

Health in our Multi-ethnic Scotland Future Research Priorities

A Draft Consultation Report

The Scottish Ethnicity and Health Research Strategy
Working Group

NHS Health Scotland
October 2008

CONTENTS

	Foreword	5
	Summary and recommendations	7
	Glossary	14
1	Why a Research Programme is Needed	17
2	The changing ethnic composition of the Scottish Population	20
3	Published research on ethnicity and health in Scotland	28
4	What is known about the health status of ethnic minority groups in Scotland?	35
5	Future research on ethnicity and health in Scotland: Ethics and methods	41
6	Future research priorities	50
	A Bibliography of publications on ethnicity and health in Scotland	55
	Appendix 1 Membership of the working group	74
	Appendix 2 Literature search strategy for period 2001-2007.	75
	Text references	77

Foreword

A review of ethnicity and health research in Scotland was commissioned by the Scottish Executive and published in 2001. It found that, despite some excellent work, not enough was known about the health of ethnic minorities in Scotland and it made a number of recommendations for future research. At a seminar four years later held by the National Resource Centre for Ethnic Minority Health, there was a consensus that little further progress had been made. At the seminar, NHS Health Scotland made a commitment to establish a working group that would develop a strategic programme of research aimed at rectifying the situation. Following discussion with the Scottish Government and a range of other stakeholders, a working group was set up under my chairmanship and met for the first time in January 2007. This report distils the findings and thoughts of the working group. We now want to hear from a much wider range of people with an interest in this field about what they think of our proposals. With your comments and suggestions we hope this will enable us to publish a final report that we hope will command widespread support and lead to real progress. The report can also be accessed and downloaded by going to www.healthscotland.com , clicking on Research Publications on the home page then typing Health in our Multi-ethnic Scotland in the search box.

The consultation period is between October 6 and December 8 2008. Please respond to the consultation by using the Health in our Multi-ethnic Scotland Consultation Proforma which can also be found at the same place on the website or by emailing Susan.Hendry@health.scot.nhs.uk. Please send your completed proforma back to Susan.Hendry@health.scot.nhs.uk by December 8.

I hope you enjoy reading the report and look forward to hearing from you.

Dr Laurence Gruer OBE
Director of Public Health Science
NHS Health Scotland.

Summary and recommendations

Chapter 1: Why a research strategy is 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 Government’s Fair for All policy, initiated in 2002, makes a commitment to promoting equality and diversity, in a fairer society where everyone can participate the differences between people are respected and valued. Fair for All requires Scotland’s health services to recognise and respond sensitively to the needs, background and circumstances of individuals across the whole population.

In the light of recent work by the National Resource Centre for Ethnic Minority Health and the Scottish Government it was clear there is a lack of reliable information about the health of ethnic minorities in Scotland and their experience within the NHS. Against this background, this report has four main aims in relation to ethnic minorities in Scotland:

- To define the key issues relating to ethnicity and health;
- 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; and
- 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 and Indians, Pakistanis, Bangladeshis and Chinese in the next 50 years. The 2001 census showed 10% of the Scottish population belonged to a White 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 thousand 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 data on the place of birth of mothers of children born in Scotland. 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 in 2006-07, of whom over 23,000 were from Poland.

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 dependents.

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. An overhaul of our data recording system is needed to address this.

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 Bhopal and colleagues in the late 1980s. From 1990-2000, a series of studies were conducted by the MRC Social and Public Health Science 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. Bowes and colleagues carried out an extensive series of studies of South Asian women and their interaction with health services in Glasgow. There was a range of other studies of smoking, alcohol, drug use and sexual behaviour among South Asians. During this period the health status of Chinese, African-Caribbean and other ethnic minorities appears to have been 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.

2001-2008 A notable change in direction has been led by 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. They 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-Caribbean 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 has been followed by 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 what the particular challenges in their own areas might be.

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 generally recorded on death certificates and health service records. Ethnic coding is currently done for only 5-10% of hospital admission records and 18% of cancer registration data. 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 colleagues have shown that the incidence of heart attack is higher among South Asians in Scotland than in the rest of the population, but 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 25-69 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) in 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 consistently to record ethnicity in primary care and hospital databases and on death certificates, our ability to assess the health of ethnic minorities in Scotland will remain extremely limited.

Chapter 5: Future research on ethnicity and health in Scotland - 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 to do more good than harm. The seven ethical principles 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. We **recommend** using the classification recently developed for the Scottish census.

The questionnaire survey is the standard method for obtaining information about knowledge, attitudes and behaviour. In order for a survey's findings to be generalisable to the group from which it is drawn, the sampling method, the number in the sample and the response rate should all be such that respondents are representative of the population from which they are drawn; the questions used should be understood by the respondents; and the answers should be objectively judged to be of acceptable validity. 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. We therefore **recommend** that all quantitative studies involving ethnic minorities should ensure that the expected sample sizes will be sufficient to validate the intended analyses.

Response rates can vary from one ethnic group to another; for some ethnic groups, cultural constraints can make it difficult to obtain data from women. 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 to be done adequately. We therefore **recommend** that in future Scottish research involving more than one ethnic group or language, all standardized questions and

their translations are 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 often no control group for comparison. The range and value of the findings from groups can be limited by the emergence of a group ideology or an opinion leader.

Evaluation of the effects on ethnic minorities of complex interventions such as laws, policies, strategies or community-based interventions can be challenging but if not done, 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 well-being of ethnic minorities, there is a need for a good understanding of their health risks and status and 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 has stated that “*research, and those pursuing it, should respect the diversity of human society and conditions and the multi-cultural nature of society*” and “*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 2003, the UK Department of Health set out more detailed guidance for its own research commissioners in the form of a four point action plan for:

- developing the evidence base on ethnic inequalities in health and well-being, in access to treatment, and in outcomes of care
- ensuring appropriate coverage of ethnic groups in all research
- ensuring appropriate representation of minority ethnic groups in R & D project and programme steering and advisory structures
- and improving representation of minority ethnic communities in the R & D workforce.

We **recommend** that similar undertakings are made by the Scottish Government.

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. This will require an energetic, proactive approach to ethnic coding, led by the Scottish Government. We thus **recommend** that the Scottish Government develops an action plan with the aim of ensuring that by 2013 at least 80% of people registered with the NHS have their ethnic identity recorded, achieving nearly 100% by 2018.

2. **Data linkage.** The second priority is to capitalise on Scotland's lead in the UK with 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 and to hospital discharge information on maternal, child and mental health. We **recommend** this work is taken further. There is considerable scope to link census data to other screening programmes such as those for colorectal cancer, diabetic retinopathy and abdominal aortic aneurysms. Linkage to primary care data would be a major step forward, allowing analyses of ethnic variations in morbidity and service use and giving an indication of variations in the quality of care by ethnic group.

3. **An ethnically boosted health survey** The third priority is to conduct a survey on a sufficiently large sample of ethnic minorities in Scotland to provide reliable information about a wide range of health behaviours, such as the prevalence of smoking, eating behaviour, levels of physical activity, obesity etc and to compare the findings with those for the population as a whole. There are two practical, complementary possibilities. The first is to extend the revised Scottish Health Survey to include an ethnically boosted sample of the population. The second is to ensure there is a substantial Scottish component of the UK Longitudinal Household Survey being led by the Institute of Social and Economic Research at the University of Essex. This will allow comparison with other parts of the UK and, because it is an ongoing study, would provide useful information for many years to come. We **recommend** that at least one of these options is supported by the Scottish Government.

4. **Coordinated research on major health topics** The fourth priority is a health research strategy to enable Scotland's research resources to be focused on larger scale, validated work that is analysed and presented in ways that are easy to interpret

and allow robust conclusions that can be applied to the wider population of ethnic minorities. We **recommend** this should focus particularly on the evaluation of interventions designed to address major, preventable or treatable contemporary health problems such as diabetes, heart disease, cancer, obesity, depression and dental caries. Such interventions need not be exclusively focused on ethnic minorities but should involve them in ways that can allow meaningful conclusions to be reached.

Achieving this will require the following components:

- Support from the Scottish Government
- A mutual commitment from academic teams and community organisations to work in collaboration so that the strengths of both can be harnessed
- Greater efforts by researchers to enable the ethnic minority public to understand the potential value of research to them and thereby to increase their willingness to participate.
- Given the similarities between ethnic minorities in Scotland, the rest of the UK and other parts of Europe, opportunities for intra- and international collaboration should be taken to the full.

5. **Audit of local health and social care services** Each area NHS Board in Scotland and each local authority provides its own distinctive range of services and has its own unique mix of ethnic minorities. In many cases the latter is rapidly changing, for example due to the dispersal of refugees and asylum seekers or the recent arrival of large numbers of newcomers from Poland and other EU countries. Consequently, given the clear potential for problems in access to and use of services, we **recommend** that each NHS Board should carry out a regular audit of the range and quality of services it provides for ethnic minorities. This will inevitably vary but key services include maternal and child care and mental health services.

6. **Coordination and monitoring of research**

We **recommend** that a Scottish Ethnicity and Health Research Strategy Implementation Group should be established with the aim of overseeing the implementation of our proposals. This could include the establishment and maintenance of an on-going register of relevant research in Scotland. Given the role of its new Equality and Planning Directorate, we **recommend** that the new Group is hosted by NHS Health Scotland.

Glossary
(abridged from Bhopal 2003¹ and Bhopal 2007²)

African	A person with African ancestral origins who self-identifies, or is identified, as African, but excluding those of other ancestry e.g. European and South Asian. This term is the currently preferred description for more specific categories, as in African American, for example. (In terms of racial classifications, this population approximates to the group historically known as Negroid or similar terms.) In practice, Northern Africans from Algeria, Morocco and such countries are excluded from this category. (See also Black.)
Afro-Caribbean/ African Caribbean	A person of African ancestral origins whose family settled in the Caribbean before emigrating and who self-identifies, or is identified, as Afro-Caribbean (in terms of racial classifications, this population approximates to the group known as Negroid or similar terms). (See also Black.)
Asian	Strictly, this label applies to anyone originating from the Asian continent. In practice, this term is used in the United Kingdom to mean people with ancestry in the Indian subcontinent. In the United States, the term has broader meaning, but is mostly used to denote people of far Eastern origins e.g Chinese, Japanese and Philipinos. More specific terms should be used whenever possible.
Bangladeshi	A person whose ancestry lies in the Indian subcontinent who self-identifies, or is identified, as Bangladeshi. (See also South Asian.) Between 1947 and 1971 the land known as Bangladesh was East Pakistan and before that India. There is no clear-cut equivalent in terms of racial classifications, though historically Northern Indians have been classified as Caucasian, and some Indian tribes as aboriginal. (The racial term Malayan, coined by Blumenbach, is forgotten as purposeless.)
Black	A person with African ancestral origins, who self identifies, or is identified, as Black, African or Afro-Caribbean (see, African and Afro-Caribbean). The word is capitalised to signify its specific use in this way. In some circumstances the word Black signifies all non-white minority populations, and in this usage serves political purposes. While this term was widely supported in the late 20th century there are signs that such support is diminishing.
Caucasian	An Indo-European. This is Blumenbach's 18 th Century term for the white race of mankind, which he derived from the people who lived in the Caucasus. This term is usually used synonymously with Caucasoid European or White. Alone amongst terms derived from traditional racial classification, Caucasian remains popular in both science and everyday language.
Chinese	A person with ancestral origins in China, who self-identifies, or is identified, as Chinese. (In terms of historical racial classifications, Chinese approximate to the group known as Mongolian or Mongoloid.)
Coronary heart disease	A group of diseases resulting from reduced blood supply to the heart, most often caused by narrowing or blockage of the coronary arteries

	that provide the blood supply to the heart.
Diabetes (mellitus)	A disease characterised by high levels of glucose in the blood caused by either lack or ineffectiveness of the hormone insulin.
Ethnic minority group	Usually, but not always, this phrase is used to refer to a non-white population. Alternatively, it may be used to describe a specific identifiable group e.g gypsy travellers, and less commonly, Irish in the UK. Some people consider the phrase inaccurate and prefer minority ethnic group, but the two phrases are used synonymously.
Ethnicity	The social group a person belongs to, and either identifies with or is identified with by others, as a result of a mix of cultural and other factors including language, diet, religion, ancestry, and physical textures traditionally associated with race (see race). Increasingly, the concept is being used synonymously with race but the trend is pragmatic rather than scientific.
General population	Everyone in the population being studied, irrespective of race or ethnicity.
Indian	A person whose ancestry lies in the Indian sub-continent who identifies, or is identified, as Indian (see, South Asian). (Major changes to India's geographical boundaries took place in 1947 when Pakistan was created.)
Irish	A person whose ancestry lies in Ireland who self-identifies as Irish but generally restricted to the White population (see, White).
Majority population	When used in race/ethnicity studies this phrase is usually used as a synonym for White or European.
Minority ethnic group	See ethnic minority group. Increasingly used as the preferred phrase and replacing ethnic minority group
Mixed and other race or ethnic group	This glossary omits a clear exposition on these terms, which require fresh thought. The increasing importance of the category mixed (ethnicity or race) is self-evident. The increasing acceptance of sexual unions that cross ethnic and racial boundaries is adding both richness and complexity to most societies. The way to categorise people born of such unions is unclear and the current approaches are inadequate, partly because the number of potential categories is huge. Another category seen in racial classifications is 'other', this permitting those not included to identify themselves, or be identified by the observer. In both instances the solution is, most probably, to offer space for free-text responses for individuals to identify themselves. These responses, however, need to be coded, analysed, summarised, quantified and published. Without this individually small, but collectively large, populations remain hidden when policy on ethnic diversity is made.
Pakistani	A person whose ancestry lies in the Indian subcontinent who identifies, or is identified, as Pakistani (see South Asian). Some Pakistanis may have birth or ancestral roots in the current territory of India but identify with Pakistan, a country created in 1947.
Population	A complex concept with multitude meanings in epidemiology, but crucially, the people in whom the problem under study occurs, and in whom the results of the research are to be applied. The concept is discussed extensively.
Race	By historical and common usage the group (sub-species in traditional

	scientific usage) a person belongs to as a result of a mix of physical features such as skin colour and hair texture, which reflect ancestry and geographical origins, as identified by others or, increasingly, as self identified. The importance of social factors in the creation and perpetuation of racial categories has led to the concept broadening to include a common social and political heritage, making its usage similar to ethnicity. Race and ethnicity are increasingly used as synonyms causing some confusion and leading to the hybrid terms race/ethnicity (see Ethnicity).
Racial prejudice	Negative beliefs, perceptions or attitudes towards one or more ethnic or racial groups.
Racism/ institutional racism	A belief that some races are superior to others, used to devise and justify individual and collective actions which create and sustain inequality among racial and ethnic groups. Individual racism is usually manifested in decisions and behaviours that disadvantage small numbers of people. Institutional racism, whereby policies and traditions, sometimes unwittingly, favour a particular racial or ethnic group, may be less obvious but may disadvantage large populations.
Risk Factor	A factor associated with an increased probability of an adverse outcome, but not necessarily a causal factor.
South Asian	A person whose ancestry is in the countries of the Indian sub-continent, including India, Pakistan, Bangladesh and Sri Lanka (in terms of racial classifications, most people in this group probably fit best into Caucasian or Caucasoid but this is confusing and is not recommended). This label is usually assigned, for individuals rarely identify with it. (See also Indian, Indian Asian, Asian, Pakistani, Bangladeshi).
Standardised mortality (or morbidity) ratio (SMR)	A summary measure of the rate of death/disease in a population adjusted for one or more confounding factors (usually age or sex or both) using the indirect method. The ratio is of deaths observed/deaths expected if the rates in the standard population had applied in the study population.
Western	A person or populations with ancestry in a region conventionally known as the West, effectively European countries, as distinguished from Eastern or Oriental populations.
White	The term usually used to describe people with European ancestral origins who identify, or are identified, as White (sometimes called European, or in terms of racial classifications, the group known as Caucasian or Caucasoid). The word is capitalised to highlight its specific use. The term has served to distinguish these groups from those groups with skin of other colours (black, yellow etc), and hence derives from the concept of race but is used as an indicator of ethnicity. There are problems of poverty and excess disease in subgroups of the White population, which cannot be unearthed and tackled by using the label White.

Chapter 1

Why a Research Strategy is Needed

1.1 Our ethnicity refers to the social group we belong to or are identified with as a result of a mix of cultural and other factors including our language, diet, religion, ancestry and physical attributes traditionally associated with race (See Glossary and Bhopal 2007²). 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. Ethnic group in the United Kingdom is currently based on self-definition: standard questions are available to collect this information, including those used successfully in the Census in the UK since 1991 (See Chapter 2).

1.2 The United Kingdom has for centuries had an ethnically diverse population but the mix has become much more complex in the last fifty years with the arrival of large numbers of people, particularly from former British colonies and most recently from other parts of the European Union. Scotland is less ethnically diverse than the United Kingdom as a whole. In the 2001 census, only 2% of the Scottish population were recorded as being in a non-White ethnic minority, rising to 3-4% in the Central Belt. This compares with 8% in the United Kingdom as a whole. However, such a bald figure gives a misleading impression of what is a complex and fast-changing situation. The census also revealed that 10% of the population in Scotland belong to White ethnic minorities. Furthermore, since the 2001 census Scotland has seen the arrival of several thousand refugees and asylum seekers from a wide range of countries and the unprecedented inward migration of large numbers of mainly young adults from Eastern Europe.

1.3 The experience of Black and ethnic minorities in this and other countries has often been far from easy. Anti-semitism in Europe and institutional racism towards Black people in the United States are vivid examples. As a result of the evidence of racial discrimination in this country, the Race Relations Act was passed in 1976. This aims to protect all racial groups from discrimination, “regardless of their race, colour, nationality, religious beliefs, national or ethnic origins”. More recently, in the wake of the racially motivated murder of Stephen Lawrence and the subsequent MacPherson Enquiry, the Race Relations (Amendment) Act 2000 extended the 1976 Act and was implemented in 2002. This places additional responsibilities on the police and other 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”.

1.4 Subsequently, the Fair for All report was commissioned by the Scottish Executive in 2001 to assess the extent to which Black and other minority ethnic communities could fairly access NHS services. This report showed that, despite good intentions, many parts of the NHS had been unable to take action to ensure their services were open and accessible to all. The Fair for All report was followed by a Scottish Executive Health Department letter [HDL 2002 (51)] which set out five key areas for delivery for all NHS Boards in the area of race equality and cultural competence. Fair for All commits the Government to promoting the ideas of both

equality and diversity, setting out a vision of a fairer society where everyone can participate and has the opportunity to fulfil their potential; and where the differences between people are respected and valued for the benefit of all. The aims of Fair for All have now been widened to ensure that Scotland's health services recognise and respond sensitively to the individual needs, background and circumstances of people's lives across the whole population (Partnership for Care SEHD 2003).

