



# **Improving Health Inequality Data in The National Clinical Audit and Patient Outcomes Programme (NCAPOP)**

**July 2023**

## About HQIP

The Healthcare Quality Improvement Partnership (HQIP) is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. It aims to promote quality improvement in patient outcomes, and to increase the impact that clinical audit, outcome review programmes and registries have on healthcare quality in England and Wales. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. The programme is funded by NHS England, the Welsh Government and, with some individual projects, other devolved administrations and crown dependencies. [www.hqip.org.uk/national-programmes](http://www.hqip.org.uk/national-programmes)

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# Executive summary

## Why –

This project was set up to identify and explore the barriers to health inequality data being routinely reported within the National Clinical Audit and Patient Outcome Programme (NCAPOP). Health inequalities are known to cause unjust and preventable differences in health outcomes. Research has shown that the implementation of a wide-ranging and diverse strategy to tackle these disparities can yield far-reaching outcomes on an individual and population health level. Reliable and accurate data is essential to further understand inequalities in health and adapt health services to address the needs of underserved communities.

## How –

A review of current health inequality reporting with the NCAPOP reports was conducted alongside a literature review to gain insight into current practices. An online survey was then conducted of the National Clinical Audit and Patient Outcome Programme providers to identify the barriers to health inequality data collection, analysis and reporting. Free text answers contained valuable insight into the challenges and perceived barriers for the programmes alongside suggestions for improvement.

## What we found –

- 1) **Review of current practice** found little improvement since a previous internal review conducted by HQIP in 2020. The results indicated significant variations in the reporting, analysis, and use of health inequality data among different programs.
- 2) **Literature review:** highlighted adverse outcomes for minority ethnic groups or socially deprived areas compared to the majority ethnic group and demonstrated limited insights into barriers related to data collection, analysis, and reporting.
- 3) **Survey responses:** despite variation between programmes, the survey responses identified several recurring themes:
  - Linked data sets: issues such as incomplete data, difficulties in categorising and coding ethnicity, multiple ethnicities documented for one patient.
  - Bespoke data sets: time pressure on clinical staff, accessibility and engagement challenges with patient/relative surveys (particularly impacting ethnic minority groups), consent issues.
  - Population data: lack of population statistics for comparison at analysis stage.
  - Costs: increased costs of analysts, increased resources for clinical audit leads.
  - Small numbers problem: at data collection stage minority ethnicity data less likely to be complete, small numbers at analysis stage make data analysis statistically inaccurate, concerns that small numbers at reporting stage make data identifiable, lack of guidance on how to aggregate small numbers.
  - Social deprivation calculation: difficulty in calculating deprivation indices if postcode data is missing, concerns about the accuracy of using postcode data as a proxy measure for social deprivation, concerns regarding identifiable data, increased time and cost of analysts/data cleaning required to calculate the deprivation score from postcode, and topic specific analysis issues (e.g., conditions with higher prevalence in older populations).

- Reporting demands: State of the nation reports have less scope for extended analysis of HIE than monthly-quarterly reports however these can lead to not enough time or resources to analyse this volume of data to acceptable standard with difficulty benchmarking themselves.

## Recommendations

### Recommendations for HQIP:

1. Ensure that ethnicity and deprivation are included in all NCAPOP specifications.
2. Convene a group to collaboratively address the small numbers problem within ethnicity data. This might involve work with the statistical and information governance community leading to guidance for the programme.
3. Provide guidance to audit providers, on the use of postcode to be used as a proxy for social deprivation, to ensure the reliability and anonymity of this measure.
4. Convene a working group to foster collaboration and knowledge sharing among different audit programmes:
  - a. Learning from each other's experiences in addressing barriers to obtaining health inequality data
  - b. Sharing innovative approaches to overcome challenges.
  - c. Evaluating the progress made in addressing health inequality data barriers including for example health group status, gender, sex, and other inclusion factors.

### Recommendations for Trusts and ICBs:

1. Trusts and ICBs to collaborate with hospitals and clinical centres to improve ethnicity coding, implementing lessons learned from the COVID-19 pandemic.

### NHS England and the Welsh Government should reflect on the following:

1. The issue of incomplete data is vitally important. Strategies need developed to ensure that all relevant patient characteristics, including ethnicity and social deprivation, are consistently recorded. This could involve providing clear guidelines, training and resources to clinicians and data collectors on the importance of capturing this information accurately.
2. There is an issue of inconsistent and duplicate ethnicity recording. This could be addressed through:
  - a. implementing digital solutions to ensure every patient has a single ethnicity recorded, linked to their NHS number.
  - b. Providing finalised, standardised definitions, to be implemented UK-wide. This will require collaboration with relevant stakeholders, including professional bodies and regulatory agencies.
  - c. Establishing best practice for capturing and categorising ethnicity data in a way that is clinically appropriate and meaningful.
  - d. Enhancing data analysis capabilities to conduct more detailed health inequality analyses.
  - e. Developing appropriate regression analysis techniques that consider multiple characteristics simultaneously, rather than focusing on comparisons with a majority group alone.

3. Ensure adequate resourcing of the additional analysis required for the health inequalities data.

UK Health Security Agency and Office for Health Improvement and Disparities should reflect on the following:

1. Making national figures relating to ethnicity and social deprivation available and accessible, to enable accurate comparison with audit data.

UK Health Security Agency and Office for Health Improvement and Disparities, NHS England and the Welsh Government and the clinical audit community should reflect on the following:

Working together to:

1. Develop strategies to address the small numbers problem associated with health inequality data, especially in minority ethnic groups.
2. Explore methods to aggregate data or analyse it at a broader level to ensure confidentiality while still providing valuable insights.
3. Collaborate with the wider clinical audit community to link data sources to increase sample sizes for more robust analysis.

## Introduction

The Healthcare Quality Improvement partnership (HQIP) commission the National Clinical Audit and Patient Outcomes Programme (NCAPOP) on behalf of NHS England (NHSE) and the Welsh Government. The NCAPOP is a collection of national healthcare quality improvement programmes managed and commissioned by HQIP (2023c). It comprises two sub-programmes: the National Clinical Audit Programmes (NCAPOP) and Clinical Outcome Review Programmes (CORPs)(Ibid). The NCAPOP covers 54 audit workstreams covering acute and chronic conditions, specialities and healthcare populations. The CORPs constitute five programmes which review maternal and child health, child mortality and medical, surgical, and mental health outcomes (HQIP, 2023a). HQIP also hosts the National Joint Registry (NJR) (The National Joint Registry, n.d.).

In October 2020, HQIP published an internal review “Addressing health equality in the National Clinical Audit and Patient Outcome Programme audits” (HQIP, 2020). This report assessed the inclusion of health inequality data in a sample of published NCAPOP national clinical audit programme-reports. It found that not all audits collected data on patient ethnicity (Ibid., p.22) and where this data is collected it is not always analysed nor reported. The same was true of socioeconomic deprivation data (Ibid., p.23). It recommended that ‘understanding the audit provider’s barriers to data collection and reporting is important to developing a strategy for inequality data in national audit’ (Ibid., p.23), thus providing the rationale for this report.

This project has been led by the National Medical Director’s Clinical Fellow at HQIP. One of the clinical fellow’s roles is to review all reports published by HQIP and collaborate with the Clinical Audit Subcommittee of the NHSE Executive Quality Group to support the implementation of national recommendations that have broader implications. The 2022-23 clinical fellow noted the ongoing

variation in focus upon health inequalities within these reports; and proposed this project to explore why health inequality data remains such a challenge to report and therefore address.

NHSE defines health inequalities as ‘unfair and avoidable differences in health across the population, and between different groups’ (NHSE, 2022a). It deems individuals living in areas of high deprivation, from minority ethnic communities and/or inclusion groups to be most vulnerable to experiencing health inequalities (Ibid.). As such, this report will focus on social deprivation and minority ethnic groups, as markers of health inequality. Given the various priorities of and outcomes measured by the NCAPOP programmes studied in this report, a broad definition of healthcare inequalities is adopted rather than focusing on specific measures e.g. life expectancy or avoidable mortality, among others (Williams et al., 2022).

The COVID-19 pandemic disproportionately affected ethnic minority communities, leading to higher rates of infection and mortality compared to the white population (Williams et al., 2022). This disparity can be attributed to a variety of factors, including variations in geographic location, occupation, levels of deprivation, living arrangements, and pre-existing health conditions like cardiovascular disease (CVD) and diabetes. The pandemic has therefore magnified the focus on health disparities and underscored the critical importance of enhancing efforts to prevent and address poor health outcomes in marginalized communities and ethnic minorities.

The government are developing what is intended to be a comprehensive approach aimed at reducing health inequalities, as well as the broader socio-economic and structural disparities that contribute to them. Furthermore, it is imperative to prioritize the diverse health requirements of all groups susceptible to adverse health outcomes and increased mortality rates. This is evident in the development of NHSE’s Core20PLUS5 approach which attempts to instigate actions that might reduce health inequalities. This approach acknowledges the most deprived 20% of the population, relevant population groups such as individuals from ethnic minority communities or whom ‘share protected characteristics as defined by equality act 2010 (NHSE, 2021a). For adults it prioritises maternity, severe mental illness, chronic respiratory disease, hypertension, and lipid management (Ibid.). For children it prioritises asthma, diabetes, epilepsy, oral and mental health (NHSE, 2021b).

### Aims and objectives.

Accurate and high-quality data play a crucial role in empowering policymakers and healthcare providers to recognize the distinct requirements of marginalised and minority ethnicity groups. It enables them to develop customized strategies to tackle disparities effectively and monitor the effectiveness of these measures.

The aim of this report is to identify, understand, and characterize the barriers to good health inequality data collection, analysis and reporting within the NCAPOP, by:

- A scoping review of recently published NCAPOP reports to evaluate the current quality of health inequality reporting within the programmes.
- A literature review to place NCAPOP projects within the context of research studies.
- A survey of the NCAPOP providers to explore current practices and views.

These have then been used to identify recommendations to improve health inequality data in the NCAPOP and ultimately improve healthcare inequalities and disparities.

## Review of current practice

### Method

A scoping review was conducted to determine the current routine practices for collecting, analysing and reporting health inequality data within the NCAPOP. These included reports published by each of the current national clinical audit programmes, published on [hqip.org.uk](http://hqip.org.uk) between 13<sup>th</sup> April 2022 – 12<sup>th</sup> April 2023 inclusive. To include results from other HQIP projects such as the CORPs, one publication from the National Child Mortality Database (NCMD) and the NJR were also reviewed. Two current HQIP audits, the National Cancer Audit Collaborating Centre (NATCAN) and the National Obesity Audit (NOA) have yet to publish any reports having been recently established; these were not included in the review.

Organisational audits were also omitted from the review given their focus on service delivery versus the demographics of and clinical outcomes experienced by the programme’s patient population which is the focus of this project. Notwithstanding, we acknowledge that healthcare access is inextricably linked to facets of health inequality such as geography and level of deprivation. For example, accessing distant services is especially challenging for those already experiencing deprivation thus perpetuating inequalities (Pinho-Gomes et al., 2022, p.504). Instead, reports included in this review were predominantly annual and state of the nation reports. A full list of the 44 reviewed reports can be found in Appendix A. This review was similar to that of the aforementioned (HQIP, 2020) report; however, we have prioritised ethnicity and social deprivation data given the focus of this project and use of survey as the primary research method.

First, each publication was reviewed to identify whether it had reported ethnicity and/ or social deprivation data. Where this data was reported, if it was used for a purpose beyond providing demographic data it was deemed to have been analysed. If the publication made recommendations pertaining to health inequalities data, this was also noted, however, only ‘key’ recommendations were considered for this purpose. In some reports (e.g. short reports) shortcomings, areas for improvement, encouragements/ ‘ambitions for change, ‘questions to consider’ or recommendations for patients and carers were identified and could be interpreted as recommendations, however, these are not included here. A full glossary of abbreviations of programmes is found on page 38.

Table 1: The 5 criteria by which each publication was assessed.

Reporting Ethnicity Data	Analysing Ethnicity Data	Reporting Social Deprivation Data	Analysing Social Deprivation Data	Recommendation(s) Made Pertaining to Health Inequality	Total/5
✓	✓	✓	✓	✓	5

### Results

Of the reviewed publications, only 7/44 (16%) fulfilled all five criteria. These were produced by the NDA, CVDPrevent, NPDA, NCMD and NMPA.

6/44 (14%) reports fulfilled 4 criteria as they did not make recommendations pertaining to health inequality. 8/44 (18%) reports fulfilled 3 criteria. 6/44 (14%) reports fulfilled 2 criteria. 1/44 (2%) report, produced by the NJR, reported on social deprivation data only. Significantly, 16/44 (36%) reports fulfilled 0 criteria. These were produced by the FFAP, NDA, NRA, NACEL, Epilepsy12, NBOCA, NOGCA, NNAP, NVR and SSNAP.

A full break down of the scoping review results can be found in Appendix A.

## Discussion

The results of this scoping review show that the reporting and analysis of healthcare inequality data, and its use to make recommendations continues to vary significantly between programmes. There has therefore been little improvement since the publication of (HQIP, 2020) which found: “17%.... audits analysed the effect of ethnicity on at least one measure” and “39% (7/18) audits analysed the effect of socio-economic status on at least one measure” (HIP 2020, p.18). Whilst the previous work reviewed fewer reports, 18 compared to the 44 in this review, and is not directly comparable, it can be inferred that the need to further understand ‘the audit barriers to data collection and reporting’ (Ibid., p.23) remains relevant and pressing.

Given the results, it is useful to look at the recommendations made, in order to understand the context in which health inequality data is being used by programmes. For example, CVDPrevent, NCMD and NPDA contextualised their recommendations in the Core20PLUS5 initiative. CVDPrevent also acknowledged integrated care systems (ICS) ‘shift to population health’ (CVDPrevent, 2022, p.7). ICSs were established in 2022, to improve population health outcomes and address preventable conditions (NHSE, 2022b).

Recommendations also acknowledged data quality, for example CVDPrevent suggested improving general practice ethnicity coding, again to ‘support’ Core20PLUS5 (CVDPrevent, 2022, p.7). Similarly, NLCA stated its ambition for ‘high levels of data completeness’ including 95% ethnicity in two national cancer datasets (NLCA, 2023, p.4). The NMPA also recognised the need to review data completeness (NMPA, 2022, p.ix). PICANet suggested working towards ‘a UK wide standardised recording of ethnicity’ (PICANet, 2023, p.4) to facilitate investigation of health inequalities. Social deprivation data was also considered, with the NCMD suggesting ‘multi agency-input into data collection and reviews’ (NCMD, 2022, p.8).

