Raising ethnicity recording in NHS Lothian from 3% to 90% in 3 years: processes and analysis of data from Accidents and Emergencies

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ABSTRACT

Background The disproportionate burden of COVID-19 on ethnic minority populations has recently highlighted the necessity of maintaining accessible, routinely collected, ethnicity data within healthcare services. Despite 25 years of supportive legislation and policy in the UK, ethnicity data recording remains inconsistent, which has hindered needs assessment, evaluation and decision-making. We describe efforts to improve the completeness, quality and usage of ethnicity data within our regional health board, NHS Lothian.

Methods The Ethnicity Coding Task Force was established with the aim of increasing ethnicity recording within NHS Lothian secondary care services from 3 to 90% over 3 years. We subsequently analysed these data specifically focusing on Accident and Emergency (A&E) use by ethnic group.

Results We achieved 91%, 85% and 93% completeness of recording across inpatients, outpatients and A&E, respectively. Analysis of A&E data found a mixed pattern of attendance amongst ethnic minority populations and did not support the commonly perceived relationship between lower GP registration and higher A&E use within this population.

Conclusions We identified a successful approach to increase ethnicity recording within a regional health board, which could potentially be useful in other settings, and demonstrated the utility of these data in informing assessment of healthcare delivery and future planning.

Keywords emergency care, ethnicity, health services

Background

The population of the UK is ethnically diverse, most recently influenced by migration from Eastern and Southern Europe. Scotland has 850 000 of ~5 million residents identifying themselves as belonging to an ethnic minority group in the 2011 census. Ethnicity relates strongly to certain health patterns, especially coronary heart disease, child health, cancer and infectious disease, the latter currently highlighted by the disproportionate burden of the COVID-19 pandemic on ethnic minority communities within the UK. Ethnic differences in COVID-19 infection, and severity, have dramatically highlighted the importance of ethnicity recording in routine health datasets to allow urgent analysis.

The relationship between ethnicity and health is contextual, for example intersecting with regional variations in ethnic minority communities' socio-economic profiles.^{3,7} In Scotland, for example, South Asian populations demonstrate longer life expectancies and lower overall mortality than the White Scottish population,⁸ despite their high risk of

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type 2 diabetes⁹ and cardiovascular disease.¹⁰ There are also inequities across ethnic groups in access to health services and in outcomes of treatment and care.^{11,12}

Health services require accurate information on service users' ethnicity, amongst other key determinants of health, to identify and address healthcare needs and assess whether services are being appropriately and effectively delivered. Information about ethnicity also helps to tailor services as an indirect indicator of language, cultural beliefs and norms and health expectations.¹³

In England mandatory recording of ethnicity data within secondary healthcare services was introduced in 1995, 14 although there remained concerns over the consistency and quality of these data, 15 and it was also recommended for Scotland. Nevertheless, 25 years later, obtaining complete and valid routinely collected data that can reliably inform health service evaluation and planning has not yet been achieved throughout the UK.¹⁶ Progress was more rapid in England, where by 2007-08 there was ~86% recording of hospital inpatients' ethnicity. ¹⁷ In Scotland the Health Service consists of 14 regional NHS Boards and, although some Boards had initiated processes to improve the recording of ethnicity in secondary care, by the end of 2008, in contrast to England, the average recording within Scottish hospital discharge data was $\sim 19\%$ (intra Board range < 1-72%). At this time, NHS Lothian collected the ethnicity of only 3% of their hospital inpatient population, 19 despite being the second largest Scottish Health Board with a more ethnically diverse population than Scotland's average.

Scottish policy development has been strong, but implementing ethnic coding lagged behind. The Scottish Government and the Commission for Racial Equality requested Health Boards to improve their ethnicity recording performance to help comply with the Race Relations (Amendment) Act 2000²¹ and subsequent Equality Act 2010, which require public authorities to proactively promote equality.

