

Health in our Multi-ethnic Scotland

Future Research Priorities



The Scottish Ethnicity and Health Research
Strategy Working Group

NHS Health Scotland
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Our five priorities

1. Good ethnic coding

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

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

2. Making the best use of data linkage methods

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

3 A health survey of ethnic minorities in Scotland

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

4. Coordinated research on major health problems and issues

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

5. Catalysing, coordinating and using research

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

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Foreword

The Scottish Government is committed to promoting the health and wellbeing of all, regardless of their background. 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, chaired by Dr Laurence Gruer, was set up and met for the first time in January 2007. The group published a draft consultation report in October 2008. The response to the draft was overwhelmingly positive. Many constructive comments were received from over 70 participants at the launch event and from 15 organisations or individuals who made written submissions. As far as possible, these have been incorporated into this final text.

The report shows the unprecedented increase in the diversity of the Scottish population in recent years. Some excellent research on ethnic minorities in Scotland has been published but this has been limited in scale and mainly focuses on the South Asian community. The report finds that surprisingly little is known about the health of ethnic minorities in Scotland. However, some of the recent findings indicate that the health of ethnic minorities is often better than that of the majority White Scottish population. There are perhaps important lessons here in relation to lifestyle factors such as smoking, drinking alcohol and diet. On the other hand, the high rates of coronary artery disease and diabetes in South Asians require our attention and action.

The reason we know less than we should is largely because we do not collect data on ethnic identity on the death certificate and efforts to do so for health records have been patchy so far. I strongly support the Working Group's conclusion that our top priority must be to improve the quality of our data collection. Without this, our ability to make those important links between ethnicity and health will be severely limited. I will be working with colleagues at the Scottish Government to help bring about the changes that are needed.

The report makes a number of other useful recommendations, which have my full support. If implemented, they will do much to expand our understanding of the ways ethnicity influences health in Scotland and give us a much stronger evidence base for taking action where important inequalities exist. That is especially important for the NHS and other statutory bodies that have a legal obligation to ensure that people receive high-quality services regardless of their ethnic background. I therefore particularly welcome the emphasis on research on such important and sensitive areas, such as mental health services and terminal care. The report also highlights the need for

researchers to engage effectively with ethnic minority communities if they are to achieve the cooperation that is essential for good research.

In conclusion, I very much welcome this report. It offers the prospect of much better information about our increasingly diverse population, leading in turn to a healthier and fairer society.

Dr Harry Burns
Chief Medical Officer

Summary and recommendations

Chapter 1: Why is a research strategy needed?

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

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

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

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

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

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

Chapter 2: The changing ethnic composition of the Scottish population

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

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

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

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

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

Chapter 3: Published research on ethnicity and health in Scotland

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

1960-1985

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

1986-2000

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

2001-2008

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

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

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

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

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

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

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

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

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

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

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

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

Chapter 5: Research ethics and methods

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

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

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

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

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

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

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

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

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

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

Chapter 6: Priorities for future research in Scotland

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

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

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

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

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

Recommendation 1

The new ethnic classification developed for the Scottish 2011 Census should be adopted by all organisations and researchers as the standard classification for routine use (para 6.12).

Recommendation 2

The death certificate in Scotland should be amended to enable ethnic identity to be recorded using the same ethnic classification as for the 2011 Census (para 6.13).

Recommendation 3

The Scottish Government should require ethnic identity to be one of the items recorded, with individuals' consent, on the CHI or its successor for every person registered with the NHS, with the aim of achieving this by 2015 (para 6.14).

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

Recommendation 4

The Scottish Government should give full support to continuing the research programme based on linking the ethnic coding on the census to a range of health-related databases (para 6.16).

3. **A health survey of ethnic minorities in Scotland.** To help understand the health of ethnic minorities, it is important to have information about a wide range of health behaviours – such as smoking, eating behaviour, physical activity, obesity, etc. – against a background of personal and social circumstances, and compare the findings with those for the population as a

whole. Linking a boosted sample from ethnic minorities with the revised Scottish Health Survey is not considered practical or cost-effective. However, a large sample of ethnic-minority households from throughout the UK will form part of the Understanding Society survey now underway. The first findings will be available in 2010. Much of the resulting information will be relevant to ethnic minorities in Scotland and this could be enhanced by a subsequent Scottish survey.