For some programmes, whilst they do not fulfil the criteria stipulated in this review, they instead consider other markers of health inequality, such as age, gender and care home residence (Royal College of Physicians, 2023, p.15). It should also be acknowledged that some audits are concerned with specific patient populations with particular characteristics (e.g. age in NABCOP) and so whilst they may not make specific recommendations pertaining to health inequalities, they remain relevant. Similarly, the outcome of interest may be influenced by health inequalities, for example, the predisposition of older, female patients to fracture (Ibid.).

We acknowledge that some audits that have yet to report on social deprivation and ethnicity data such as in the FFAP’s Fracture Liaison Service Database (FLS-DB) which described ambition to do so in the future (Ibid., p.18). Finally, given that annual report data is presented in retrospect, several of the reports considered data from during the COVID-19 pandemic. The impact of the pandemic on healthcare

and thereby the NCAPOP may have altered the priorities of these reports and/or impede their ability to draw comparison to previous reports.

## Literature review

### Method

A literature review was completed to determine how NCAPOP data has been used to facilitate research, particularly pertaining to ethnicity and social deprivation. In doing so, we aimed to gain further insight into data collection, analysis, and reporting; further elucidate health inequalities and provide additional rationale for our own research.

Full details of the search query and results is outlined in Appendix B. The 189 total results were aggregated to identify and remove duplicates, leaving 84 unique results. The abstract of each result was then reviewed for relevance, principally, whether it used a national clinical audit data source. 40 results were deemed relevant, with publication dates ranging between 2004 and 2023. An informal supplementary literature review was also conducted to achieve a broader perspective of health inequality data.

Relevant results utilised data from numerous NCAPOP programmes. Frequently cited programmes included the NDA, NLCA and NEIAA. Non-NCAPOP programmes included the National Institute for Cardiovascular Outcomes Research's (NICOR) Myocardial Infarction National Audit Project (MINAP), the British Heart Foundation's National Audit of Cardiac Rehabilitation (NACR) and The Royal College of Ophthalmologists' National Ophthalmology Database Audit for cataract surgery among others. The literature therefore considered a variety of both acute and chronic clinical conditions, interventions and outcomes alongside ethnicity, social deprivation or both. It should be noted that some studies received funding from HQIP including (Jardine et al., 2021a, p.740) and (Jardine et al., 2021b, p.1905).

### Limitations

The number and variety of datasets identified in this review meant it was sometimes challenging to determine whether they were equivalent to those comprising the NCAPOP. It is possible then that some literature has erroneously been deemed irrelevant to this report. Similarly, some datasets have changed over time which also creates challenges in determining their relevance. For example, the Myocardial Ischaemia National Audit Project (MINAP) was formerly commissioned by HQIP until 24<sup>th</sup> June 2022 (HQIP, 2022).

Due to our focus on national clinical audit data, inevitably there were some papers that utilised the same datasets and presented similar research questions and conclusions, or offered only abstracts or commentary. However, the persistence of these questions over time may indicate important shortcomings. It is also worth noting that the studies included often used datasets from several years before publication. For example, of the three papers in this review published this year, the data utilised ranged from 2014 (Fluck et al., 2023) to 2021 (Schlief et al., 2023) and this may impact their relevance.

### Results

The NCAPOP programmes collect, analyse and report data on patient characteristics/demographics to varying extents. This data is collected by the programmes themselves or obtained from linked data

sources such as HES, Office for National Statistics (ONS) and national registries e.g. National Cancer Registration and Analysis Service (NCRAS) among others. These national datasets facilitate a wealth of research as detailed in the preceding literature review.

The fact that national clinical audit draws upon data from across (often multiple) countries, devolved nations, and crown dependencies, facilitates a multitude of observational population-level research. The search query therefore predominantly returned both prospective and retrospective longitudinal cohort studies. Other studies used the data to conduct cross-sectional analyses. The review also provided useful insight into the methods used to achieve this, including data linkage, and logistic regression analyses.

Though service delivery is not the priority of this report, use of national clinical audit data also enabled commentary on the NHS as a 'universal healthcare system' and the equity of care that it provides (Hawkins et al., 2013, p208). This was often achieved by studying adherence to care standards stipulated by organisations such as The National Institute for Health and Care Excellence (NICE). Similarly, it may act as a comparator for local-level data, from individual clinical units or health authorities (e.g. Goyal et al., 2004, p.773). This data can also be used to consider population health improvement such as cost effectiveness of interventions (as per Hinde et al., 2019)'s consideration of cardiac rehabilitation.

Literature was justified on a background of evidence showing that there are significant variations in 'disease prevalence and outcomes by ethnic group' (Morrison et al., 2014, p.119), for example with predisposition for certain cancers and chronic conditions such as diabetes and coronary heart disease in the South Asian population (Iqbal et al., 2012b, p.1). This provides rationale for our project as the literature demonstrates that health inequalities remain pervasive and that complete and accurate ethnicity data has a role in addressing these.

Of the literature identified, objectives varied. Whilst it is not possible to consider the findings of every study, many considered how patients from minority ethnic groups or more socially deprived areas may experience inequities in healthcare access, standards of care and adverse outcomes (Poulton et al., 2020, p.73) which varied depending on the research focus. Often this was in comparison to the majority ethnic group (e.g. white British, or Caucasian etc.). Others also considered incidence, disease severity and the treatments or interventions received (ibid.)

This led to recommendations that broadly concerned further research into how health inequalities arise and developing approaches to address and reduce them (Schlief et al., 2023, p.2), be that adaptation of clinical or health policy (Jardine et al., 2021a, p.740) or services among others. Supplementary literature had similar findings, in describing the role of ethnicity data in identifying inequalities and providing equitable access to and receipt of healthcare (Morrison et al., 2014, p.128). Shortcomings in data therefore impede the ability to do this and impact on service commissioning (Ibid., p.129) and resource allocation (Iqbal et al., 2012, p.281).

## Discussion

### Ethnicity data

The barriers identified here predominantly concern ethnicity data collection, particularly its completeness and quality. However, these aspects are also relevant to analysis and reporting given the interdependence of these stages.

### *Source of ethnicity data*

Ethnicity data may be obtained from several sources with varying levels of quality and completeness, and it is useful to consider the barriers associated with these. For example, ethnicity 'self-identified' by the patient may be the 'gold standard' (Iqbal et al., 2012, p.287) for accuracy. However, literature has identified the role of 'staff embarrassment, fear of causing offense and in some cases perceived irrelevance' in discouraging staff from asking patients their ethnicity and inaccurately determining it from observation only (Morrison et al., 2014, p.126).

Ability to obtain self-reported ethnicity may also vary by audit, for example Jardine et al., 2021a which utilises NMPA data noted that ethnicity is self-reported by patients at antenatal booking appointments (Ibid., 2021a, p.734). Similarly, NPDA data is submitted by healthcare professionals in paediatric diabetes clinics (Khanolkar et al., 2019, p.822). Ethnicity data can therefore vary depending on the time and location it was obtained as NPDA also use the most recently recorded ethnicity for analysis (Khanolkar et al., 2019, p.823) assuming this is the most accurate. These factors may lead to a greater level of data quality and completeness.

In considering data source, one must also consider linked datasets, for example hospital episode statistics (HES) data, registries or other 'national administrative databases' (Poulton et al., 2020, p73). HES is a database that details patient, clinical, administrative and geographical information regarding hospital admissions and other activities (NHS Digital, 2015). This data is then made available for various uses including research via as the secondary uses service (SUS) dataset (ibid.). In 1995, it became a requirement to record ethnicity data in HES (Mathur et al., 2013, p.648). Some papers emphasised the quality of these datasets (Jardine et al., 2021a, p.739) and their use was often cited as a strength in permitting population-level research (Best et al., 2019, p.F628). However, one paper found that comparison between coded and self-reported ethnicity was poorer 'for distinguishing specific minority ethnic groups' therefore requiring broader ethnicity categories (Jardine et al., 2021b, p.1910)

### *Missing data*

Some papers' discussion of limitations focused on missing clinical data. For example, evaluation of HES largely surrounded it's under-reporting of clinical measures rather than patient characteristics (Vallance et al., 2018, p.1589). Similarly, the UK cancer registry for incomplete staging data (Forrest et al., 2014b, p.139)

However, several papers also commented on how ethnicity data is often unknown or missing. Missing data is problematic in that it limits the conclusions that can be draw or sometimes requires omission and therefore reduced sample size (Harrison et al., 2020, p.5). One paper deemed missing data to be reflective of wider inadequacies in NHS health records (Fluck et al., 2023, p.2078). Whilst proxy measures of ethnicity are available, such as country of birth or name, the accuracy of these has been questioned (Fluck et al., 2023, p.2078)

Ability to include individuals with missing data varied between studies understandably due to differences in analysis and statistical power. Multiple imputation or other statistical methods may be used to mitigate for missing data, however this assumes that 'data are missing at random' which may not be true of ethnicity (Jardine et al., 2021a, p.739).

### *Categorising ethnicity*

Irrespective of the data source and quality, where ethnicity was considered, it was noteworthy to see how the data was categorised and aggregated (if at all). NHS Digital describes the ONS 2011 census categorisation of ethnicity as the ‘gold standard’ (NHS Digital, 2023). However, NHS digital and the NHS Data Model and Dictionary utilise the ONS 2001 census categorisation of ethnicity, which is in turn used by various other datasets including HES (NHS Digital, n.d.). Therefore, many studies aligned their categorisation with this (Adas et al., 2022b, p170). The 2001 categorisation is as follows (NHS Digital, 2021):

<i>A = British (White)</i>	<i>L = Any other Asian background</i>
<i>B = Irish (White)</i>	<i>M = Caribbean (Black or Black British)</i>
<i>C = Any other White background</i>	<i>N = African (Black or Black British)</i>
<i>D = White and Black Caribbean (Mixed)</i>	<i>P = Any other Black background</i>
<i>E = White and Black African (Mixed)</i>	<i>R = Chinese (other ethnic group)</i>
<i>F = White and Asian (Mixed)</i>	<i>S = Any other ethnic group</i>
<i>G = Any other Mixed background</i>	<i>Z = Not stated</i>
<i>H = Indian (Asian or Asian British)</i>	<i>X = Not known (prior to 2013)</i>
<i>J = Pakistani (Asian or Asian British)</i>	<i>99 = Not known (2013 onwards)</i>
<i>K = Bangladeshi (Asian or Asian British)</i>	

Irrespective of whether the 2001 or 2011 census categorisation is used, the NHS has acknowledged the age of this data and potential to misrepresent the population (NHS Digital, 2023). For the purpose of COVID planning, NHS Digital ‘amalgamated’ ethnicity category data from HES and general practice data to obtain an improved ethnic category representation of England (Ibid.). However, this dataset cannot be used for purposes beyond covid planning and research due to legalities surrounding the data’s collection (Ibid.).

The categorisation of ethnicity is particularly relevant for individuals from minority and especially mixed ethnicities as the small numbers of individuals in each group sometimes leads to neglect by research (Valles, Bhopal and Aspinall, 2015, p.269). One paper explained that odds ratios varied in size between ethnic groups and some groups ‘failed to reach significance compared to the merged sample’ (Schlieff et al., 2023, pp.7-8).

Therefore, in several studies it was necessary to aggregate multiple groups containing fewer individuals to one broad heterogeneous group to enable comparison to a majority population reference group (i.e. white/ Caucasian group) (Fluck et al., 2023, p.2077). Though this defeats the purpose of accurately recording ethnicity, sometimes aggregation is necessary to maintain confidentiality (Knox et al., 2019, p.749). However, this is not a prerequisite for omission as ‘data perturbation’ may be used to protect anonymity (Valles, Bhopal and Aspinall, 2015, p.269).

For example, if we consider two papers utilising the same NEIAA audit dataset, one used five groups ‘White, Black, Asian, Mixed, Other’ (Adas et al., 2022b, p.548), however, another considered only ‘white’ and ‘non-white’ groups (James et al., 2020, pii43). Whilst we appreciate that these studies are not directly comparable, it is relevant for us to consider the variation in ethnicity data analysis as this may be reflective of the source data quality.

This grouping may also overlook differences between and within minority ethnic groups (Fluck et al., 2023, p.2078). Larger sample sizes such as those using MBRRACE-UK's perinatal mortality surveillance programme reduced the need for aggregation of ethnic groups, and 'avoid[ed] combining groups with different cultural, religious, social and economic experiences' (Matthews et al., 2022, p.6). Only one paper (Zaman et al., 2013) considered a specific ethnic group in their study of south Asian patients and coronary disease with subgroups of Bangladeshi, Pakistani and Indian patients (Ibid, p.729).

Therefore, some programmes may be better equipped to consider health inequalities than others. Some audit programmes, and therefore clinical conditions or specialties were represented to a greater extent than others, and we postulate that it may be for the same reason. For example, several results utilised data from the NDA and MINAP programmes. It is interesting to draw comparison to the scoping review here as, the literature review included data from several NCAPOP programmes that fulfilled 4-5 criteria including NDA, NPDA, NMPA, and NEIAA among others.

### Social deprivation data

We found that a greater number of papers considered social deprivation over ethnicity. Interestingly, this was not reflected in the scoping review, as there was a minimal difference in the number of reports that reported or analysed social deprivation versus ethnicity data. It is possible that this is because social deprivation data is more accessible or widely available than ethnicity data. For example, of the literature that considered social deprivation several utilised index of multiple deprivation (IMD) quintiles or deciles as a measure of this. This is a composite of seven different measures of deprivation calculated from census data for small geographical areas and can therefore be determined from other data such as postcode (Ministry of Housing, Communities & Local Government, 2019, p.6).

It was also more challenging to identify barriers surrounding social deprivation data, however, some of the above discussion particularly regarding data collection and quality is also applicable to social deprivation data. Similar to ethnicity data, due to the derivation from postcode, IMD is impacted when postcode data is missing (Jardine et al., 2021a, p.739). The predominant criticism, however, was that socioeconomic status may vary within an IMD group as it describes the area not the individual (Steiner et al., 2017, p.536) and so its use may underestimate differences in outcomes by social deprivation (Jardine et al., 2021b, p.1910) create an 'ecological fallacy' (Poulton et al., 2020, p.81). Some called for deprivation measures that consider smaller geographical areas as a result (Jardine et al., 2021b, p.1910).