Consequently, NHS Lothian's Director of Public Health established an Ethnic Coding Task Force (ECTF) in 2009. The ECTF's aim was to accelerate NHS Lothian's coding performance and increase ethnicity recording within secondary care services from 3% to 90% in 3 years. This goal appeared highly challenging when it was set, particularly considering the historical lack of progress; however, the target was achieved. From 2012, an ethnicity subgroup assessed the potential of these data by overseeing ethnicity data analyses, reporting and dissemination.

In this paper we describe the work undertaken by NHS Lothian (http://www.nhslothian.scot.nhs.uk/Pages/default. aspx) in meeting this target and report on the analysis of these data (2012–14), with a focus on Accident and Emergency

(A&E) service use. This builds upon work recently published for Scotland as a whole, ²³ showing the extra challenges and opportunities of Health Board (Health Authority) level data. We draw attention to the relevance of this work in the context of the COVID-19 pandemic.

Methods

Improving coding procedures and performance

The ECTF, a 3-year working group, had a broad-ranging membership with clinical and non-clinical representation from primary and secondary care, local authority, thirdsector organizations and patient groups. The ECTF action plan focused on communication and awareness-raising; staff training; sharing guidance for collecting accurate, highquality data and ensuring procedures for reporting progress. Meetings were arranged with the executive and senior management teams of NHS Lothian to engage clinical and non-clinical colleagues and ensure understanding of the clinical importance of ethnicity data. Site visits by ECTF members were organized with key staff including health records management, reception staff and chief nurses. The purpose of these visits was to understand current procedures and awareness about ethnicity recording; identify barriers to progress and areas needing support; assess the most effective and efficient methods for data collection, avoiding duplication of work and provide resources.

These visits prioritized gaining senior management support, improving attendance at ethnicity recording training and addressing apprehension of staff when asking service users for their ethnic group. Adopting high-quality ethnicity recording procedures became an integral part of standard staff and management training programmes, as well as part of the performance appraisal system. Posters and patient information leaflets, available in the 10 main languages spoken within Lothian, raised staff and patient awareness. Staff were supported in asking service users' ethnicity in the most appropriate way and in explaining why they were asking the question. Feedback was given to staff about their performance. Lastly, the NHS Lothian Chief Executive, with support of the management team, agreed an amendment to the Health Board's hospital e-Health systems to make ethnicity a mandatory field from 1 March 2011.

Analysing data

We analysed data for 2012–14 as this period followed the ECTF work and was close to the 2011 Scotland Census data, which was required for the population denominator for calculating rates. The analysis plan included five stages:

- Data were screened for NHS Board of residence and only Lothian Health Board residents were included, to allow analysis with Census denominator data for this area.
- 2. Service usage was examined by ethnic group across all service sites (pan-Lothian), at patient level. Crude rates were calculated and stratified by sex.
- 3. Age standardized rates of service use, stratified by sex, were calculated using European Standard Populations 2013 and 2011 Census data for Lothian.
- Primary care registration was examined to explore whether lack of registration may correlate with higher A&E service use.
- Lastly, to assess how non-ethnic codes (e.g. 'Unknown')
 might skew our data, we scrutinized these codes more
 closely using Onomap name recognition software
 (http://www.onomap.org/) in an attempt to clarify the
 direction of any bias.²⁴

The 2011 Census ethnic categories were used for our analyses. However, clinical e-Health systems retained older ethnic codes (e.g. Northern European and Australasian), and these were mapped to Census categories. Our mapping is outlined in Table 1. Also, three ethnic codes, ('Other African', 'Other Caribbean or Black' and 'Gypsy/Traveller') contained numbers too small to analyse reliably. 'Other African' was combined with 'African, African Scottish or African British' and 'Other Caribbean or Black' combined with 'Caribbean, Caribbean Scottish or Caribbean British'. Analysis was not undertaken of 'Gypsy/Traveller' as combining this category with another was not appropriate. Analysis suggested that the White Scottish, White Irish and White British populations contained considerable miscoding between groups, and therefore, these were combined as a single reference group.

Ethics

This work was service development, and evaluation done under the direction of NHS Lothian Board and their Analytical Services Department. No datasets were removed from NHS Lothian premises. Ethical approval was, therefore, not required. Ethnicity data were provided by patients' voluntarily, who knew the purposes for which these data were to be used.