1.5 In 2002, the Scottish Executive established the National Resource Centre for Ethnic Minority Health (NRCEMH), initially hosted by the Public Health Institute of Scotland and subsequently by NHS Health Scotland. In April 2008, NRCEMH's functions were incorporated in the new Equalities and Planning Directorate within NHS Health Scotland. NRCEMH provided an invaluable focus for a wide range of work aimed at ensuring all parts of the NHS fulfilled their legal obligations under the Race Relations (Amendment) 2000 Act and Fair for All 2002, providing training and support and improving the availability of information. In addition, in 2006, the Scottish Executive set up a web-based resource designed to hold information about completed or continuing studies in Scotland across all the Fair for All strands. Emerging from this work was a recognition that there was a serious dearth of reliable information about the health of ethnic minorities in Scotland and their experience within the NHS. Whilst there was a lot of small-scale activity, it lacked the strategic direction and central support necessary to provide a clear picture.

Ethnic diversity and health: many questions to be answered

1.6 From a health perspective, this increasing diversity raises many questions. To what extent does the health of minority ethnic backgrounds differ, for better or for worse, from that of the majority White population? Are people in some ethnic groups more susceptible to particular health problems and if so what are the nature, extent and causes of these differences? Does people's ethnic or cultural background contribute to differences in their use of health and social services in Scotland? Are there particular obstacles to people's access to and use of our health and related services that may be influenced by their ethnic group? To what extent are people subjected to unfair or discriminatory treatment as a result of their ethnic background due to the attitudes, lack of knowledge or misunderstandings of service providers? What can we learn from our study of diversity and health to benefit the whole population. To answer these questions requires well designed and executed research and the careful interpretation of the resulting data. Conducting such research is not easy for many reasons, not least because ethnicity and race are sensitive issues.

1.7 This report therefore aims to set out the future research and information needs in Scotland in the area of ethnicity and health. It will do this against a background of our current understanding of ethnicity and health in Scotland and a review of what research in this field has been conducted over the last forty years.

1.8 There is an almost unlimited number of research questions which could be asked but the funding and other resources available to carry out such research will always be limited. Without a coherent view of what it is important to know, there is a danger that some research of limited value will be done whilst important gaps in knowledge remain. There is therefore a need to identify the range of relevant issues regarding ethnicity and health which research could illuminate. It is then important to review what research has already been done around each of these issues and what

conclusions have been reached. This should then lead to an understanding of the main gaps in knowledge which research might fill. A process of prioritisation will be needed, leading to recommendations on which types of research should be conducted.

Aims of the report

1.9 The aims of this report in relation to Scotland are therefore fourfold:

- To define the key issues relating to ethnicity and health;
- 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; and
- To propose a programme of research that will fill these.

We hope thereby to stimulate high quality research which will contribute to achieving greater equity in health between the ethnic groups in Scotland and improve the health and well-being of both Scotland's ethnic minorities and majority alike.

Chapter 2

The changing ethnic composition of the Scottish Population

Introduction

2.1 Ethnic diversity in human populations is created by migration. This chapter briefly describes the historical pattern of immigration into Scotland. It then reviews the most recently available information about the ethnic composition of the Scottish population, based largely on the 2001 population Census in Scotland, and considers the changes that have occurred since the 1991 Census. As country of birth and religion contribute to the concept of ethnicity these are also described. Finally, the limited data sources on more recent migrant populations are reviewed.

Immigration to Scotland

2.2 For several hundred years, huge numbers of people born in Scotland have emigrated to the four corners of the world. This has tended to overshadow the arrival in Scotland of significant numbers of immigrants. Many thousands of Irish came in the nineteenth century. Smaller numbers of Lithuanians arrived between the 1860s and 1914. By 1914 there were also at least 4,500 Italians living in Scotland and many more came in subsequent decades. Substantial numbers of Eastern European Jews settled in Scotland around the same time, mainly in Glasgow. During the second world war, several thousand Polish soldiers were stationed in Scotland and the Polish medical school was temporarily located in Edinburgh; after the war, a small but significant community remained. In the 1950s immigration to Britain from the Indian sub-continent and China began in earnest with significant numbers of Indians, Pakistanis, Bangladeshi and Chinese settling in Scotland over the next fifty years, mainly in and around Glasgow and Edinburgh. During the past ten years the number and diversity of immigrants has increased substantially. Several thousand asylum seekers and refugees from mainly African and middle eastern countries have been officially “dispersed” to Glasgow. Since the expansion of the European Union in 2004, arrivals of workers from Poland, the Baltic States and other eastern European countries have increased substantially. As a result, Scotland’s population is becoming increasingly diverse and in 2007, for the first time since records began, the annual number of immigrants has exceeded the number of emigrants.

The 2001 Census in Scotland

2.3 The main source of information on the current ethnic composition of the Scottish population is the decennial population census. The most recent census, in 2001, included questions about country of birth, current religion and religion of upbringing, and ethnic group. Respondents were asked about knowledge of Scottish Gaelic, but other languages were not included. It is important to note that the classification of ethnic groups was slightly different from that used in the other countries of the United Kingdom. In 2001, non-White ethnic minorities accounted for 101,677 people, or just over 2% of the population (table 2.1³). A further 501,263 (9.9% of the total population) were from White ethnic minority groups. Pakistanis were the largest non-White minority ethnic group, followed by Chinese, Indians and those of mixed ethnic backgrounds.

Table 2.1: Scottish population by ethnic group- All People

	% of total population	% Minority ethnic population	Base
White Scottish	88.09	na	4,459,071
Other White British	7.38	na	373,685
White Irish	0.98	na	49,428
Any other White background	1.54	na	78,150
Indian	0.30	14.79	15,037
Pakistani	0.63	31.27	31,793
Bangladeshi	0.04	1.95	1,981
Chinese	0.32	16.04	16,310
Other South Asians	0.12	6.09	6,196
Caribbean	0.04	1.75	1,778
African	0.10	5.03	5,118
Black Scottish or any other Black background	0.02	1.11	1,129
Any Mixed Background	0.25	12.55	12,764
Any other background	0.19	9.41	9,571
<i>All minority ethnic population</i>	2.01	100	
All population	100.00	na	5,062,011

Changes since the 1991 Census

2.4 Scotland is less ethnically diverse than some other parts of the United Kingdom; in 2001 2.0% of the Scottish population was from non-White ethnic minority groups compared with 7.9% of the population of the UK as a whole. However, rapid changes in the ethnic composition of the Scottish population are taking place. Evidence for this comes from the 2001 Census, in which 101,677 people (2%) reported a non-White ethnic group compared with 62,634 people (1.25%) in 1991. This represents an increase of 62% in ten years. There were large increases in the numbers who classified themselves as Indian (49.6% increase) Pakistani (50.0%), Bangladeshi (74.7%) and Chinese (55.7%). However comparisons between the 1991 and 2001 Censuses for specific ethnic groups are made difficult by the fact that the classifications of ethnicity used were different. In particular the 2001 Census used the “Mixed” category, which was not offered in the 1991 Census.

Country of birth

2.5 In 2001 Scotland was either the most common or the second most common country of birth for all ethnic groups. However, the percentages vary greatly between different ethnic groups: for example, 47% of Pakistanis were born in Scotland compared to only 18% of Africans.

Table 2.2 Mother's country of birth of children born in Scotland in 1991, 2001 and 2004-07⁴

		Year of birth					
		1991	2001	2004	2005	2006	2007
UK	Scotland	56,880	43,518	43,813	43,650	44,386	45,330
	England	6,214	5,076	5,221	5,356	5,371	5,327
	Wales	244	186	191	215	209	225
	Northern Ireland	338	417	493	472	492	536
	UK (part not stated)	2
	Isle of Man, Chann Is	24	16	20	18	10	14
	All	63,702	49,213	49,738	49,711	50,468	51,432
European, pre-2004	Austria	3	4	12	6	10	6
	Belgium	13	21	19	21	14	14
	Denmark	15	27	19	28	24	24
	Finland	5	15	17	9	17	22
	France	47	93	94	98	89	103
	Germany	334	354	385	382	396	397
	Greece	4	4	16	12	16	22
	Ireland (Republic)	254	205	230	272	257	303
	Italy	27	30	28	32	40	32
	Luxembourg	1	.
	Netherlands	39	43	42	65	47	62
	Portugal	6	7	17	27	29	25
	Spain	15	33	49	59	51	59
	Sweden	8	21	32	25	39	31
All	770	857	960	1,036	1,030	1,100	
Joined in 2004	Cyprus	45	23	28	24	15	38
	Czech Republic	4	7	6	14	25	45
	Estonia	.	2	3	6	10	12
	Hungary	2	2	6	8	13	28
	Latvia	.	1	5	12	35	62
	Lithuania	.	8	13	20	42	70
	Malta	45	17	12	14	16	8
	Poland	17	25	31	114	365	934
	Slovakia	.	2	6	17	31	53
	Slovenia	.	.	4	3	1	.
All	113	87	114	232	553	1,250	
Joined in 2007	Bulgaria	.	3	9	13	10	16
	Romania	2	19	13	18	22	22
	All	2	22	22	31	32	38
Total	All (non-UK) EU countries	885	966	1,096	1,299	1,615	2,388

Non-EU	Australia, Canada, NZ	296	308	399	347	412	381
	India, Bdes, Sri L, Pak	708	696	829	933	979	1,048
	W Indies, Belize, Guyana	28	14	31	31	27	27
	Africa (commonwealth)	267	275	410	499	573	687
	Other Commonwealth	198	111	153	132	121	121
	Other countries	937	942	1,297	1,431	1,493	1,692
	Not known	3	2	4	3	2	5
	All	2,437	2,348	3,123	3,376	3,607	3,961
Grand Total	All births	67,024	52,527	53,957	54,386	55,690	57,781

Mother's country of birth

2.6 When births are registered, the mother's country of birth is recorded. This gives a good indication of the nationality and ethnic group of mothers and recently born children in Scotland. Table 2.1 shows all births in 1991, 2001 and the last four years. They first show a 23% fall from 63702 to 49213 between 1991 and 2001 in the number of births to mothers born in Scotland or other parts of the United Kingdom followed by a 4.5% rise in the next seven years. During the same period, numbers of births to women born in countries of the European Union (EU) rose from 885 to 2388 (170% increase). The largest single contributor to this dramatic increase was Poland with births rising from 31 in 2004 to 931 in 2007. There were smaller increases from other countries which joined the EU since 2004. Births to women born in countries outside the EU rose from 2437 to 3961 (62% increase). These were mainly accounted for by the Indian subcontinent (48% increase), African commonwealth countries (157% increase) and other countries (80% increase). Despite these increases, the total number of births in Scotland in 2007 was still 14% lower than it had been in 1991.

Religion

2.7 Around two-thirds (67%) of the Scottish population reported having a religion; of which the most common was Christianity (Table 2.3). 65.1% of the population were members of the Church of Scotland, Roman Catholic Church or Other Christian churches. The next most common faith was Islam (0.84%) followed by Other religions (0.53%), Buddhism (0.13%), Judaism (0.13%), Sikhism (0.13%) and Hinduism (0.11%).

2.8 Tracking the numbers and movements of migrant workers to and around Scotland is currently not possible. Some registration data for migrant workers is available but it is incomplete and not all migrants work legally.

2.9 From May 1 2004, nationals of the new EU member states (except Cyprus and Malta) who wish to work for more than one month for an employer in the UK need to register under the Workers Registration Scheme. However, many do not register and there is no need to de-register on leaving. This scheme costs applicants £90 and is administered by the Department of Work and Pensions.

Migrant Workers

2.10 Migrant workers entering the UK apply to Jobcentre Plus for a National Insurance Number which once allocated is recorded onto the National Insurance Recording System held by Her Majesty's Revenue and Customs. These sources provide the bulk of data to estimate migrant numbers. Again, not all migrant workers apply and movements are not tracked. The figures only reflect the region the application was made in, and not where the person may ultimately work. General practice (GP) registrations are potentially a further method. However it is known that many migrants do not register and their ethnicity may not be recorded.

Table 2.3 : Scottish population by current religion – All People

	<i>Thousands</i>	<i>Percentages</i>
Church of Scotland	2,146	42.4
Roman Catholic	804	15.9
Other Christian	345	6.8
Buddhist	6.8	0.13
Hindu	5.6	0.11
Jewish	6.4	0.13
Muslim	43	0.84
Sikh	6.6	0.13
Another Religion	27	0.53
<i>All Religions</i>	<i>3,389</i>	<i>67</i>
No religion	1,394	27.5
Not stated	278	5.5
<i>All no religion/not stated</i>	<i>1,672</i>	<i>33</i>
Base	5,062	100

2.11 Statistics relating to the numbers of National Insurance Numbers allocated by the Department of Work and Pensions are regularly published. They have clearly shown that since the accession of new member states to the European Union in 2004, registrations of overseas nationals have rapidly increased, with 349,000 overseas nationals entering the UK 2002/03, rising to 439,000 in 2004/05 and 713,000 in 2006/07. The age profile is largely confined to the 18-34 years group. Of note, in

2005 dependants accompanied only 5% of registered workers, rising to 9% in 2006. Dependants were roughly equally split between those aged over and under 17 years. Where new migrant entrants chose to base themselves within the UK is varied, with 8% relocating to Scotland. The largest proportion find work in the hospitality and catering industry (29%) followed by food/fish/meat processing (14%). These business areas are quite different from the rest of the UK where the administration sector was more common. Table 2.4 summarises the source countries of new residents entering Scotland specifically. Whilst Polish migrants form the largest proportion they are followed most closely by non-European countries. Migrants are found in all regions in Scotland with the highest proportionate influxes to Angus, Western Isles, West Lothian, Moray and Dumfries and Galloway. However, the largest numbers are found in the city regions . Fifty-five percent of workers indicated on the Workers Registration Scheme application form that they intended to stay in the UK for less than 3 months and only 14% intended staying longer than 1 year.

Table.2.4 Overseas nationals entering Scotland and allocated a National Insurance Number: top twelve countries 2006/07⁵

<i>Country</i>	<i>Number</i>
Poland	23,140
India	3,460
Slovak Rep	1,730
Australia	1,690
China Peoples Rep	1,590
Rep of Ireland	1,250
Pakistan	1,180
France	1,160
Czech Rep	1,120
Rep of Lithuania	1,070
Spain	1,070
Nigeria	1,020

2.12 Although there are no reliable sources of information on their exact numbers, migrant workers now make up a significant proportion of the population in some areas of Scotland and the numbers are continuing to rise.

Asylum seekers and refugees

2.13 At the UK level, the Home Office provide statistics on the number of asylum seekers in the UK and the number dispersed to various parts of the UK including Scotland. For example these statistics indicate that by the end of 2006, 5,010 asylum seekers had been dispersed to Glasgow⁶. Figures up to the end of 2007 indicate that there were 3,910 asylum seekers in supported accommodation in Scotland, 3,905 of which were in the city of Glasgow⁷. However, these figures do not provide a reliable guide to the number of asylum seekers 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 dependents. There are no reliable estimates of the number of illegal migrants.

2.14 The Confederation of Scottish Local Authorities (COSLA) provide statistics for the number of asylum seekers up to the end of 2006⁸ (COSLA 2008) drawing on Home Office statistics. They also provide information on the geographical

distribution of asylum seekers in Glasgow, the nationality of asylum seekers and reviews of ad hoc surveys conducted in Glasgow to examine the needs of asylum seekers. The COSLA website also provides information about refugees in Scotland. The Information Centre about Asylum Seekers and Refugees in the UK (ICAR) maintains a website which includes an overview of statistics on refugees in the UK⁹. The Department of Work and Pensions reports that 2,080 refugees were registered with Jobcentre Plus in Glasgow during 2005¹⁰. In addition there were 500 children with refugee status in Glasgow schools.

2.15 The Fresh Talent: Working in Scotland scheme was set up in Scotland to attract 'bright talented, hard working people to work in the Scottish economy and in the 3 years of its existence between June 2005 and June 2008 it had 8,475 successful applications. These applications came from many countries with the 5 most numerous being India (2,828), China (2,119), Nigeria 1027, Pakistan (435) and the USA (382). The Fresh Talent :Working in Scotland scheme has now been overtaken by a UK 'points based scheme'.

Conclusion

2.16 The diversity of the population of Scotland has been increasing rapidly over the past decade as a result of inward migration. Immigration has been the main reason why the Scottish population has increased since 2003¹¹. The changes have been much greater in some parts of the country than others. However, a good understanding of their true extent is hampered by a lack of accurate data. If this lack of information is to be improved, an overhaul of our data recording system is needed.

Acknowledgements

The material on migrant workers in Scotland was provided by Dr Joanne Morling. We thank Dr Morling and also the Scottish Public Health Network who sponsored the work.