Recommendation 5

A survey of ethnic minorities living in Scotland should be conducted between 2011 and 2012 with the aim of adding significantly to the information obtained from the UK Understanding Society survey (para 6.19).

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

Recommendation 6

The Scottish Government should encourage and support:

- evaluations of larger scale interventions aimed at preventing or treating major health problems affecting ethnic minorities
- qualitative research designed to provide insights into perceptions, attitudes, behaviour and experience of health and social care services of relevance to major health issues in different ethnic minority groups (para 6.22).

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

Recommendation 7

A Scottish Ethnicity and Health Research Group should be established to catalyse and coordinate relevant high-quality research and make the best use of the findings of research from Scotland and elsewhere. The Group should be hosted by NHS Health Scotland (para 6.23).

Glossary
(abridged from Bhopal 2003 and Bhopal 2007)

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 .)
African-Caribbean/ Afro-Caribbean	A person of African ancestral origins whose family settled in the Caribbean before emigrating and who self-identifies, or is identified, as African-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 African-Caribbean. (See also African and African-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 twentieth century there are signs that such support is diminishing.
Caucasian	An Indo-European. This is Blumenbach's eighteenth-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 or (less commonly in the UK) Irish. 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 attributes traditionally associated with race. (See also 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. This term is 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	Increasingly used as the preferred phrase and replacing ethnic minority group. (See 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 permits those not included in other categories 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 roots 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 that 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, Asian, Pakistani and 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	<p>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, 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 that cannot be unearthed and tackled by using the label 'White'.</p>
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Chapter 1

Why is a research strategy 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, 2007). 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 50 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 experiences 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 (HM Government 2000). 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'. These responsibilities are commonly referred to as the Race Equality Duty. In order to demonstrate that public bodies are meeting their obligations under the Race Relations (Amendment) Act 2000, routine recording of ethnicity is required.

1.4

The Scotland Act (HM Government) 1998 gave the Scottish Parliament power to encourage equal opportunities. It defined equal opportunities as 'the prevention, elimination or regulation of discrimination between persons on the grounds of sex or marital status, on racial grounds, or on grounds of disability, age, sexual orientation, language or social origin, or of other personal attributes, including beliefs or opinions such as religious beliefs or political opinions'. The Scottish Executive moved quickly to give practical meaning to this power. In 1999, it published *Making it Work Together: a Programme for Government* which stressed its commitment to promoting equality for all and its determination to place equality at the heart of policy making (Scottish Executive, 1999). After a period of consultation, it launched its *Equality Strategy: Working Together for Equality* the following year (Scottish Executive 2000a). This set out a wide range of initiatives which the Scottish Executive then took forward. It included a commitment to 'mainstreaming equality', which it defined as 'the systematic integration of an inequalities perspective into the everyday work of government, involving policy makers across all government departments, as well as equality specialists and external partners'. In a section on 'Research and Measurement', the strategy expressed a commitment to 'developing better statistics that provide information for different equality groups'. It recognised the importance of research to 'identify issues to be addressed, provide the evidence to support action and help to signpost solutions to problems'. Among other things, it proposed conducting a survey on ethnic minorities in Scotland.

1.5

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 access NHS services fairly. 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 (Health Department, 2002) which set out five key areas for delivery for all NHS Boards in the area of race equality and cultural competence. These were:

- energising the organisation
- demographic profile – i.e. surveying the local population, needs assessment, and commitment to research
- access and service delivery
- human resources
- community development.

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 (Scottish Executive, 2003).

1.6

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 into 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, 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 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.

1.7

The Equality and Human Rights Commission was formed in 2007 with the aim of promoting human rights and creating a fairer Britain. It took over the role and functions of the Commission for Racial Equality, the Disability Rights Commission and the Equal Opportunities Commission, adding new responsibilities for sexual orientation, age, religion and belief, and human rights. The Commission in Scotland is committed to seeking evidence of where the most significant inequalities lie and understanding the underlying causes. They are currently working with the Scottish Government and others to improve the collection and presentation of equality statistics in national and other surveys (Equality and Human Rights Commission in Scotland, 2009). The Mutuality, Equality and Human Rights Board was established in October 2008. Its responsibilities include overseeing commitments across the NHS in Scotland on equality and human rights.

