

# Health in our Multi-ethnic Scotland

## Future Research Priorities

### Report Summary



The Scottish Ethnicity and Health Research  
Strategy Working Group

NHS Health Scotland  
November 2009



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## **Introduction**

The Scottish Government is committed to promoting the health and well-being of all, regardless of their background. However, a review of ethnicity and health research in Scotland, published in 2001, found that surprisingly little was known about the health of ethnic minorities in Scotland.

The review made a number of recommendations about how to improve the situation but at a seminar four years later there was a consensus that little further progress had been made.

Following discussion with the Scottish Government and a range of other stakeholders, NHS Health Scotland agreed to set up a working group chaired by Dr Laurence Gruer, their Director of Public Health Science.

It met for the first time in January 2007 with the aim of developing a strategy for future research on ethnicity and health in Scotland.

This booklet summarises the evidence gathered by the group and the conclusions they reached. The group's five priorities for the future are set out overleaf.

The full report can be found on NHS Health Scotland's website at [www.healthscotland.com/documents/3768.aspx](http://www.healthscotland.com/documents/3768.aspx)

## **Our five priorities**

### **1. Good ethnic coding**

To ensure high quality ethnicity and health research in Scotland, consistent ethnic coding is needed. To achieve this we recommend that:

- the ethnic classification developed for the 2011 Census in Scotland is adopted as the standard for routine use
- the death certificate in Scotland is amended to enable ethnic identity to be recorded using the same ethnic classification as the census
- the ethnic identity of every person registered with the NHS should be recorded, with consent, on the Community Health Index (CHI) or its successor.

### **2. Making the best use of data linkage methods**

For at least several years to come, ethnic identity will not be readily linked to death certificates, hospital admissions or other health service databases. We thus recommend that the Scottish Government gives full support to the current research programme, which links the ethnic coding on the census to a range of health-related databases.

### **3 A health survey of ethnic minorities in Scotland**

Information is needed on a wide range of health behaviours and risk factors such as the prevalence of smoking, alcohol consumption, eating behaviour, levels of physical activity, obesity, etc. which enable the larger ethnic minorities in Scotland to be compared with those of the majority White population. We thus recommend that a survey of ethnic minorities living in Scotland is conducted between 2011 and 2012 with the aim of adding significantly to the information obtained from the large, ongoing Understanding Society survey which is now being conducted across the United Kingdom.

### **4. Coordinated research on major health problems and issues**

Research is needed to address the major preventable or treatable contemporary health problems and key health-related issues affecting ethnic minorities. We therefore recommend that the Scottish Government encourages and supports evaluations of larger scale interventions aimed at preventing or treating major health problems affecting ethnic minorities; and qualitative research designed to provide insights into the perceptions, attitudes, behaviour and experience of health services of relevance to major health issues in different ethnic minority groups.

### **5. Catalysing, coordinating and using research**

We recommend the establishment of a Scottish Ethnicity and Health Research Group to catalyse and coordinate high quality relevant research and make the best use of the findings.

## Summary and recommendations

### Chapter 1: Why is a research strategy needed?

Ethnicity refers to our social group as defined by a mix of cultural and other factors including our language, diet, religion, ancestry and physical attributes traditionally associated with race. It has long been recognised that health is influenced by ethnicity in a number of ways through the interplay of these factors and how they affect our behaviour and the behaviour of others towards us.

The Race Relations (Amendment) Act 2000 places additional responsibilities on public authorities, including the NHS, to 'eliminate unlawful racial discrimination and to promote equality of opportunity and good relations between people of different racial groups'. The Scottish Parliament is empowered to encourage equal opportunities for all in Scotland. The Scottish Government's Making it Work Together programme (1999) stresses its determination to place equality at the heart of policy making. The Equality Strategy (2000) set out a wide range of initiatives to make this happen, including a commitment to 'developing better statistics that provide information for different equality groups'. Its Fair for All policy (2002) places an obligation on the NHS to meet a range of standards on race equality and cultural competence, including conducting needs assessments and showing a commitment to research. The aims of Fair for All have since been widened to require Scotland's health services to recognise and respond sensitively to the needs, background and circumstances of individuals across the whole population.

