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Raising ethnicity recording in NHS Lothian from 3% to 90% in 3 years

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4 **Raising ethnicity recording in NHS Lothian from 3%-90% in three**
5 **years: processes and analysis of data from Accidents and**
6 **Emergencies.**
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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 3-90% over three 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.

Word count: 198 (200 word limit)

Background

The population of the United Kingdom (UK) is ethnically diverse, most recently influenced by migration from Eastern and Southern Europe.¹ Scotland has 850,000 of about 5 million residents identifying themselves as belonging to an ethnic minority group in the 2011 census.^{2,3} Ethnicity relates strongly to certain health patterns⁴ especially coronary heart disease, child health, cancer,⁵ and infectious disease, the latter currently highlighted by the disproportionate burden of the COVID-19 pandemic on ethnic minority communities within the UK.⁶ Ethnic differences in COVID-19 infection, and severity, have dramatically highlighted the importance of ethnicity recording in routine health datasets to allow urgent analysis.⁶

The relationship between ethnicity and health is contextual, for example intersecting with regional variations in ethnic minority communities' socioeconomic 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 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, among 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 which 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 2007-2008 there was around 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

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3 recording within Scottish hospital discharge data was around 19% (intra Board range <1% to
4 72%).¹⁸ At this time, NHS Lothian collected the ethnicity of only 3% of their hospital
5 inpatient population,¹⁹ despite being the second largest Scottish Health Board with a more
6 ethnically diverse population than Scotland's average.
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11 Scottish policy development has been strong, but implementing ethnic coding lagged
12 behind.²⁰ The Scottish Government and the Commission for Racial Equality requested
13 Health Boards to improve their ethnicity recording performance to help comply with the
14 Race Relations (Amendment) Act 2000²¹ and subsequent Equality Act 2010²² which require
15 public authorities to proactively promote equality.
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21 Consequently, NHS Lothian's Director of Public Health established an Ethnic Coding Task
22 Force (ECTF) in 2009. The ECTF's aim was to accelerate NHS Lothian's coding performance
23 and increase ethnicity recording within secondary care services from 3% to 90% in three
24 years. This goal appeared highly challenging when it was set, particularly considering the
25 historical lack of progress; however, the target was achieved.¹⁹ From 2012, an ethnicity sub-
26 group assessed the potential of these data by overseeing ethnicity data analyses, reporting
27 and dissemination.
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35 In this paper we describe the work undertaken by NHS Lothian
36 (<http://www.nhsllothian.scot.nhs.uk/Pages/default.aspx>) in meeting this target and report
37 on the analysis of these data (2012-2014), with a focus on Accident and Emergency (A&E)
38 service use. This builds upon work recently published for Scotland as a whole,²³ showing the
39 extra challenges and opportunities of Health Board (Health Authority) level data. We draw
40 attention to the relevance of this work in the context of the COVID-19 pandemic.
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50 **Methods**

51 ***Improving coding procedures and performance***

52 The ECTF, a three year working group, had a broad-ranging membership with clinical and
53 non-clinical representation from primary and secondary care, local authority, third sector
54 organisations and patient groups. The ECTF action plan focused on communication and
55 awareness-raising; staff training; sharing guidance for collecting accurate, high quality data;
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3 and ensuring procedures for reporting progress. Meetings were arranged with the executive
4 and senior management teams of NHS Lothian to engage clinical and non-clinical colleagues
5 and ensure understanding of the clinical importance of ethnicity data. Site visits by ECTF
6 members were organised with key staff including health records management, reception
7 staff and chief nurses. The purpose of these visits was to understand current procedures
8 and awareness about ethnicity recording; identify barriers to progress and areas needing
9 support; assess the most effective and efficient methods for data collection, avoiding
10 duplication of work; and provide resources.
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19 These visits prioritised gaining senior management support, improving attendance at
20 ethnicity recording training, and addressing apprehension of staff when asking service users
21 for their ethnic group. Adopting high quality ethnicity recording procedures became an
22 integral part of standard staff and management training programs, as well as part of the
23 performance appraisal system. Posters and patient information leaflets, available in the ten
24 main languages spoken within Lothian, raised staff and patient awareness. Staff were
25 supported in asking service users' ethnicity in the most appropriate way and in explaining
26 why they were asking the question. Feedback was given to staff about their performance.
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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:

1. 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 standardised rates of service use, stratified by sex, were calculated using European Standard Populations 2013, and 2011 Census data for Lothian.

