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Research into practice:

understanding ethnic differences in healthcare usage and outcomes in general practice

INTRODUCTION

Why is recording ethnicity important?

The Race Relations Act of 1968 required all public bodies to consider the race equality implications in all policies. Since then, the official collection of ethnic group statistics has been mandated as an essential first step towards identifying and addressing ethnic inequalities.

Capturing ethnic group information in routine health records is recognised in the UK as a necessary prerequisite to addressing need and inequalities in health service usage and health-related outcomes.

As recommended by the Commission for Racial Equality, ethnic identity must be chosen by the individual. As such, ethnicity refers to the individual's self-perception, rather than how he or she appears to others, and recognises that an individual's self-conceptualisation may change over time.

The concept of ethnicity draws on a range of socially constructed characteristics, hence the meaning and interpretation of ethnic differences is entirely context dependent. Despite this temporal instability, ethnicity is currently the best marker we have for defining population subgroups that may have differing needs. This is because it can serve as a surrogate for shared exposures or risks for people with similar social, biological, and cultural characteristics.

This article describes how the Clinical Effectiveness Group at Queen Mary University London has, over the past 20 years, worked alongside the east London primary care community to identify and describe ethnic differences in the local population, and their impact on disease management in primary care.

Origins of GP research on differences by ethnicity in east London

Since 1993, the Clinical Effectiveness Group has supported primary care service provision across the three east London boroughs of Tower Hamlets, Newham, and City and Hackney. This area has a highly diverse

ethnic population, with over 50% of residents of non-white ethnicity, and includes some of the most socially-deprived communities in the UK. The Clinical Effectiveness Group has a longstanding commitment to improving equity of health services provision across the area. A central component of this initiative has been to improve the recording of ethnicity, in order to better understand the make-up and needs of local population groups.

In 1993 the Healthy East Enders project, a collaboration between local practices, was formed as a local quality improvement programme with a focus on preventive activity. Exploring variation by ethnic group in preventive activity, at that time, required hand-searching patient records from 43 general practices. This was followed by a trial of breast screening telephone support by using advocates speaking in the patient's language of choice, which significantly improved uptake.¹ Data entry templates for routine recording of self-reported ethnicity were first introduced to east London in 2001 to support quality improvement audits for people on chronic disease registers. We subsequently provided guidelines and practice facilitation to support annual audits and related projects (<http://blizard.qmul.ac.uk/ceg-home.html>). The need to record ethnicity, and also identify the need for language interpretation and advocacy, became apparent at the time of the GP contract in 2004. This contract used the Carr-Hill funding formula for resource allocation in primary care, which took no account of the additional need generated by ethnicity and language, giving the reason that these were nowhere recorded in general practices. Following this, a local enhanced service was developed throughout east London that supported patient profiling, provided regular audits on progress in ethnicity and language recording, and supported staff to understand the fundamental principle of self-assessment of ethnicity. The identification of need was linked to practice provision of advocacy services by the primary care trust.

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Over 5 years, ethnicity recording increased from 38% to 80% in the practice-registered population and by 2007 was over 90% on the chronic disease registers. During this period primary care commissioning organisations continued to use census-based attribution methods to monitor practice prevalence of chronic diseases. In urban areas where practice boundaries overlap, this is an unreliable method, as patient choice often overrides geographical location as the primary driver of patient registration. We explored this topic in two studies, showing that once practice ethnicity recording reaches 50% it is more accurate than census-based attribution.^{2,3}

Effects on access and utilisation of health care

Ethnic disparities in health are inextricably linked to socioeconomic factors, with ethnic minority groups more likely to live in the most deprived boroughs of the UK. For example, maps created by our group in 2012 illustrating 'hot spots' for diabetes risk in Tower Hamlets highlight not only the uniformly elevated risk for South Asian individuals across the borough but also reveal striking similarities to poverty maps created in the late 19th century, with areas of high diabetes risk overlapping areas of high deprivation.⁴

An example illustrating the effects of cultural beliefs on health comes from our work evaluating the childhood immunisation arm of a major quality improvement programme involving the formation of GP networks in Tower Hamlets. We found that a borough-wide target of 95% for first mumps, measles, and rubella (MMR) by 2 years of age was achievable.⁵ However, Somali population groups continue to have concerns about MMR links to autism, and had significantly lower rates of immunisation (56% compared with 93.6% for South Asian groups). This prompted a public health education intervention to reduce these differences in health service utilisation, which would have contributed to future differences by ethnicity in disease burden.

The particular benefits of the east London primary care database for research is that it includes all 139 practices in the east London cluster of Tower Hamlets, Newham, and City and Hackney. This means that we can examine the prevalence of illness and the process of care in a population that is not geographically dispersed, and where there is no selection of practices based on the completeness of data recording, or other markers of practice performance. The downside, as with all routine data, is the

selective nature of coded data, particularly in response to the introduction of new guidelines and financial incentives, along with incompleteness.