The National Resource Centre for Ethnic Minority Health (NRCEMH) was established in 2002 to ensure the NHS fulfilled its Fair for All obligations and to act as a focus for work on ethnicity and health. NRCEMH was incorporated into the new Equalities and Planning Directorate of NHS Health Scotland in 2008. Other important recent developments have included the establishment in 2007 of the Equality and Human Rights Commission in Scotland and in 2008 of the Mutuality, Equality and Human Rights Board whose responsibilities include overseeing NHS commitments on equality and human rights.

Therefore, Scotland has a strong policy commitment to protecting and promoting the health and wellbeing of ethnic minorities. However, this can only be done effectively if there is accurate information about the health status of ethnic minorities in Scotland and a good understanding of the factors which influence it. A review of research on ethnic minority issues in Scotland, published in 2001, revealed there was a lack of reliable information about many aspects of the health of ethnic minorities in Scotland (Netto *et al*, 2001). With the support of the Scottish Government, a working group, chaired by Dr Laurence Gruer, was set up in 2007 to establish what could be done to improve the situation. It had four main aims:

- To define the key issues relating to ethnicity and health in Scotland.
- To establish what is already known about the demography and health status of ethnic minorities.

- To highlight and prioritise the most important gaps in current knowledge.
- To propose a programme of research that will fill these.

## **Chapter 2: The changing ethnic composition of the Scottish population**

The emigration of millions of Scots over several hundred years has overshadowed the immigration into Scotland of Irish, Lithuanians, Jews, Italians and Poles in the century before 1950, as well as Indians, Pakistanis, Bangladeshis and Chinese in the next 50 years. The 2001 Census showed 10% of the Scottish population belonged to a White ethnic minority and 2% to a non-White ethnic minority, with large increases in the numbers of non-White minorities having occurred in the previous ten years.

Since 2001, and especially since 2004, there have been several tens of thousands of new arrivals, mainly accounted for by asylum seekers, refugees and Eastern European migrants. In 2007, the annual number of immigrants exceeded the number of emigrants for the first time since records began. This is highlighted by the census of children in publicly funded schools in Scotland. The percentage of pupils from ethnic minorities rose from 4.8% in 2004 to 6.9% in 2008. In Glasgow in 2008, 13.9% of pupils were from an ethnic minority and 3.3% were asylum seekers or refugees. Data on the place of birth of mothers of children born in Scotland are also revealing. Since 1991 there has been a large decrease in the number of mothers born in Scotland, partly offset by recent increases in births to mothers born in other European Union countries, most notably in Poland.

Accurately tracking the numbers and movements of migrant workers to and around Scotland is currently not possible. Based on applications for national insurance numbers, at least 40,000 migrant workers entered Scotland between 2006 and 2007, of whom over 23,000 were from Poland. How the movement of migrants will be affected by the economic recession remains unclear.

At the end of 2007, there were thought to be 3,910 asylum seekers in supported accommodation in Scotland, almost all in Glasgow. However, these figures may not be reliable since they do not take account of the numbers who subsequently leave or move to other parts of the United Kingdom. In addition the totals do not always include dependants.

A good understanding of the true extent of the ethnic diversity of Scotland and the current changes is hampered by a lack of accurate data. The 2011 Census will provide a welcome update, but improvements in other data recording systems are needed.

## **Chapter 3: Published research on ethnicity and health in Scotland**

A review was conducted of all research that related to the health of ethnic minorities in Scotland, which had been published since 1960. It revealed that the relatively modest output was carried out in three phases:

### *1960-1985*

Pioneering work, beginning in the 1960s, was done by Dunnigan and colleagues to investigate rickets and osteomalacia among South Asian children in Glasgow, followed by an evaluation of a subsequent successful preventative campaign.