Despite the shortcomings of area-based deprivation calculations, the feasibility of collecting individual-level socioeconomic status information is questionable. However, some used only the income domain of the IMD and stated this is advantageous in capturing individual and environmental deprivation information (Belot et al., 2018, p.57). Alternatively, one paper utilised the 'Children in Low-Income Families Local Measure' (Best et al., 2019, p.F625).

### Other measures of health inequalities

Whilst some papers were able to consider ethnicity and social deprivation together (see figure 1), often one characteristic was prioritised and the other adjusted for as a potential confounder and it is not always possible to include 'other potentially relevant covariates' (Schlief et al., 2023, p.10). This may be visible in divergence from predominant trends or expected findings. For example, (Holman et al., 2016) found that 'the greatest disparities in mortality risk between those with Type 2 diabetes and the general

population are found in areas of low social deprivation', however, acknowledged that further investigation is necessary to identify other explanations for this finding (Ibid., p89). As we will discuss from the findings of our survey data (e.g. CVDPrevent), it is important to remain mindful that data can often be skewed depending on adjustment for other patient characteristics, or lack thereof.

## Conclusion

This literature review has identified some barriers arising from national audit data sources particularly in more recent literature relating to ethnicity data. However, the fact that this research could be produced may be indicative of the quality of the ethnicity and social deprivation data available to some programmes, as were the data sources inadequate to the purposes of the research question it may not have been feasible to proceed. It is possible then, that this literature review is at risk of overlooking some of the well-documented issues surrounding ethnicity and social deprivation data. It also fails to provide the perspective of the audit programmes. We will therefore consolidate our findings from this literature review with our survey data to further explore the barriers to collecting, analysing and reporting ethnicity and social deprivation data experienced by NCAPOP programmes and thereby better understand health inequalities.

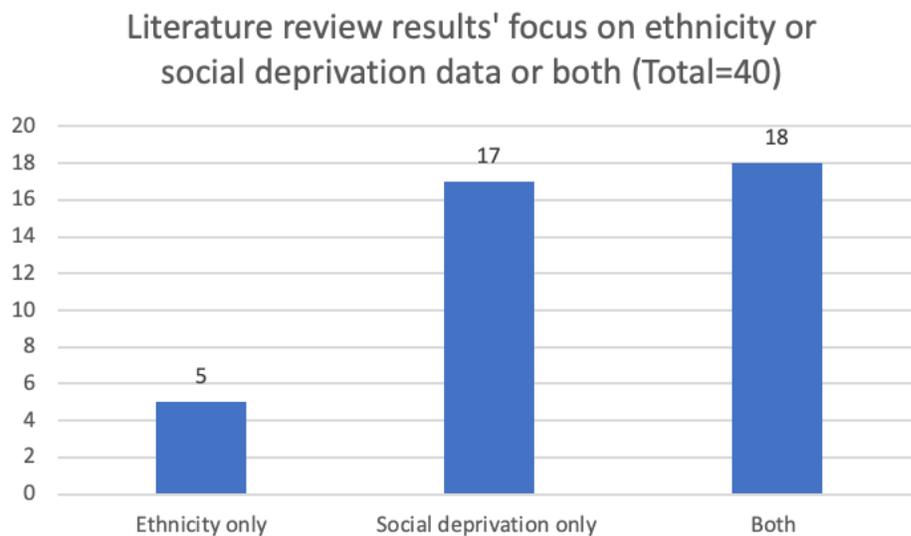


Figure 1: Literature review results' focus on ethnicity or social deprivation data or both (Total=40)

## Methodology

### Survey development

To further elucidate the current routine practices for collecting, analysing and reporting health inequality data within the NCAPOP as well as identify the barriers to doing so, a survey was developed and distributed to all twenty-three National Clinical Audit Programme and five CORPs in the NCAPOP. A list of survey recipients and respondents can be found in Appendix C. Two individuals representing each

programme were identified to respond to the survey, ideally holding the role of (lead) methodologist or (deputy) director of operations. These individuals were chosen because of their expert knowledge of the data collection, analysis and reporting process within their programme. Respondents completed the survey throughout April 2023.

Seven patient characteristics were selected, to compare collection of ethnicity and social deprivation data to the more routinely collected demographics. They are as follows:

- Age
- Sex
- Gender
- Ethnicity
- Postcode/Geography
- Social Deprivation
- Care home status

As explained, due to IMD postcode/ geography, and care home status can be used in estimation of social deprivation status (Ministry of Housing, Communities & Local Government, 2019, pp.5-6). Whilst we recognise that other protected characteristics as per the Equality Act 2010 such as disability, gender reassignment, marital/ civil partnership status, pregnancy/maternity, religion/belief, and sexual orientation (Equality and Human Rights Commission, 2021) all contribute significantly to health inequality, collection of these were outside the scope of this project.

Multiple choice questions that permitted more than one selection were included to categorise responses, with the option to add a free text 'other' response if required. To build on the work of (HQIP, 2020) this survey focused on barriers to the same categories of data collection, analysis and reporting (Ibid., p.30). Pre-populated multiple-choice suggestions of barriers included:

- Cost
- Coding
- Analysts
- Not specified in tender
- Data not available
- Not relevant to audit subject matter
- Data completeness
- Timeliness of data

These barriers were chosen because of themes identified in scoping exercises such as the literature review as well as informal meetings with stakeholders.

A pilot survey was conducted in March 2023 by two National Clinical Audit Programmes: NOGCA and NBoCA (both constituents of the National Gastro-Intestinal Cancer Audit Programme), in addition to NJR. This was conducted to assess the quality and utility of the survey and to gain feedback from audit providers to improve the value of the survey. As only small changes to wording of questions and accessibility of the survey were made following the pilot, those programmes that completed the pilot

were not required to complete the survey again; and the results of the pilot were included in the overall survey results.

A copy of the final survey is included in Appendix D.

## Results

Twenty-six responses were received from twenty-three different programmes. Two responses were received from NOA, NPDA, PICANet, and these were aggregated to prevent overrepresentation of any one programme in the results. The responses of both The National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH) and the Mental health outcome review programme were also aggregated as the latter is facilitated by the former. One response was shared by both the Medical and Surgical outcome review programme and Child Health CORP, giving a total of twenty-two responses.

Survey respondents' roles included methodologists, programme directors and managers, information managers, analysis and clinical leads, chief executives, research fellows and database developers among others.

### *Programme perceptions of their own health inequality data*

Respondents were first asked whether they thought their programme is currently recording and analysing health inequality data well (Question 3), to gauge the perceived quality and focus upon health inequalities within their programme. The question was interpreted broadly, however, it introduced many of the overall themes that recurred throughout the survey.

Many believed they were collecting health inequality data well, but this was often limited to specific patient characteristics. For example, NOGCA explained that some elements of data sourced from HES such as age and socioeconomic deprivation are analysed well however ethnicity is less so. Some programmes seemed to prioritise social deprivation data over other characteristics, such as Epilepsy12, which explained that their data shows geographical variation in care. They explained that they complete some analyses on this but have only begun collecting ethnicity and learning disability data this year.

NAD described issues regarding social deprivation and care home status, as the former could not be analysed in the past due to the 'extent of data cleaning required'. Some quality issues may arise from the fact that many programmes obtain some inequality characteristics data from linked datasets. On this topic, it is useful to have the perspective of a newly established national audit such as NOA. Though they were less able to comment on their current HES reporting, they explained they are using 'established datasets and believe inequality data is 'generally well recorded'. The NNAP explained that data quality has been improved by including ethnicity and postcode data completeness in 'quarterly data quality reports to trusts and networks'.

Issues regarding data quality were not expressed by other programmes who use other means to record and analyse health inequality data. For example, the medical and surgical CORP and child health CORP stated they 'collect clinician views on whether inequalities were present and if they impacted on care'. They explained that this information cannot be 'teased out' of larger datasets (such as linked data) as 'it would not be robust'. Similarly, NACEL described collecting health inequality data from alternative sources including case note review and NACEL quality review survey. The CORPs therefore felt well

placed to consider health inequalities, with the NCMD highlighting a recent thematic report on child mortality and social deprivation (NCMD, 2021) and an upcoming publication on ethnicity and social deprivation. Given the different natures of the national clinical audit and CORP programmes, it is unsurprising that data quality provides less of a barrier as CORPs predominantly facilitate outcome reviews and confidential enquiries.

### Current plans to improve health inequality data within their programme.

Several programmes expressed plans or ambitions to improve their use of health inequality data in their responses to questions 3 and 6. Some, such as PICANet, described recent changes with improvements in data recording and analyses. They also shared their aim to continue developing this, having reported on ethnicity for 2 years and more recently social deprivation data. This was like CVDPrevent who have introduced age standardisation to their data and further analysis of select characteristics. However, they have yet to consider other characteristics indicative of health inequalities such as learning disability or severe mental illness.

NNAP noted plans to produce analyses of ethnicity, sex and deprivation index metrics this year. Similarly, NCMD explained their plans to develop their analyses of mortality rates in the context of multiple characteristics, aided by ethnicity data from the 2021 census. These will be communicated in monthly surveillance reports to key stakeholders and thematic reports. NOA also expressed ambitions that health inequality data recording and analysis will be done well as the programme becomes more established. Finally, NCAP noted that health inequalities were not reported in 2023 despite doing this the previous year due to contract variation, however they are being incorporated as a 'key measure' for the programme from 2023 onwards.

NBOCA stated that they have planned to complete methodological development work to assess the validity of ethnicity data and place of residence. Similarly, NRAP stated they were 'exploring the granularity of the fields collected' whilst PICANet are focusing on cleaning ethnicity data. Meanwhile NOA explained that they want to work with data providers to improve the quality of submissions but have 'limited resources to do so'. Several stated that they do not have any current plans for improvement, with the medical and surgical and child health CORPs citing a recent review of this. The NPDA stated their data was already comprehensive at nearly 100% and therefore did not have plans for improvement. Similarly, NELA stated they have 'comprehensive data' on the characteristics they collect 'with the exception of ethnicity' and do not plan to collect on the outstanding characteristics gender and care home status. NAD explained that they may revisit their decision to not collect identifiable data 'if an opportunity for linked data is identified'.

Question 24 and 25 asked respondents if they felt they needed more support to include health inequality data in their reports and for any other comments. There were calls for increased funding for additional analyst time and more audit nurses to improve data quality. Two respondents noted the importance of data quality to report on health inequality and how this is often informed by staffing levels of participant organisations. Again, there was reference to the quality of linked datasets. One respondent expressed interest in learning from other programmes as to how they have addressed ethnicity data barriers including 'cost' and 'data completeness'. Despite the aforementioned linked data issues, one respondent expressed interest in linking to additional NHS digital datasets to improve data

completeness with data that is 'standardised and coded' and thereby conduct more detailed health inequality analyses.

### Data Collection

Respondents were asked which of the seven patient characteristics they were routinely collecting or acquiring data on (question 4). All (100%) of respondents are collecting data on patient age. 90.9% self-reported that they were collecting data on sex and postcode/geography. 77.3% respondents stated they are collecting data on social deprivation, however as indices of deprivation can be calculated from postcode, this number could potentially be higher than reported, as postcode data was available for 3 respondents who denied collecting social deprivation data. Ethnicity data was routinely collected by 81.8% respondents. Finally, care home status was collected by 27.3% respondents. Only the NCISH and SSNAP reported collecting data on all seven patient characteristics of interest. The majority 54.5% had data on five characteristics. It is worth noting that some characteristics are not applicable to specific programmes' patient population, for example for NNAP data pertaining to care home status is irrelevant.

## Q4 - What characteristics are programmes routinely collecting data on?

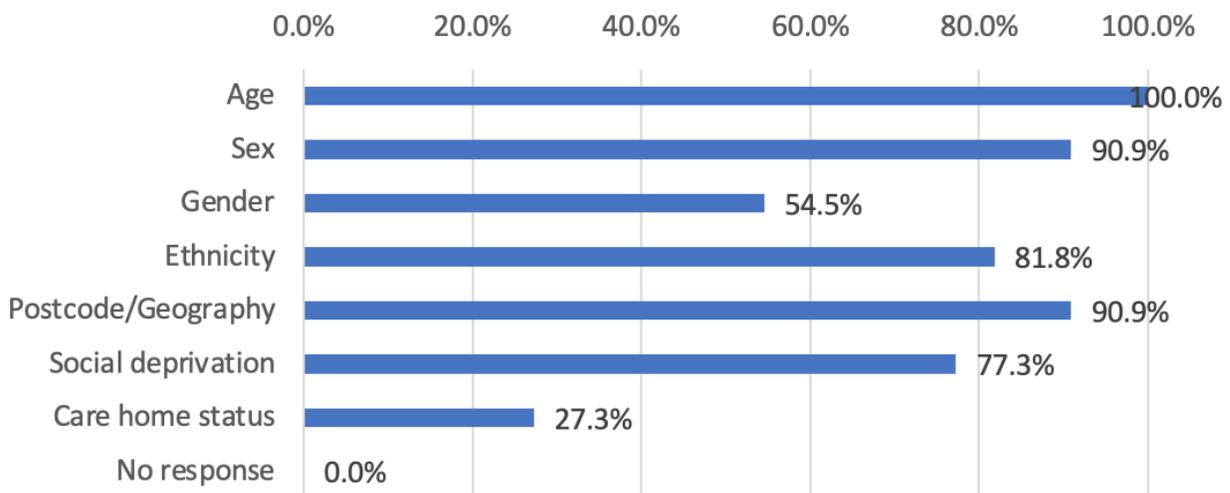


Figure 2: Q4 - What characteristics are programmes routinely collecting data on?

When asked what sources are used to collect data on those characteristics responses differed slightly from the above. It is possible that respondents interpreted question 4 to consider collection by the programme only, and therefore disregarded characteristics where data is obtained from other sources. Alternatively, in question 5 respondents may have detailed data sources they have access to but choose

not to use. It may be preferable then to look at responses to question 5 in answer to question 4 to get the most accurate perspective of data availability.

There was no difference in age, sex and postcode/geography data between answers to questions 4 and 5. In question 5, ethnicity data was collected by 90.9% respondents and 81.8% for social deprivation data however the aforementioned caveat about calculating social deprivation from postcode applies. Gender data was collected by 59.1% and care home status data by 31.8%. According to question 5 responses, 13.6% respondents had data for all 7 characteristics, however one of these programmes NBOCA stipulated that their gender data was likely entered as sex. In Question 3, they explained that they were not able to distinguish between these two characteristics because the differentiation of these terms is not 'explicit in what we are asking for'. It is therefore possible that the terms 'sex' and 'gender' may have been conflated in other responses to question 4 and 5 also. Again, the majority, 59.1% collected data on 5 characteristics.