4. Primary care registration was examined to explore whether lack of registration may correlate with higher A&E service use.
5. Lastly, to assess how non-ethnic codes (e.g. 'Unknown') might skew our data, we scrutinised 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 (for example 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 2010-2012 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-standardised 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-standardised rates of attendance were higher than the reference group (White Scottish,-British,-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 utilisation

We examined GP registration of A&E attendees. Figure 3 shows the age-standardised 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

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3 these populations within the NHS Lothian area census figures 2011 (88.6% and 11.4%
4 respectively).
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7 **Discussion**

8 ***Main findings of this study***

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10 Our Task Force model was successful in raising ethnicity recording within NHS Lothian, an
11 improvement which was not wholly mirrored across other Health Boards, thereby moving
12 NHS Lothian's ethnicity recording from amongst the bottom four to the top three
13 performing Scottish Boards.²⁵ Contributors to success¹⁹ were thought to be communication
14 with, and training of, individuals responsible for data collection, and awareness-raising with
15 relevant groups of management and clinical staff. Feedback to staff on their performance
16 motivated them and helped identify priority groups requiring additional support.
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20 Obtaining executive level buy-in from senior clinical colleagues and hospital management on
21 the principle of recording ethnicity was key, and ensured staff were able to give the task
22 appropriate parity.¹⁹ A senior executive decision for ethnicity to become a mandatory field
23 on hospital e-health systems was crucial and ethnic coding rose dramatically after
24 implementation in March 2011 (Figure 1). Although A&E had been excused from meeting
25 the 90% target, due to the nature of emergency work, it achieved over 90% completeness
26 just three months after the ethnicity field was made mandatory. During the active period of
27 the ECTF, a snapshot of inpatient/day-patient data had shown that only one in 930 service
28 users were coded as having 'refused/not given' their ethnicity.¹⁹ The 'refused/not given'
29 data was substantially greater for our A&E analysis 2012-14 at 5.7%. This may be due to the
30 much larger, more representative, sample and potentially a reflection of the active ECTF
31 work programme, at the time of the first analysis, positively influencing staff performance
32 and the resultant service user's responses.
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36 We analysed several outcomes (see online appendix) but focus on A&E in this paper, finding
37 varying patterns of A&E usage between ethnic groups, both higher and lower than the
38 reference population. However, what influences these patterns seems complex. We
39 explored the hypothesis that people might attend A&E in lieu of primary care if they were
40 not registered with a GP practice; however, although levels of GP registration differed
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3 between ethnic groups, there was not sufficient evidence to support or refute this
4 hypothesis.
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7 Routine ethnic monitoring can provide basic epidemiological information but deeper
8 investigation is required for explanations including varying health needs of populations, the
9 quality of care received in primary care and the community, and social influences such as
10 living in deprived neighbourhoods or employment in more hazardous work environments.⁷
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15 ***What is already known on this topic***