### *1986-2000*

Several studies of health-related behaviours among South Asians in Glasgow were conducted by Raj Bhopal and his colleagues in the late 1980s. From 1990 to 2000, a series of studies was conducted by the MRC Social and Public Health Sciences Unit on the physical and mental health status and related knowledge, attitudes and behaviours of South Asians in Glasgow and Irish immigrants. The Department of Human Nutrition at the University of Glasgow studied health behaviours and dietary changes in South Asian and Italian communities. Alison Bowes and her colleagues carried out an extensive series of studies of South Asian women and their interaction with health services in Glasgow. Several other studies were conducted on smoking, alcohol and drug use, and sexual behaviour among South Asians. The health status of Chinese, African and other ethnic minorities was largely overlooked. A more extensive description of studies during this period is given in the Audit of Research on Minority Ethnic Issues in Scotland from a 'Race' Perspective published by the Scottish Executive in 2001.

### *2001-2008*

A notable change in direction has been led by Raj Bhopal and his colleagues. They have sought to address the lack of data on mortality and hospital admission rates among South Asians by devising a method for linking ethnic identity as recorded in the 2001 Census with death certificates and health records. This has enabled the relatively high rates of myocardial infarction to be studied as part of a wider programme of research into the health status of South Asians in general and their higher risk of coronary heart disease and diabetes in particular. Bhopal and his colleagues have also examined the use by ethnic minorities of questionnaires about key behaviours, such as smoking, and concluded that great care needs to be taken in their adaptation to take account of important cultural, linguistic and conceptual differences.

The previous dearth of research among the Chinese community has been at least partly rectified by studies of the attitudes and experiences of Chinese women around childbirth and an interview survey of a sample of 350 Chinese adults in Glasgow. This survey was later combined with surveys of the Pakistani, Indian, African and White populations to provide a useful comparative analysis of ethnic differences in health-related perceptions and behaviours in Glasgow. There have been several more studies of tobacco, alcohol and drug use among South Asians in Glasgow.

The dispersal of several thousand refugees and asylum seekers to Glasgow led to a number of small studies of their experiences and use of health services. In fulfilment of the requirements of Fair for All, all NHS Boards have conducted health needs assessments of the ethnic minorities in their areas. Given the lack of available local data, these have largely drawn on

experiences elsewhere, extrapolating from these findings to what the particular challenges in their own areas might be.

From this review of published research, a number of issues were identified:

- Research has focused on illnesses that are more common in some ethnic minorities (such as rickets, coronary heart disease and diabetes), with little attention to major illnesses (such as cancer and stroke) that may be as common in ethnic minority groups as in the majority population.
- The effectiveness of health promotion strategies delivered by mainstream statutory organisations to ethnic minority groups has not been evaluated.
- Little research in Scotland has examined the relationship between ethnicity and socio-economic status and how they combine to influence health.
- Very little research has been undertaken to evaluate the appropriateness and effectiveness of statutory mental health services for minority ethnic communities.

#### **Chapter 4: What is known about the health status of ethnic minority groups in Scotland?**

We know surprisingly little about the health status of ethnic minority groups in Scotland. This is largely because ethnicity is not recorded on death certificates and rarely on health service records. Only 15% of hospital admission records and 18% of cancer registration data currently have an ethnic code. There are no national analyses by ethnicity of primary care data. The Scottish Diabetes Register has an ethnic code on 60% of records.

By using name searching, country of birth analysis, modelling and data linkage, Bhopal and his colleagues have shown that the incidence of heart attack is higher among South Asians in Scotland than in the rest of the population. However, South Asians' survival after a heart attack is better, reflecting the very high mortality in the White Scottish population. Country of birth analyses show that, compared to women born in Scotland, women born in the rest of the UK, Pakistan, Bangladesh, China and the rest of the world had significantly lower all-cause mortality rates. Compared to men born in Scotland, men born in the rest of the UK (except Northern Ireland), India, Pakistan, Bangladesh, China and the rest of the world also had significantly lower mortality rates. A comparison of English and Scottish residents, according to their place of birth, showed that both women and men aged 25 to 69 born in Scotland, Ireland, India and Pakistan and living in Scotland had significantly higher death rates from coronary heart disease than those living in England – although there are important ethnic differences within the two countries. The highest all-cause mortality rates are in those born in Scotland and the Republic of Ireland. Mortality rates are relatively low in other country-of-birth groups, especially China, Pakistan, Bangladesh and Hong Kong. High



rates of death for specific causes, for example coronary heart disease in some populations, need to be interpreted within this wider mortality context.