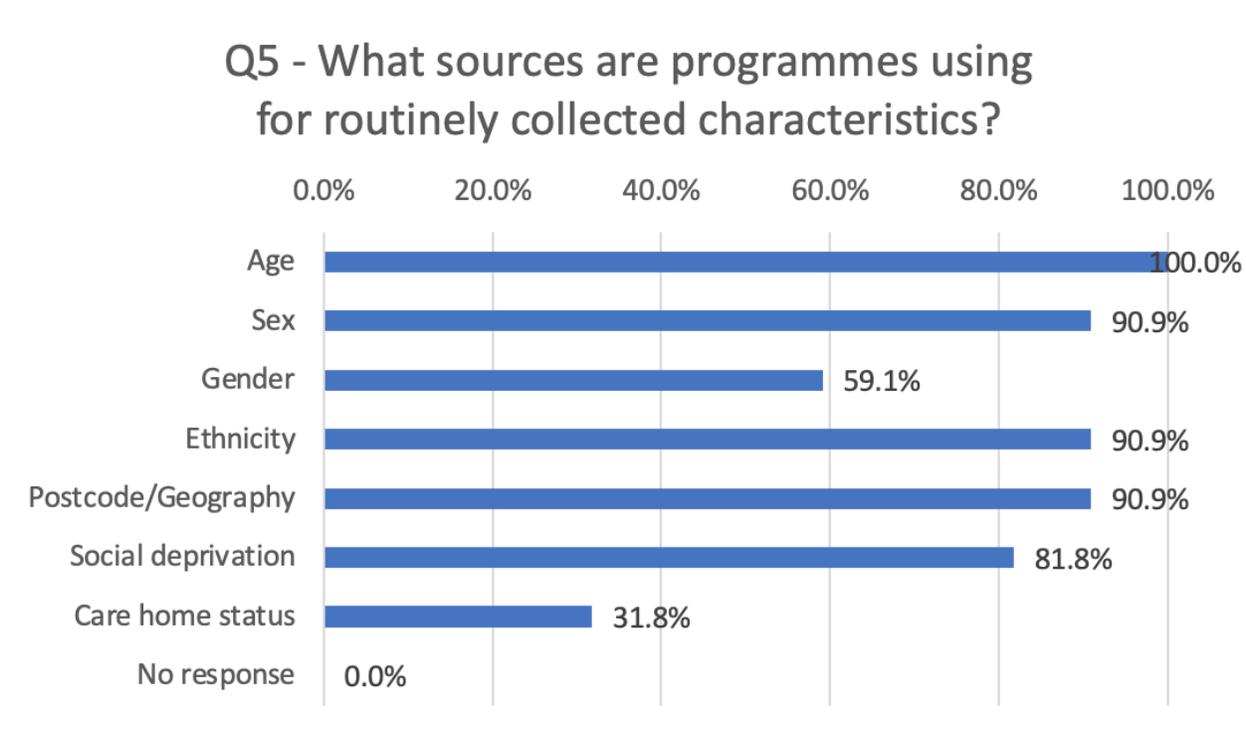


Figure 3: Q5 - What sources are programmes using for routinely collected characteristics?

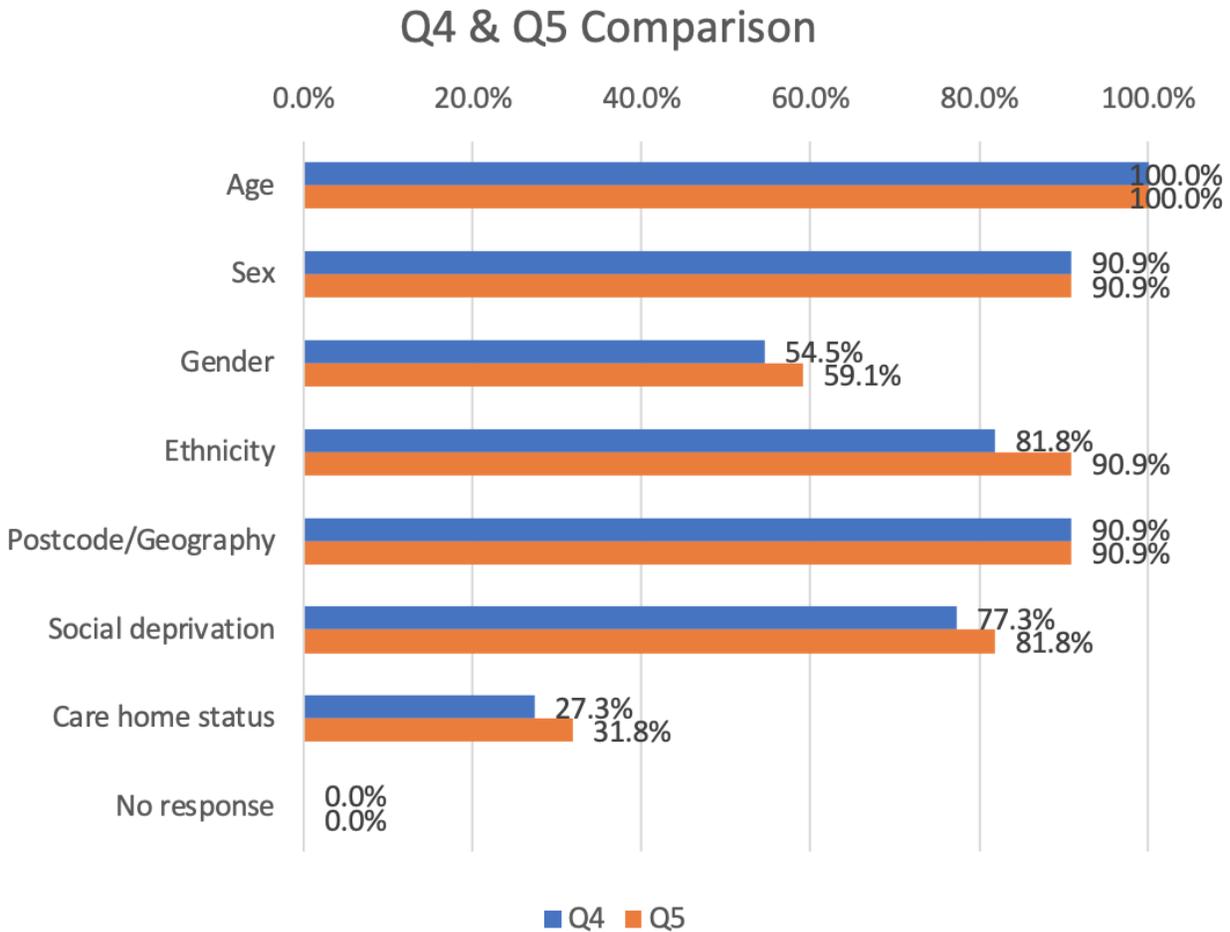


Figure 4: Q4 & Q5 Comparison

A wide array of data sources was identified in responses in question 5. These can be broadly categorized as below:

- **Audit dataset**
  - often data is submitted directly by clinical centre/teams via a dedicated platform.
  - Survey/questionnaire/data collection forms via patient/clinician/next of kin.
- **Linked datasets**
  - Office for national statistics (ONS)
  - General Register Office for Scotland (GROS)
  - Northern Ireland Statistics and Research Agency (NISRA)
  - Hospital episode statistics (HES)
  - National Cancer Registration and Analysis Service (NCRAS)
  - Community Services Data Set (CSDS)
  - Mental Health Services Data Set (MHSDS)
  - BadgerNet Neonatal and Paediatrics continuous care record
  - Child death review data

- GP register/ data
- Department for Work and Pensions Children in Low Income Families dataset
- Patient records/ notes
  - Hospital/ Secondary or Tertiary care
  - General Practice/ primary care

Some respondents were more specific than others in their responses, so it is possible that some data sources have been overlooked here.

### Barriers to ethnicity data:

#### Collecting:

With regards to ethnicity data, respondents were asked about the barriers to collecting/acquiring data. The most cited reason was 'data completeness' (63.6%). This was followed by 40.9% citing 'data not available', 27.3% 'coding' and 22.7% 'cost'. Only two respondents cited 'timeliness of data' (9.1%) and one respondent each chose 'analysts' or 'not relevant to audit subject matter' as a barrier (4.5%). None chose 'not specified in tender'. Two respondents skipped this question.

## Q7 - What are the barriers to collecting ethnicity data?

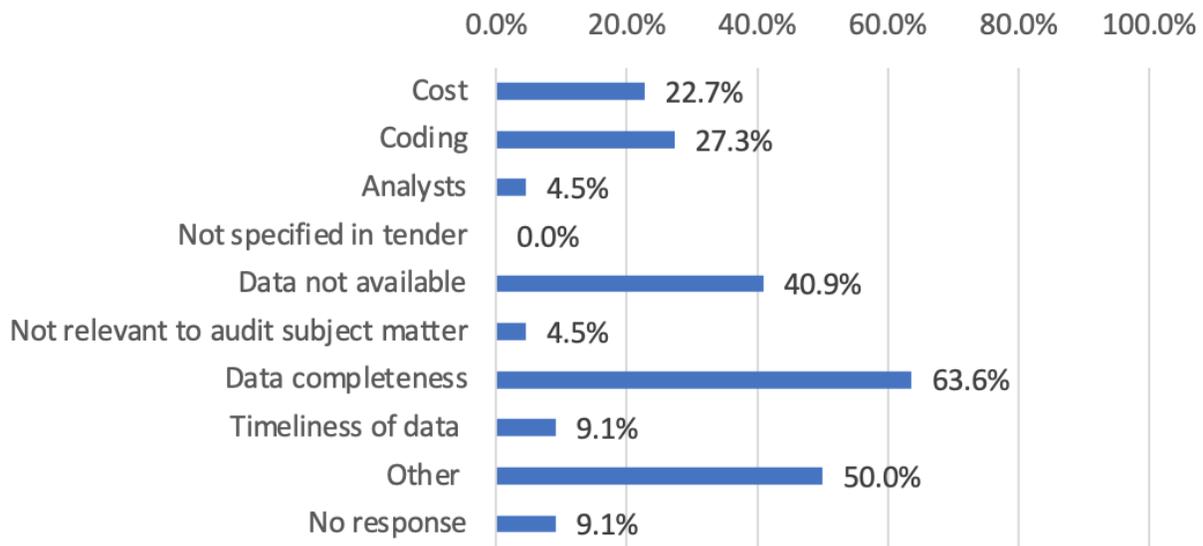


Figure 5: Q7 - What are the barriers to collecting ethnicity data?

56% of all respondents chose 'other'. Whilst three of the programmes used this to explain that they feel they have no barriers, given high collection rates, most programmes felt there were several other barriers. NACEL explained that when collecting bespoke data via a quality survey, they encounter significant under-representation in responses from ethnic minority groups, so it is not fully representative of the population. As a programme, they have provided tools and resources to hospitals to try to improve this, but it remains a consistent feature over 4 iterations of the audit.

Where programmes collect ethnicity data, some described constraints on clinician’s time to collect and categorise this and their confidence in doing so. Specifically, PICA Net, commented on the limited opportunity to collect this data within the Paediatric intensive care environment. Similarly, many programmes felt ethnicity was poorly documented in the patient notes and is not recorded on death certificates, so this is a significant barrier when used as a data source. Some described issues with how to categorise ethnicity, for example, NCISH stated that ethnicity is clinician-reported rather than self-reported and therefore categorised broadly.

Analysing:

The same question was asked as to the barriers to analysing ethnicity data, once received. 41% of respondents cited ‘data completeness’ as a barrier to analysing ethnicity data.

### Q9 - What are the barriers to analysing ethnicity data?

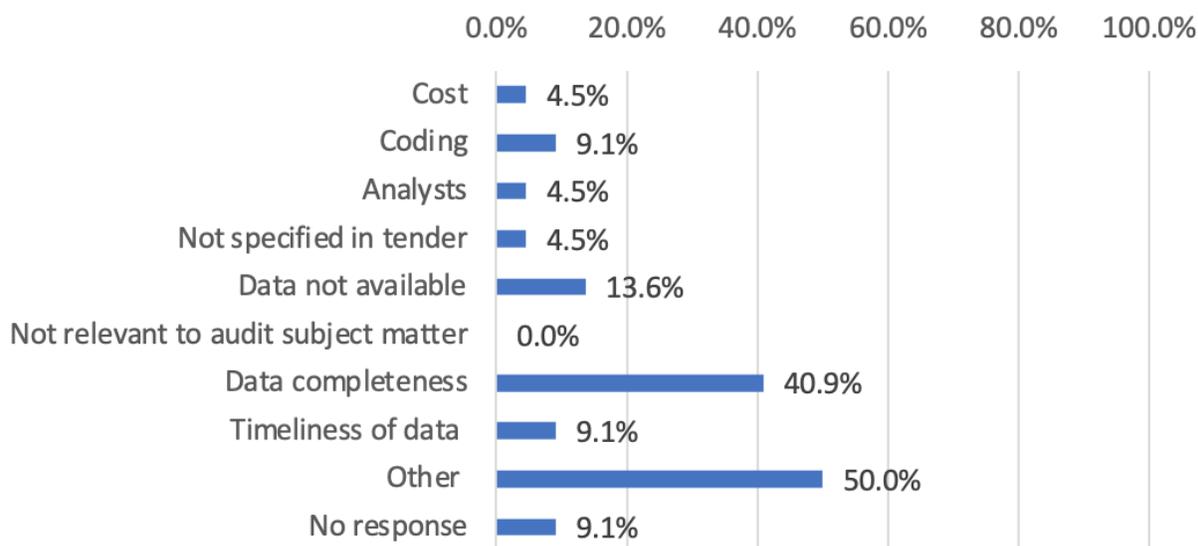


Figure 6: Q9 - What are the barriers to analysing ethnicity data?

52% of respondents chose ‘other’, some again used this to declare no barriers, such as NCMD who achieve ‘timely and very well completed’ ethnicity data analysis due to the statutory requirement to notify child deaths within 24 hours. Their analyses and risk calculations will be further strengthened by the data of the most recent census.