16 Information systems collecting routine healthcare data pose challenges, with many not
17 utilised to their potential.²⁶ The effort required to ensure effective implementation is often
18 underestimated,²⁶ especially challenges of training a large workforce. A multilevel approach
19 has been recommended to improve healthcare quality²⁷ and race equality in health in
20 particular.²⁸ Maximising staff involvement in change;²⁶ sharing a clear purpose and vision;²⁹
21 the backing of senior and clinical leaders;²⁹ and having adequate time and resources to raise
22 awareness and provide training^{29,30} are recommended. We found these principles helped
23 the ECTF but the executive decision, itself a consequence of following these principles, to
24 make coding mandatory had the most rapid influence.
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34 Given the lack of routinely-collected ethnicity data within health services, most previous
35 work has used other sources such as health survey data,^{11,31} or linked ethnicity data from
36 the census to health service data.^{5,8,10,12,32} For example, The Scottish Health and Ethnicity
37 Linkage Study which was done under intense ethical scrutiny and with little flexibility on the
38 outputs analysed.⁵ This method is not suitable for producing ongoing, routine analyses for
39 the health service.
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46 The importance of service-users' ethnicity in planning appropriate services and identifying
47 and addressing inequalities is increasingly recognised,³³ with data compliance being made
48 compulsory in certain areas.^{14,15} Nevertheless, there is still poor completeness of data and,
49 consequently, data are underutilised and seldom published.^{16,33}
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54 Scotland recently examined the use of routinely-collected data to compare all-cause
55 hospital admissions nationally by ethnicity.²³ Seventy-six percent of admissions had ethnic
56 codes and analytic methods were developed to increase data completeness. However, the
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3 authors concluded that the validity of findings were variable across ethnic groups and that
4 further improvements were needed to render these routinely-collected data useful for
5 national public health surveillance.
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10 A&E usage was also examined in the national work and patterns differed from those found
11 in NHS Lothian, other than higher service use for Caribbean and Black populations and lower
12 use for Arab and Chinese populations (for both males and females).^{16,23} The differing
13 patterns may be due to true regional variation or, more likely, to methodological differences
14 between these analyses including in data completeness. The importance of this work in
15 Scotland is to utilise analyses to drive methodological refinements, and assess the utility of
16 these data, both nationally and locally. Data are of no value if they are not regularly
17 analysed and used for service evaluation and improvement.³⁴ Demonstrating the use of
18 ethnicity information is also important for continuing to motivate the staff collecting data.³⁰
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27 Throughout Europe, there has been a sentiment, perpetuated by media, that migrant and
28 ethnic minority populations overuse A&E, and attend A&E for less urgent issues.³⁵ However,
29 a systematic review investigating the factors which impact on A&E use found mixed
30 evidence in relation to the effect of ethnicity.³⁶ A study conducted in London, using name-
31 based ethnicity classification, also found no difference in occasional usage of A&E by
32 ethnicity and no relationship between GP registration and light A&E use.³⁷ However data
33 quality was a recognised limitation of both papers.
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41 Systematic reviews of A&E usage within Europe³⁸⁻⁴¹ and internationally⁴² have mostly
42 focused on migrant status, not ethnicity, and show a mixed picture with equivalent, lower
43 and higher service use by migrant populations when compared with non-migrants. These
44 studies all acknowledge difficulties in obtaining accurate data for these analyses due to the
45 substantial contextual variation in data collection across countries;⁴³ for example, there is
46 discrepancy in the definitions and use of terminology;³⁸⁻⁴¹ sources of data;⁴⁰ whether data is
47 collected, leading to a limited evidence base;^{38,39} and the nature of healthcare systems.⁴²
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54 ***What this study adds***

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56 Our approach could help other healthcare organisations wishing to increase levels of ethnic
57 coding and develop systems for analysis. Our data provide the first information about A&E
58 usage by ethnicity in NHS Lothian in Scotland demonstrating that commonly held beliefs of
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3 overuse of A&E by ethnic minority populations, overall, are not clearly supported, and that
4 there is no unequivocal relationship between lower GP registration and A&E use within
5 these populations. Our work underscores the importance of routinely-collected ethnicity
6 data in providing evidence to assess the validity of perceptions.
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11 The COVID-19 pandemic's likely disproportionate impact on ethnic minority populations in
12 the UK has highlighted the need for routinely available data that can be analysed quickly. It
13 is disconcerting, however, to find that 25 years after collecting ethnicity data in hospitals in
14 England was made mandatory (and highly recommended in Scotland) our systems are still
15 struggling to provide near-complete and valid data, and to use the information to improve
16 health-care. Data have been collected but too seldom analysed.
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23 ***Limitations of this study***

24 The quality of data may be affected by both choices of classification and misclassification,
25 for example, in the mapping and combining of ethnic codes, sometimes from more than one
26 source of classification (table 1), which may disguise important heterogeneity between
27 groups. There may be classification errors during recording and, despite our staff training
28 prioritising appropriate collection methods, it is not always certain whether data are self-
29 assigned (as recommended) or assigned by a healthcare worker. Studies in England have
30 examined data quality through linkage and comparison of databases, and concordance is
31 found to vary across different data sources³³ and different ethnic groups.⁴⁴ However, we
32 were not able to cross-compare data for this study. Another limitation relates to non-ethnic
33 codes, which we investigated using name-recognition software, but which may still have
34 biased results. Methods are under development nationally for dealing with incompleteness
35 of ethnicity recording.^{16,23}
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48 ***Conclusions***

49 There is limited collection of ethnicity data internationally even at census level.^{4,43,45} Routine
50 ethnically coded data within health services data remain incomplete and underutilised. Our
51 successful approach to increasing ethnicity recording within a local setting and analysing
52 data may have wider applicability. Local data may be used as complementary to national or
53 international data for service planning and quality improvement, especially as the latter can
54 be delayed by years before publication.
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Conflicts of interest

We have no conflicts of interest to declare.