1.8

In 2008, the Scottish Government published *Equally Well*, the report of a ministerial task force on health inequalities (Scottish Government, 2008). Whilst its main focus was on health inequalities associated with socio-economic circumstances, it also acknowledged the important role of other factors, such as ethnicity. In particular, it recommended that the Government should commission a review of health data needs that covers gender, ethnicity, age, disability, religion and belief, sexual orientation and transgender, and which should include a plan of action to fill the information gaps identified.

Ethnic diversity and health: many questions to be answered

1.9

Scotland now therefore has a very strong policy foundation for addressing the health and social inequalities that may exist in relation to ethnicity and other factors such as disability, religion and sexual orientation. However, as the policies themselves recognise, taking effective action to address inequalities requires accurate information about their nature and extent, as well as a good

understanding of the many factors which may contribute to them. A review of research in Scotland on ethnic minority issues was commissioned by the Scottish Government and published in 2001 (Netto *et al*, 2001). This demonstrated clearly that there was relatively little information about many aspects of the health of ethnic minorities in Scotland (see Chapter 3). The review made a series of recommendations about how to improve the situation, but by 2005 little progress had been made.

1.10

With the support of the Scottish Government, the Working Group responsible for this report has therefore taken up the challenge which the review by Netto and colleagues has highlighted. The report aims to make a set of practical proposals for how we can use research to improve the availability of accurate and up-to-date information about the links between ethnicity and health in Scotland and the nature and extent of related inequalities. Providing better information should lead to better policies decisions, which should in turn contribute to better health and a fairer society.

1.11

Our report starts with a brief look at the rapidly changing ethnic makeup of Scotland, charting how we arrived at where we are today. It then reviews the research on ethnicity and health conducted in Scotland over the last forty years. This is followed by a summary of our knowledge of the health status of the main ethnic minorities in Scotland. We then consider the key ethical questions which need to be addressed and highlight some of the methodological issues that research in this field throws up. Finally we set out the five priorities for action, which we believe will enable Scotland's research needs in this area over the next decade or so to be met.

1.12

Our report should be seen in the context of the wider equality agenda described above, which stresses the importance of making sure that information on all the different equality groups is available 'to inform and support the process of mainstreaming and developing work on equality' (Scottish Executive, 2000b). The research and information needs of each equality group vary greatly and each presents different challenges which cannot necessarily be addressed in the same way. It is hoped that developments in the field of ethnicity and health can pave the way for progress on the other equality groups.

Aims of the report

1.13

The aims of this report for 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.
- 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 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. Already by the 1850s, there were around a quarter of a million Irish-born people in Scotland, representing 7.2% of the Scottish population in the 1851 Census. Irish immigration continued on a significant scale until the 1920s, when it started to decline. 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. A vivid account of the varied experience of Irish, Lithuanian, Italian and Jewish immigrants in Scotland is provided by Devine (2000).

2.3

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, Bangladeshis and Chinese settling in Scotland over the next 50 years, mainly in and around Glasgow and Edinburgh. During the past 10 years, the number and diversity of immigrants has increased substantially. Several thousand asylum seekers and refugees, mainly from 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 exceeded the number of emigrants (Registrar General, 2008).

Table 2.1: Scottish population by ethnic group at the 2001 Census

<i>Base population</i>	<i>Number</i>	<i>% of total population</i>	<i>% of minority population</i>
White Scottish	4,459,071	88.09	na
Other White British	373,685	7.38	na
White Irish	49,428	0.98	na
Any other White background	78,150	1.54	na
Indian	15,037	0.30	14.79
Pakistani	31,793	0.63	31.27
Bangladeshi	1,981	0.04	1.95
Chinese	16,310	0.32	16.04
Other South Asians	6,196	0.12	6.09
African-Caribbean	1,778	0.04	1.75
African	5,118	0.10	5.03
Black Scottish or any other Black background	1,129	0.02	1.11
Any Mixed background	12,764	0.25	12.55
Any other background	9,571	0.19	9.41
All minority ethnic population	106,302	2.01	100
All population	5,062,011	100.0	na

The 2001 Census in Scotland

2.4

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. Table 2.1 shows that in 2001, non-White ethnic minorities accounted for 101,677 people, or just over 2% of the population (Chief Statistician, 2004). 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.