Chapter 3

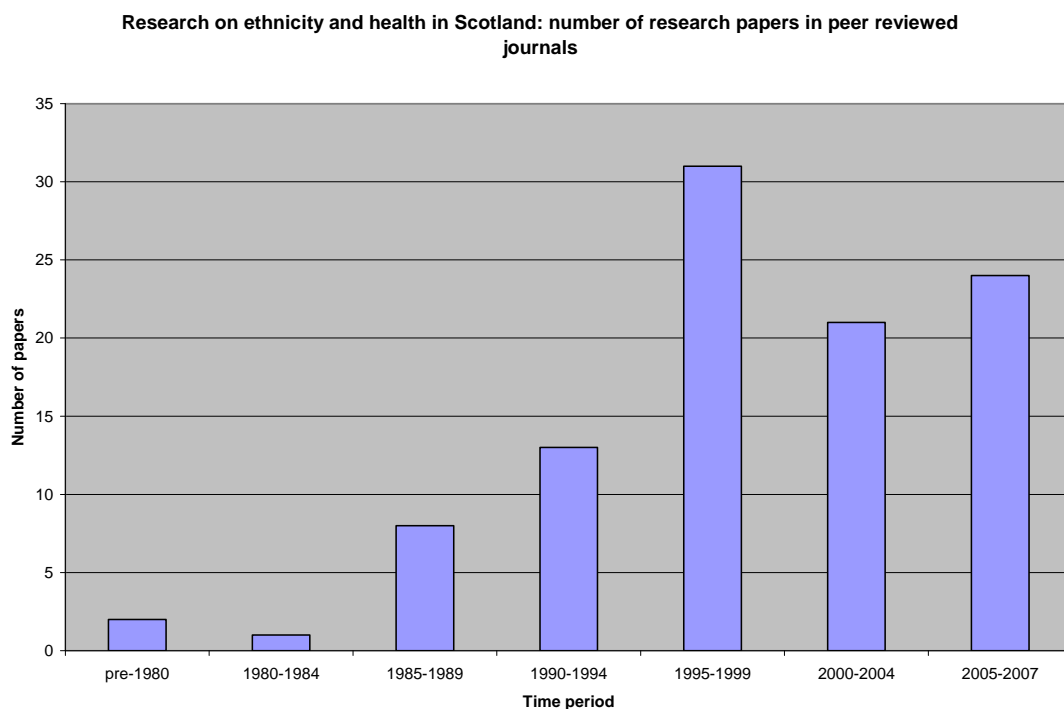
Published research on ethnicity and health in Scotland

Method of research review

3.1 A comprehensive review of health-related research on ethnic minorities in Scotland was conducted as part of the Audit of Research on Minority Ethnic Issues in Scotland from a “Race” Perspective¹². This involved an extensive literature search of electronic databases together with a postal questionnaire of a wide range of organisations. Research was included if it was health-related, involved ethnic minorities in Scotland and was published or completed during the period 1991-2000. For the present report, the literature search was extended to include the periods 1960-1990 and 2001-2007. Details of the search strategy for the updated review are given in Appendix 2.

Types and volume of research and their impact

3.2 With a few important exceptions, the studies of ethnicity and health in Scotland have been mainly small in scale. The choice of topics seems mostly driven by academic interests, local community perceptions of need and the feasibility of collecting data. There has been a preponderance of research involving South Asian communities, with very little on smaller and “invisible” minorities. A relatively small proportion of the total research activity has been published in peer-reviewed journals. Many have been written up as inaccessible local reports or academic theses. Figure 3.1 shows the number of papers on studies of ethnicity and health in Scotland published in peer-reviewed journals between 1965 and 2007. Most of the research upon which these papers have been based has been conducted by six research groups:



Matthew Dunnigan and colleagues at Greater Glasgow Health Board (1965-1985)
Raj Bhopal and colleagues at the University of Glasgow, Department of Public Health (1986-91)

Rory Williams and colleagues at the MRC Social and Public Health Sciences Unit (1992-1999)

Mike Lean and colleagues at the Department of Human Nutrition, University of Glasgow (1995-)

Alison Bowes and colleagues at the University of Stirling 1992-

Raj Bhopal and colleagues at the Department of Public Health Sciences, University of Edinburgh (2001-

The MRC Social and Public Health Science Unit continues to run an ethnicity and health research programme but this concentrates on UK level research .

Main findings of the published research

1960-1985

Rickets and osteomalacia

3.3 Reports published by Matthew Dunnigan and colleagues in 1962 and 1965 showed a high incidence of rickets and osteomalacia in the Glasgow Pakistani Community. This was thought due to inadequate exposure to sunlight and possibly a diet deficient in vitamin D (Dunnigan et al 1965). It was not until 1979 that a campaign was launched to provide children in the Glasgow Asian Community with vitamin D supplements. An evaluation published in 1985 showed a considerable reduction in the total prevalence of rickets compared with pre-campaign levels (Dunnigan et al 1985). Hospital discharges of Asian children with rickets declined rapidly after the start of the campaign. To this day, this is the only example of a successful public health campaign aimed at addressing a specific health problem in an ethnic minority group in Scotland.

1986 to 2000

South Asians

3.4 Raj Bhopal and his colleagues initiated the modern era of ethnicity and health research in Scotland with studies of the use of traditional medicine, reproductive health, dental health and school-age smoking and drinking among South Asians in Glasgow (Bhopal 1986, Firdous and Bhopal 1989, Kay et al 1989, Kohli 1989). Studies by Rory Williams and colleagues comparing a South Asian, predominantly Punjabi, population aged 30 to 40 years with the general population in Scotland revealed that "South Asian men had a number of health advantages including less long-standing diseases than the general population whereas South Asian women were relatively disadvantaged in a number of respects, reporting more chronic conditions (Ecob and Williams, 1991). Those who had been long resident in Glasgow fared significantly worse than those who had newly arrived (Williams et al 1993). Elliott and colleagues found that Asian men in Glasgow had more negative attitudes towards people with AIDS than did White males (Elliott et al 1992). The only established risk factor related to coronary heart disease to which South Asians had less exposure than the general population was smoking. Dietary choices of the South Asian population played a contributory role but did not fully account for the higher rates of CHD. The higher incidence of CHD in South Asian people was thought to result from a complex

interaction of risk factors including insulin resistance, stress and socio-economic circumstances (Williams et al 1994).

South Asians and Italian women

3.5 In a series of studies comparing South Asian and Italian women living in the West of Scotland the following were the main findings:-

Differences in diet exercise and fat deposition were consistent with differences in rates of coronary heart disease. (Williams et al 1996) Traditional family hospitality meals play a more important part in the life of migrant South Asians and Italians than in the general population. In an environment where energy-dense foods are readily available, this pattern of hospitality may result in high energy intake and increased coronary risk (Bush et al 1995, 1998; Williams et al 1996). The traditional diet of South Asian people is generally considered healthy and cardio-protective terms. Surveys of dietary patterns found that South Asians were increasingly consuming high fat Western foods and although aware of the dangers to health were reluctant to change their behaviour (Munday and Oswald 1999). British-born South Asians were found to approximate the general population more closely than recent South Asian migrants in relation to dietary choices, exercise and waist measurement. (Williams et al 1996). However, another study by Williams and Shands (1998) found that young British Asians most of whom were British born were taller than older migrants and reported lower levels of psychological distress, although these levels were a little higher than a comparable non Asian sample (Bradby and Williams 1998). Williams and colleagues (1998) showed that in the 1970s there was not a social class gradient in mortality among South Asian but this appeared to be developing in the 1990 as a standard of living gradient developed in the South Asian population.

Irish

3.6 A substantial body of research on the Irish population in Scotland found differences in mortality between those of Irish decent and others which appear related to socio-economic factors (Williams, 1992, 1993, 1994, 1997). However, no significant differences in health behaviours or in illness behaviour between Catholics and non-Catholics were observed (Abbot et al 1999).

South Asian and Chinese Women

3.7 A number of studies in the 1990 focused on access to and use of health services by South Asian and Chinese women in Scotland. It was found that in general these women were interested in health and keen for support in health improvement. Their inability to obtain their full health carer entitlement appeared more closely related to features of the healthcare system, including racism, than to "Asian culture" (Bowes and Dokomos 1993). A study of almost 500 people of Chinese origin found 50% reported long term illness but GP visits were lower compared with the White population (Xiao-hui Liao and McIlwaine 1995). Many preferred a mix of traditional and Western medicine. Studies of disparate groups of ethnic minorities (Zainal et al 2001) found a great need for interpreting and advocacy services to enable members of these groups to access health services. Other difficulties they faced included the lack of single sex wards, inappropriate catering to meet religious requirement, insufficient female doctors and a lack of knowledge of how to access emergency services.

Communication with health professionals

3.8 Communication with health professionals was seen as a key issue (Bowes and Dokomos 1996 and others). However, Bowes and Dokomos pointed out that the pre-occupation with language problems as the main barrier to communication masks other significant barriers such as the effect of power differentials and the additional factors of racism. They argued that it is important to disentangle the effects of racism from other effects such as gender, class or the power of professionalism. However, racism was seen as “the one clearly distinctive aspect of the relationship between South Asian women and health services” (Bowes and Dokomos 1996(a)).

Travellers

3.9 The disadvantages faced by the Scottish travellers community in accessing health services were described by Lloyd and Moran (1999). This included an inability to register with a health service, the low use of health visitors, the possibility of eviction or removal while pregnant, and low rates of immunisation.

Access to services

3.10 Several studies evaluated the role of particular services or projects. Many of these highlighted the greater difficulties of ethnic minorities in accessing specialist services in relation to specific health conditions. This was attributed to lack of knowledge of existing services and screening procedures and an inability to communicate effectively with general practitioners. A recurrent theme in many studies was the need for effective transmission of health messages through culturally sensitive means. Some studies gave examples of good practice including the use of trained bilingual workers, opening hours which take into account the employment patterns of patients and venues which accommodate the preferences of their users. (Achmed et al 1995; Hampton 1995; Mackintosh 1998; and Rowe 1996).

Mental health

3.11 The mental health needs of minority ethnic people and the evaluation of services to meet these needs have been the focus of many studies (King and Riggs, 1991; Srivastava and Bowes, 1996; Tyrell, 1998; Austin and Munro 1997; Fatunmbi and Lee, 1999; Kaifi et al 1995; Shariff, 2000.). Common themes include: the importance of valuing peoples’ own understanding of mental illness and wellbeing; the need to respect religious or cultural beliefs; the role of social support in preventing psychological distress, the inability of general practitioners to identify a need and make appropriate referrals to specialist services at the early stages of mental illness; the different pathways by which minority ethnic people enter mental health services, a common pattern being entry at crisis point; and the low uptake of mainstream preventative and community based services such as counselling and befriending. Two studies of complimentary therapies and counselling services for Asian people suffering from depression, stress or anxiety found that both services were extremely helpful to users with the confidential and non-judgemental nature of the service being particularly appreciated. (Hampton 2000b; Netto et al 2001).

2001 to 2007

Linking ethnic identity with death certificates and hospital data

3.12 A major difficulty in assessing the health status of ethnic minority groups is the lack of information on ethnic identity in routine health service and death certificates. This problem has been addressed by Raj Bhopal and colleagues. Having successfully addressed issues of patient confidentiality, they linked information on individual ethnic groups from the 2001 census with Scottish hospital discharge and mortality data (Bhopal et al 2006). Using this technique, they linked over 85% of South Asians with hospital discharge and mortality data. They found that the incidence of acute myocardial infarction (heart attack) was higher amongst South Asians than non South Asian men and women but the survival of South Asians was better. This technique opens up new opportunities to compare the health status of ethnic minorities with the majority population (Fischbacher et al 2007).

Diabetes and heart disease among South Asians

3.13 A number of studies have focused on the higher incidence of diabetes and coronary heart disease among South Asians than in the general population. In a study of diabetes care for ethnic minority groups in Scotland, 69% of primary care respondents reported that ethnic group was not recorded by community services and GP's and 80% did not monitor trends of complications of diabetes by ethnic group (Baradan, 2006). A smaller study in five general practices in Edinburgh found Indian and Pakistani patients had complex and ambivalent views about the drugs used to treat their diabetes (Lawton et al 2005). A large study in Glasgow comparing South Asian and European patients with diabetes found that South Asians were younger than Europeans when first diagnosed and had poorer control of diabetes with smaller improvements in blood pressure and cholesterol (Mukhopadhyay et al, 2006). A well-designed evaluation of a cardiovascular risk control project for South Asians (Khush Dil) found modest reductions after six months follow-up in cholesterol, blood pressure and weight (Matthews et al, 2007).

Greater Glasgow surveys

3.14 In 2004, Greater Glasgow and Clyde NHS Board conducted a series of surveys of minority ethnic groups in Glasgow including people of Chinese, Pakistani, Indian, African and Caribbean origins. The findings have been compared with those from a similar general population survey, conducted in 2005 (Greater Glasgow 2005). They have been usefully supplemented by other studies.

Smoking, alcohol and drug use

3.15 There were wide variations in smoking rates. All ethnic minorities with the exception of Pakistani men had much lower smoking rates than the general population as shown in Table 3.1. Smoking rates among female ethnic minorities were particularly low at 4-5%. These survey results should be interpreted with caution. Other studies have shown a high prevalence of use of other tobacco products, particularly in the Pakistani and Bangladeshi communities. Bhopal and colleagues have also shown that questionnaires about smoking may be misinterpreted by the respondents unless they are carefully adapted for use in each ethnic community (Bhopal et al, 2004).

Table 3.1 The percentage of smokers by gender and ethnic group in Greater Glasgow in 2004 (Greater Glasgow 2005).

Population Group	% current smokers	
	Male	Female
Chinese	24	4
Pakistani	36	5
Indian	16	4
African and Caribbean	16	5
General Population	35	32

3.16 Self reported consumption of alcohol was much lower among ethnic minority respondents compared with the general population (Table 3.2). Women from all minority ethnic groups were more likely than men to report never having drunk alcohol.

Table 3.2 Percentage of each ethnic group in Greater Glasgow in 2004 that did NOT drink alcohol (Greater Glasgow 2005)

Population group	% reporting they did NOT drink alcohol
Pakistani	91
African and Caribbean	64
Chinese	63
Indian	57
General Population	30

A report by Heim (2004) found that in general Pakistani young people were much less likely to drink alcohol than their White counterparts, spending more time in religious or family activities. Relatively little is known about drug use among ethnic minority groups although both surveys and data from drug treatment services suggest that problem drug use is at a much lower level than in the White population.

Diet and physical activity

3.17 Around half the Chinese and African and Caribbean respondents, a third of the general population and Indian respondents and a fifth of the Pakistani respondents met the target of at least 5 portions of fruit and vegetables daily (Table 3.3). Women from all ethnic groups were found to eat more fruit and vegetables than men. A smaller percentage of respondents in each of the minority ethnic groups reported eating two or more portions of sweets and/or crisps daily compared with the general population. Among all groups, those aged 16-24 reported a higher consumption of sweets/crisps than other age groups. Respondents in all the ethnic minority groups were less likely to engage in moderate physical activity five or more times a week than the general population. Only 25% of Pakistani respondents said they took moderate exercise five or more times a week. Except for Africans and Caribbeans, the average number of days of moderate activity decreased with age.

Table 3.3 Percentage of each ethnic group in Greater Glasgow in 2004 eating 5 + portions of fruit and/or vegetables daily (Greater Glasgow 2005).

Population group	% eating 5+ fruit/veg daily
Chinese	53
African and Caribbean	47
General Population	34
Indian	33
Pakistani	19

Oral and dental health

3.18 Chinese, African and Caribbean people were more likely than the general population to brush their teeth at least twice a day whereas Indian groups were the same as the general population and Pakistanis less likely. Africans and Caribbeans were most likely to have all their own teeth but least likely to have visited a dentist in the last six months.

Sexual health

3.19 There has been relatively little focus on sexual health with only small scale local studies being conducted. Abstinence from sexual behaviours before marriage was high among young Asian women and moderate among young Asian men. A comparative study of the perceptions, attitudes and sexual health needs of Pakistani, Indian and White secondary school students found sex education was insensitive to the needs of all three groups of children in Glasgow (Mirza 1997). A small study of South Asians with diabetes living in Lothian highlighted the many practical social and attitudinal factors impeding physical activity especially for women. It recommended a realistic and culturally sensitive approach focussing on the kinds of activity patients already do in their everyday lives (Lawton et al 2005).

Asylum seekers and refugees

3.20 A report on asylum seekers in Glasgow described many negative aspects of their experiences in Glasgow, with criticism of the overall dispersal policy and the accommodation they receive. Social isolation, racism, lack of interpreting services and limited health services were highlighted (Green 2006). Mental health problems were common (Ferguson 2002). In a study of socially isolated refugees in Edinburgh over half had symptoms compatible with a diagnoses of anxiety disorder and 40% with a diagnoses of depression (Ager 2002). Although likely to be a biased sample, the study provides useful pointers to refugees' experience and the scope for supportive action. A study in Greater Glasgow involving 113 asylum seekers and refugees living in north Glasgow found that by far the biggest health issue was the high prevalence of mental health problems, with traumatic experiences before migration being compounded by their circumstances in the United Kingdom. This study provides useful insights into the experiences and needs of a heterogeneous group of many nationalities who share the status of being asylum seekers or refugees.

Major Gaps in our Knowledge about Ethnicity and Health in Scotland

3.21 Whilst this review shows that we have some knowledge about various health-related aspects of life for ethnic minorities in Scotland, there are a number of areas where far too little is known. The working group has highlighted the following:

- Because ethnic identity is not routinely recorded on GP records, hospital discharge records, death certificates and other health related data, remarkably little is known about the actual health status of minority ethnic groups in Scotland. What is known is summarised in Chapter 4.
- Research attention has focused on illnesses which are more common among ethnic minorities, notably cardiovascular disease and diabetes among South Asians, with very little attention to major illnesses such as cancer and cerebrovascular disease (stroke) which are also common in ethnic minority groups.
- Little attention has been paid to evaluating the effectiveness of health promotion strategies delivered by mainstream statutory organisations to ethnic minority groups.
- Very little research has been undertaken to evaluate the appropriateness and effectiveness of statutory mental health services for minority ethnic communities.
- Few of the findings from this body of research have been acted upon. Until recently, there had been only one major intervention – preventing rickets in Glasgow – specifically aimed at addressing a health problem in an ethnic minority in Scotland. The campaign started 17 years after the problem was first recognised.
- Even when data are available, little effort has been made to analyse them from an ethnicity perspective, for example using country of birth.

Chapter 4

What is known about the health status of ethnic minority groups in Scotland?

4.1 This chapter examines in more detail the information we currently have about how the health of ethnic minorities in Scotland compares with that of the population as a whole. For a nation with powerful laws and policies, and positive attitudes towards promoting equity in relation to the health and health care of its ethnic minorities, the answer to the question posed by the chapter's title is surprising. At the national level, we know very little, and, in one or two cities, a modest amount.

4.2 The key measures of health status at a national level are: mortality patterns; morbidity patterns and measures of health through surveys of both self-reported and examined health such as the Scottish Health Survey. Large quantities of health-related data are routinely collected by a range of agencies and can be used to describe the health of the population. These include birth and death certificate data; hospital admissions; cancer registration data and laboratory results; screening and immunisation data. However, in most cases, information about the subject's ethnicity is not known and therefore these sources are unusable for describing the health of ethnic minorities and comparing this to the rest of the population. Unless the recording of ethnicity in routine data can be substantially improved, much crucial information about the health of ethnic minorities will be difficult or impossible to obtain.

4.3 Bhopal and colleagues reviewed the potential for assessing the health status of ethnic minorities using Scotland's internationally renowned health databases. They concluded that these databases were either not useful or had not been used for this purpose. They proceeded to develop ways of extracting some value from these databases - by name searching, country of birth analysis, modelling and data linkage. The results are summarised and discussed below in the wider context of the question posed in the chapter's title.