Again, there were issues of data completeness, as the NNAP queried the ‘clinical appropriateness’ of using mother’s ethnicity as a proxy for the patients’. Similarly, NBOCA noted data completeness is particularly problematic in the Rapid Cancer Registration Dataset. Where data is complete, PICA Net noted the time needed to review and group ethnicity categories when at the analysis stage, particularly when it is entered in a free text ‘other’ category. NAD stated that whilst they complete initial analysis

comparing results for the majority group (White British) against an aggregate of all others, they have not undertaken regression analyses with more than one characteristic.

The issue of data quality also resurfaced with NBOCA citing (Jardine et al., 2021c) which concluded that HES ethnicity coding accuracy supported aggregation (Ibid., p.1). This was reiterated by NVR and NELA, with the latter stating that they have not analysed ethnicity due to HES data being poorly coded unless aggregated. This was not unique to HES, as programmes that rely on clinician data submission such as PICANet also experienced missing data. They also postulated that missing data is 'more likely' in minority ethnic groups. NOGCA stated that the data incompleteness is compounded by the small numbers problem, thus limiting their ability to draw conclusions.

Practically, Epilepsy12 noted that they had not analysed ethnicity data as it was not specified in their contract or deemed relevant to their programme. For CVDPrevent, the barrier was largely at the analysis stage, as they stated the issue was not with their own ethnicity data but in finding 'whole population denominator figures for ethnicity'. This problem was reiterated by NCISH, who explained there is not data for ethnicity and suicides in the general population, thus preventing analysis.

Finally, NOA mentioned the unavailability of analysts and FFAP noted the additional unknown costs from sub-contracted analysts which cannot be confirmed until new HQIP contracts are received.

#### Reporting:

Question 11 considered barriers to reporting the collected and analysed data. Over half of respondents chose 'data completeness' and again over half chose 'other'.

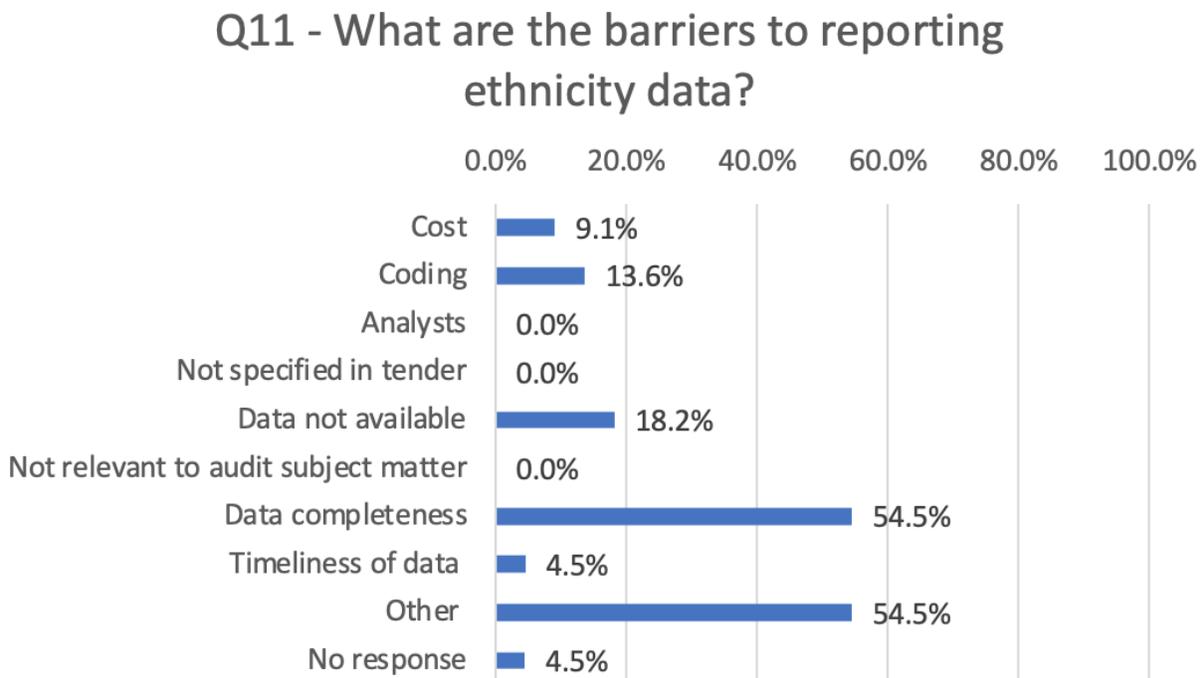


Figure 7: Q11 - What are the barriers to reporting ethnicity data?

At the reporting stage, the small numbers problem featured again with NRAP explaining that they cannot disclose small numbers, presumably because of issues with identifiability. NBOCA stated that small numbers make it 'difficult to understand variations in care and outcomes. In turn, this makes analysis challenging, and prevents 'nuanced reporting' according to NCISH. Again, data completeness concerns featured, especially where ethnicity data is missing (or categorised as 'not documented', 'declined' etc.) This was noted by Epilepsy 12 and CVDPrevent who explained they cannot know the 'spread', how this might skew the data and thus cannot report this. New programme NOA explained that they wish to complete further analysis before reporting. Similarly, FFAP explained they would be 'hesitant to present the data without accounting for all characteristics'.

### Barriers to social deprivation data:

#### Collecting:

The same questions as to collecting, analysing and reporting barriers, were asked with regards to social deprivation data. In terms of barriers to collecting this data, five respondents chose 'data completeness'.

### Q15 - What are the barriers to collecting social deprivation data?

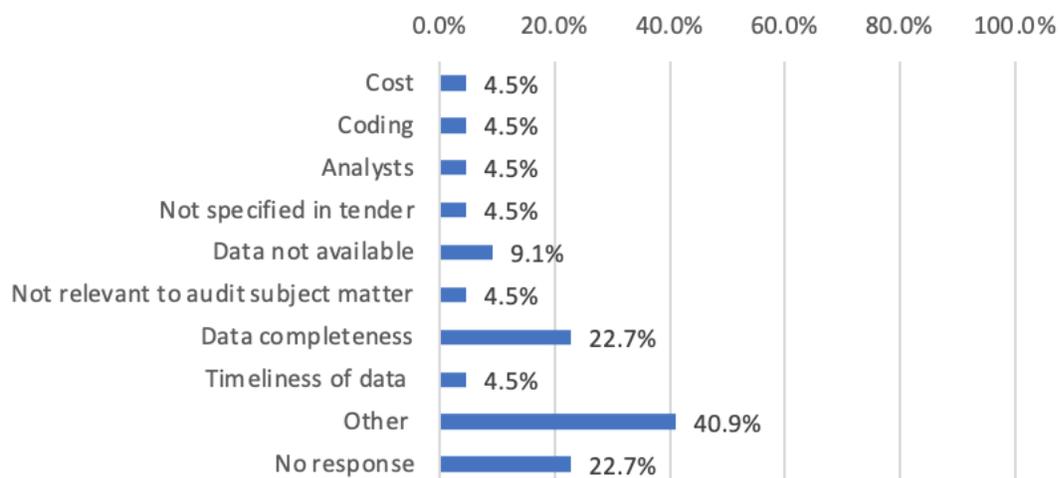


Figure 8: Q15 - What are the barriers to collecting.

43% chose 'other', again with several using this response to state there were no barriers. Most respondents noted the derivation of Lower Layer Super Output Area (LSOA) or index of multiple deprivation (IMD) from postcode, so it cannot be calculated if this data is missing. This was reflected in responses to question 16 to which 76% responded. Several respondents explained that as postcode is identifiable data it is not yet collected or would require justification if it were. NAD explained that if this data were to be added to their dataset it would 'add 4-8 weeks to analysis time', due to the necessity to 'query incomplete data' and 'ensure compliance with NDOO [National data opt-out]'. Another respondent noted incomplete data entry at the source, as per previous questions. PICANet noted the data quality issue where postcode is missing, especially in relation to overseas patients and anonymised records such as 'secure addresses'. Where this data is available, Epilepsy12 explained that it is a 'proxy

measure' of social deprivation and may not be 'fully representative of...socioeconomic status'. The availability of the data from linked sources meant that there wasn't incentive to collect it for some programmes and was therefore a lower priority characteristic. Others believed that social deprivation data is 'generally well collected' (NOA) with NPDA reporting 99% data completeness.

Analysing:

Question 17 considered barriers to analysing social deprivation data. Three each chose 'coding', 'analysts' or 'data completeness'. Two chose 'data not available'. None chose 'not specified in tender' or 'timeliness of data'.

### Q17 - What are the barriers to analysing social deprivation data?

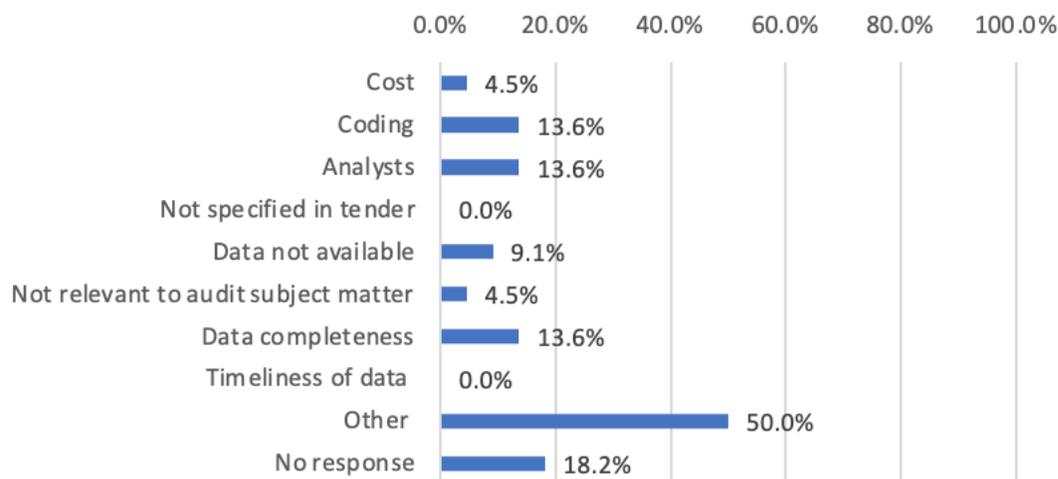


Figure 9: Q17 - What are the barriers to analysing social deprivation data?

Again, 50% chose 'other'. These responses spoke to the complexity of analysis required with regard to social deprivation. In question 18, CVDPrevent explained that the differences between levels of deprivation in terms of other patient characteristics, such as age, 'skews prevalence data, and using only postcode does not accommodate' for this. In this example, those in more deprived areas have a lower life expectancy, whereas cardiovascular disease (CVD) is more prevalent in older populations, therefore it erroneously appears that CVD is more prevalent in less deprived areas; thus, requiring this data to be age standardised. Similarly, Epilepsy12 explained that it is difficult to directly compare deprivation quintiles between England and Wales as they are not 'like for like'. Given these points, and the need to derive deprivation data in the first place, NOA acknowledged the availability and costs of analysts as a barrier.

With regards to analysis, respondents were also asked specifically whether health inequality data was integrated into programmes' audit risk algorithms (question 23). Response was limited by lack of understanding as to what 'audit risk algorithm' meant or what the question was asking, with four

respondents querying this. Three who responded ‘no’ questioned why this was the case or how they would achieve this and suggested this as an area for investigation or requested guidance. Two respondents interpreted this as risk adjustment of outcomes/indicators. For example, NOGCA explained that social deprivation didn’t improve risk adjustment and ethnicity isn’t included in their models. Similarly, NBOCA does the same due to the risk of adjusting away any quality-of-care differences that result from ethnicity or deprivation. Two interpreted it as case-mix adjustment, with NPDA explaining that they adjust mean HbA1c by patient demographics for benchmarking. Another two respondents explained that clinically relevant data is the focus of their modelling rather than health inequality data. Epilepsy12 explained they do not have risk algorithms due to ‘scope and capacity’ but expressed ambition to do this in future. NAD explained they do not produce an audit risk algorithm as data is not collected at the point of onset. SSNAP stated that data quality and completeness needed improvement before they could be used in risk modelling. This question was not relevant to CORP’s who do not utilise algorithms.

Reporting:

### Q19 - What are the barriers to reporting social deprivation data?

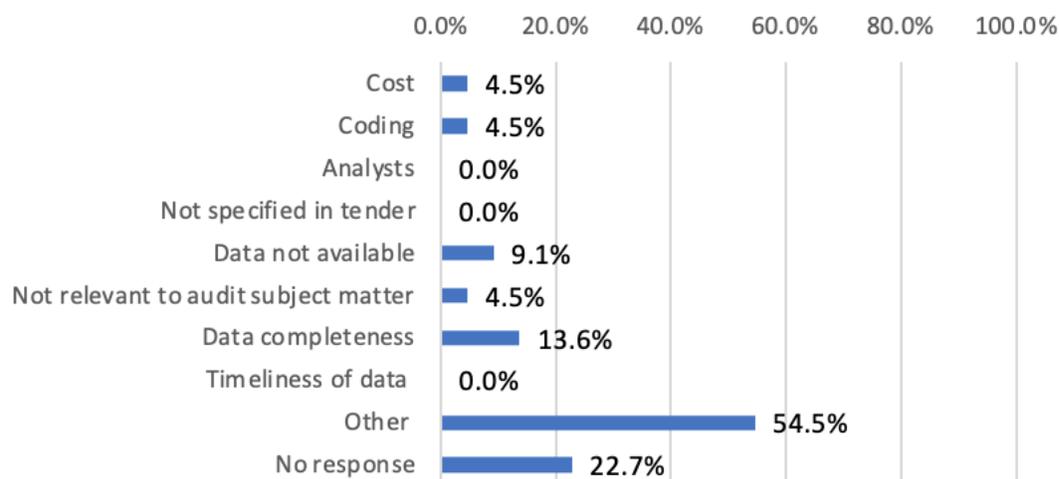


Figure 10: Q19 - What are the barriers to reporting social deprivation data?

In response to question 19 regarding barriers to social deprivation data reporting, three chose ‘data completeness’ and two chose ‘data not available’. There was one respondent each for ‘cost’, ‘coding’ or ‘not relevant to subject matter’. None chose ‘analysts’, ‘not specified in tender’ or ‘timeliness of data’. 12 respondents chose ‘other’. Responses included the move to quarterly and monthly reporting, space in 10-page annual reports and varying abilities to report identifiable data. Many of the themes described in previous questions remained relevant, including constraints on and complexity of reporting. CVDPrevent expanded on their previous answer, explaining that they ‘don’t see particularly strong trends in our deprivation data but we think that is because we need to factor more things into the analysis’. NELA explained this is ‘particularly pressing given the new report format and decisions about what can be included [in reports] and to what level of detail’. Similarly, Epilepsy12 explained that they needed to

‘minimise misinterpretation of data’ in their publications. Given these complexities, the newly established NOA stated they were yet to access all data sources and wanted to better analyse and understand this data before reporting on it. Positively, PICANet explained that whilst there was previously lack of demand for this data it said that it was ‘prominent in the tender and on the agenda now’.