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Table 1: Mapping of ethnic categories

Old categories	Census 2011	Combined categories for our analysis	Reasons for combining and any remaining concerns
White:			
Scottish (0) White Scottish (20)	1A White: Scottish	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
Other British (1) White English (21) White Welsh (22) White Northern Irish (23) White British (24)	1B White: Other British		
Irish (2) White Irish (25)	1C White: Irish		
Any other White background (3) Any other White ethnic group (28) N Europe (Denmark, Norway, Sweden) (70) W Europe (France, Germany, Netherlands) (71) E Europe exc Poland (Balkans, Russia) (72) S Europe (Cyprus, Greece, Italy, Spain, Turkey) (73) Australasia (Australia, New Zealand) (74)	1D White: Other White Background 1Z 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 (26)	1K 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 ethnicity
White Polish (27)	1L White: Polish	No change	
Mixed or Multiple			
Any mixed background (4) Any mixed or multiple ethnic group (29)	2A Any mixed or multiple ethnic group	Mixed or multiple ethnic group	
Asian, Asian Scottish or Asian British			

Indian (5)	3A Indian, Indian Scottish, or Indian British 3G	No change	
Indian, Indian Scottish or Indian British (31)			
Pakistani (6)	3B Pakistani, Pakistani Scottish or Pakistani British 3F	No change	
Pakistani, Pakistani Scottish or Pakistani British (30)			
Bangladeshi (7)	3C Bangladeshi, Bangladeshi Scottish or Bangladeshi British 3H	No change	
Bangladeshi, Bangladeshi Scottish or Bangladeshi British (32)			
Chinese (8)	3D Chinese, Chinese Scottish or Chinese British 3J	No change	
Chinese, Chinese Scottish or Chinese British (33)			
Other Asian (34)	3E Other Asian 3Z	No change	
Any other Asian Background (9)			
Far East Asia (eg Japan, Korea) (80)			
South East Asia (eg Malaysia, Thailand, Philippines) (81)			
African, African Scottish or African British			
African (11)	4B African, African Scottish or African British 4D	African, African Scottish or African British and Other African combined	These groups were combined as there appeared to be miscoding between these groups and the numbers in these groups are also small (at an NHS Lothian level) to analyse separately
African, African Scottish or African British (40)			
Other African (44)	4Y Other African		
Caribbean or Black			
Caribbean (10)	5C Caribbean, Caribbean Scottish or Caribbean British 4A	Black, Black Scottish or Black British; Caribbean, Caribbean Scottish or Caribbean British; and Other Black or Caribbean combined	These groups were combined as there appeared to be miscoding between these groups and the numbers in these groups are also small (at an NHS Lothian level) to analyse separately
Caribbean, Caribbean Scottish or Caribbean British (41)			
Any other Black background (12)	5Y Other Caribbean or Black 4C		
Other Black (43)			
Black, Black Scottish or Black British (42)	5D Black, Black Scottish or Black British		There are concerns of combining people who identify as being Caribbean with those identifying as Black as these are distinct groups
Other Ethnic Groups			

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Arab (50)	6A Arab, Arab Scottish, or Arab British	No change	
Any other ethnic background (13) Any other ethnic group (51) Other non-European (N Africa, S America) (75)	5A Other ethnic group 6Z 5Z	No change	
Other			
Refused/ not given by patient (60) Refused / Not provided by patient (15)	98 Not Given	No change	
Unknown (61) Not Known (14)	99 Unknown	No change	