Analysis of routine data

Patterns of Mortality

Ethnicity

4.4 The death certificate does not record ethnicity so direct analyses by ethnic group are impossible. This, arguably, needs to be rectified. Bhopal and colleagues have shown that ethnic codes on the census can be linked to the death certificate by probability matching techniques, with acceptable levels of accuracy and completeness (The Retrocoding Project: Fischbacher et al 2007). The analysis done so far shows survival after a heart attack is better in South Asians in Scotland than in the rest of the population. This finding reflects the very high mortality in the White Scottish population. Ethical approval has been given to proceed to Phase 2 of the project in which ethnicity and mortality will be studied in relation to cardiovascular disease, cancer, maternal and child health and mental health.

Country of Birth

4.5 Country of birth is on the death certificate, as provided by the informant. This is also collected in the census as provided by the person completing the form on behalf

of the household. This information can therefore be used to calculate mortality rates by country of birth. However, errors may arise from a mismatch between the information from the census and on the death certificates. There are a number of other problems with country of birth analyses discussed by Bhopal (2007). For example, in the first half of the 20th century a relatively large number of White Scottish people were born abroad because of Scotland's major role in the British Empire and the missionary movement. As result, among people aged over 70, living in Scotland now but born in India, most are White and only a minority are of Indian ethnic origins. Despite these problems, country of birth analyses have provided interesting and useful, because for relatively recent immigrant populations, especially for the older age groups (where most deaths occur) country of birth and ethnic group correspond fairly well, at least in England.

4.6 The Scottish all-cause mortality results by country of birth are presented in Table 4.1. They 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 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. Table 4.2 compares people living in England with Scottish residents, according to where they were born. It focuses on people dying of coronary heart disease aged 25-69. This shows that women born in Scotland, Ireland, India and Pakistan had significantly higher death rates from coronary heart disease than women living in England. Similar results were found for men. The results show both that younger people living in Scotland appear to have higher rates of coronary heart disease than people living in England but that within Scotland there are important ethnic differences. These patterns are unlikely to be explained by data errors.

4.7 The key message from the all-cause mortality analysis is that the highest rates are in those born in Scotland and the Republic of Ireland and that 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.

Patterns of Morbidity

Hospital Data

4.8 *Ethnically Coded data.* Although the Scottish Morbidity Record (SMR01) of hospital admissions has an ethnic group variable and hospital staff are recommended to complete it, it is only available on about 5-10% of records, rendering it, at present, useless for studies by ethnic group.

4.9 *Linked data.* Fischbacher and colleagues (2007) have shown that census ethnic codes can be linked to the SMR01 database for admissions to Scottish hospitals. Analysis was done for acute myocardial infarction. Compared to the remainder of the population the incidence of acute myocardial infarction was about 70% higher in South Asians. This analysis has shown the value of the work done and its potential for phase 2 (See 4.4).

Table 4.1 Observed and expected deaths among Scottish residents (25 years and older) from all causes for 6.25 years (Jan 1997 – Mar 2003), by country of birth and sex, with standardised mortality ratios (95% confidence interval) using death rates among those born in Scotland as reference. (Fischbacher et al 2007)

Country of birth	Observed	Expected	SMR	95% confidence interval	
Women					
<i>Scotland</i>	171488	171488.0	100	100	100
UK (other)	12827	15634.1	82.0***	81	83
N. Ireland	1336	1429.5	93.5*	89	99
R/ Ireland	1716	1687.9	101.7	97	107
India	419	430.9	97.2	88	107
Pakistan	110	155.6	70.7***	58	85
Bangladesh	5	11.3	44.1	14	103
China	71	95.3	74.5*	58	94
Hong Kong	93	108.0	86.1	69	105
Rest of the world	2760	3332.1	82.8***	80	86
Men					
<i>Scotland</i>	152456	152456.0	100	99	101
UK (other)	11889	15765.8	75.4***	74	77
N. Ireland	1204	1200.6	100.3	95	106
R/ Ireland	1507	1393.4	108.2**	103	114
India	473	535.3	88.4**	81	97
Pakistan	171	271.6	62.9***	54	73
Bangladesh	9	20.7	43.6**	20	83
China	67	93.0	72.0**	56	91
Hong Kong	103	148.5	69.3***	57	84
Rest of the world	3325	3848.0	86.4***	83	89

(*) Two sided $p < .05$ (**) Two sided $p < .01$ (***) Two sided $p < .001$

Table 4.2 Observed and expected deaths among Scottish residents (25 – 69 years) from coronary heart disease for 6.25 years (Jan 1997 – Mar 2003), by country of birth and sex, with standardised mortality ratios (95% confidence interval) using death rates from England and Wales as reference (Fischbacher et al 2007).

Country of birth	Observed	Expected	SMR	95% confidence interval	
Women					
<i>Engl/Wales(ref)</i>	38017	38018	100	99	101
Scotland	5466	3526	155.0***	151	159
UK (other)	282	317	89	79	100
N. Ireland	36	25	143.2*	100	198
R/Ireland	54	33	165.6***	124	216
India	23	11	209.8**	133	315
Pakistan	19	7	258.4***	156	404
Bangladesh	2	0	741.8	90	2680
China	1	2	50	1	279
Hong Kong	3	3	88	18	257
Rest of the world	66	68	96.8	75	123
Men					
<i>Engl/Wales(ref)</i>	118464	118462	100	99	101
Scotland	13944	10255	136.0***	134	138
UK (other)	967	1045	92.6*	87	99
N. Ireland	111	75	148.4***	122	179
R/Ireland	100	76	131.7**	107	160
India	61	44	137.8*	105	177
Pakistan	49	31	159.9**	118	211
Bangladesh	1	3	37.7	1	210
China	3	6	48.5	10	142
Hong Kong	8	16	51.3	22	101
Rest of the world	209	182	114.7	100	131

(*) Two sided $p < .05$ (**) Two sided $p < .01$ (***) Two sided $p < .001$

Cancer Registration Data

4.10 As with hospital admissions, ethnicity recording is very incomplete - around 18%. Country of birth is not held. Consequently, it has not yet been possible to make comparisons of cancer rates between ethnic groups. This is a serious limitation. The potential for linkage and the value of the information so obtained is part of the Phase 2 of the Retrocoding Project.

General Practice Data

4.11 There are no national analyses in Scotland (unlike England) by ethnic group of general practice or other primary care databases. Ethnic coding of general practice databases is starting but it is likely to be many years before useful statistical information emerges. In the meantime, exploration of the potential for linkage is urgent.

Other Data

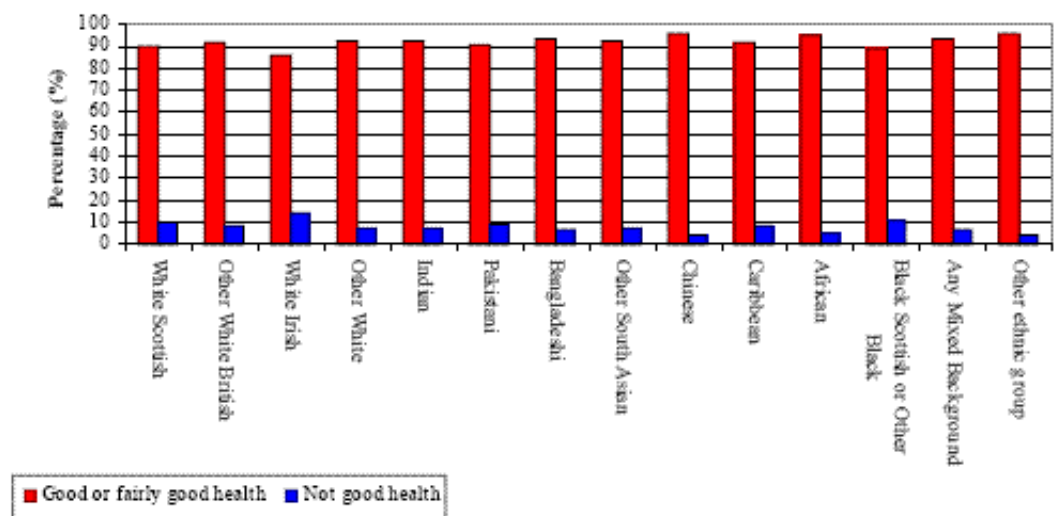
4.12 Some disease registers include ethnic data. For example, the Scottish Diabetes Register has an ethnic code on 60% of records. Other major data sets either hold no or very few data on ethnicity. The potential for retrospectively adding an ethnic group indicator has seldom been explored. An attempt to examine immunisation by ethnic group (by a medical student) did not yield reliable outputs.

Population surveys

Census

4.13 The census contains data on ethnicity, religion and country of birth. Unfortunately, the only information collected about health is on limiting long-term illness. The results show substantial variations between ethnic groups. The cross-cultural validity of such self-reported data is unknown. An example of data available is shown in the Figure below.

Chart 4.1: General health by ethnic group - All People



Scottish Health Survey and other surveys

4.14 This survey collects ethnicity data but there is no targeting of ethnic minority groups. As a result, the number of people from minority ethnic groups is too small to allow any meaningful analysis. There is no special effort to ensure cross-cultural validity of questions and measurements. This needs to be assessed more systematically, particularly to see whether data from the three surveys done so far can be combined. A survey with a boosted sample – as done in England in 1999 and 2004

– is long overdue. The Scottish Adolescence Lifestyle and Substance Use Survey (SALSUS), with a sample size of 22,000 in 2002 was large enough to permit a limited analysis of South Asian pupils only. There is a lack of usable ethnicity information in surveys such as the Scottish Household survey, the Health Education Population Surveys and the surveys of young people's behaviour.

Local work

4.15 As discussed in Chapter 3, a significant amount of research and health survey work has been done in health boards, cities and areas within cities. Most has been done in and around Glasgow. This work has been characterised by its sporadic, ad-hoc nature. While some important insights into health related knowledge, attitudes and behaviour have been gained, very little has been learned from these sources about the actual health status of ethnic minorities and how this compares with the majority population. Much of the work is not published in a way, or at a standard, that leads to generalised benefits. A small fraction has been of national or international significance.

Conclusions

4.16 Until now the picture of the health status of ethnic minorities in Scotland has been very sketchy, but there are signs the situation is improving a little. By the end of 2009, the Retrocoding Project should produce results for mortality and hospital admissions in relation to cardiovascular disease, cancer, maternal and child health and mental health. There are positive developments in the ethnic coding of diabetes registers. However, unless a means can be found consistently to record ethnicity in primary care and hospital databases and on death certificates, our ability to assess the health of ethnic minorities in Scotland will remain extremely limited.

Chapter 5

Future research on ethnicity and health in Scotland

Ethics and methods

5.1 The aims of this chapter are

1. to provide a set of clear principles for the conduct of research on ethnicity and health in Scotland;
2. to describe the main research methods that can be used, highlighting their strengths and weaknesses.

Ethical principles

5.2 Used wisely, research on ethnicity has the potential to improve public health, health care, clinical care and medical science. However, history has shown that used unwisely it can be harmful. Careful attention to ethics – widely accepted principles of right behaviour - is thus essential. In addition, if the methods used to conduct research are flawed, the results can be at best unhelpful and at worst positively misleading or damaging.

5.3 The conduct of research in the United Kingdom is already governed, implicitly if not explicitly, by a set of widely accepted ethical principles. These therefore do not need to be reinvented for research on ethnicity and health. However, it is important to consider the particular issues that relate to ethnicity which might require changes in their emphasis or application. There are seven ethical principles that we propose should underlie all research on ethnicity and health.

5.4 **Do no harm.** This is perhaps the most important principle for research on ethnicity and health. Simply expressing the concept of ethnicity draws attention to differences, potentially magnifying their importance. These differences can be used in damaging ways. Researchers and practitioners need to be sensitive to wider events: for example, the influence of religious or political extremism on attitudes towards certain ethnic groups. In the past, racist attitudes have permitted ethnic groups to be subject to harmful research (for example, the infamous US study of the natural history of syphilis among African-Americans); or research has been conducted which has been used to perpetuate racist stereotypes (for example, that certain races are less intelligent than others). Researchers should be aware of the potentially adverse outcomes that could take them further away from the goal of health improvement. They have a secondary duty linked to the primary one of gaining and using knowledge—to foster an atmosphere of equality, justice, tolerance and sensitivity.

5.5 **Do good.** This lies at the heart of public health, medicine and all health professions. Unfortunately, the intention to do good does not always lead to good outcomes. Furthermore, health and health care interventions are not usually implemented in a climate of undiluted good intentions and there are often if not always conflicting social, political, commercial and other motives that can get in the way. In particular, good intentions towards minority ethnic groups are by no means universal. Doing good in this context - researching and then using the research to improve the health and health care of ethnic minority groups - requires special efforts, and a struggle against lack of knowledge, information, expertise, leadership and resources. This principle of doing good is, in the long term, more powerful than

even legislation and policy, for it should be an ingrained part of every health professional's attitude and training. Unless the principle of doing good is in place, it is possibly better not to draw attention to ethnic differences. If it is, the challenges are worth tackling.

5.6 Respect. Respecting and understanding others is often not easy. It requires both tolerance of and an interest in others, a wish to learn about them, and an active effort to perceive their world view in a positive light. Research informed by a sense of respect for and a wish to understand others can enable the wider community to benefit from learning about the advantages enjoyed by ethnic minorities as well the disadvantages they may endure. Examples include the impressive educational achievements of many Chinese and Japanese children, the low levels of psychological stress in Bangladeshis in East London despite economic deprivation, the continuing low prevalence of smoking amongst Sikhs and South Asian women, and the low levels of coronary heart disease in African-origin men. There are also other values that may exist in ethnic minority communities which may bring health benefits, for example, practising religion on a daily basis, close-knit families, traditional health care, herbal remedies and systems of health such as yoga. There may be much to be learned from practices that may be portrayed negatively by the media, for example, arranged marriages.

5.7 Autonomy The autonomy of ethnic minority populations to live in their own traditional way is not easy to achieve in multi-ethnic societies. Compromises are essential. Tensions have arisen on matters such as Sikhs refusing to wear helmets while motorcycling, the lack of organ donations from some ethnic minority populations, the larger family sizes of some ethnic minority groups because of positive attitudes to children and negative ones to contraception and pressure exerted on young people by the family in favour of arranged marriages. These are a few examples of cultural issues that relate to public health and health care. Researchers inquiring into such contentious areas need to be aware of the potential sensitivities if they challenge or are perceived to challenge the rights of ethnic groups to maintain deeply rooted cultural traditions.

5.8 Justice, fairness and equality. Good justice is fairness that is built into social structures. The importance of justice to the ethnicity and health agenda is great. In the modern era in many countries justice requires that people are treated equally. In most modern societies, it is seen as unfair, unjust and in some places illegal to deliver a service, knowingly or unknowingly, to one racial or ethnic group that is either superior or inferior to that delivered to another group. By the same token, research on ethnicity and health should seek to avoid the injustices of the past where certain groups have been subjected to research that has not been in their best interests or, at the other extreme, where the absence of research means that significant health inequalities and unfairness remain invisible. The Scottish Government's strategy for ethnic minority health is aptly called Fair for All, a title that has been extended to the wider diversity agenda embracing inequalities in gender, sexual orientation, disability and other grounds for potential discrimination. This laudable strategy needs to be carried through into research.

5.9 Inclusivity and participation. Alongside the general principle that research should do good is the specific imperative that some populations, ethnic minorities being an example, should not be excluded from research. Minority groups that are relatively small in number and/or widely dispersed within the majority population create many challenges for research. They may simply be forgotten; they may be excluded on the grounds that recruiting sufficient numbers would make the study too expensive; or their inclusion may be in such small numbers that no reliability can be attached to the findings. Generally speaking, it is thus easier to exclude than include. Ethnic minority groups have been largely bypassed in the larger scale and expensive kinds of research such as trials and cohort studies.⁵ Thus, if ethnicity is to be treated as an important issue in health and health care research, the principle of inclusion needs constantly to be reinforced. As described in Chapter 6, the United States has been leading the world in this respect, enshrining in law an obligation on researchers to ensure that ethnic minorities are included in research unless there is an over-riding reason for not doing so. Scotland needs to follow. But inclusion alone is not enough. Unless ethnic groups have the opportunity to participate meaningfully in the research process, researchers are less likely to achieve a research design that can uncover the truth or to engage the cooperation of sufficient numbers of participants for the results to be representative of the group as a whole. Inclusion and participation are thus crucial pre-requisites for good research on ethnicity and health. However, upholding these principles does not come cheap, as it requires more resources and effort than would otherwise be the case.

5.10 Informed consent and confidentiality The Nuremberg Code emphasises the principle of informed consent and is an excellent starting point for use with ethnic minority populations. Indeed, the code was designed to prevent a repetition of the abuses by Nazi scientists of ethnic and other minorities. All potential participants in research need to have sufficient information about the research to decide whether or not participation is in their best interests. Equally, participants need to have confidence that their personal data will not be misused. However, ethical codes on confidentiality and informed consent may need modification. If a potential participant does not read, it is unethical to use only written materials as the initial form of communication. It may even alienate such persons by pointing to their illiteracy, and hence belittling them. It may be ethical to telephone or even call at the doorstep of such a person, an approach that ethics committees may frown upon, because it is considered a greater infringement of privacy than a letter. The right to be invited in an appropriate manner needs to be balanced against the right to privacy of personal data such as a telephone number. Informed consent may be difficult to gain or to record in writing: using a video or audio recorder to record consent may be a practical alternative. Where this is not possible, a witness may need to confirm oral consent. A thumbprint should be considered as a time-honoured alternative to a signature. Ethical codes should also consider research in cultures where it is most common for the head of the household or the whole family to decide on participation. Thus individual informed consent is not always the only and best way forward - although it is an essential component of the process of informed consent.

Methodological issues

5.11 Research is only likely to provide accurate and credible answers to the questions it addresses if it employs appropriate, tried and tested methods. The main

methods used to conduct research on ethnicity and health are no different from those used in health and social research in general. However, there are some particular features of ethnic minority groups which have an important impact on the use of these methods and the validity of the results. Table 1 summarises the strengths and weaknesses of a number of methods of research in the context of ethnicity and health. Sometimes there will be a need for a mix of methods and designs. More detailed consideration of these methods and their uses in research on ethnicity and health can be found in Bhopal (2007), Chapter 9 and Nazroo (2006). A recommended general textbook on health research methods is by Bowling and Ebrahim (2006). What follows highlights some of the key issues relating to research methods which need to be addressed if useful, high quality research on ethnicity and health in Scotland is to be achieved.