The census contains data on ethnicity, religion and country of birth but the only information collected about health is on limiting, long-term illness. The results show substantial variations between ethnic groups but the cross-cultural validity of such self-reported data is unknown. The Scottish Health Survey collects ethnicity data but the number of people from minority ethnic groups is too small to allow any meaningful analysis. The Scottish Adolescence Lifestyle and Substance Use Survey (SALSUS) (2002) was large enough to permit a limited analysis of South Asian pupils only. There is a lack of usable ethnicity information in other surveys.

Unless a means can be found to record ethnicity consistently – in primary care, and on hospital databases and death certificates – our ability to assess the health of ethnic minorities in Scotland will remain extremely limited.

### **Chapter 5: Research ethics and methods**

Research on ethnicity has the potential to improve health and health care but needs to follow agreed ethical principles and rigorous scientific methods if it is to do more good than harm. The seven ethical principles which we propose should underlie all research on ethnicity and health are:

- do no harm
- do good
- respect
- autonomy
- justice, fairness and equality
- inclusivity and participation
- informed consent and confidentiality.

The main methods used to conduct research on ethnicity and health are no different from those used in health and social research in general, but some particular features of ethnic minority groups have an important impact on the use of these methods and the validity of the results.

Defining ethnicity is a complex issue and creating an ethnic minority classification that is universally accepted has proved elusive. Future research in Scotland should, as far as possible, use a standard classification of ethnic identity. The classification proposed for the 2011 Census may well meet that need.

The questionnaire survey is the standard method for obtaining information about knowledge, attitudes and behaviour. There are several ways of sampling ethnic minority groups, including random sampling, sampling people using a service, or using more informal networking to find people. All have drawbacks. Because ethnic minorities make up a small percentage of the population, special techniques are usually needed to ensure that the sample sizes are large enough. If this is not done, the findings can be seriously misleading and the research devalued. All quantitative research involving

ethnic minorities should ensure that the expected sample sizes will be sufficient to validate the intended analyses.

If standardised questions are to be successfully used across cultures and in different languages, great care is needed to ensure the concepts are similarly understood or, if not, to clarify what the differences are. There is also a need for the meaning of the questions to be accurately translated. A considerable amount of additional work may be required if this is to be done adequately. In future Scottish research involving more than one ethnic group or language, all standardised questions and their translations should be prepared with the help of interpreters and validated before use in the field.

When analysing the results, adjustments may need to be made, for example, to take account of the younger age structure of some ethnic minority populations compared with the majority population.

Qualitative research has been extensively used in research on ethnicity and health. This involves conducting more extensive interviews with relatively small numbers of subjects, either individually or in small groups. It allows complex issues to be explored to a depth not offered by structured questionnaires, often providing useful insights. However, because they involve small numbers of people, the results can be unrepresentative. There is also a risk of over-interpretation of the data, particularly as there is usually no control group for comparison.

Evaluation of the effects on ethnic minorities of complex interventions – such as laws, policies, strategies or community-based interventions – can be challenging, but if this evaluation is not carried out, the effect of the intervention can never be known. To date, there have been only two evaluations of interventions in Scotland specifically designed to benefit people in ethnic minorities: the campaign to prevent rickets in South Asian children and the Khush Dil cardiovascular prevention project. The evaluation of a diabetes prevention intervention is underway.

### **Chapter 6: Priorities for future research in Scotland**

The Scottish Government is committed to treating ethnic minorities as equal members of the Scottish population. If that commitment is to safeguard and enhance the health and wellbeing of ethnic minorities, there is a need for a good understanding of their health risks and status, as well as their experience of access to and use of health and related services. That cannot be achieved without a wide range of good research. There is therefore a strong argument for a lead to be taken by Government, supported by national research bodies, to ensure that appropriate research is conducted.