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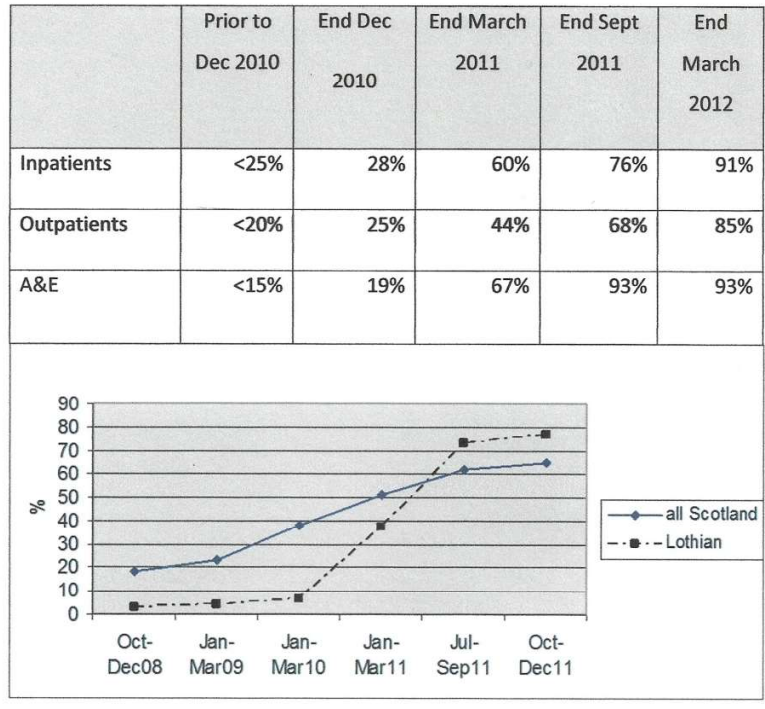


Figure 1: NHS Lothian progress with ethnicity recording prior to and during the ECTF period

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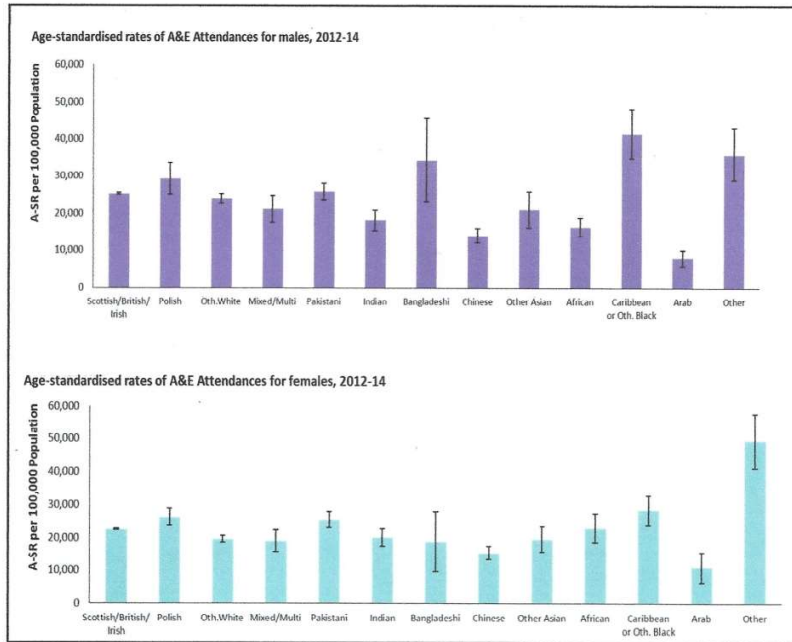


Figure 2: Age-standardised rates of A&E attendances for males and females 2012-14

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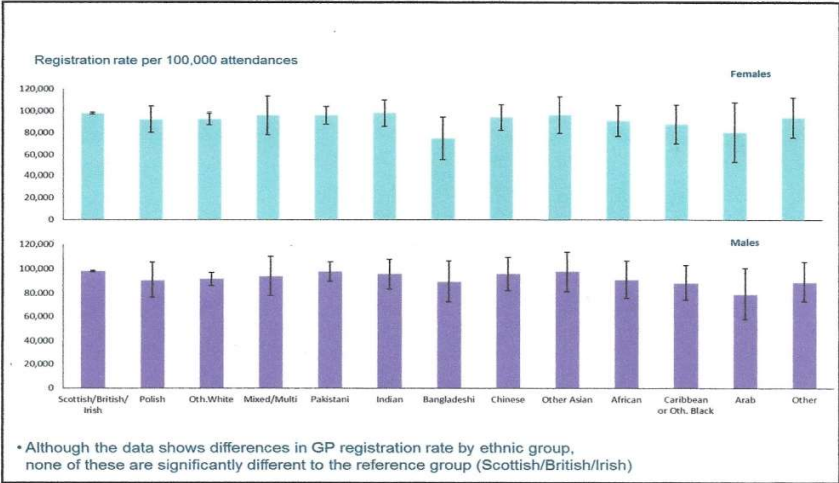