Quantitative surveys among ethnic minorities

5.12 A questionnaire survey of a population sample is the standard method for obtaining information about the knowledge, attitudes and behaviour of the general population or subgroups of it. In order for the findings from the sample to be generalisable to the group from which it is drawn, the sample should satisfy the following requirements:

- the sampling method, the number in the sample and response rate are such that respondents are representative of the population from which it is drawn;
- the questions used are understood by the respondents
- the answers are objectively judged to be of acceptable validity i.e. they are a true reflection of reality.

When it comes to satisfying these requirements for ethnic minorities a number of conditions need to be met if the research results are to be reliable.

5.13 *Classifying the population of interest* As discussed earlier, defining ethnicity is a complex issue and creating an ethnic minority classification that is universally accepted has proved elusive. Even once a classification is agreed, assigning individuals to the appropriate categories can be difficult. Future research in Scotland should as far as possible use a standard classification of ethnic identity. We currently **recommend** using the classification developed for the Scottish census.

5.14 *Sampling* There are several ways of sampling ethnic minority groups but all have drawbacks. These include random sampling, sampling people using a service or using more informal networking to find people. A common method, particularly for small scale work is to use the register of a community organisation. Where the ethnic minority of interest represents a small proportion of the population, a truly random sample can yield few people in that group. Selecting ethnic names can work for some groups but not others. Service sampling and more informal methods have all been successfully used but, as they are non-random, run the risk of creating a sample that is unrepresentative of the ethnic group as a whole.

5.15 *Sample sizes* A survey may focus on one or more ethnic groups. How far this will be possible will be limited by sample size requirements and the level of funding for the survey. In practice, this tends to lead to a focus on the most populous ethnic groups. Even then, because they make up a small percentage of the population,

special techniques to boost the numbers are usually needed to ensure that the sample sizes are large enough for statistically valid comparisons to be made. If this is not done the findings can be seriously misleading and the research devalued. We therefore **recommend** that all quantitative studies involving ethnic minorities should ensure that the expected sample sizes will be sufficient to validate the intended analyses.

5.16 *Response rates* In practice these can vary from one ethnic group to another with some being typically higher and some lower than those obtained from the general population. For some ethnic groups, cultural constraints can make it difficult to obtain data from women. Acceptable response rates are typically considered to be above 60-70%. Findings based on lower response rates are of questionable value as they cannot be seen as reliably reflecting what would have been found if the whole sample had been involved.

5.17 *Questionnaire content* 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. Some questions, for example on sexual behaviour or substance use, may not be acceptable in some cultures; some, for example on diet, may need to be modified according to the ethnic group. Bhopal and colleagues have done much to identify the challenges of adapting questionnaires for use with different ethnic minorities and how these can be overcome (Hanna et al 2004, 2008). This has included developing guidelines for adapting questionnaires into different languages and guidelines for cross cultural validity to try to overcome the issue of discrepancies between surveys. Their recommendations are given in the box below. A considerable amount of additional work may be required if it is to be done adequately. If not, however, the validity of the results may be seriously diminished. We therefore **recommend** that in future Scottish research involving more than one ethnic group or language, all standardized questions and their translations are prepared with the help of interpreters and validated before use in the field.

5.18 *Data analysis* When it comes to analysis, if comparisons are being made between ethnic minorities and the general population, 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.

Guidelines for adapting questionnaires into different languages to improve cross-cultural validity (Hanna et al 2008).

Panels of bilingual people translate questionnaires into the target languages. As there are several ways to translate the panel members, the panel members negotiate a best fit.

As bilingual people may not be representative of the target population because of education, age and in some cases, sex, the people who are monolingual in the target languages assess meaning and acceptability of the translations and the appropriateness of the response options and instructions and modification are made

Field testing of the resultant questionnaire is done to check face and content validity; further changes are made

Where there has been translation into more than one language, each language version is compared with every other to ensure comparability; this may lead to further adjustment of the items

Test of criterion and construct validity, reliability and responsiveness are carried out in the target languages

Qualitative research among ethnic minorities

5.19 Qualitative research has been extensively used in research on ethnicity and health. This is an approach which seeks to achieve a better understanding of people's perceptions and experiences by conducting more extensive interviews with relatively small numbers of subjects. Researchers can explore complex issues to a depth not offered by structured questionnaires and can enable the participants to express themselves in their own words. Interviews are conducted either with individuals or with small groups (often called focus groups), typically led by a facilitator. The interviews are usually less structured than survey questionnaires and the subjects' words are often recorded verbatim. Individual interviews and focus groups generate different material and both can provide important insights not obtainable by other means. However, because they typically involve small numbers of people, the results can be unrepresentative. The information obtained can be difficult and time-consuming to analyse systematically due to the voluminous and unstructured nature of the data. There is also a risk of over-interpretation of the data, particularly as there is often no control group for comparison. The range and value of the findings from focus groups can be limited by the emergence of a group ideology or an opinion leader.

Evaluating interventions

5.20 Evaluating the impact of interventions is difficult, even when it is a specific action such as giving a drug to treat high blood pressure or an infection. Studying this type of intervention usually requires the complexities and expense of a randomised, double-blind, placebo controlled trial. Evaluation of the effects on ethnic minorities of more complex interventions such as laws, policies, strategies or community-based interventions can be much more challenging. Nevertheless unless it is done, and done well, it can never be reliably known what the effect of the intervention has been. The type of question to be asked is: "Is this activity benefiting our society, and the ethnic minority groups within it and are the costs justified by the benefits?" Answering the question will typically require a mix of approaches including monitoring of health and related conditions, and both observational and experimental data on specific interventions. 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 (Dunnigan et al, 1985) and the Khush Dil cardiovascular prevention project (Matthews et al 2007). The evaluation of a diabetes prevention intervention is underway (Bhopal et al 2007). A recent literature review by

Netto et al has highlighted the worldwide dearth of studies of health promotion interventions involving ethnic minorities (Netto et al 2008).

Conclusions

5.21 Research involving ethnic minorities should comply with ethical principles relevant to all research involving human subjects. Specific issues need to be addressed if harm is to be avoided. These include avoiding the perpetuation of racist stereotypes; treating members of ethnic minorities and their traditions with respect; and ensuring that ethnic minorities are included in research. How informed consent is obtained may need adaptation in some circumstances.

Whilst standard research methods should be employed, a number of specific issues are relevant to research involving ethnic minorities. These include the lack of information about ethnic identity in current routine data sources; the challenge of obtaining sufficiently large and representative population samples; and the need to ensure that the concepts and meaning of questions are understood and culturally appropriate. There is a dearth of evaluations of interventions involving ethnic minorities. All these issues will need to be addressed if the contribution of research to the health of ethnic minorities is to be increased.

Table 1 Strengths and weakness of a number of methods of research in the context of ethnicity and health (Bhopal 2007)

Method	Strengths	Weaknesses
Literature review	Quick, brings experience from all over the world, cheap	Often no or weak literature by ethnic group for many topics; much work is unpublished or difficult to obtain; may be published in reports; may be in languages other than English so adding translation difficulties and costs; hard to generalise between studies because of different contexts and terminology; and may lead to biased conclusions and recommendations.
Systematic review	As above, except that it is much more time-consuming, but in return this ensures work is comprehensive and minimises biases	As above, and synthesis may be impossible for lack of work; lack of clarity in concepts and terminology; and heterogeneity of populations or study methods.
Meta-analysis	Permits quantitative synthesis of key outcomes and relations between risk factors and outcomes	As above and may not be reported in a way that permits synthesis of questionnaire data; and getting hold of original data may prove too difficult because researchers are scattered and not organised into cooperative groups.
Case reports	Rapid highlighting of issues for fuller investigation	Likely to be on rare and obscure or exotic issues e.g. a case report is not going to be on lung cancer but may be on lead poisoning.
Clinical series	As above, but brings together experience of a clinician. Rapid publication of admittedly selective statistics on large populations; gives overview of a clinical problem	As above, but more likely than a single report to be on matters of central importance.
Population case series	As above but the series is of all the known experience in a defined area and population so less biased.	The statistical summary is often not by ethnic group (for lack of ethnic coding); the information is limited; errors such as numerator/denominator mismatch.
Case-control studies	Feasible at reasonable cost and timescales, particularly when based in places where ethnic minority populations are large	The number of cases (outcomes) of interest may be too small, particularly for studies of incident as opposed to prevalent cases; problem of identifying cases and controls by ethnic group in the absence of ethnic coding; recall bias may be great and medical records may be incomplete for recent migrants in particular.
Cross-sectional studies	The most feasible design for new research and best for burden of risk factors and common disease	Needs a sampling frame so representative samples can be identified – there lists are not usually ethnically coded; response rates may not be consistent across ethnic groups.
Cohort studies	Excellent for measuring incidence rates, survival and risk-factor outcome relationships.	Need to be large, long-term and so are very expensive. Hard to set up and maintain. Experience in such work is very limited worldwide.
Trials	The definitive method for evaluation of drugs, services and public health interventions, especially if it is the placebo controlled, randomised design.	For legal and ethical reasons trials are even harder to set up than cohort studies but otherwise have similar weaknesses. Multi-ethnic trials designed to compare effects by ethnic group are virtually unknown, with only two or three reported – all from the USA. The theoretical basis and need for such studies has not been agreed and is

		under intense debate.
Genetic studies	These are necessary to quantify what we already know – that health states arise mostly from gene-environment interactions. The large family size and close family links (including consanguinity in some populations) makes ethnic minority populations attractive for such work.	The techniques are evolving and the ideas are unfamiliar to all populations but particularly ethnic minority groups. There is the danger that these studies will focus on specific issues and stigmatise ethnic minority groups.

Chapter 6

Priorities for future research in Scotland

6.1 In this chapter, we make a series of proposals for action we consider is needed if useful research on ethnicity in Scotland is to be fostered. We then suggest what the future research priorities should be.

6.2 Until now, although the Scottish Government has promoted research on ethnicity and health, little practical action has been taken. There continues to be no requirement upon health researchers to include ethnic minorities in their studies.. Research so far undertaken has thus been largely dependent upon the initiative of researchers with a special interest in this area or on the promptings of ethnic groups themselves. As is seen in Chapters 3 and 4, the consequence is that both the range and quality of completed research have been patchy and our understanding of the health status of ethnic minorities in Scotland is poor. In some respects health status is likely to be better, in some respects worse. The limited evidence from Scotland is in contrast to the much larger body of information from England. This is unsatisfactory.

6.3 Given the Scottish Government's commitment to making Scotland both healthier and fairer, and the principles set out in Fair for All, a strong underlying commitment to treating ethnic minorities as equal members of the Scottish population would appear already to exist. How can such a commitment be put into effect in a way that safeguards and ideally enhances the health and well-being of ethnic minorities in Scotland? An essential pre-requisite is for there to be a good understanding of what it means to be a member of an ethnic minority both in terms of health risks and status and of the experience of access 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. How this can be made to happen is illustrated by developments in the United States and England.

The example of the United States

6.4 In the United States, the National Institutes of Health, the main body responsible for funding and coordinating biomedical research, has had a clear policy since the 1993 Revitalisation Act, implemented in 1994. This makes it a legal requirement for all clinical research studies to include members of minority groups and their subpopulations unless there is a compelling justification to do otherwise¹³. There is evidence that the impact of this legislation has been substantial. A recent review of 72 North American and European cardiovascular cohort studies found that 15 were either designed to compare White and non-White populations or focused on one non-White ethnic group: all were American (Ranganathan and Bhopal 2006).

UK Department of Health

6.5 The UK Department of Health in its Research Governance Framework for Health and Social Care makes the following statement: *Research, and those pursuing it, should respect the diversity of human society and conditions and the multi-cultural*

nature of society. Whenever relevant, it should take account of age, disability, gender, sexual orientation, race, culture and religion in its design, undertaking, and reporting. 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 any legal teeth or resources to support it, it is unclear whether this injunction has had any effect to date.

6.6 In 2003, the UK Department of Health set out more detailed guidance for its own research commissioners in the form of a four point action plan for:

- developing the evidence base on ethnic inequalities in health and well-being, in access to treatment, and in outcomes of care
- ensuring appropriate coverage of ethnic groups in all research
- ensuring appropriate representation of minority ethnic groups in R & D project and programme steering and advisory structures
- and improving representation of minority ethnic communities in the R & D workforce.

We **recommend** that similar undertakings are made by the Scottish Government.

Policies of other bodies

6.7 We found little evidence that relevant research institutions in the United Kingdom had policies which actively promoted research related to ethnicity. The National Research Ethics Service does not offer any specific guidance and the Research Ethics Framework of the Economics and Social Research Council refers only to ethnicity as an issue which requires to be addressed with care and sensitivity. Neither the Medical Research Council nor the Wellcome Foundation have a published policy although we were told the MRC is developing one.

Priorities for future research in Scotland

6.8 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.

Priority 1: Good ethnic coding

6.9 In Chapter 5, we described how the lack of ethnic coding in Scotland's main health-related databases meant that the health status of ethnic minority groups relative to the population as a whole could not be properly assessed. Unless people's ethnicity is recorded on or can be linked to routine data systems such as birth and death registers, hospital discharge forms or GP medical records, it is never going to be possible to explore the relationship between ethnicity and health as we do for age, gender and place of residence. Without this information it will not be possible to know accurately whether certain ethnic groups are more at risk of certain conditions and therefore need more attention or help, or, conversely they have lower risk and therefore may offer pointers to how better health in the wider population can be achieved. Without this information, we will forever be limited in scope to ad hoc studies of relatively small and often unrepresentative samples.

6.10 In the view of the working group, the top priority for future ethnicity and health research in Scotland is therefore the creation of a system that ensures consistent ethnic coding within Scotland's generally excellent health information systems. This will require an energetic, proactive approach to ethnic coding, led by the Scottish

Government. The goal will need to be declared a priority within NHS Scotland and key individuals will need to be held accountable through performance assessment. For example, if the completeness of ethnic coding was part of performance management targets (eg HEAT) NHS Scotland would make faster progress. Progress could be evaluated through board accountability reviews.

6.11 Although there is the opportunity for doing so, Scottish NHS Boards do not at present insist on ethnic coding of data on, for example, hospital discharges. Consequently, the proportion of cases where this is done is generally very low and averages across the country at 8-9% in Scotland. However, rates vary enormously, being only 1% at Edinburgh Royal Infirmary but 70% at the Royal Edinburgh Hospital, the latter showing it can be done. Rates have been rising fast in the Edinburgh Sick Children's Hospital. There has been recent work by the Scottish Health Council, asking boards about data on ethnicity, but the response has been slow.

6.12 In this respect, England is well ahead of Scotland, with 70-80% of hospital admissions now being ethnically coded. This did not happen overnight however. The first Department of Health letter urging ethnic coding of hospital admissions was issued in 1991 and ethnic coding became compulsory in 1995. It was only in the last two to three years that rates have improved following extensive negotiations. We need to follow England's example.

6.13 Systems for recording this information should be as simple as possible. Ideally information about ethnic identity should be held on the Community Health Index (CHI) database (or its eventual replacement). CHI is a unique number which is given to every NHS patient in Scotland and which is already linked to the individual's date of birth and gender. Thus, whenever the CHI number is linked with other information, for example about a hospital admission or a visit to a GP, it could be automatically linked to ethnic identity. As achieving this will take time, in the short-term, patients should be routinely asked about their ethnic identity whenever they are admitted to hospital or registered for a new hospital clinic appointment.

6.14 A clear plan of action is needed to make the achievement of high recording rates a priority throughout the NHS. For this to happen, two main conditions need to be satisfied:

- Patients need to be confident that they are providing information about their own ethnic identity to help plan and provide better care for all and that the information will not be used in any way that could harm themselves or others.
- Everyone who collect information on patients should understand that they should ask patients about and record their preferred ethnic identity. This will normally require looking at a standard list and indicating which category they think they best relate to.

6.15 We thus **recommend** that the Scottish Government develops an action plan with the aim of ensuring that by 2013 at least 80% of people registered with the NHS have their ethnic identity recorded, achieving nearly 100% by 2018.

Priority 2: Making the best use of data linkage methods

6.16 The second priority is to capitalise on Scotland's lead in the UK with linkage methods where the ethnic code from the census permits more effective analysis of existing databases. Through the Retrocoding Project (see 4.4), linkage to general hospital discharge and deaths databases has already been carried out and work is in progress (Phase 2) to link census information to cancer registry and breast screening databases and to hospital discharge information on maternal, child and mental health. There is considerable scope to link census data to other screening programmes such as those for colorectal cancer, diabetic retinopathy and abdominal aortic aneurysms. Linkage to primary care data would be a major step forward (Phase 3), allowing analyses of ethnic variations in morbidity and service use and giving an indication of variations in the quality of care by ethnic group.

Priority 3: An ethnically boosted health survey

6.17 The third priority is to conduct a survey on a sufficiently large sample of ethnic minorities in Scotland to provide information about a wide range of health behaviours, such as the prevalence of smoking, eating behaviour, levels of physical activity, obesity etc and to compare the findings with those for the population as a whole. In the working group's view there are two practical, complementary possibilities. The first is to extend the revised Scottish Health Survey to include an ethnically boosted sample of the population. Starting in 2008, the new SHS will be a continuous survey with a sufficiently large cumulative sample to enable analysis down to NHS Board level every three years. Adapting and extending it to include ethnic minorities would provide a wealth of useful information. The second approach is to ensure there is a Scottish component of the UK Longitudinal Household Survey being led by the Institute of Social and Economic Research at the University of Essex. This will have a total sample size of 40,000 households with an ethnic minority sample of 4,000 households and will be conducted from 2008-12. This will allow comparison with other parts of the UK and, because it is an ongoing study would provide useful information for many years to come.

Priority 4: Coordinated research on major health topics

6.18 The fourth priority is a health research strategy to enable Scotland's research resources to be focused on larger scale, validated work that is analysed and presented in ways that are easy to interpret and allow robust conclusions that can be applied to the wider population. In the working group's view, this should focus particularly on the evaluation of interventions designed to address major, preventable or treatable contemporary health problems such as diabetes, heart disease, cancer, obesity, depression and dental caries. Such interventions need not be exclusively focused on ethnic minorities but need to involve them in ways that can allow meaningful conclusions to be reached.