As demonstrated in the graphs below, comparing perceived data barriers between ethnicity and social deprivation, at all stages, data completeness is perceived as a much more significant barrier to good quality ethnicity data collection than social deprivation data. Cost and coding are also perceived as larger factors in relation to ethnicity data, particularly at collection stage.

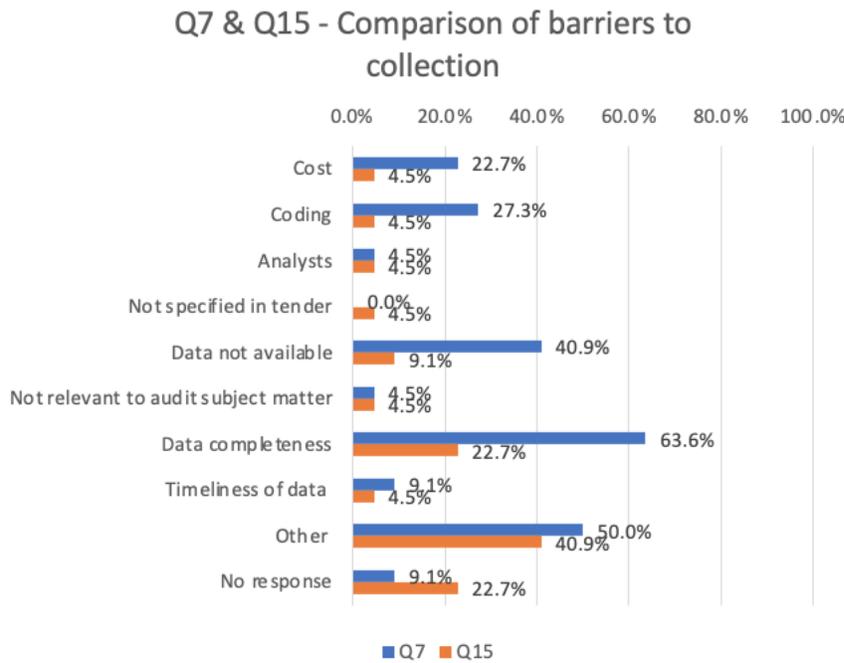


Figure 11: Q7 & Q15 - Comparison of barriers to collection

### Q9 & Q17 - Comparison of barriers to analysis

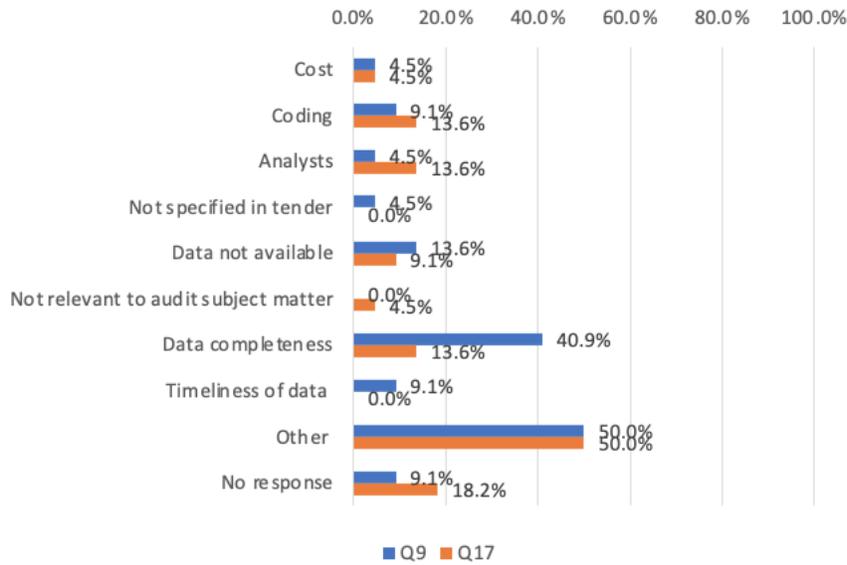


Figure 12: Q9 & Q17 - Comparison of barriers to analysis

### Q11 & Q19 - Comparison of barriers to reporting

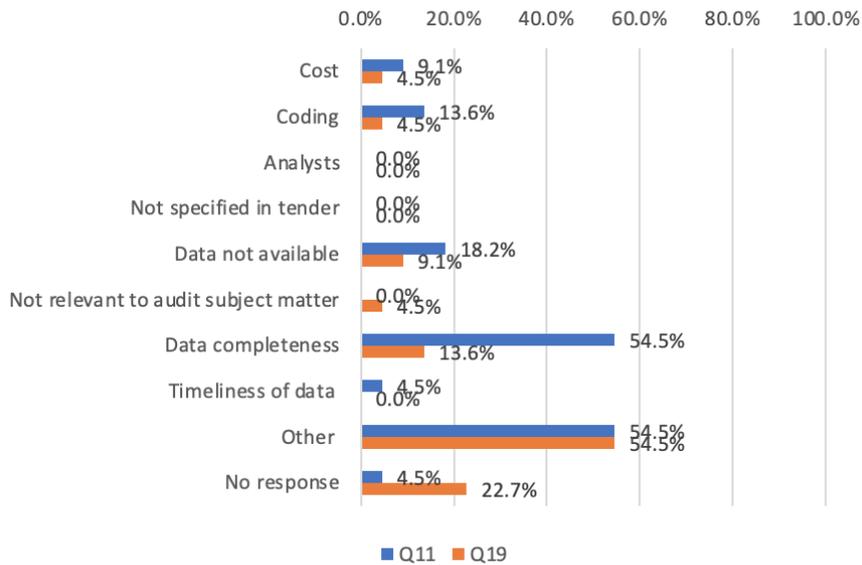


Figure 13: Q11 & Q19 - Comparison of barriers to reporting.

## Discussion

For the purposes of detailed analysis and nuance, programmes were asked about barriers to the collection, analysis and reporting stages separately. However, given that none of these stages can take place in isolation (as per figure 14) many of the barriers identified in the survey data arose recurrent across these three foci, despite large variation in the responses across the programmes. We will discuss some of these recurring themes now.

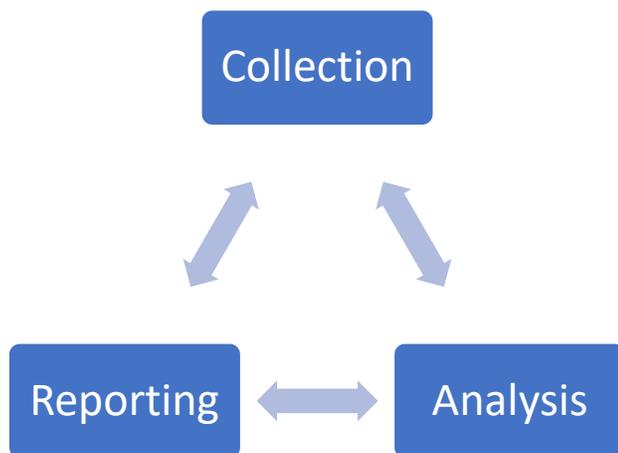


Figure 14: Interdependence of data collection, reporting and analysis.

### Linked data sets & Bespoke data sets

When considering barriers to health inequality data collection, concerns about data quality were frequent and often dictated by the data source, which differed between programmes as identified by the results of question 5.

Data quality is determined by what data is inputted. There is great variation as to how and when this is done, and by whom. Where ethnicity was inputted by clinicians, there are a variety of factors that impact the accuracy of this data collection; these include whether the clinician asks the patient, or makes a ‘best guess’, whether the patient is happy to provide this information, and whether they feel there is an ethnicity category that truly represents them, alongside the time constraints upon clinicians.

Many audits rely on linked data sources to provide some categories of health inequality data. For example, in question 5, seven programmes included NHS Digital’s HES database as a source of ethnicity data. Several of these, cited the sourcing of ethnicity data via HES as preventing good data from being collected. Alongside data completeness issues, difficulties can also arise when a single patient is documented as having several different ethnicities. However, HES was not the only linked data source receiving scrutiny, with others citing ethnicity data completeness issues in the Rapid Cancer Registration Dataset also.

There are, nonetheless, great benefits to using HES data. For example, FFAP acknowledged that using HES data is necessary given the fact that some programmes’ patient populations are often unable to give consent, thereby making it inappropriate and potentially harmful to ask patients to self-report their ethnicity. Using HES data also reduces the aforementioned burden on clinical staff to identify ethnicity

data from alternative sources which have their own completeness and quality issues. Furthermore, where audits use self-reporting, or patient/relative surveys to collect data, there are data completeness issues because of accessibility barriers. NACEL, for example, use surveys of relatives, and have consistently found that certain minority ethnic groups are underrepresented within their data because of this.

NBOCA alluded to this conflict within using HES data stating ‘It doesn't prevent us analysing ethnicity data but there are data quality issues’. Literature has shown that HES is able to capture broad ethnicity groups but is poor at capturing specific ethnicities’ (Jardine et al., 2021).

Irrespective of linked data quality concerns, there is also an issue of access to these sources. The existing NBOCA, NPCA, NOGCA, NABCOP and NLCA national cancer audits of the Royal College of Surgeons and London School of Hygiene and Tropical Medicine’s Clinical effectiveness unit (Royal College of Surgeons of England, n.d.) will imminently no longer be collecting data due to their upcoming incorporation into the NATCAN. This centre will bring together these audits with five new audits to improve understanding of how cancer care varies nationally and improve cancer detection, treatment, and patient outcomes (Ibid., 2022). This makes the issue of linked dataset quality more pressing.

### Small numbers of certain Ethnicities

With regards to analysis, there were two separate major themes that each arose for ethnicity and social deprivation. For ethnicity, this was the issue of the ‘small numbers problem’ which describes the challenge of obtaining meaningful insights from data, when it is derived from a limited sample size. For instance, survey data that relies on smaller participant numbers may exhibit wider confidence intervals, making it more difficult to discern significant variations between various groups. Additionally, such data may not be directly comparable to other datasets of interest. Several respondents commented on the challenges of having a small number of individuals in some minority ethnicity groups’ data, thus hindering their ability to draw meaningful conclusions about outcomes from the data, whilst others were concerned about identifiability.

Respondents were asked how many categories each programme uses for ethnicity data (Question 13), with responses ranging from 5 to 21. Some responses aligned with either NHS data dictionary, HES, OHID or various census categorisations. Therefore, for some programmes, the number of categories is dependent on the dataset.

Due to the number of categories, it is often necessary to aggregate them into fewer groups consisting of a greater number of individuals. Respondents were asked about this in (question 14), again with large variation in responses. These ranged from some programmes aggregating ‘all except White British’, to five subcategories (typically White, Black, Asian, Mixed, Other), whilst only one programme reported data without aggregation. It is possible that some audits do not report ethnicity data because of this issue. Two programmes stated plans to report at a national level to avoid the small numbers problem.

### Social deprivation calculation

With regards to social deprivation, a major theme was the use of postcode as a proxy measure for social deprivation. The English Index of Multiple Deprivation (IMD) measure relative levels of deprivation in

32,844 small areas or neighbourhoods, called LSOAs, in England (Ministry of Housing, Communities & Local Government, 2019, p.12). The IMD, while serving as an indicator, have limitations in their ability to specifically capture information regarding financial deprivation and lack absolute measures. Moreover, due to variations in the calculation methodology over time, each version of the IMD is not directly comparable to others. Another drawback of reporting at the local authority level using the IMD is that it can obscure significant disparities.

Several respondents commented on the accuracy of using postcode data or LSOA code as a marker of social deprivation. Epilepsy12, for example, were concerned that the proxy measure of home postcode may not be accurate and fully represent a patient's socio-economic status. Others commented on the challenges posed by postcode being identifiable data and the additional cost implications of analysis time. FFAP commented that their database provider is able to 'convert postcode to social deprivation in the new contract, however, additional funding would be required so it might not be possible due to funding limitations'. Positively, NCAP stated that in 'previous years, it has not been possible to look at social deprivation as postcode/identifiable data was not collected. Moving forward in the new programme, NCAP will be collecting this data'.

### Population data

Some respondents described a lack of population-level data to facilitate comparative analyses.

### Costs

Another barrier identified was the cost of both additional analysts and resources to enable analyses.

### Reporting demands

Even if health inequality data were to be collected and analysed without issue, many respondents spoke of the constraints that arise from different reporting requirements. As with all health data, there is a conflict between the benefits of timely, 'live' reporting and high-level analysis of less-frequent, extended reporting.

Several survey respondents mentioned recent changes to reporting expectations as a barrier to reporting analysed health inequality data. This included limiting outputs to 10-page 'state of the nation' reports recently introduced by HQIP and more frequent monthly-quarterly reporting, thus reducing what can be reported nationally. For example, NPDA expressed concerns that 'the basic reporting we're increasingly asked to do threatens the sustainability of our comprehensive analysis' and questioned whether the move to more frequent reporting will mean that data is not reported 'in a timely fashion' or case mix adjusted and thus will prevent centres from 'benchmarking themselves'. Concerns were shared by PICANet who said the 'competing areas' to report on means only 'simplistic high-level data' can be reported. One respondent also noted the time and resources required to produce these analyses and questioned what other outputs could be 'dropped' (sic. removed) to facilitate this. Central guidance was therefore requested as to how much 'weight' or priority to give health inequality analyses in these reports, or how to publish separate extended analyses instead. Guidance was also requested as to how to improve consistency and therefore make different programmes' outputs comparable.

Two survey respondents described using live data reporting. Given changes to reporting requirements, FFAP discussed ambitions to present the data in live benchmarks or run charts however acknowledged this may not be possible due to subcontractor costs and funding limitations. The Medical and Surgical and Child Health CORP's explained that their data is contributing to a live annually updated health inequalities report. Movement to live reporting would improve data timeliness, compared to reports which often present data in arrears by months to years, however the scope for higher-level analysis of these without extra resource is limited.