Figure 3: GP registration of A&E attendees 2012-2014

576x477mm (96 x 96 DPI)

Online Appendix

Figure 1: Outpatients appointments

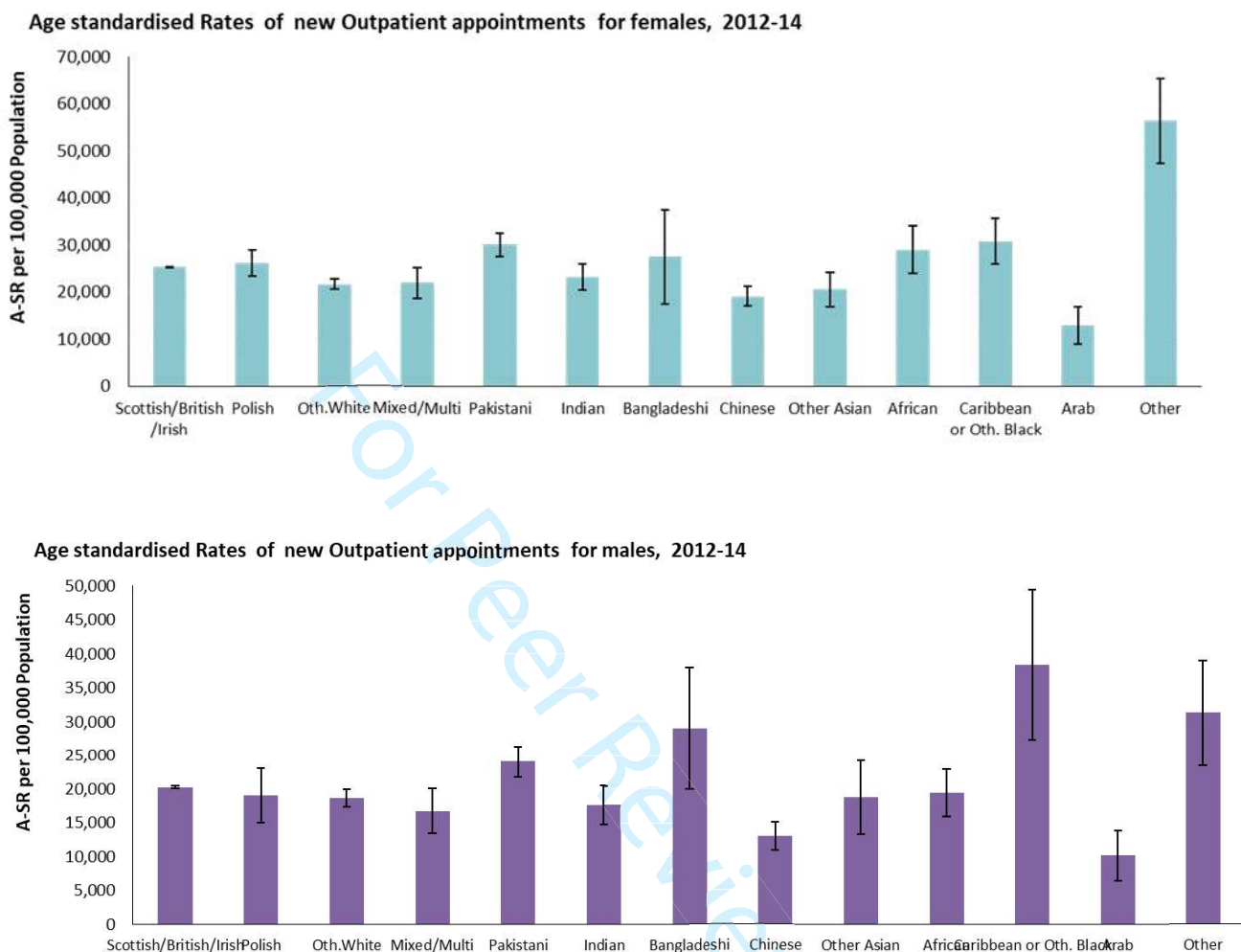