Achieving this will require the following components:

- Support from the Scottish Government
- A mutual commitment from academic teams and community organisations to work in collaboration so that the strengths of both can be harnessed
- Greater efforts by researchers to enable the ethnic minority public to understand the potential value of research to them and thereby to increase their willingness to participate.

- Given the similarities between ethnic minorities in Scotland, the rest of the UK and other parts of Europe, opportunities for intra- and international collaboration should be taken to the full.

Priority 5 Audit of local health and social care services

Each area NHS Board in Scotland and each local authority provides its own distinctive range of services and has its own unique mix of ethnic minorities. In many cases the latter is rapidly changing, for example due to the dispersal of refugees and asylum seekers or the recent arrival of large numbers of newcomers from Poland and other EU countries. Consequently, given the clear potential for problems in access to and use of services, we **recommend** that each NHS Board should carry out a regular audit of the range and quality of services it provides for ethnic minorities. This will inevitably vary but key services include maternal and child care and mental health services.

Priority 6 Coordination and monitoring of research

A Scottish Ethnicity and Health Research Strategy Implementation Group should be established with the aim of overseeing the implementation of our proposals. This could include the establishment and maintenance of an on-going register of relevant research in Scotland. Given the role of its new Equality and Planning Directorate, we **recommend** that the new Group is hosted by NHS Health Scotland.

A BIBLIOGRAPHY OF PUBLICATIONS ON ETHNICITY AND HEALTH IN SCOTLAND

Abbotts J, Williams R and Davey Smith G (1998). 'Mortality in men of Irish heritage in West Scotland' *Public Health* Vol. 112: pp 229-232

Abbotts J, Williams R and Davey-Smith G (1999a) 'Association of medical, physiological and socio-economic factors with elevated mortality in men of Irish Catholic heritage in West Scotland' *Journal of Public Health Medicine* Vol. 21 No. 1: pp 46-54.

Abbotts J, Williams R, Ford G, Hunt K and West P (1997) 'Morbidity and Irish Catholic descent in Britain: an ethnic and religious minority 150 years on' *Soc. Sci. Med.* Vol. 45 No.1: pp 3-14.

Abbotts J, Williams R, Ford G, Hunt K and West P (1999b). Morbidity and Irish Catholic descent in Britain: relating health disadvantage to behaviour. *Ethnicity and Health* Vol. 4 No. 4: pp 221-230.

Acheson, D (1998) *Independent Inquiry into Inequalities in Health Report* London: HMSO

Ager A, Malcolm M, Sadollah S, O'May F. Community contact and mental health amongst socially isolated refugees in Edinburgh. *Journal of Refugee Studies* 2002; 15(1):71-80

Ager, A (1999) *A study of socially isolated refugees in Edinburgh*. Unpublished paper.

Ahmed, M, Morrison, S and Gardee R (1996) *Podiatry (Chiropody) Report: a snapshot of attitudes, perception and knowledge of podiatry services by the ethnic minority Asian 'elderly' clients attending some day centres* Glasgow: Greater Glasgow Community and Mental Health Services NHS Trust

Anderson A and Lean MEJ (1995) 'Healthy changes? Observations on a decade of dietary change in a sample of Glaswegian South Asian migrant women' *J. Human Nutrition and Dietetics* Vol. 8: 129-136.

Anderson A S, Bush H, Lean M, Bradby H, Williams R, Lea E. Evolution of atherogenic diets in South Asian and Italian women after migration to a higher risk region. *Journal of Human Nutrition and Dietetics* 2005; 18(1): 33-43

Asghar S. Black and minority ethnic views on smoking: patterns, prevalence and needs in Glasgow. 2001.

ASH Scotland. Tobacco and inequalities project needs assessment research: summary report [Online]. 2005. Available from: <http://www.ashscotland.org.uk/ash/3548.html>

ASH Scotland. Tobacco and inequalities project: a mapping exercise and directory of services, resources and training for ethnicity, mental health and older adults. Edinburgh: ASH Scotland; 2005.

Austin E and Munro A (1997) *Older Peoples Needs Assessment of Multicultural issues in the Community Mental Health Nursing Service* Edinburgh: Royal Edinburgh Hospital

Avan, G (1995) *Perceived health needs of Black and ethnic minority women: an exploratory study* Glasgow: Glasgow Healthy City Partnership

Ayrshire and Arran NHS Board. Race equality scheme and Fair for All action plans [Online]. Available from: <http://www.nhsayrshireandarran.com/uploads/1220/race.pdf>

Ayrshire and Arran NHS Board. Revised race equality scheme 2002-2005 [Online]. Available from: <http://www.nhsayrshireandarran.com/uploads/1218/revisedrace.pdf>

Baines L S, Joseph J T, Jindal R M. A public forum to promote organ donation amongst Asians: the Scottish initiative. *Transplant International* 2002; 15(2-3): 124-131.

Baradaran H R, Jamieson J, Gardee R, Knill-Jones R P. Scottish survey of diabetes services for minority ethnic groups. *BMC Health Services Research* 2006; 130

Baradaran H R, Knill-Jones R P, Wallia S, Rodgers A. A controlled trial of the effectiveness of a diabetes education programme in a multi-ethnic community in Glasgow. *BMC Public health* 2006; 134

Baradaran H. Knill-Jones R. Assessing the knowledge, attitudes and understanding of type 2 diabetes amongst ethnic groups in Glasgow, Scotland. *Practical Diabetes International* 2004; 21(4):143-8

Baraitser, P (1999) 'Family planning and sexual health: understanding the needs of South Asian women in Glasgow' *Journal of Ethnic and Migration Studies* Vol 25 No 1: pp 133-149

Barakat K, Stevenson S, Wilkinson P, Suliman A, Ranjadayalan K, Timmkis A D. Socioeconomic differentials in recurrent ischaemia and mortality after acute myocardial infarction. *Heart* 2001; 85(4): 390-394.

Barclay A, Bowes A, Ferguson I, et al. Asylum seekers in Scotland. Edinburgh: Scottish Executive; 2003.

Bartlett C, Doyal L, Ebrahim S, Davey P, Bachmann M, Egger M, Dieppe P. The causes and effects of socio-demographic exclusions from clinical trials. *Technology Assessment* 2005; 9(38): iii-118.

Bhatnagar, A and Ineson, A (1994) *Health and health care: the needs of women of Bangladeshi and Pakistani origin in Edinburgh* Edinburgh: Nari Kallyan Shangho and Lothian Health Promotion Department

Bhopal R S, Samin A K. Immunisation uptake of Glasgow Asian children: paradoxical benefit of communication barriers? *Community Medicine* 1988;10:215-220 <http://jpubhealth.oxfordjournals.org/cgi/reprint/10/3/215>

Bhopal R S. Asian's knowledge and behaviour on preventive health issues: smoking, alcohol, heart disease, pregnancy, rickets, malaria prophylaxis and surma. *Community Medicine* 1986;8:315-321

Bhopal R S. Bhye Bhaddi: a food and health concept of Punjabi Asians. *Soc Sci Med* 1986;23:687-88

Bhopal R S. The interrelationship of folk, traditional and western medicine within an Asian community in Britain. *Soc Sci Med* 1986;22:99-105

Bhopal R, Douglas A, Wallia S, Murray G for the PODOSA investigators. Prevention of type 2 diabetes and obesity in South Asians (PODOSA): a new trial. *Diabetes Lifestyle* [Summer], 7-8. 2007. London, Diabetes UK.

Bhopal R, Fischbacher C M, Steiner M et al. Ethnicity and health in Scotland: can we fill the information gap? A demonstration project focusing on coronary heart disease and linkage of census and health records [Online]. 2005. Available from: <http://www.chs.med.ed.ac.uk/phs/research/Retrocoding%20final%20report.pdf>

Bhopal R, Vettini A, Hunt S, Wiebe S, Hanna L, and Amos A. Review of Prevalence data in, and evaluation of methods for cross cultural adaptation of, UK surveys on tobacco and alcohol in ethnic minority groups. *BMJ* 328: 2004;76-80.

Bhopal, R, Hunt, S, Amos A, Wiebe, S and Vettini, A (forthcoming) *Cross-cultural validity of methods of measurement of alcohol and tobacco consumption*. Public Health Sciences Department of Community Health, University of Edinburgh

Bhopal, R. (1997) 'Is research into ethnicity and health racist, unsound or important science?' *British Medical Journal* Vol 314 pp 1751-1756

Bhopal, R. (1998) 'Spectre of racism in health and health care: lessons from history and the United States.' *British Medical Journal* Vol. 316 pp. 1970-1973

Bitel M, Ssanyu-SSeruma W. The Evaluation of building a bridge: building a bridge project. Edinburgh: NHS Health Scotland; 2005.

Blackwood, J. (1998) *A review of ethnic minority catering provision*. Glasgow: Greater Glasgow Community and Mental Health Services

Bowes A M and Domokos T M (1992) *Asian women and health in Glasgow*; Final report to Health Services Committee, Scottish Home and Health Department.

- Bowes A M and Domokos T M (1993) 'South Asian women and health services: a study in Glasgow' *New Community* Vol. 19 No 4: pp 611-626
- Bowes A M and Domokos T M (1995a) 'Key issues in South Asian Women's Health: a study in Glasgow' *Social Sciences in Health* Vol.1 No 3: pp 145-157
- Bowes A M and Domokos T M (1995b) 'South Asian Women and their GPs: some issues of communication' *Social Sciences in Health* Vol 1 No 1: 22-33
- Bowes A M and Domokos T M (1996a) 'Race, Gender and Culture in South Asian Women's Health: a study in Glasgow' in L McKie (ed) *Researching Women's Health: Methods and Process*. Salisbury: Mark Allen
- Bowes A M and Domokos T M (1996b) 'Pakistani women and maternity care: raising muted voices' *Sociology of Health and Illness* Vol. 18, No 1: pp 45-65
- Bowes A M and Domokos T M (1996c) *Issues of communication between general practitioners health visitors and women of Pakistani heritage* Department of Applied Social Science, University of Stirling
- Bowes A M and Domokos T M (1997a) 'Pakistani women, general practitioners and health visitors: communication and service access' in Bowes, A M and Sim D F (eds) *Perspectives on Welfare* Aldershot: Ashgate
- Bowes A M and Domokos T M (1997b) *Phase 2 of work on women of Pakistani heritage and their experience and use of health services (maternity services, breast feeding and health visiting)* Final Report to Health Services Research Committee, Chief Scientist's Office Edinburgh: Scottish Office
- Bowes A M and Domokos T M (1997c) 'I wasn't rocking any boats' Pakistani women, White women and their experiences of maternity care' *Maternity Action* 78: pp 6-7
- Bowes A M and Domokos T M (1998a) 'Health visitors' work in a Multi-Ethnic Society: A Qualitative Study of Social Exclusion' *Journal of Social Policy* 27, No 4: pp 489-506
- Bowes A M and Domokos T M (1998b) 'Negotiating breast-feeding: Pakistani women, White women and their Experiences in Hospital and at Home' *Sociological Research Online* Vol. 3, No. 3 <
<http://www.aoxewaonline.org.uk/socresonline/3/3/5.html>>
- Bowes A. Sim D. Advocacy for Black and minority ethnic communities: understandings and expectations. *British Journal of Social Work* 2006; 1209-25.
- Bowes A. Wilkinson H. 'We didn't know it would get that bad': South Asian experiences of dementia and the service response. *Ethnicity and Health* 2003; 11(3): 387-96.

- Bowling A, Ebrahim S. Handbook of Health Research Methods: investigation, measurement and analysis. Maidenhead, Open University Press, 2006.
- Bradby H (1996) Cultural strategies of young women of South Asian origin in Glasgow, with special reference to health. PhD thesis, University of Glasgow.
- Bradby H (1997) 'Health, eating and heart attacks: Glaswegian Punjabi women's thinking about everyday food' in Caplan P (ed.), *Food, Health and Identity*, London: Routledge.
- Bradby H and Williams R (1998) *Health and health behaviour among Glasgow 18-20 year olds of South Asian and non-Asian background: a follow-up* Glasgow: MRC Medical Sociology Unit, Working Paper no. 59.
- Bradby H. Watch out for the aunties! Young British Asians' accounts of identity and substance use. *Sociology of Health and Illness* 2007; 29(5): 656-672.
- Bradby H. Williams R. Is religion or culture the key feature in changes in substance use after leaving school? Young Punjabis and a comparison group in Glasgow. *Ethnicity and Health* 2006; 103(3):307-24.
- Bradby, H (forthcoming). 'Communication, interpretation and translation', in Dyson S and Culley L (eds), *Sociology, ethnicity and nursing* Basingstoke, Macmillan.
- Bradby, H. and Williams R (1999) 'Behaviour and expectations in relation to sexual intercourse among 18-20 year old Asians and non-Asians' *Sexually Transmitted Infections* 75: 162-167.
- Bush H, Williams R, Anderson A, Lean M and Bradby H (1996a). 'Symbolic meals of Asian and Italian women in Glasgow' *Scandinavian Journal of Nutrition* (Proceedings of First European Workshop on Human Migration and Nutrition) Vol. 40: pp. S91-2.
- Bush H, Williams R, Bradby H, Anderson A and Lean M (1998). 'Family hospitality and ethnic tradition among South Asian, Italian and general population women in the West of Scotland' *Sociology of Health & Illness* 20(3): pp 351-380.
- Bush H, Williams R, Bradby H, Lean M, Anderson A and Han T (1996b) 'Weight consciousness and body image among South Asian, Italian and general population women in Britain' *Journal of Epidemiology and Community Health* Vol. 50: pp. 600.
- Bush H, Williams R, Lean M, Anderson A and Bradby H (1995a). 'Obesity as a risk factor for coronary heart disease in Glaswegian South Asian women' in Feichtinger, E and Kohler, BM (eds.) *Current Research into Eating Practices: Contributions to Social Science*. AGEV Publication Series, Vol. 10. Supplementum to Ernährungs-Umschau.

Bush HM, Anderson AS, Williams RGA, Lean MEJ and Bradby H (1995b) 'Dietary change in South Asian and Italian women in the West of Scotland' Glasgow: MRC Medical Sociology Unit, Working Paper no.54.

Cancerlink (1999) *Cancer Support and the needs of Asian women in Scotland* Edinburgh: Cancerlink

Cassidy C, O'Connor R, Dorrer N. Young people's experiences of transition to adulthood: a study of minority ethnic and White young people. York: Joseph Rowntree Foundation; 2006.

Causeway Mental Health Project and Renfrewshire Association for Mental Health (unknown) *Changing minds...ascertaining the mental health needs of Black and minority ethnic people* Glasgow: Causeway Mental Health Project/Renfrewshire Association for Mental Health

Cheung NF. Choice and control as experienced by Chinese and Scottish childbearing women in Scotland. *Midwifery* 2002; 18(3): 200-13

Cheung NF. The cultural and social meanings of childbearing for Chinese and Scottish women in Scotland. *Midwifery* 2002; 18(4): 279-95.

Chinese Health Force (1998) *Report on the Glasgow Chinese Health Seminars* Glasgow: Chinese Health Force

Closs A, Stead J, Arshad R, Norris C. School peer relationships of 'minority' children in Scotland. *Child: Care, health and Development* 2001; 27(2): 133-48.

Conway D, Quarrell I, McCall D R et al. Dental caries in 5-year-old children attending multi-ethnic schools in Greater Glasgow – the impact of ethnic background and levels of deprivation. *Community Dental Health* 2007; 24(3): 161-165

Cosgrove, K, Hui, Y, Hampton, K and Laughlin S (1999) *Assessing the Sexual Health and Family Planning Needs of Chinese Women in Glasgow* Glasgow: Greater Glasgow Health Board/Scottish Ethnic Minorities Research Unit

Davey Smith G, Chaturvedi N, Harding S, Nazroo J and Williams R (2000). 'Ethnic inequalities in health: a review of UK epidemiological evidence.' *Critical Public Health* Vol. 10 No. 4: pp 377-408.

Department of Community Health Sciences, University of Edinburgh. Measurement of risk factors for cancer in ethnicity and health research: a case study of tobacco and alcohol. Report to the Scottish Cancer Group of the Scottish Executive. Edinburgh: University of Edinburgh, Department of Public Health Sciences; 2002.

Donaghy, E (1997) 'Understanding depression in young South Asian women in Scotland' in Bowes, A M and Sim, D F (eds) *Perspectives on Welfare* Aldershot: Ashgate

Drug and alcohol issues affecting Pakistani, Indian and Chinese young people and their communities: a study in Greater Glasgow. Glasgow NHS Board (GGNHSB). 2004. jac.ross@gghb.scot.nhs.uk

Dumfries and Galloway NHS Board. Needs assessment report [Online]. Available from: <http://www.nhsdg.scot.nhs.uk/dumfries/files/Minority%20Ethnic%20HNA.pdf>

Dunnigan M McIntosh W, Sutherland G, Gardee R, Glekin R, Glekin B, Ford J.

Dunnigan M, Glekin B, Henderson J, McIntosh W, Sumner D, Sutherland G. Prevention of rickets in Asian children: assessment of the Glasgow campaign. *British Medical Journal* 1985; 291; 239-242.

Dunnigan M, Smith C. The aetiology of late rickets in Pakistani children in Glasgow. Report of a diet survey. *Scottish Medical Journal* 1965; 10: 1- 9.

Ecob R, Williams R. Sampling Asian minorities to assess health and welfare. *Journal of Epidemiology and Community Health* 1991; 45(2): 93-101

Elliott L, Parida K, Gruer L. Differences in HIV-related knowledge and attitudes between Caucasian and « Asian » men in Glasgow. *AIDS Care* 1992; 4: 389-393.

Equality and diversity population profile. NHS Tayside. 2005. Phyllis.easton@nhs.net

Ethnic background and oral health ideas and practices: a qualitative study. University of Glasgow. 2003. k.mullen@clinmed.gla.ac.uk

Ethnic minority health needs assessment. NHS Tayside. 2003. ali.farquharson@nhs.net

Fatunmbi, A and Lee, C (1999) *Silence of the Lads* Edinburgh: EAMH/Men in Mind

Ferguson I, Barclay A. Seeking peace of mind: the mental health needs of asylum seekers in Glasgow. Stirling: University of Stirling; 2002.