Results

Improving coding procedures and performance

Figure 1 shows the progress in ethnicity recording within secondary care from 2010 to 2012 and charts NHS Lothian's improving position in Scotland. By 2012 the 90% target was reached for almost all services with 91%, 85% and 93%

completeness of recording across inpatients, outpatients and A&E, respectively.

Analysing data

Data were analysed for NHS Lothian A&E, outpatients and inpatients/day patient attendances. We present here the results of A&E, as they achieved the most complete ethnicity recording, and the other analyses are available in online appendices. Such data have not been published before and A&E data were most beneficial in informing enquiries about equity of service provision.

Figure 2 shows the age-standardized rates of A&E attendance for females and males for 2012–14 in NHS Lothian. During this time, 215 250 people had at least one unplanned A&E attendance (106 621 females and 108 629 males). For females, age-standardized rates of attendance were higher than the reference group (White Scottish, White British and White Irish) for ethnic groups including Polish, Pakistani, Caribbean or Black and Other origin ethnic groups. Attendances were lower for all other groups, in particular for Other White, Mixed, Indian, Chinese and Arab origin populations.

For males, attendances were higher than the reference group for Polish, Bangladeshi, Caribbean or Black and Other origin ethnic groups. Attendance rates were lower for all other groups, in particular for Indian, Chinese, African and Arab origin populations.

GP registration in relation to A&E utilization

We examined GP registration of A&E attendees. Figure 3 shows the age-standardized rates for GP registration within A&E attendees. Lower GP registration rates were seen for women from Bangladeshi, Caribbean or Black and Arab ethnic origin groups and for men from Polish, Bangladeshi, African, Caribbean or Black, Arab and Other ethnic origin groups. However, the confidence intervals around many of these data were wide and all overlapped with the confidence intervals of the reference group.

Name recognition software

For 2012–14, the percentage of records with non-ethnic codes ('refused/not given', 'unknown/not known' and 'incomplete') was 9.7%. Name recognition software assigned an ethnic identity to 99% of these records. The percentage of records assigned to a 'White British or Irish' ethnicity (87% males and 88% females) and those assigned to an 'ethnic minority' ethnicity (12% males and 11% females) broadly aligned with the representation of these populations within the NHS Lothian area census figures 2011 (88.6% and 11.4%, respectively).

Table 1 Mapping of ethnic categories

Old categories in e-Health system	Census 2011	Combined categories for our analysis	Reasons for combining and any remaining concerns
White Scottish White Scottish Other British White English White Welsh White British	White: Scottish White: Other British	Scottish, Other British and Irish combined	These groups were combined as in our first analysis; there appeared to be a large degree of miscoding between these groups
Irish White Irish	White: Irish		
Any other White background Any other White ethnic group N Europe (Denmark, Norway, Sweden) W Europe (France, Germany, Netherlands) E Europe exc Poland (Balkans, Russia) S Europe (Cyprus, Greece, Italy, Spain, Turkey) Australasia (Australia, New Zealand)	White: Other White Background White: Any Other White Ethnic Group	Other White Ethnic Group	There is concern that some of these groups from the old categories may not be 'White', e.g. could be from S Europe and be of African descent
White Gypsy/Traveller	White: Gypsy/Traveller	No change	Numbers are small in this category and there may be undercounting in healthcare services as people do not want to disclose their athairity.
White Polish	White: Polish	No change	
Mixed or multiple Any mixed background Any mixed or multiple ethnic group	Any mixed or multiple ethnic group	Mixed or multiple ethnic group	
Asian, Asian Scottish or Asian British Indian Indian, Indian Scottish or Indian British	Indian, Indian Scottish, or Indian British	No change	
Pakistani Pakistani, Pakistani Scottish or Pakistani British	Pakistani, Pakistani Scottish or Pakistani British	No change	