## Limitations and considerations

This report provides a snapshot of the current practices of collecting, analysing, and reporting of health inequality data within the NCAPOP. The national clinical audit picture is constantly evolving and thus this report provides a picture limited by time, specific clinical areas and is prioritised by the knowledge and experiences of those completing the survey. Other limitations of the report include non-response, from three cancer audits and both the NMPA and maternal, newborn, and infant outcome review programme. In addition, where respondents thought that a category of data was collected/ analysed/ reported well this often led to non-response to the relevant questions. This was especially true of social deprivation data. Please see figure 15, for full breakdown of non-response per question. It should be noted that non-response to questions regarding barriers may have actually been a statement of no barriers. It should be noted that some National Clinical Audit Programmes inherently prioritise specific characteristics that confer information about health inequality due to their clinical focus e.g., age in FFAP.

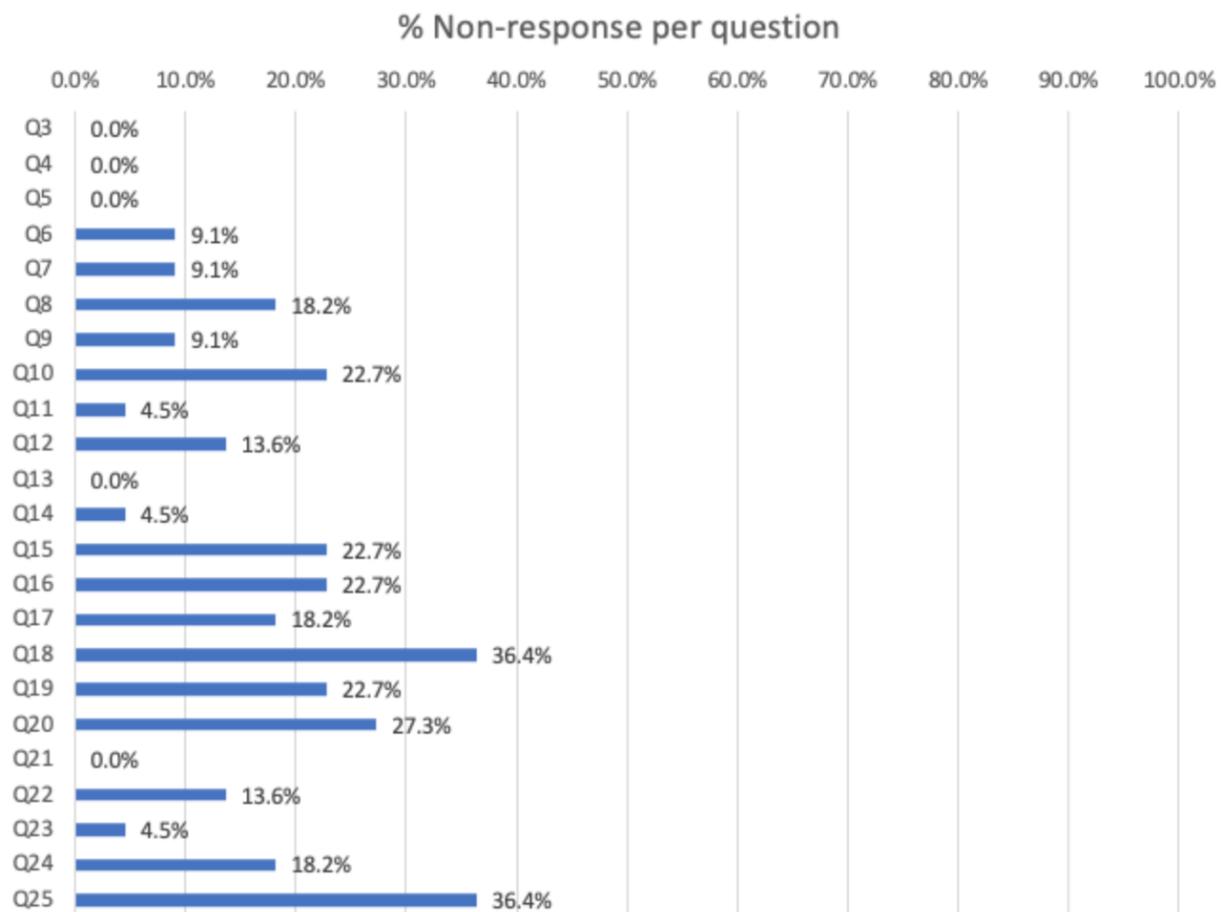


Figure 15: % non-response per question

## Recommendations

Based on the major themes identified from the qualitative results regarding barriers to obtaining good health inequality data in the national clinical audit program, the following recommendations can be made:

Recommendations for HQIP:

5. Ensure that ethnicity and deprivation are included in all NCAPOP specifications.
6. Convene a group to collaboratively address the small numbers problem within ethnicity data. This might involve work with the statistical and information governance community leading to guidance for the programme.
7. Provide guidance to audit providers, on the use of postcode to be used as a proxy for social deprivation, to ensure the reliability and anonymity of this measure.
8. Convene a working group to foster collaboration and knowledge sharing among different audit programmes:
  - a. Learning from each other's experiences in addressing barriers to obtaining health inequality data
  - b. Sharing innovative approaches to overcome challenges.
  - c. Evaluating the progress made in addressing health inequality data barriers including for example health group status, gender, sex, and other inclusion factors.

Recommendations for Trusts and ICBs:

2. Trusts and ICBs to collaborate with hospitals and clinical centres to improve ethnicity coding, implementing lessons learned from the COVID-19 pandemic.

NHS England and the Welsh Government should reflect on the following:

4. The issue of incomplete data is vitally important. Strategies need developed to ensure that all relevant patient characteristics, including ethnicity and social deprivation, are consistently recorded. This could involve providing clear guidelines, training and resources to clinicians and data collectors on the importance of capturing this information accurately.
5. There is an issue of inconsistent and duplicate ethnicity recording. This could be addressed through:
  - a. implementing digital solutions to ensure every patient has a single ethnicity recorded, linked to their NHS number.
  - b. Providing finalised, standardised definitions, to be implemented UK-wide. This will require collaboration with relevant stakeholders, including professional bodies and regulatory agencies.
  - c. Establishing best practice for capturing and categorising ethnicity data in a way that is clinically appropriate and meaningful.
  - d. Enhancing data analysis capabilities to conduct more detailed health inequality analyses.
  - e. Developing appropriate regression analysis techniques that consider multiple characteristics simultaneously, rather than focusing on comparisons with a majority group alone.

6. Ensure adequate resourcing of the additional analysis required for the health inequalities data.

UK Health Security Agency and Office for Health Improvement and Disparities should reflect on the following:

2. Making national figures relating to ethnicity and social deprivation available and accessible, to enable accurate comparison with audit data.

UK Health Security Agency and Office for Health Improvement and Disparities, NHS England and the Welsh Government and the clinical audit community should reflect on the following:

Working together to:

4. Develop strategies to address the small numbers problem associated with health inequality data, especially in minority ethnic groups.
5. Explore methods to aggregate data or analyse it at a broader level to ensure confidentiality while still providing valuable insights.
6. Collaborate with the wider clinical audit community to link data sources to increase sample sizes for more robust analysis.

## Glossary of abbreviations

Abbreviation	Term
CORPs	Clinical Outcome Review Programmes
CSDS	Community Services Data Set
CVD	Cardiovascular disease
CVDPrevent	National Audit of Cardiovascular Disease Prevention in Primary Care (CVDPrevent) Workstream
Epilepsy12	National Epilepsy 12 Audit
FFAP	Falls and Fragility Fracture Audit ( <i>includes the Hip Fracture Database</i> )
FLS-DB	Fracture Liaison Service Database
GROS	General Register Office for Scotland
HES	Hospital Episode Statistics
HQIP	Healthcare Quality Improvement Partnership
ICBs	Integrated Care boards
ICSs	Integrated Care Systems
IMD	Index of multiple deprivation
LSOA	Lower Layer Super Output Area
MBRRACE-UK	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
MHSDS	Mental Health Services Data Set
MINAP	Myocardial Ischemia National Audit Project
MNI-CORP	Maternal, Newborn and Infant clinical Outcome Review Programme (MNI-CORP)
NABCOP	National Audit of Breast Cancer in Older Patients
NACAP	National Asthma and COPD Audit Programme
NACEL	National Audit of Care at the End of Life
NACR	National Audit of Cardiac Rehabilitation
NAD	National Audit of Dementia
NATCAN	National Cancer Audit Collaborating Centre
NBoCA	The National Bowel Cancer Audit
NCAP	National Clinical Audit of Psychosis
NCAPOP	National Clinical Audit and Patient Outcomes Programme
NCISH	The National Confidential Inquiry into Suicide and Safety in Mental Health
NCMD	National Child Mortality Database
NCRAS	National Cancer Registration and Analysis Service
NDA	National Adult Diabetes Audit
NDOO	National data opt-out
NEIAA	National Early Inflammatory Arthritis Audit
NELA	National Emergency Laparotomy Audit

NHSE	NHS England
NICE	The National Institute for Health and Care Excellence
NICOR	National Institute for Cardiovascular Outcomes Research
NISRA	Northern Ireland Statistics and Research Agency
NJR	The National Joint Registry
NLCA	National Lung Cancer Audit
NMPA	National Maternity and Perinatal Audit
NNAP	National Neonatal Audit Programme
NOA	National Obesity Audit
NOGCA	National Oesophago-Gastric Cancer Audit
NPCA	National Prostate Cancer Audit
NPDA	National Pediatric Diabetes Audit
NRAP	National Respiratory Audit Programme
NVR	National Vascular Registry
OHID	Office for Health Improvement and Disparities
ONS	Office for National Statistics
PICANet	Paediatric Intensive Care Audit Network
SSNAP	Sentinel Stroke National Audit Programme
SUS	Secondary Uses Service Dataset
UKHSA	UK Health Security Agency

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## Appendices

### Appendix A: Scoping review table of results

National Clinical Audit	Publication Title	Publication Date	Reporting Ethnicity Data	Analysing Ethnicity Data	Reporting Social Deprivation Data	Analysing Social Deprivation Data	Recommendation(s) Made Pertaining To Health Inequality	Total
National Adult Diabetes Audit (NDA)	National Diabetes Audit, 2020-21 : Type 1 Diabetes	16/06/2022	✓	✓	✓	✓	✓	5
National Audit of Cardiovascular Disease Prevention in Primary Care (CVDPrevent) Workstream 3	Cardiovascular disease - Third annual audit report	09/03/2023	✓	✓	✓	✓	✓	5
	CVDPrevent Second Annual Report	16/06/2022	✓	✓	✓	✓	✓	5
National Child Mortality Database (NCMD)	The contribution of newborn health to child mortality across England	14/07/2022	✓	✓	✓	✓	✓	5
National Maternity and Perinatal Audit (NMPA)	MBRRACE-UK Perinatal Mortality Surveillance Report 2020	13/10/2022	✓	✓	✓	✓	✓	5

National Paediatric Diabetes Audit (NPDA)	National Paediatric Diabetes Audit Annual Report 2020/21	14/04/2022	✓	✓	✓	✓	✓	5
	Paediatric diabetes report on care and outcomes 2021/22	09/03/2023	✓	✓	✓	✓	✓	5
Falls and Fragility Fracture Audit (includes the Hip Fracture Database) (FFFAP)	The National Hip Fracture Database report on 2021	08/09/2022	✓	✓	✓	✓		4
National Adult Diabetes Audit (NDA)	National Diabetes Audit, 2020-21 Report 1: Care Processes and Treatment Targets	14/07/2022	✓	✓	✓	✓		4
	National Diabetes Audit : Non-Diabetic Hyperglycaemia, 2020-21 Diabetes Prevention Programme	14/07/2022	✓	✓	✓	✓		4
	National Diabetes Inpatient Safety Audit 2018-2021	14/07/2022	✓	✓	✓	✓		4
National Early Inflammatory Arthritis Audit (NEIAA)	National Early Inflammatory Arthritis Audit (NEIAA) Year 4 Annual Report (Data collection: 1 April 2021 -31 March 2022)	13/10/2022	✓	✓	✓	✓		4
National Prostate Cancer Audit (NPCA)	National Prostate Cancer Audit Short Report: Patient and tumour characteristics associated with metastatic prostate cancer diagnoses in England	08/09/2022	✓	✓	✓	✓		4
National Audit of Dementia (NAD)	National Audit of Dementia: Memory Assessment Services Spotlight Audit 2021	08/11/2022	✓	✓			✓	3
National Clinical Audit	National report for England	14/07/2022	✓	✓			✓	3

of Psychosis (NCAP)	Early Intervention in Psychosis Audit 2021/22							
National Child Mortality Database (NCMD)	Sudden and Unexpected Deaths in Infancy and Childhood (NCMD thematic report)	08/12/2022	✓		✓		✓	3
National Lung Cancer Audit (NLCA)	National Lung Cancer Audit (NLCA) – State of the nation report 2023	12/04/2023	✓		✓		✓	3
National Maternity and Perinatal Audit (NMPA)	National Maternity and Perinatal Audit: Clinical report 2022	16/06/2022	✓		✓		✓	3
Pediatric Intensive Care Audit Network (PICANet)	Paediatric Intensive Care – State of the Nation Report 2022 (PICANet)	03/09/2023	✓		✓		✓	3
National Emergency Laparotomy Audit (NELA)	Eighth Patient Report of the National Emergency Laparotomy Audit December 2020 to November 2021	09/02/2023			✓	✓	✓	3
National Gastro-Intestinal Cancer Audit Programme - National Oesophago-Gastric Cancer Audit (NOGCA)	Oesophago-gastric cancer report 2022 (NOGCA)	12/01/2023			✓	✓	✓	3
National Paediatric Diabetes Audit (NPDA)	National Paediatric Diabetes Audit Report: Parent and patient reported experience measures PREMs 2021	08/09/2022	✓	✓				2
National Audit of Breast Cancer in Older Patients (NABCOP)	National Audit of Breast Cancer in Older Patients: 2022 annual report	12/05/2022	✓		✓			2
National Paediatric Diabetes Audit (NPDA)	National Diabetes Audit, 2017-21: Adolescent and Young Adult Type 1 Diabetes	16/06/2022	✓		✓			2