Fife NHS Board. Race equality action plan [Online]. Available from: <http://www.nhsfife.scot.nhs.uk/DIVERSITY&EQUALITY/NHSFifeRacialEqualityActionPlan05-08.pdf>

Firdous R, Bhopal R S. Reproductive health of Asian women: a comparative study with hospital and community perspectives. *Public Health* 1989; 103(4): 307-315.

Fischbacher C M, Bhopal R, Povey C, Steiner M, Chalmers J, Mueller G, Jamieson J, Knowles D. Record linked retrospective cohort study of 4.6 million people exploring ethnic variations in disease: myocardial infarction in South Asians. *BMC Public Health* 2007; 142:

Fischbacher C M, Steiner M, Bhopal R, Chalmers J, Jamieson J, Knowles D, Povey C. Variations in all cause and cardiovascular mortality by country of birth in Scotland, 1997-2003. *Scottish Medical Journal* 2007; 52(4): 5-10.

FMR Research. Chinese health and wellbeing study. Present findings from a health and wellbeing study of the Chinese community in Greater Glasgow, commissioned by the Chinese Healthy Living Centre in partnership with Greater Glasgow NHS Board [Online]. 2004. Available from:

<http://www.glasgowchlc.com/home/Chinese%20Healthy%20Living%20Centre%20final%20report.pdf>

Ford J, Colhoun E, McIntosh W, Dunnigan M. Rickets and osteomalacia in the Glasgow Pakistani Community, 1961-71. *British Medical Journal* 1972; 2: 677-680.

Forth Valley NHS Board. Race equality scheme 2005-2008 [Online]. Available from: [http://www.nhsforthvalley.com/web/files/Fair for All files/NHS FV Race Equality Scheme 2005 2008.pdf](http://www.nhsforthvalley.com/web/files/Fair%20for%20All%20files/NHS%20FV%20Race%20Equality%20Scheme%202005%202008.pdf)

Freeman G K, Rai H, Walker J J et al. Non-English speakers consulting with the GP in their own language: a cross-sectional survey. *British Journal of General Practice* 2002; 52(474): 36-38.

Gardee, R *other authors not known- do you want to include?* (forthcoming) *Working towards culturally competent services: improving the health of minority ethnic groups and the wider community in Scotland: Guidance for Health Boards and NHS Trusts* Edinburgh: Scottish Executive

Gardee, R, and Hussain, A (unknown) understanding, adopting and implementing diverse religious beliefs and cultural practices in the provision of health care. Glasgow: Gartnavel Royal Hospital/University of Glasgow

Gardee, R, Kaifi, R Razak, A and Mirza, A, Makherjee, M. Kohli, K and Craise, L (unknown) *A report on ethnic carers' perception of needs for learning disabilities in Glasgow* Glasgow: Community and mental health services NHS Trust, Greater Glasgow Health Board/Community Relations Council/Barnados

Gilmore, A, Davidson, F and Kidd, V (unknown) *A collaborative action research: an exploratory study on ethnic minority perceptions on the services provided in an inner city GP practice* Glasgow: Greater Glasgow NHS trust

Glasgow Health City Partnership (2001) *Healthy cities for all? An audit of health-related services for Black and minority ethnic communities in Glasgow*. Glasgow: Glasgow Healthy City Partnership

GP Practices – Needs assessment of ethnic minority healthcare. NHS Lanarkshire. 2005. Paul.Wraight@Lanarkshire.scot.nhs.uk

Grampian NHS Board. Race equality scheme 2005-2008 [Online]. Available from: [http://www.nhsgrampian.org/nhsgrampian/files/Race%20Equality%20Scheme%20Nov%202005%20\(final\).doc](http://www.nhsgrampian.org/nhsgrampian/files/Race%20Equality%20Scheme%20Nov%202005%20(final).doc)

Greater Glasgow and Clyde NHS Board. Asylum seekers and refugees participatory action research project.

Greater Glasgow and Clyde NHS Board. Black and minority ethnic health in Greater Glasgow. A comparative report on the health and wellbeing of African and Caribbean, Chinese, Indian, and Pakistani People and the general population 2005 Available from: http://library.nhs.uk/mediaAssets/library/nhs.uk/report_bme_health_and_wellbeing_summary.pdf

Greater Glasgow and Clyde NHS Board. Supporting new communities: a qualitative study of health needs among asylum seekers and refugee communities in North Glasgow.

Greater Glasgow Health Board (1997) *The health needs of minority ethnic groups* Glasgow: Greater Glasgow Health Board

Green M. They think we are nothing: a survey of destitute asylum seekers and refugees in Scotland [Online]. 2006. Available from: <http://www.scottishrefugeecouncil.org.uk/pub/Researchreports>

Griffiths L J, Tate A R, Dezateux C, Bartington S, Bedford H, Cole T,

Hampton, K (1995) *Fook Hong/Sehat, Asian and Chinese Women's Project, Interim Evaluation Report* Scottish Ethnic Minorities Research Unit, Glasgow Caledonian University

Hampton, K (1997) *Fook Hong/Sehat, Asian and Chinese Women's Project, SEMRU Research Paper No 7 Series 2* Scottish Ethnic Minorities Research Unit, Glasgow Caledonian University

Hampton, K (2000b) *Saheliya Complementary Therapies Evaluation* Edinburgh: Saheliya

Hampton, K (forthcoming) *Black and ethnic minority views on smoking* Edinburgh: Ash Scotland

Hampton, K. (2000a) 'Communicating health messages to marginalised communities - a culture sensitive approach' *International Journal of Health Promotion and Education*. Vol. 38 No. 2 pp 40-46

Hanley O. A drug and alcohol needs assessment with the Black and minority communities of Castlemilk. Castlemilk Partnership Addictions Task Group; 2004

Hanna L, Hunt S, Bhopal R S. Cross-cultural adaptation of a tobacco questionnaire for Punjabi, Cantonese, Urdu and Sylheti speakers: qualitative research for better clinical practice, cessation services and research. *J Epidemiol Community Health* 2006;60:1034-1039. <http://jech.bmj.com/cgi/reprint/60/12/1034>

Hanna L, Hunt S, Bhopal R. Assessing tobacco use in multi ethnic communities: report of the PATH funded project – use of tobacco and related substances by ethnic minorities: the development of a culturally valid measure [Online]. 2004. Available from: <http://www.ashscotland.org.uk/ash/4385.html>

Hanna L, Hunt S, Bhopal R. Insights from Research on Cross-Cultural Validation of Health-Related Questionnaires: The Role of Bilingual Project Workers and Lay Participants. *Current Sociology* 2008 Jan 1;56(1):115-31.

<http://csi.sagepub.com/cgi/reprint/56/1/115>

Hawkins S S, Law C, Peckham C, Samad L, Walton S. Do early infant feeding practices vary by maternal ethnic group? *Public Health Nutrition* 2007; 10(9): 957-964.

Hay G, Kohli H, McKeganey N. Drug and alcohol issues affecting Black and minority ethnic communities. Glasgow: University of Glasgow; 2001.

Health and well being study – Survey of health perceptions, health service use, health related behaviours, social health. NHS Greater Glasgow. 1999. Julie Truman, Public Health Resource Unit, 0141 201 4935

Heim D, Hunter S C, Ross A, Bakshi N, Davies J B, Flatley K J, Meer N. Alcohol consumption, perception of community responses and attitudes to service provision: results from a survey of Indian, Chinese and Pakistani young people in Greater Glasgow, Scotland and UK. *Alcohol and alcoholism* 2004; 39(3): 220-226.

Henderson J, Dunnigan M, McIntosh W, Abdul-Motaal A, Gettinby G, Glekin B. The Importance of limited exposure to Ultraviolet Radiation and Dietary Factors in the Aetiology of Asian rickets: a risk factor model. *Quarterly Journal of Medicine* 1987; 63: 413-425.

Hopkins P, Hill M. This is a good place to live and think about the future. The needs and experiences of unaccompanied asylum-seeking children in Scotland [Online]. 2006. Available from: <http://www.scottishrefugeecouncil.org.uk/pub/Researchreports>

Ineson, A and Bhopal, R (2000) '*Meeting the needs of minority ethnic groups in Lothian*' in *Public Health* 2000 Edinburgh: Lothian Health

Jindal R M, Joseph J T, baines L S. Development of a questionnaire to assess attitudes and beliefs toward organ donation among Asians. *Progress in Transplantation* 2003; 13(4): 289-295.

Kaifi, R, Bhatti, I, Gardee, R and Hampton, K (1995) *Black and ethnic communities: the service providers' perception of mental health services in Glasgow*. Glasgow: Community and Mental Health Services NHS Trust/Scottish Ethnic Minorities Research Unit/Glasgow District Council

Kay E J, Shaikh I, Bhopal R S (1990) 'Health knowledge, beliefs, attitudes and behaviour of the Asian community in Glasgow' *Health Bulletin* Vol. 48 No. 2: pp73-79

Kay E J, Shaikh I, Bhopal R S. Dental knowledge, beliefs, attitudes and behaviour of the Asian community in Glasgow. *Health Bull* 1990;48:73-80

Kerr L, Wilson D, Murray S. Crossing the language and cultural barriers of diabetes. Edinburgh: Lothian NHS Board; 2006.

Khan, F and Ditton, J, (1998b) *Ethnic Minority Drug Use in Glasgow Part Two: Special Problems Experienced and Possible Gaps in Service Provision* Glasgow: Glasgow Drugs Prevention Team

Khan, F, Ditton, J, Hammersley, R, Phillips S and Short, E (1998a) *Ethnic Minority Drug Use in Glasgow Part One: Comparative attitudes and behaviour of young White and Asian males* Glasgow: Glasgow Drugs Prevention Team

King, S and Rigg, S (1991) *Investigative Report on the Mental Health Needs of Black Women* Edinburgh: Craigentiny Health Project

Kohli H and Reid M (1994) 'What well woman services do 'Asian' woman need?' Department of Public Health, University of Glasgow

Kohli H S. A comparison of smoking and drinking among Asian and White schoolchildren in Glasgow. *Public Health* 1989; 103(6): 433-439.

Lai, C (1999) *Reaching out to Black ethnic minorities: a voluntary sector perspective on mental health*. MSc dissertation, Robert Gordon University, Aberdeen

Lai, C (unknown) 'Reaching out to Black ethnic minorities: a voluntary sector perspective on mental health' *Practice* Vol 12: No. 1 pp 7- 26

Lanarkshire NHS Board. The geography of ethnic and religious groups within NHS Lanarkshire area. Hamilton: NHS Lanarkshire Board; 2004.

Lawrence J M, Devlin E, Macaskill S et al. Factors that affect food choices made by girls and young women, from minority groups, living in the UK. *Journal of Human Nutrition and Dietetics* 2007; 20(4): 311-319.

Lawton J, Ahmad N, Hallowell N, Hanna L, Douglas M. perceptions and experiences of taking oral hypoglycaemic agents among people of Pakistani and Indian origin: qualitative study. *British Medical Journal* 2005; 330(7502); 1247-1249.

Lawton J, Ahmad N, Hanna L et al. 'I can't do any serious exercise': barriers to physical activity amongst people of Pakistani and Indian origin with type 2 diabetes. *Health Education Research* 2006; 21(1): 43-54.

Lawton J, Ahmad N, Hanna L, Douglas M, Hallowell N. Diabetes service provision: a qualitative study of the experiences and views of Pakistani and Indian patients with type 2 diabetes. *Diabetic Medicine* 2006; 23(9): 1003-1007.

Lean M E J, Han T S, Bush H, Anderson A S, Bradby H, Williams R. Ethnic differences in anthropometric and lifestyle measures related to coronary heart disease risk between South Asian, Italian and general-population British women living in the west of Scotland. *International Journal of Obesity* 2001; 25(12): 1800-1805.

- Listening to communities: involving people in health. NRCEMH. 2003.
- Lloyd, M and Morran R (1999) *Travellers and health* Edinburgh: Save the Children Fund
- Lothian NHS Board. Lothian health and life survey 2002 [Online]. 2004. Available from: <http://www.lothianhealthandlife.scot.nhs.uk/lhls2002/index.html>
- Macdonald J, Giri B. The issues: East Lothian minority ethnic carers and people needing services [Online]. 2007. Available from: <http://www.mecopp.org.uk/downloadsresearch.php>
- MacIntosh, S (1998) *Evaluation of the Sunday Clinic: A Pilot Project* Glasgow: Chinese Health Force
- Mahmood, S and Shariff, I (2000) *Promoting social inclusion for deaf people from a minority ethnic background* Glasgow: Deaf Connections and Greater Glasgow Primary Care NHS Trust
- Marsden R, Aldegheri E, Khan A et al. 'What's going on?' A study into destitution and poverty faced by asylum seekers and refugees in Scotland [Online]. 2005. Available from: <http://www.asylumscotland.org.uk/asylumresearch.php>
- Martin C, Sheehy C, Hayes F. Report of interviews with service providers: section 5. Edinburgh: NHS Health Scotland; 2004.
- Matheson L, Dunnigan M, Hole D, Gillis C. Incidence of colo-rectal, breast and lung cancer in a Scottish Asian population. *Health Bulletin* 1985?; 43: 245-249.
- Matthews G, Alexander J, Rahemtulla T, Bhopal R. Impact of a cardiovascular risk control project for South Asians (Khush Dil) on motivation, behaviour, obesity, blood pressure and lipids. *J Public Health* 2007 Dec 1;29:388-97. <http://jpubhealth.oxfordjournals.org/cgi/content/abstract/29/4/388>
- Milne, R, Wyke, S and Donaghy, E (1998) *Health Services for Women of African Origin in Scotland* Department of General Practice, University of Edinburgh
- Minhas, N (1999) *Assessing the Gap: the problems faced by South Asian women in accessing health services in Edinburgh* Edinburgh: Nari Kallyan Shangho
- Minnis H, Kelly E, Bradby H, Oglethorpe R, Raine W, Cockburn D. Cultural and language mismatch: clinical complications. *Clinical Child Psychology and Psychiatry* 2003; 8(2): 179-186.
- Mirza, A (1997) *Sex education: a comparative study of the perceptions, attitudes and sexual health needs of Pakistani, Indian and White secondary school children in Edinburgh*. Masters in Public Health. Department of Public Health, University of Glasgow

Mojee M, Shariff I, Douglas A, Rai-Chaudhuri N, Douglas A. 'Involving People' – An evaluation of mental health services by asylum seekers in Glasgow [Online]. 2003.

<http://www.nhsggcequality.co.uk/equality/healthpro/research/reports/pdf/LtcSummaryReport.pdf>

Moriarty J, Butt J. Inequalities in quality of life among older people from different ethnic groups. *Ageing & Society* 2004; 24(5): 729-753.

Morran D. Negotiating marginalized identities: social workers and settled Travelling People in Scotland. *International Social work* 2002; 45(3): 337-51, 390.

Mukhopadhyay B, Forouhi N G, Fisher B M, Kesson C M, Sattar N. A comparison of glycaemic and metabolic control over time among South Asian and European patients with type 2 diabetes: results from follow-up in a routine diabetes clinic. *Diabetic Medicine* 2006; 23(1): 94-8.

Mullen K (1992) 'A question of balance: health behaviour and work context among male Glaswegians' *Sociology of Health and Illness* Vol. 14: pp. 73-39.

Mullen K (1994) Control and responsibility: moral and religious issues in lay health accounts. *Sociological Review* Vol. 43 No. 3: pp 414-437.

Mullen K, Chauhan R, Gardee R et al. Exploring issues related to attitudes towards dental care among second-generation ethnic groups. *Diversity in Health and Social Care* 2007; 4(2): 91-99

Mullen K, Chauhan R, Gardee R et al. Exploring issues related to oral health and attitudes to diet among second-generation ethnic groups. *Diversity in Health and Social Care* 2006; 3(2):

Mullen K, Williams R and Hunt K (1996) 'Irish descent, religion and alcohol and tobacco use' *Addiction* Vol. 91 No. 2: pp 243-254

Mullen K, Williams R and Hunt K (2000). Irish descent, religion and food consumption in the west of Scotland. *Appetite* Vol. 34: pp. 47-54.

Munday S and Oswald C (2000) *Black and Minority Health Inequalities Framework Document* Edinburgh: Lothian Health Department

Munro, A (1996) *Needs Assessment of Multi-cultural issues affecting older people with arthritis* Edinburgh: Pilmeny Development Project/Arthritis Care and Milan (Senior Welfare Council)

Munro, A (1999) *Minority Ethnic Arthritis Project Evaluation/Update Report*. Edinburgh: Pilmeny Development Project/Arthritis Care and Milan (Senior Welfare Council)

Murray S, Bashir K, Penrice G et al. Epidemiology of multiple sclerosis in Glasgow. *Scottish Medical Journal* 2004; 49(3): 100-104

Myers F, McCollam A, Woodhouse A. Equal minds: addressing mental health inequalities in Scotland. Edinburgh: Scottish Executive; 2005.

National Resource Centre for Ethnic Minority Health (NRCEMH). 'Voices from the North' Exploratory Needs Assessment of Gypsy/Traveller communities in the North of Scotland [Online]. 2007. Available from:

<http://www.nrcemh.nhsscotland.com/publications.html>

National Resource Centre for Ethnic Minority Health, Scottish Diabetes Group. Diabetes in minority ethnic groups in Scotland: main report. Glasgow: NHS Health Scotland; 2004.

Nazroo J Y ed. Health and Social Research in Multi-ethnic societies. Routledge, Oxford 2006.

Nazroo, J Y. 'Health and Health Services' in Modood, T Berthoud, R, Lakey J Nazroo, J, Smith, P, Virdee, S and Beishon, S (eds) *Ethnic minorities in Britain* London: Policy Studies Institute, 1997.

Netto G, McClooughan L, Bhatnagar A. Effective heart disease prevention: Lessons from a qualitative study of user perspectives in Bangladeshi, Indian and Pakistani. *Public Health* 2007; 121(3): 177-186.

Netto G. A review of policy, practice and research relating to Black disabled people in Scotland. Joseph Rowntree Foundation; 2002.

Netto G. Creating a suitable space: a qualitative study of the cultural sensitivity of counselling provision in the voluntary sector in the UK. *Journal of Mental Health* 2006; 15(5):593-604,

Netto, G (1998). 'I forget myself: the case for the provision of culturally sensitive respite services for minority ethnic carers of older people' *Journal of Public Health Medicine Vol 20/2: 221-226*

Netto, G, Gaag, S, Thanki, M, Bondi, L and Munro, M (2001) *A suitable space: Improving counselling services for Asian people*. York: Joseph Rowntree Foundation.