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Old categories in e-Health system	Census 2011	Combined categories for our analysis	Reasons for combining and any remaining concerns
Bangladeshi Bangladeshi, Bangladeshi Scottish or Bangladeshi British	Bangladeshi, Bangladeshi Scottish or Bangladeshi British	No change	
Chinese Chinese, Chinese Scottish or Chinese British	Chinese, Chinese Scottish or Chinese British	No change	
Other Asian Any other Asian Background Far East Asia (e.g. Japan, Korea) South East Asia (e.g. Malaysia, Thailand, Philippines)	Other Asian	No change	
African, African Scottish or African British African African, African Scottish or African British	African, African Scottish or African British	African, African Scottish or African British and Other African combined	These groups were combined as there appeared to be miscoding
Other African	Other African		between these groups and the numbers in these groups are also small (at an NHS Lothian level) to analyse separately
Caribbean or Black Caribbean	Caribbean, Caribbean Scottish or Caribbean British	Black, Black Scottish or Black	These groups were combined as
Any other Black background Other Black	Other Caribbean or Black	Scottish or Caribbean British and Other Black or Caribbean	between these groups and the numbers in these groups are also small (at an NHS I orthism lovel)) to
Black, Black Scottish or Black British	Black, Black Scottish or Black British		analyse separately
Other ethnic groups Arab	Arab, Arab Scottish or Arab British	No change	There are concerns of combining people who identify as being Caribbean with those identifying as
Any other ethnic background Any other ethnic group Other non-European (N Africa, S America)	Other ethnic group	No change	Black as these are distinct groups
Other Refused/not given by patient Refused/not provided by patient	Not Given	No change	
Unknown Not known	Unknown	No change	

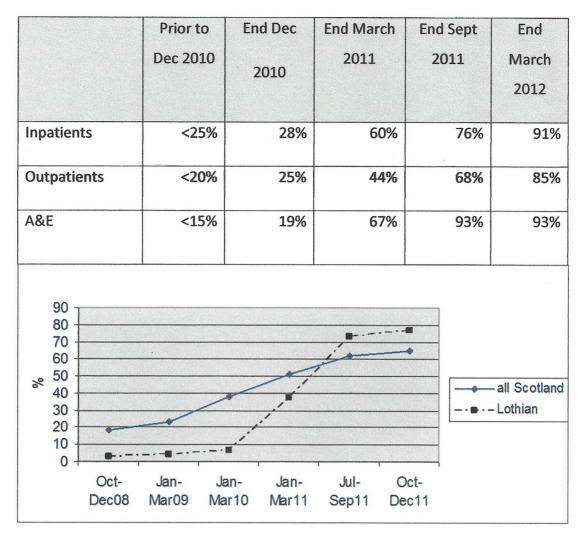


Fig. 1 NHS Lothian progress with ethnicity recording prior to and during the ECTF period.

Discussion

Main findings of this study

Our Task Force model was successful in raising ethnicity recording within NHS Lothian, an improvement that was not wholly mirrored across other Health Boards, thereby moving NHS Lothian's ethnicity recording from amongst the bottom four to the top three performing Scottish Boards. Contributors to success were thought to be communication with, and training of, individuals responsible for data collection and awareness-raising with relevant groups of management and clinical staff. Feedback to staff on their performance motivated them and helped identify priority groups requiring additional support.

Obtaining executive level buy-in from senior clinical colleagues and hospital management on the principle of recording ethnicity was key and ensured staff were able to give the task appropriate parity.¹⁹ A senior executive decision for

ethnicity to become a mandatory field on hospital e-health systems was crucial and ethnic coding rose dramatically after implementation in March 2011 (Fig. 1). Although A&E had been excused from meeting the 90% target, due to the nature of emergency work, it achieved over 90% completeness just 3 months after the ethnicity field was made mandatory. During the active period of the ECTF, a snapshot of inpatient/day patient data had shown that only 1 in 930 service users were coded as having 'refused/not given' their ethnicity. The 'refused/not given' data were substantially greater for our A&E analysis 2012–14 at 5.7%. This may be due to the much larger, more representative, sample and potentially a reflection of the active ECTF work programme, at the time of the first analysis, positively influencing staff performance and the resultant service user's responses.

