, not stated, an 'other' group and 'any other ethnic group'.
  Action: NHS Digital

- The UK Statistics Authority should review the quality of ethnicity coding within health statistics, in order to identify and make recommendations for improving the quality and consistency of data.
  Action: UK Statistics Authority

- Analyses of health care activity should routinely include the ethnic dimension, and consider and report on the quality of coding.
  Action: Data analysts and users

- Analysis methods to address data quality issues in analysis of ethnic differences should be clearly described and, where appropriate and

feasible, the methodology developed by Public Health England for reassigning ethnicity in health records should be used.
Action: Data analysts and users

To improve the quality of source data on ethnicity in the future, we recommend the following:

- The Health Inequalities Improvement Programme at NHS England and NHS Improvement should work with NHS Digital and the NHS Race and Health Observatory on developing and implementing guidance for ethnicity coding in the NHS, in keeping with priority 3 of the NHS England and NHS Improvement operational guidance[2]. Guidance needs to cover NHS-funded care, wherever this is provided, and include protocols for asking patients their ethnicity and recording it in health records, using the updated 2021 census categories.
Action: NHS England and NHS Improvement

- Integrated care system leaders should use their role to reduce inequalities to improve the quality of ethnicity coding in health records, ensuring that the updated guidance on ethnicity coding is implemented, and learning from local partners and spreading best practice in data quality and analysis.
Action: Integrated care system leaders

- Boards and leaders of NHS providers and commissioners, and GP practices, should take ownership of the quality of ethnicity coding for their patients, ensure that the updated guidance is implemented, routinely monitor the quality of coding, identify how it can be improved, and put in place actions to achieve this. Once guidance on ethnicity coding is available, all health care providers should endeavour to record/update/correct ethnicity coding in all patient records.
Action: All NHS providers and commissioners, and GP practices

- The Care Quality Commission should incorporate the assessment of the quality of ethnicity coding in its inspections and ratings, and address independent providers' poor-quality coding, taking action where the data suggest possible shortfalls and a failure to implement the updated guidance.
Action: Care Quality Commission

Appendix 1: Emergency Care and Community Services data

Table A1: Data included from the Emergency Care Data Set (ECDS) and the Community Services Data Set (CSDS)

Financial year	Number of A&E attendances (ECDS)	Community services – number of referrals	Community services – number of individuals
2019/20	21,798,300	21,158,500	10,947,900

Note: The fields available in the ECDS did not allow us to identify individuals.

Appendix 2: Population estimates for ethnic groups

In order to interpret the distribution of ethnicity codes within NHS datasets, we would ideally compare the distribution with the ethnic composition of the general population. However, there is currently no ‘gold standard’ for such a comparison and estimates of the ethnic composition of the population vary between sources (see Table A2).

The most recent census data are from 2011, so will not reflect significant migration into and out of England in the past decade, or differential rates of births and deaths between ethnic groups.

The most recent population estimates by ethnic group published by the ONS, accounting for the ageing of the population and migration since the 2011 census, are for 2018. We have used these in our analysis because they are available by age group, and for individual ethnic groups. However, it should be noted that they show a higher proportion of non-White minority ethnic population groups than other estimates: the Annual Population Survey, and estimates from a linked dataset used for analysing Covid-19 mortality.

The Annual Population Survey is not available for individual White, Mixed and Black ethnic groups.

Table A2: Percentage of the population of England, by ethnic group

	2011			2018	2020	
	Census	Population estimate	Annual Population Survey	Population estimate	Annual Population Survey	Covid-19 linked dataset
White	86%	84%	89%	85%	87%	86%
Mixed/multiple ethnic group	2.2%	2.8%	0.9%	2.2%	1.5%	2.1%
Indian	2.5%	2.7%	2.9%	2.6%	3.2%	2.6%
Pakistani	2.0%	2.3%	1.3%	2.1%	1.4%	2.1%
Bangladeshi	0.8%	0.9%	0.5%	0.8%	0.6%	0.8%
Chinese	0.7%	0.7%	0.5%	0.7%	0.6%	0.6%
Any other Asian background	1.5%	1.6%	1.1%	1.5%	1.2%	
Black/African/Caribbean/Black British	2.9%	3.8%	2.6%	3.5%	3.2%	2.7%
Other ethnic group (including other Black)	2.5%	1.1%	1.5%	1.0%	1.5%	
Other ethnic group (including other Black and any other Asian)						2.6%

Sources: 2011 census,[25] Annual Population Survey, [26] 2018 population estimates[22] and a Covid-19-linked dataset. [27]

[25] UK Government (2020) 'Population of England and Wales, 2020'. www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/national-and-regional-populations/population-of-england-and-wales/latest#by-ethnicity. Accessed 11 May 2021.

[26] NOMIS (2021) 'Annual population survey – regional – ethnicity by industry'. www.nomisweb.co.uk/datasets/aps180. Accessed 11 May 2021.

[27] Office for National Statistics (2021) 'Coronavirus (COVID-19) related deaths by ethnic group, England and Wales methodology'. www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/methodologies/coronaviruscovid19relateddeathsbyethnicgroupenglandandwalesmethodology. Accessed 11 May 2021.

Appendix 3: Options to enhance ethnicity coding using linked data

Why might linked data be used?

Linking records for the same person from different health datasets, or with other sources, can enable analysis of ethnic differences in health to be undertaken that would otherwise not be possible. The ONS is using census records to ascribe the ethnicity of people who have died, in order to undertake analysis of mortality by ethnic group, and. Public Health England routinely use hospital data to allocate ethnicity to health related datasets. Given the gaps and biases in ethnic group coding, there is a strong case for taking steps to address them. Undertaking analysis without doing this will not produce reliable findings, and will undermine the action needed to address ethnic disparities in health.

Issues and challenges

However, there are a number of issues and challenges in linking data, both ethical and practical.

As discussed above, ethnicity is a self-identified characteristic. Individuals can choose to not state their ethnicity, or identify as an 'other' ethnic category, if this is the option that best represents how they identify at the time of data collection. Using data for the same person, but a different data source or health record, could be counter to an individual's identification of their ethnicity. However, our analysis strongly suggests evidence of some miscoding of ethnicity, for example where ethnic codes differ for patients with multiple contacts with health services or where the over-representation of 'other' groups distorts the results. Where the aims of analysis are to support population health improvement, it could be argued that the public health benefits support the case for reassigning ethnicity to correct for such miscoding.

In practical terms, there are significant challenges in deciding how to approach data linkage and the potential reallocation of ethnic codes. The most appropriate method will depend on what data sources are available and the aims of analysis. The ONS is responsible for carrying out the census and therefore has access to it, and when 2021 census data are available, this will provide the 'gold standard' of comprehensive self-reported ethnicity for the population. Other organisations without access to personal census records may have access only to additional health datasets – for example, NHS Digital has linked inpatient and GP records to obtain additional ethnicity codes.

PHE have recently started using ethnicity from multiple records for the same person, to reduce the number of cases where ethnic group is not known, not stated or is categorised as 'any other ethnic group'.[24]

Nuffield Trust is an independent health think tank. We aim to improve the quality of health care in the UK by providing evidence-based research and policy analysis and informing and generating debate.

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