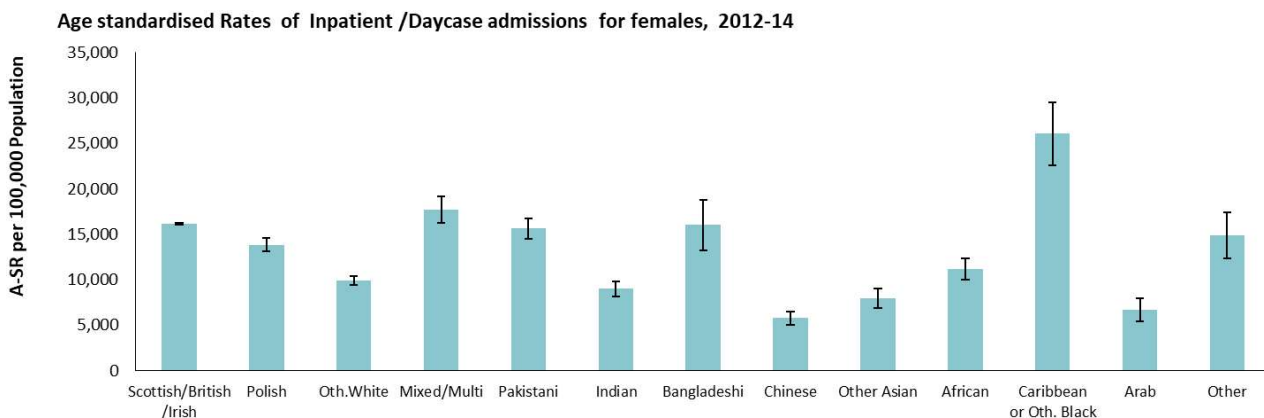
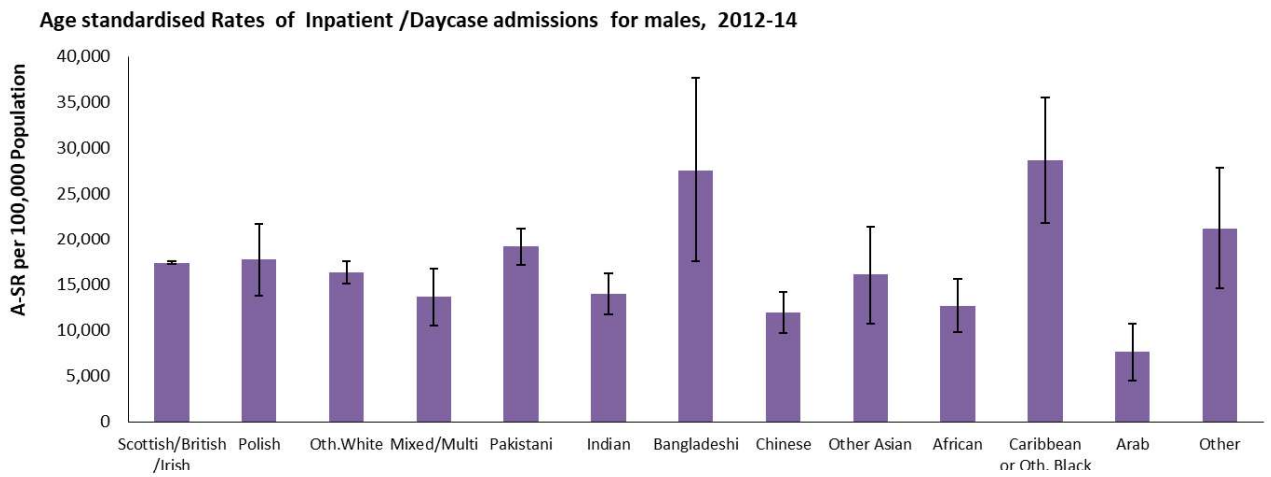


Figure 2: Inpatient/Day case admissions





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