We analysed several outcomes (see online appendix) but focus on A&E in this paper, finding varying patterns of A&E usage between ethnic groups, both higher and lower than

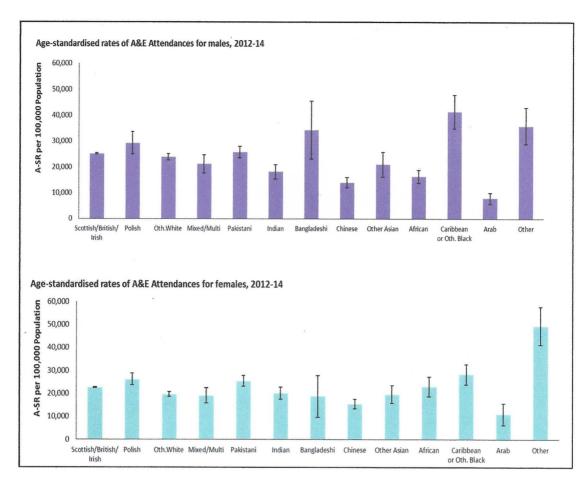


Fig. 2 Age-standardized rates of A&E attendances for males and females 2012–14.

the reference population. However, what influences these patterns seems complex. We explored the hypothesis that people might attend A&E in lieu of primary care if they were not registered with a GP practice; however, although levels of GP registration differed between ethnic groups, there was not sufficient evidence to support or refute this hypothesis.

Routine ethnic monitoring can provide basic epidemiological information, but deeper investigation is required for explanations including varying health needs of populations, the quality of care received in primary care and the community and social influences such as living in deprived neighbourhoods or employment in more hazardous work environments.⁷

What is already known on this topic

Information systems collecting routine healthcare data pose challenges, with many not utilized to their potential.²⁶ The effort required to ensure effective implementation is often underestimated,²⁶ especially challenges of training a large workforce. A multilevel approach has been recommended

to improve healthcare quality²⁷ and race equality in health in particular.²⁸ Maximizing staff involvement in change;²⁶ sharing a clear purpose and vision;²⁹ the backing of senior and clinical leaders²⁹ and having adequate time and resources to raise awareness and provide training^{29,30} are recommended. We found these principles helped the ECTF but the executive decision, itself a consequence of following these principles, to make coding mandatory had the most rapid influence.

Given the lack of routinely collected ethnicity data within health services, most previous work has used other sources such as health survey data^{11,31} or linked ethnicity data from the census to health service data.^{5,8,10,12,32} For example, the Scottish Health and Ethnicity Linkage Study that was done under intense ethical scrutiny and with little flexibility on the outputs analysed.⁵ This method is not suitable for producing ongoing, routine analyses for the health service.

The importance of service users' ethnicity in planning appropriate services and identifying and addressing inequalities is increasingly recognized, ¹⁷ with data compliance being made compulsory in certain areas. ¹⁴, ¹⁵ Nevertheless, there is

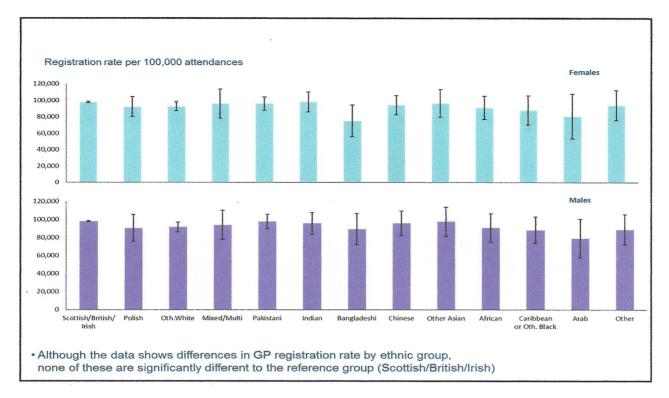


Fig. 3 GP registration of A&E attendees 2012–14.

still poor completeness of data and, consequently, data are underutilized and seldom published. 16,17

Scotland recently examined the use of routinely collected data to compare all-cause hospital admissions nationally by ethnicity.²³ Seventy-six percent of admissions had ethnic codes and analytic methods were developed to increase data completeness. However, the authors concluded that the validity of findings was variable across ethnic groups and that further improvements were needed to render these routinely collected data useful for national public health surveillance.