In the United States, a legal requirement has existed since 1993 for all clinical research studies to include members of minority groups and their subpopulations, unless there is a compelling justification to do otherwise. This may have led to more research on ethnic minorities in the United States than in other countries. The UK Department of Health states that ‘research, and those pursuing it, should respect the diversity of human society and conditions

and the multi-cultural nature of society’ and that ‘the body of research evidence available to policy makers should reflect the diversity of the population’. This statement has been adopted by the Chief Scientist’s Office of the Scottish Government. However, without legal force or resources to support it, it is unclear whether it has had any effect to date. We found little evidence that relevant research institutions in the United Kingdom had policies which actively promoted research related to ethnicity.

In the light of our review of the current situation in Scotland and the widely held view that this must be substantially improved in the future, the Working Group proposes the following priorities over the next five years:

1. **Good ethnic coding.** Our top priority for future ethnicity and health research in Scotland is the creation of a system that ensures consistent ethnic coding within Scotland’s generally excellent health information systems. We thus recommend the following:

*Recommendation 1*

The new ethnic classification developed for the Scottish 2011 Census should be adopted by all organisations and researchers as the standard classification for routine use

*Recommendation 2*

The death certificate in Scotland should be amended to enable ethnic identity to be recorded using the same ethnic classification as for the 2011 Census.

*Recommendation 3*

The Scottish Government should require ethnic identity to be one of the items recorded, with individuals’ consent, on the CHI or its successor for every person registered with the NHS, with the aim of achieving this by 2015.

2. **Data linkage.** The second priority is to make further use of linkage methods where the ethnic code from the census permits more effective analysis of existing databases. Linkage to general hospital discharge and deaths databases has already been carried out and work is in progress to link census information to cancer-registry and breast-screening databases, as well as to hospital discharge information on maternal, child and mental health.

*Recommendation 4*

The Scottish Government should give full support to continuing the research programme based on linking the ethnic coding on the census to a range of health-related databases.

3. **A health survey of ethnic minorities in Scotland.** To help understand the health of ethnic minorities, it is important to have information about a wide range of health behaviours – such as smoking, eating behaviour, physical activity, obesity, etc. – against a background of personal and social circumstances, and compare the findings with those for the population as a whole. Linking a boosted sample from ethnic minorities with the revised Scottish Health Survey is not considered practical or cost-effective. However,

a large sample of ethnic-minority households from throughout the UK will form part of the Understanding Society survey now underway. The first findings will be available in 2010. Much of the resulting information will be relevant to ethnic minorities in Scotland and this could be enhanced by a subsequent Scottish survey.

*Recommendation 5*

A survey of ethnic minorities living in Scotland should be conducted between 2011 and 2012 with the aim of adding significantly to the information obtained from the UK Understanding Society survey.

4. **Coordinated research on major health topics.** The fourth priority is to conduct health-related research with two main aims. The first is to focus on the evaluation of larger-scale interventions designed to address major preventable or treatable contemporary health problems such as diabetes, heart disease, cancer, obesity and depression. The second is to facilitate smaller-scale qualitative studies of key related issues – such as understanding of and attitudes towards mental illness, HIV infection or terminal illness – and the experience of relevant services, or barriers to behaviour change in relation to diet, physical activity or tobacco use.

*Recommendation 6*

The Scottish Government should encourage and support:

- evaluations of larger scale interventions aimed at preventing or treating major health problems affecting ethnic minorities
- qualitative research designed to provide insights into perceptions, attitudes, behaviour and experience of health and social care services of relevance to major health issues in different ethnic minority groups.

5. **Catalysing, coordinating and using research** Until now, research on ethnicity and health in Scotland has lacked a focal point through which ideas can be stimulated and supported, the overall research effort can be coordinated, and the findings disseminated and channelled into policy and service delivery as appropriate. We think this could best be achieved by establishing a new multi-disciplinary steering group.

*Recommendation 7*

A Scottish Ethnicity and Health Research Group should be established to catalyse and coordinate relevant high-quality research and make the best use of the findings of research from Scotland and elsewhere. The Group should be hosted by NHS Health Scotland.

## **Membership of the Working Group**

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