National Clinical Audit of Psychosis (NCAP)	National report for Wales Early Intervention in Psychosis Audit 2021/22	14/07/2022	✓				✓	2
National Asthma and COPD Audit Programme (NACAP)	Clinical outcomes October 2018 - March 2020	09/03/2023			✓	✓		2
National Prostate Cancer Audit (NPCA)	Annual report 2022 – Prostate cancer services during the COVID-19 pandemic (NPCA)	12/01/2023			✓	✓		2
National Joint registry (NJR)	National Joint Registry 19th Annual Report 2022	01/11/2022			✓			1
Falls and Fragility Fracture Audit (includes the Hip Fracture Database) (FFFAP)	Annual report: Rebuilding FLSs to meet local patient need	12/01/2023						0
	Fragility fractures- State of the nation Wales report	09/03/2023						0
	National Audit of Inpatient Falls annual report 2022	10/11/2022						0
National Adult Diabetes Audit (NDA)	National Diabetes Foot Care Audit: Interval review	11/05/2022						0
National Asthma and COPD Audit Programme (NACAP)	Drawing breath (NACAP)	12/01/2023						0
National Asthma and COPD Audit Programme (NACAP)	National Asthma and Chronic Obstructive Pulmonary Disease Audit Programme (NACAP) Wales primary care clinical audit 2021	14/07/2022						0
National Audit of Care at the End of Life (NACEL)	National Audit of Care at the End-of-Life Mental Health Spotlight Audit Summary Report England and Wales (2021/22)	14/07/2022						0
	National Audit of Care at the End of Life:	14/07/2022						0

	Third round of the audit (2021/22) report							
National Epilepsy 12 Audit	Epilepsy 12 2022 Combined organisational and clinical audits: Report for England and Wales Round 3, Cohort 3 (2019-21)	14/07/2022						0
National Gastro-Intestinal Cancer Audit Programme - National Bowel Cancer Audit (NBoCA)	Bowel cancer annual report 2022 (NBOCA)	12/01/2023						0
National Gastro-Intestinal Cancer Audit Programme - National Oesophago-Gastric Cancer Audit (NOGCA)	National Oesophago-Gastric Cancer Audit Short Report 2022: Postoperative nutritional management among patients with oesophago-gastric cancer in England	11/08/2022						0
National Neonatal Audit Programme (NNAP)	National Neonatal Audit Programme summary report on 2021 data	10/11/2022						0
National Vascular Registry (NVR)	National Vascular Registry 2022 annual report	10/11/2022						0
	Use of implantable medical devices in aortic aneurysm repair (NVR)	08/12/2022						0
Sentinel Stroke National Audit Programme (SSNAP)	Sentinel Stroke Audit Programme Annual Report 2022	10/11/2022						0
	Sentinel Stroke National Audit Programme, MIMIC Audit 2021: Short report	16/06/2022						0

## Appendix B: Literature review search queries, justification and results

### Search query

Search query	Database	Search within fields	Search results
(((health* AND (inequ* or dispar*)) AND ((soci* AND depriv*) OR ethnic*) AND (national OR clinical) AND audit AND (uk OR "united kingdom" OR england OR wales OR scotland OR ireland OR jersey OR guernsey OR "isle of man"))))	Embase	Title Abstract Author keywords	40
	Ovid	Book Title Abstract Keywords	39
	PubMed	Title Abstract	25
	SCOPUS	Article title Abstract Keywords	63
	Web of science	Title OR Abstract OR Author keywords	22

Results after removal of duplicates shared between searches: 83

The search was conducted across five databases: Embase (inclusive of MEDLINE), Ovid, PubMed, SCOPUS and Web of science. The terms 'health\*', 'inequ\*' and 'dispar\*' were truncated to accommodate variations of the term health inequalities and or disparities (e.g., healthcare, inequity, disparity etc.). Whilst these terms are often used interchangeably and this report prioritises the term inequality over disparity, disparity is included given its use by the UK government e.g. OHID. The same is true of the terms 'soci\*' and 'depriv' to accommodate variations of the term social deprivation (e.g., socioeconomic, deprived etc.). The term 'ethnic\*' was truncated to accommodate terms including e.g. ethnicity, ethnic minorities etc.). These latter two terms were searched for in conjunction with 'health\* inequ\*' in order to eliminate results that focused on the variations of healthcare service provision, such as healthcare equity which is less relevant to this project. Similarly, this avoided inclusion of results where 'health

inequalities’ or variations thereof are referred to generally but without focus on a specific facet like ethnicity or social deprivation, as is the interest of this report.

The terms ‘national’ ‘clinical’ and ‘audit’ were also used to narrow results to national datasets such as the NCAPOP. Of the current HQIP national clinical audit programmes, two (FFAP and PICANet) do not include the term ‘national’ in the title so may be underserved by the search criteria. The term ‘national’ was further consolidated by inclusion of multiple location keywords to refine results to the United Kingdom, devolved nations and crown dependencies that contribute to some NCAP and CORPs. The term ‘Ireland’ was not refined to “Northern Ireland” as, for example, PICANet utilises data from both the UK and Republic of Ireland. Though the search query focused on national audit rather than CORP the search still returned results that utilised CORP data such as the Maternal, Newborn and Infant clinical Outcome Review Programme (MNI-CORP).

Having identified how ethnicity and social deprivation national clinical audit data is being used for research, a second search query was completed to provide additional context. The search query is detailed in the table below. The breadth of sources (beyond national clinical audit) and uses of ethnicity and social deprivation data makes it challenging to refine the numerous search query results to what is relevant. For this reason, the search was limited to the article title field. Of the 128 results 50 results remained after removal of duplicates. Many results were similar to the previous search in considering ethnicity and social deprivation data in relation to specific clinical outcomes. The titles and abstracts were therefore considered relevant if they commented on aspects relating to collecting, analysing or reporting ethnicity or social deprivation data, leaving 9 relevant results.

Search query	Database	Search within fields	Search results
((soci* AND depriv*) OR ethnic*) AND (data AND (collect* OR analys* OR report*) AND (uk OR "united kingdom" OR england OR wales OR scotland OR ireland OR jersey OR guernsey OR "isle of man"))	Embase	Title	31
	Ovid	Book Title	10
	PubMed	Title	24
	SCOPUS	Article title	29
	Web of science	Title	34

#### Appendix C: List of audit programme invitees/ respondents

Programme type	Survey responses	Programme
NATIONAL CLINICAL AUDIT PROGRAMME	0	National Cancer Audit Collaborating Centre (NatCan)

<b>NATIONAL CLINICAL AUDIT PROGRAMME</b>	0	National Audit of Breast Cancer in Older Patients (NABCOP)
<b>NATIONAL CLINICAL AUDIT PROGRAMME</b>	1	National Gastro-Intestinal Cancer Audit Programme National Oesophago-Gastric Cancer Audit (NOGCA)
<b>NATIONAL CLINICAL AUDIT PROGRAMME</b>	1	National Gastro-Intestinal Cancer Audit Programme National Bowel Cancer Audit (NBOCA)
<b>NATIONAL CLINICAL AUDIT PROGRAMME</b>	0	National Lung Cancer Audit (NLCA)
<b>NATIONAL CLINICAL AUDIT PROGRAMME</b>	0	National Prostate Cancer Audit (NPCA)
<b>NATIONAL CLINICAL AUDIT PROGRAMME</b>	1	<b>National Audit of Care at the End of Life (NACEL)</b>
<b>NATIONAL CLINICAL AUDIT PROGRAMME</b>	1	<b>Sentinel Stroke National Audit Programme (SSNAP)</b>
<b>NATIONAL CLINICAL AUDIT PROGRAMME</b>	1	<b>National Emergency Laparotomy Audit (NELA)</b>
<b>NATIONAL CLINICAL AUDIT PROGRAMME</b>	1	<b>National Respiratory Audit Programme (NRAP)</b>  <i>(Formerly National Asthma and COPD Audit Programme (NACAP))</i>
<b>NATIONAL CLINICAL AUDIT PROGRAMME</b>	1	<b>National Adult Diabetes Audit (NDA)</b>
<b>NATIONAL CLINICAL AUDIT PROGRAMME</b>	2	<b>National Obesity Audit (NOA)</b>
<b>NATIONAL CLINICAL AUDIT PROGRAMME</b>	1	<b>Falls and Fragility Fracture Audit (FFFAP)</b>
<b>NATIONAL CLINICAL AUDIT PROGRAMME</b>	1	<b>National Early Inflammatory Arthritis Audit (NEIAA)</b>

<b>CORP</b>	<b>1</b> <b>(Shared response with</b> <b>Child Health Clinical</b> <b>Outcome Review</b> <b>Programme)</b>	<b>Medical and surgical outcome review programme</b>
<b>NATIONAL CLINICAL</b> <b>AUDIT PROGRAMME</b>	<b>1</b>	<b>National Audit of Cardiovascular Disease</b> <b>Prevention in Primary Care</b> <b>(CVDPrevent) Workstream 3</b>
<b>NATIONAL CLINICAL</b> <b>AUDIT PROGRAMME</b>	<b>1</b>	<b>National Vascular Registry (NVR)</b>
<b>NATIONAL CLINICAL</b> <b>AUDIT PROGRAMME</b>	<b>1</b>	<b>National Clinical Audit of Psychosis (NCAP)</b>
<b>NATIONAL CLINICAL</b> <b>AUDIT PROGRAMME</b>	<b>1</b>	<b>National Audit of Dementia (NAD)</b>
<b>CORP</b>	<b>2</b>	<b>Mental health outcome review programme</b>
<b>CORP</b>	<b>1</b> <b>(Shared response with</b> <b>Medical and surgical</b> <b>outcome review</b> <b>Programme)</b>	<b>Child Health Clinical Outcome Review Programme</b>
<b>NATIONAL CLINICAL</b> <b>AUDIT PROGRAMME</b>	<b>1</b>	<b>National Epilepsy 12 Audit</b>
<b>CORP</b>	<b>0</b>	<b>Maternal, newborn and infant outcome review</b> <b>programme (MNI-CORP)</b>
<b>CORP</b>	<b>1</b>	<b>National Child Mortality Database (NCMD)</b>
<b>NATIONAL CLINICAL</b> <b>AUDIT PROGRAMME</b>	<b>0</b>	<b>National Maternity and Perinatal Audit (NMPA)</b>
<b>NATIONAL CLINICAL</b> <b>AUDIT PROGRAMME</b>	<b>1</b>	<b>National Neonatal Audit Programme (NNAP)</b>
<b>NATIONAL CLINICAL</b> <b>AUDIT PROGRAMME</b>	<b>2</b>	<b>Pediatric Intensive Care Audit Network (PICANet)</b>
<b>NATIONAL CLINICAL</b> <b>AUDIT PROGRAMME</b>	<b>2</b>	<b>National Paediatric Diabetes Audit (NPDA)</b>
<b>Other</b>	<b>1</b>	<b>National Joint Registry (NJR)</b>

## Appendix D: Survey questions

1. Audit title
2. Role of person selected to complete the survey.
3. Do you think your audit is recording and analysing health inequality well? (Free text)
4.
  - a. Is your audit currently routinely collecting data on the following characteristics:
    - i. Age
    - ii. Sex
    - iii. Gender
    - iv. Ethnicity
    - v. Postcode/Geography
    - vi. Social Deprivation
    - vii. Care home status
5. What sources are you using to collect data on the following characteristics:
  - a. Age
  - b. Sex
  - c. Gender
  - d. Ethnicity
  - e. Postcode/Geography
  - f. Social Deprivation
  - g. Care home status
6. Are you aware of any plans to improve recording of health inequality data within your audit?
7.
  - a. What are the barriers to collecting ethnicity data in your audit?
    - i. Cost
    - ii. Coding
    - iii. Analysts
    - iv. Not specified in tender
    - v. Data not available
    - vi. Not relevant to audit subject matter
    - vii. Data completeness
    - viii. Timeliness of data
    - ix. Other- please specify
  - b. How does the above prevent good ethnicity data being collected? (free text)
8.
  - a. What are the barriers to analysing ethnicity data in your audit?
    - i. Cost
    - ii. Coding
    - iii. Analysts
    - iv. Not specified in tender
    - v. Data not available
    - vi. Not relevant to audit subject matter

- vii. Data completeness
    - viii. Timeliness of data
    - ix. Other- please specify
  - b. How does the above prevent good ethnicity data being analysed? (free text)
- 9.
  - a. What are the barriers to reporting ethnicity data in your audit?
    - i. Cost
    - ii. Coding
    - iii. Analysts
    - iv. Not specified in tender
    - v. Data not available
    - vi. Not relevant to audit subject matter
    - vii. Data completeness
    - viii. Timeliness of data
    - ix. Other- please specify
  - b. How does the above prevent good ethnicity data being reported? (free text)
- 10.
  - a. How many categories do you use for ethnicity?
  - b. Do you aggregate the ethnicity categories in any way to avoid a small numbers problem?
- 11.
  - a. What are the barriers to collecting social deprivation data in your audit?
    - i. Cost
    - ii. Coding
    - iii. Analysts
    - iv. Not specified in tender
    - v. Data not available
    - vi. Not relevant to audit subject matter
    - vii. Data completeness
    - viii. Timeliness of data
    - ix. Other- please specify
  - b. b) How does the above prevent good social deprivation data being collected? (free text)
- 12.
  - a. What are the barriers to analysing social deprivation data in your audit?
    - i. Cost
    - ii. Coding
    - iii. Analysts
    - iv. Not specified in tender
    - v. Data not available
    - vi. Not relevant to audit subject matter
    - vii. Data completeness
    - viii. Timeliness of data
    - ix. Other- please specify

- b. How does the above prevent good social deprivation data being analysed? (free text)
- 13.
- a. What are the barriers to reporting social deprivation data in your audit?
    - i. Cost
    - ii. Coding
    - iii. Analysts
    - iv. Not specified in tender
    - v. Data not available
    - vi. Not relevant to audit subject matter
    - vii. Data completeness
    - viii. Timeliness of data
    - ix. Other- please specify
  - b. How does the above prevent good social deprivation data being reported? (free text)
14. Where does your audit currently publish its data on health inequality data? (Annual reports, thematic reports, dashboards etc.) (free text)
15. Why do you think ethnicity and social deprivation data are not routinely analysed with regards to performance measures, as with other demographics (age, gender etc.) (free text)
16. Is health inequality data (ethnicity and social deprivation) integrated into your audit risk algorithms? If yes, please explain how. (free text)
17. Do you feel you need more support to include health inequality data? (free text)
18. Do you have any other comments relating to health inequalities data within your audit, not covered in the survey? (free text)
19. Would you be willing to undertake a short interview to discuss the themes of this survey further? (yes/no)
- a. If yes, please provide your email address for further information.