A&E usage was also examined in the national work and patterns differed from those found in NHS Lothian, other than higher service use for Caribbean and Black populations and lower use for Arab and Chinese populations (for both males and females). The differing patterns may be due to true regional variation or, more likely, to methodological differences between these analyses including in data completeness. The importance of this work in Scotland is to utilize analyses to drive methodological refinements and assess the utility of these data, both nationally and locally. Data are of no value if they are not regularly analysed and used for service evaluation and improvement. Demonstrating the use of ethnicity information is also important for continuing to motivate the staff collecting data.

Throughout Europe, there has been a sentiment, perpetuated by media, that migrant and ethnic minority populations overuse A&E and attend A&E for less urgent issues.³⁴ However, a systematic review investigating the factors that impact on A&E use found mixed evidence in relation to the effect of ethnicity.³⁵ A study conducted in London, using name-based ethnicity classification, also found no difference in occasional usage of A&E by ethnicity and no relationship between GP registration and light A&E use.³⁶ However, data quality was a recognized limitation of both papers.

Systematic reviews of A&E usage within Europe^{37–40} and internationally⁴¹ have mostly focused on migrant status, not ethnicity, and show a mixed picture with equivalent, lower and higher service use by migrant populations when compared with non-migrants. These studies all acknowledge difficulties in obtaining accurate data for these analyses due to the substantial contextual variation in data collection across countries;⁴² for example, there is discrepancy in the definitions and use of terminology;^{37–40} sources of data;³⁹ whether data are collected, leading to a limited evidence base^{37,38} and the nature of healthcare systems.⁴¹

What this study adds

Our approach could help other healthcare organizations wishing to increase levels of ethnic coding and develop systems for

analysis. Our data provide the first information about A&E usage by ethnicity in NHS Lothian in Scotland demonstrating that commonly held beliefs of overuse of A&E by ethnic minority populations, overall, are not clearly supported and that there is no unequivocal relationship between lower GP registration and A&E use within these populations. Our work underscores the importance of routinely collected ethnicity data in providing evidence to assess the validity of perceptions.

The COVID-19 pandemic's likely disproportionate impact on ethnic minority populations in the UK has highlighted the need for routinely available data that can be analysed quickly. It is disconcerting, however, to find that 25 years after collecting ethnicity data in hospitals in England was made mandatory (and highly recommended in Scotland); our systems are still struggling to provide near-complete and valid data and to use the information to improve healthcare. Data have been collected but too seldom analysed.

Limitations of this study

The quality of data may be affected by both choices of classification and misclassification, for example, in the mapping and combining of ethnic codes, sometimes from more than one source of classification (Table 1), which may disguise important heterogeneity between groups. There may be classification errors during recording and, despite our staff training prioritizing appropriate collection methods, it is not always certain whether data are self-assigned (as recommended) or assigned by a healthcare worker. Studies in England have examined data quality through linkage and comparison of databases, and concordance is found to vary across different data sources¹⁷ and different ethnic groups.⁴³ However, we were not able to cross-compare data for this study. Another limitation relates to non-ethnic codes, which we investigated using name recognition software, but which may still have biased results. Methods are under development nationally for dealing with incompleteness of ethnicity recording. 16,23

Conclusions

There is limited collection of ethnicity data internationally even at census level. 4,42,44 Routine ethnically coded data within health services data remain incomplete and underutilized. Our successful approach to increasing ethnicity recording within a local setting and analysing data may have wider applicability. Local data may be used as complementary to national or international data for service planning and quality improvement, especially as the latter can be delayed by years before publication.

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Conflicts of interest

We have no conflicts of interest to declare.

Supplementary data

Supplementary data are available at the *Journal of Public Health* online.

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