Using ethnicity recording to explore utilisation of health services and health inequalities

Cardiovascular disease. By 2009 we were able to use ethnicity data to explore differences in prescribing for secondary prevention of cardiovascular disease (CVD). The differences by ethnicity (in particular low rates of statin prescribing for black African-Caribbean groups) were overshadowed by systematic under-prescribing for women.⁶ This led us to initiate a borough-wide quality improvement programme focused on the management of chronic disease, with health equity audits provided for each of the 35 practices in the area. These helped to unmask the differences, and inequalities, in treatment decisions, by age, sex, and ethnicity. These differences are usually invisible to the GP in the consulting room. The audits stimulated locality-wide strategies for change, and management improved for all. However, the differences by ethnicity appeared highly resistant to change and the prescribing gap for CVD did not diminish. The dashboard of indicators we developed to identify inequalities in the management of chronic disease continues to be used within public health as a local monitoring tool.⁷

Extending the theme of cardiovascular prescribing, we later combined east and south London data to examine stroke risk and the use of anticoagulation in atrial fibrillation (AF).

We found that in spite of a lower prevalence of AF, South Asians had a higher risk of stroke according to the CHA2DS2-VASc score, which calculates stroke risk among individuals with AF.⁸ In common with other investigators we found anticoagulation prescribing rates of 50%, and that prescribing was poorly related to the risk of stroke.

Diabetes and renal disease. South Asians experience earlier onset and increased risk of diabetes. In 2006, we reported poorer control of cardiovascular risk factors and glucose in South Asian patients compared with white patients attending a large east London secondary care diabetes clinic.⁹ More recently, we have shown that ethnicity significantly impacts on glycaemic control in patients with diabetes.¹⁰ South Asian and black African-Caribbean subjects had poorer glucose control compared with white ethnic groups in spite of using a greater number of medications. Increasing socioeconomic

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Provenance

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Competing interests

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deprivation is independently associated with worse control.¹¹

Our exploration of the local diabetic and hypertension disease registers demonstrated an earlier onset and higher prevalence of both conditions among minority groups. The prevalence of chronic kidney disease (CKD) showed significant variation by ethnicity, with higher rates of more severe CKD (stages 4–5) and proteinuria among non-white groups.^{12,13}

We found that patients with diabetes without proteinuria had a rate of decline very similar to the consensus on age-related (eGFR) decline of 1 ml/min per year, with clinically unimportant differences between ethnic groups. Among those with proteinuria, we found double the rate of decline, with both black African-Caribbean and South Asian patients declining faster than white ethnic groups.¹⁴ Greater decline in South Asians, in spite of having the best adherence to target blood pressure, suggests there may be other mechanisms to uncover. It is possible that 'normal' blood pressure for South Asian populations may be lower than National Institute for Health and Care Excellence (NICE) guidance. Alternatively, a lower nephron mass may predispose patients to hyperfiltration and consequent progressive glomerular scarring and give less resilience in the face of drug toxicity or other insults. We have recently published a study looking at non-steroidal anti-inflammatory drug prescribing, by ethnicity, among patients with CKD. Contrary to our hypothesis that prescribing would be highest among South Asian patients, potentially contributing to their greater renal decline, we found that white ethnic groups had the highest rates of prescribing (calculated as daily defined doses).¹⁵

Cardiovascular multimorbidity. The increased burden of multiple cardiovascular morbidity, and the difficulties of delivering effective management in the absence of national guidance, is of particular importance to general practice. In a study from 2011, we found that South Asian patients were twice as likely to have multiple cardiovascular conditions in comparison with white ethnic groups (OR = 2.04, 95% CI = 1.94 to 2.15). The surprising finding from this study was that risk factor management (lipids, blood pressure, and HbA1C) improved with increasing levels of multimorbidity. However, once again stratification by ethnicity revealed important differences, with black African-Caribbean and South Asian groups consistently having worse diabetic control.¹⁶ A similar pattern was later demonstrated among patients with cardiovascular and mental health

morbidity, with better glycaemic and blood pressure control among those with severe mental health disorders.¹⁷

Liver disease. Liver-related mortality is rising faster than any other cause of death in the Western world. The majority of liver-related morbidity is due to viral hepatitis, excessive alcohol consumption, and, increasingly, non-alcoholic fatty liver disease (NAFLD).

Our group is interested in ethnic variation in non-alcoholic fatty liver disease: the hepatic manifestation of the metabolic syndrome. We conducted a large community-based study of almost 700 000 adults to test the hypothesis that, given the high rates of metabolic syndrome in South Asian populations, NAFLD would be more prevalent in these ethnic groups. We found that Bangladeshi ethnicity, but not any other South Asian ethnicity, was an independent risk factor for NAFLD (OR 1.86, 95% CI = 1.56 to 2.23, $P < 0.001$).¹⁸

CONCLUSION

The major determinants of health are genetic/biological, poverty, inequality, and education. For many ethnic minority groups in the UK these factors overlap to create disease profiles and outcomes that are often significantly worse than those in the majority white population. Understanding the ethnicity and risk profile of a local population allows for a coordinated response, enabling health service commissioning decisions to contribute their part to the reduction of inequalities.

The relationship between ethnicity and health is complex, in ways we are only beginning to understand. Good-quality data are critical for researchers to fully understand how ethnicity relates to a wide range of health outcomes, particularly long-term conditions with complex causal mechanisms such as diabetes and stroke. Projects that link genetic information to the phenotypes coded in the primary care record, such as the UK Biobank, offer the opportunity to further unravel the role of ethnicity in disease prevalence and progression.

Finally, as the ethnic minority population of the UK is, on average, younger than the white British population, ethnicity data are of vital importance in predicting the burden of disease that is yet to peak in these population groups, and for allocation of health resources and infrastructure.⁴ Large routine healthcare data sets are uniquely valuable, in that they offer sufficient power to study individual ethnic groups, sex differences, and trends across generations.

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