Netto G, Bhopal R, Khatoon J, Lederle N, Jackson A. Health promotion and revention interventions in Pakistani, Chinese and Indian communities related to CVD and Cancer: A review of the published evidence in the UK, other parts of Europe and the United States. NHS Health Scotland 2008

NHS Highland NHS Board. Vaughan S. Health needs assessment: BME populations in Highland [Online]. 2005. Available from:

<http://www.nhshighland.scot.nhs.uk/Publications/Pages/HealthNeedsAssessment-BMEPopulationsintheHighlands.aspx>

Obike, P (1998) *The awareness of sickle cell disorder and thalassaemia among the community and frontline healthcare professionals in Glasgow* Masters' thesis, Department of Medical Genetics, Glasgow: Yorkhill Hospitals

Pang, M (2000) *Communication barriers? An explorative study of two groups in the Chinese community in Aberdeen* BSc Health Sciences, Department of Public Health, University of Aberdeen

Patel K C R, Shah A M. Prevention, treatment and rehabilitation of cardiovascular disease in South Asians. London: TSO; 2005.

Patel, A (1996) *Black women in Edinburgh: An investigation into their needs and experiences as users of health services* [Edinburgh](#): Shakti Women's Aid

Paul S (1997) 'South Asian women's access to cervical cytology' in Bowes, A M and Sim D F (eds) *Perspectives on Welfare* Aldershot: Ashgate

Pershad, P and Tyrrell (1995) *Access to antenatal and postnatal services for Asian women living in East Pollokshields*, Glasgow: Save the Children

Policy for the prevention of Asian Rickets in Britain: a preliminary assessment of the Glasgow rickets campaign. *British Medical Journal* 1981;282: 357-360

Procter N G. 'They first killed his heart (then) he took his own life'. Part I: A review of the context and literature on mental health issues for refugees and asylum seekers. *International Journal of Nursing Practice* 2005; 11(6): 286-291.

Quickfall J. Developing a model for culturally competent primary care nursing for asylum applicants and refugees in Scotland: a review of the literature. *Diversity in Health and Social Care* 2004; 1(1):53-64.

Ranganathan M, Bhopal R (2006) Exclusion and inclusion of non-white ethnic minority groups in 72 North American and European cardiovascular cohort studies. *PLoS Med* 3(3): e44.

Rehman, U (1996) *Health and health education needs of young Pakistani women* Glasgow: Glasgow Healthy City Partnership

Reiss, G. (1994) *Refugee doctors in Scotland* Edinburgh: Scottish Refugee Council.

Ross A, Heim D, Bakshi N, Davies J B, Flatley K J, Hunter S C. Drug issues affecting Chinese, Indian and Pakistani people living in Greater Glasgow. *Drugs: Education, Prevention & Policy* 2004; 11(1): 49-65.

Samad L, Tate A R, Dezateux C, Peckham C, Butler N, Bedford H. Differences in risk factors for partial and no immunisation in the first year of life: prospective cohort study. *British Medical Journal* 2006; 332 (7553): 1312-1313.

Scanlon K. Wood A. Breast cancer awareness in Britain: are there differences based on ethnicity? *Diversity in Health and Social Care* 2005; 2(3): 211-21.

School of the Built Environment, Heriot Watt University. An assessment of the housing needs and aspirations of Gypsies/Travellers in Tayside Edinburgh:

- Communities Scotland [Online]. 2004. Available from:
<http://www.communitiesscotland.gov.uk/stellent/groups/public/documents/webpages/cs009023.pdf>
- Scottish Consumer Council (forthcoming) *Access to Primary Care Services*. Glasgow: Scottish Consumer Council
- Scottish Executive (1999) *Towards a Healthier Scotland* Edinburgh: Stationary Office
- Scottish Executive (2000) *Equality in Scotland: Guide to Data Sources* Edinburgh: Central Statistics Unit, Scottish Executive
- Scottish Executive (2001) *Our National Health: a plan for action, a plan for change* Edinburgh: Scottish Executive
- Scottish Executive. Analysis of ethnicity in the 2001 Census: summary report [Online]. 2004. Available from:
<http://www.scotland.gov.uk/Publications/2004/02/18876/32937>.
- Scottish Office (1991) *Ethnic Minorities in Scotland* Edinburgh: Scottish Office
- Scottish Office (1998) *Working together for a healthier Scotland: a consultation document* Edinburgh: the Stationary Office
- Se Chan C ML (1998) *A survey of health behaviour, health problems and the health needs among the Chinese in Edinburgh*, Queen Margaret College
- Secretary of State (1998a) *Our Healthier Nation* London: HMSO
- Shams M and Williams R (1995) 'Differences in perceived parental care and protection and related psychological distress between British Asian and non-Asian adolescents' *Journal of Adolescence* Vol.18: 329-348.
- Shams M and Williams R (1997) 'Generational changes in height and body mass differences between British Asians and the general population in Glasgow' *Journal of Biosocial Science* Vol. 29: pp. 101-109.
- Shariff, I. (2000) *Black and minority ethnic health needs assessment* Glasgow: Maryhill Community Health Project (moved in keeping with alphabetical order)
- Sheikh A and Jiwa, S (1993) *Heart disease and the Asian Community in Lothian* Edinburgh: Lothian Health Education Department/Roundabout Centre
- Shetland NHS Board. Health needs assessment for minority ethnic groups in Shetland (draft). 2003
- Shrestha, S (1996) *A health survey of Asian workers in Indian restaurants in Glasgow* Master of Public Health, Department of Public Health, University of Glasgow.

Simkhada P, Van Teijlingen E, Yakubu B et al. Systematic review of sexual health interventions with young people from Black and minority ethnic communities. Edinburgh: NHS Scotland; 2007

Sinyemu E, Sedzro S. An investigation into social and health needs of Black Africans living in Scotland. Waverley Care 2004

Smart H, Titterton M, Clark C. A literature review of the health of gypsy/traveller families in Scotland: the challenges for health promotion. *Health Education* 2003; 103(3): 156-165.

South Asian patients' experiences of Scottish diabetes services. University of Edinburgh. 2004. j.lawton@ed.ac.uk

Srivastava, A and Bowes A M (1996) *Mental health among elderly South Asians: a review in the light of mental health services in Scotland* Department of Applied Social Science, University of Stirling.

Stead, M (1996) *The health of minority ethnic populations in Scotland: A literature review for the Health Education Board for Scotland* Glasgow: Centre for Social Marketing, University of Strathclyde

Tayside Adult Health and Lifestyle Survey: lifestyle, smoking, diet, physical activity, long term illness, disability. NHS Tayside. 1994. Zelda.mathewson@nhs.net

Tayside NHS Board. Ethnic minority health needs assessment [Online].2003. Available from: <http://www.thpc.scot.nhs.uk/PDFs/FFA%20HNA%202003.pdf>

The results of the 2002 Scottish social attitudes survey on discriminatory attitudes towards disabled people, women, minority ethnic groups and gay men and lesbians. Scottish Executive. 2002. Executive Health Department Analytical Services Division 0131 244-3777.

Tyrrell, H (1998) *Needs, services and priorities for Mental Health in Pollockshields* Glasgow: *a local perspective*. Glasgow: Glasgow Association for Mental Health and Save the Children

Umeed, I (2000) *Health Needs, Knowledge: a self-reported health status of South Asian men in Glasgow* Glasgow: I Umeed

Walking to health: people in Scotland are being inspired to walk the path to better health. *Prim Health Care* 2003; 13(10): 22-24.

Well what do you think? A national Scottish survey of public attitudes to mental health, well being and mental health problems. Scottish Executive. 2002. Scottish Executive Health Department Analytical Services Division 0131 244 3777.

Williams R (1992a) 'The health of the Irish in Britain' in Ahmad ,W (ed) *The politics of race and research* Bradford: Race Relations Unit, University of Bradford *delete pg numbers*

Williams R (1993a) 'Can data on Scottish Catholics tell us about descendants of the Irish in Scotland? A research note' *New Community* Vol. 19 No. 2: pp 296-309

Williams R (1993b) 'The health costs of Britain's industrialisation: a perspective from the Celtic periphery' in Platt S, Thomas A, Scott S, and Williams G (eds.) *Locating health: sociological and historical explorations*. Aldershot: Avebury.

Williams R (1993c) 'Religion and illness' In Radley A, (ed.) *Worlds of illness*. London: Routledge.

Williams R (1993d) Health and length of residence among South Asians in Glasgow: a study controlling for age. *Journal of Public Health Medicine* 15: No. 1 pp 52-60.

Williams R (1994a) Britain's regional mortality: a legacy from disaster in the Celtic periphery? *Soc Sci Med* Vol. 39 No. 2: pp 189-199.

Williams R (1994b) Medical, economic and population factors in areas of high mortality in Britain: the case of Glasgow. *Sociology of Health & Illness* Vol.16 No. 2: pp 143-181

Williams R (1997) 'The health legacy of the emigration: the Irish in Britain and elsewhere, 1845-1995' *Irish Journal of Sociology* 6: pp 56-78.

Williams R and Ecob R (1999). 'Regional mortality and the Irish in Britain.' *Sociology of Health and Illness* Vol. 21 No.3: pp 344-367

Williams R and Hunt K (1997) 'Psychological distress among British South Asians: the contribution of stressful situations and subcultural differences in the West of Scotland Twenty-07 Study' *Psychological Med.* Vol. 27 : pp 1173-1181.

Williams R and Shams M (1998) 'Generational continuity and change in British Asian health and health behaviour' *Journal of Epidemiology and Community Health* Vol. 52: pp 558-563.

Williams R, Bhopal R and Hunt K (1993) 'Health of a Punjabi ethnic minority in Glasgow: a comparison with the general population' *Journal of Epidemiology and Community Health* Vol. 47: pp 96-102.

Williams R, Bhopal R and Hunt K (1994) 'Coronary risk in a British Punjabi population: comparative profile of non-biochemical risk factors' *International Journal of Epidemiology* Vol. 23: pp 28-37.

Williams R, Bush H, Anderson A, Lean M and Bradby H (1996). *Dietary change in South Asian and Italian women in the West of Scotland* Final report to the ESRC Glasgow: MRC Medical Sociology Unit.

Williams R, Bush H, Lean M, Anderson A and Bradby H (1998a) 'Food choice and culture in a cosmopolitan city: South Asians, Italians and other Glaswegians' in

Murcott A (ed.), *The nation's diet: the social science of food choice* London: Addison Wesley Longman

Williams R, Eley S, Hunt K and Bhatt S (1997) 'Has psychological distress among British Asians been underestimated? A comparison of three measures in the West of Scotland population' *Ethnicity and Health* Vol. 2 No. 1/2: pp 21-29.

Williams R, Wright W and Hunt K (1998b) 'Social class and health: the puzzling counter-example of British South Asians' *Social Science and Medicine* 47 No. 9: pp 1277-1288.

Wraight P S. *Ethnicity and Health Inequalities in Lanarkshire*. MPH Project. Glasgow: University of Glasgow; 2005.

Xiao-hui Liao, McIlwaine G (1995) 'The health status and health needs of Chinese population in Glasgow' *Scottish Medical Journal* 40: pp 077-080

Zainal, K, Sharif I, Gardee R and Mohammed, F. (2000) *Health needs of the Arab Community: an exploratory review* Glasgow: Greater Glasgow Primary Care NHS Trust

Appendix 1

Membership of the Working Group

Dr Laurence Gruer (Chair)	NHS Health Scotland
Shabir Banday	REACH Community Health Project
Professor Raj Bhopal	Public Health Sciences Section, Division of Community Health Sciences, University of Edinburgh
Professor Alison Bowes	Dept of Applied Social Science, University of Stirling
Dr Colin Fischbacher	Information Services Division (ISD)
Dr Dermot Gorman	Lothian NHS Board
Dr Imelda Hametz	Analytical Services, Scottish Executive
Dr Russell Jones	Glasgow Centre for Population Health
Philomena deLima	UHI Policy Web, Inverness College
Dr Gina Netto	School of the Built Environment, Heriot Watt University
Tanveer Parnez	Black and Ethnic Minority Infrastructure in Scotland (BEMIS)
Julie Truman	NHS Greater Glasgow and Clyde

Appendix 2

Published Health-related Research on Ethnic minorities in Scotland An Update on the 1991-2001 Audit

Purpose and Scope of the Audit

An audit was commissioned in 2001 by the Scottish Executive of all health-related research on ethnic minorities in Scotland published during the ten years 1991-2001. The audit was conducted by Dr Gina Netto and colleagues¹⁵ It identified 125 relevant papers and reports and a number of other policies and sources of statistical data.

The Ethnicity and Health Research Group is a short-life working group set up and chaired by NHS Health Scotland and supported by the Scottish Executive. Its aim is to develop a strategic programme of research aimed at answering important questions relating to ethnicity and health of people living in Scotland.

The aim of the proposed audit is to extend and update Dr Netto's review by identifying and assessing all relevant research on this topic published during the period 2001-2007 and, if time allows, during 1971-1991. This will ensure that there is comprehensive coverage of all relevant published research, establish what is already known and help guide the Ethnicity and Health Research Group in planning future research.

Defining the literature research strategy

Year of publication:

- a) 2001-2007
- b) before 1991

Location:

Conducted exclusively in Scotland or involving people living in Scotland
Title or text must include at least one of the following:
Scotland, Scottish, Glasgow, Edinburgh.

Population search terms:

Must include at least one of the following
Ethnic minorities, minority group, ethnicity, racial minority, Asian, South Asian, Indian, Pakistani, Punjabi, Gujarati, Hindu, Muslim, Sikh, Chinese, African, West Indian, Caribbean, Afro-caribbean, gypsy travellers, refugees, asylum seekers, migrants, immigrants, Eastern European, International workers, Accession 8.

Research topics

Must include at least one of the following
Health, disease, illness, health care, health services,
Knowledge, attitudes, beliefs, behaviours,
Smoking, exercise, physical activity, alcohol, diet, coronary heart disease, cardiovascular disease, CHD, heart disease, coronary artery disease, CAD, stroke, angina, myocardial infarction, heart attack, heart failure, cerebro-vascular disease, atherosclerosis, diabetes, neoplasms, tumour, cancer, injuries, accidents, falls, fracture, burns, poisoning, haemoglobinopathies.

Exclusions

Comparisons between White Scottish or White people living in Scotland and ethnic minorities living elsewhere.

Sources for search**Books and peer reviewed literature**

MEDLINE

EMBASE

Web of Knowledge

CINAHL

PsycINFO

Government or NHS Board reports, “routine” analyses of health service data, ISD

Analytical Services Division, Scottish Executive

Scottish Executive Equality website

NHS Boards

Text References

- ¹ Bhopal R S. Glossary of terms relating to ethnicity and race: for reflection and debate. *Journal of Epidemiology and Community Health*. 2003; 58: 441-5.
- ² Bhopal R S Ethnicity, race and health in multicultural societies: foundations for better epidemiology, public health and health care. OUP, Oxford 2006.
- ³ Analysis of ethnicity in the 2001 Census: Summary Report. Scottish Executive: Office of the Chief Statistician, Edinburgh. February 2004
- ⁴ General Register Office of Scotland 2008
- ⁵ National Insurance Number Allocations to Overseas Nationals Entering the UK 2006/2007. Department for Work and Pensions.
http://www.dwp.gov.uk/asd/asd1/niall/registration_tables2007.xls
- ⁶ Home Office. Asylum Statistics UK 2006. Home Office Statistical Bulletin. 2007. Accessed at:
<http://www.homeoffice.gov.uk/rds/pdfs07/hosb1407.pdf>
- ⁷ Home Office. Asylum Statistics 4th Quarter 2007. Accessed at:
<http://www.homeoffice.gov.uk/rds/pdfs08/asylumq407.pdf>
- ⁸ COSLA. Asylum and migration statistics. Accessed at
<http://www.asylumscotland.org.uk/asylumstatistics.php>
- ⁹ Information Centre about Asylum Seekers and Refugees in the UK. Accessed at:
<http://www.icar.org.uk/>
- ¹⁰ Accession Monitoring Report A8 Countries May 2004 – March 2007. A joint online report by the Border and Immigration Agency, Department for Work and Pensions, HM Revenue and Customs and Communities and Local Government. Available at:
<http://www.ind.homeoffice.gov.uk/6353/aboutus/AccessionMonitoringReport11.pdf>
- ¹¹ General Register Office of Scotland 2008. <http://www.gro-scotland.gov.uk/files1/high-level-summary-of-statistics-population-and-immigration/j926005.htm>

¹² Netto G, Arshad R, de Lima P, Diniz F A, McEwen M, Patel V, Syed R. Audit of Research on Minority Ethnic Issues in Scotland from a “race” perspective. Central Research Unit, Scottish Executive 2001.

¹³ NIH POLICY AND GUIDELINES ON THE INCLUSION OF WOMEN AND MINORITIES AS SUBJECTS IN CLINICAL RESEARCH – Amended, October, 2001.

II. POLICY

A. Inclusion of Women and Minorities as Subjects in Clinical Research

It is the policy of NIH that women and members of minority groups and their subpopulations must be included in all NIH-funded clinical research, unless a clear and compelling rationale and justification establishes to the satisfaction of the relevant Institute/Center Director that inclusion is inappropriate with respect to the health of the subjects or the purpose of the research. Exclusion under other circumstances may be made by the Director, NIH, upon the recommendation of an Institute/Center Director based on a compelling rationale and justification. Cost is not an acceptable reason for exclusion except when the study would duplicate data from other sources. Women of childbearing potential should not be routinely excluded from participation in clinical research. This policy applies to research subjects of all ages in all NIH-supported clinical research studies.

The inclusion of women and members of minority groups and their subpopulations must be addressed in developing a research design or contract proposal appropriate to the scientific objectives of the study/contract. The research plan/proposal should describe the composition of the proposed study population in terms of sex/gender and racial/ethnic group, and provide a rationale for selection of such subjects. Such a plan/proposal should contain a description of the proposed outreach programs for recruiting women and minorities as participants.

B. NIH-defined Phase III Clinical Trials: Planning, Conducting, and Reporting of Analyses for Sex/Gender and Race/Ethnicity Differences.

When an NIH-defined Phase III clinical trial is proposed, evidence must be reviewed to show whether or not clinically important sex/gender and race/ethnicity differences in the intervention effect are to be expected. This evidence may include, but is not limited to, data derived from prior animal studies, clinical observations, metabolic studies, genetic studies, pharmacology studies, and observational, natural history, epidemiology and other relevant studies.