Changes since the 1991 Census

2.5

Scotland is less ethnically diverse than some other parts of the United Kingdom. In 2001, 2% 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 belonging to 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.

Pupils in Scotland

2.6

The growth in the proportion of the Scottish population who are from ethnic minorities is reflected in the 2008 census of children in publicly funded schools in Scotland (Chief Statistician, 2009). This found that 6.9% of pupils were recorded in categories other than 'White-UK' or 'unknown' in 2008 compared with 4.8% in 2004. Between 2004 and 2008, the number of pupils recorded as 'White-UK' fell from 663,000 to 619,000, whereas the number of pupils rose in every category of ethnic minority. The largest rise was seen in pupils recorded as 'White-other' (Table 2.2). The 2008 Census found that 13.9% of pupils in Glasgow were from an ethnic minority and 3.3% were asylum seekers or refugees – the latter representing 91% of all such children in Scotland.

Country of birth

2.7

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 with only 18% of Africans.

Table 2.2 Pupil ethnicity in the census of children in publicly funded schools in Scotland, 2004-2008

	2004	2005	2006	2007	2008
White – UK	662,856	656,059	644,649	632,154	618,829
White – Other	8,022	8,926	10,357	12,566	14,401
Mixed	4,814	5,208	5,458	5,805	6,146
Asian - Indian	2,163	2,223	2,388	2,591	2,825
Asian - Pakistani	8,680	8,753	9,129	9,505	9,850
Asian - Bangladeshi	473	499	515	511	541
Asian - Chinese	2,200	2,276	2,275	2,246	2,248
Asian - Other	1,531	1,906	2,199	2,538	2,749
Black - Caribbean	105	105	110	124	126
Black - African	1,529	1,834	2,090	2,431	2,815
Black - Other	490	508	464	470	460
Occupational Traveller	176	176	207	208	219
Gypsy / Traveller	349	418	428	448	504
Other Traveller	56	76	91	105	92
Other	2,500	2,250	2,284	3,017	3,005
Not known / not disclosed	27,066	21,663	19,747	17,174	16,467
Total	723,010	712,880	702,391	691,893	681,277

Mother's country of birth

2.8

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 2.3 shows all births in 1991, 2001 and the last four years. Overall, the proportion of births to mothers born outside the UK rose from 5% to 11%. Births to mothers born in the UK fell from 63,702 in 1991 to 51,432 in 2007 – a fall of 19%. Births to mothers born outside the UK rose from 3,322 in 1991 to 6,349 in 2007, a rise of 91%. Of these births, women born in countries of the European Union (EU) rose from 885 to 2,388 (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 2,437 to 3,961 (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.

Table 2.3 Mother's country of birth of children born in Scotland in 1991, 2001 and 2004-07 (Registrar General 2008)

		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, Channel 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	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, Bdesh, 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

Religion

2.9

In the 2001 Census, two thirds of the Scottish population reported having a religion; of which, the most common was Christianity (Table 2.4). 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%).

Migrant Workers

2.10

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. From 1 May 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 have had to register under the Workers Registration Scheme administered by the Department of Work and Pensions. However, many do not register and there is no need to de-register on leaving.

2.11

Migrant workers entering the UK apply to Jobcentre Plus for a National Insurance number which is recorded on the National Insurance Recording System held by Her Majesty's Revenue and Customs. These sources provide the bulk of data to estimate migrant numbers. Not all migrant workers apply and movements within the UK are not tracked. The figures thus 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, but many migrants do not register and their ethnicity may not be recorded.

Table 2.4 : Scottish population by current religion in the 2001 Census

	<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>	3,389	67
No religion	1,394	27.5
Not stated	278	5.5
Total	5,062	100

2.12

Statistics relating to the numbers of National Insurance numbers allocated by the Department of Work and Pensions are regularly published. They show 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 in 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. In 2005, dependants accompanied only 5% of registered workers, rising to 9% in 2006. Dependants were roughly equally split between those aged over 17 years and those under 17 years. Eight per cent of all new migrant entrants to the UK were initially based in Scotland. The largest proportion of these found work in the hospitality and catering industry (29%) followed by food/fish/meat processing (14%). The proportions in these business areas are quite different from the rest of the UK, where the administration sector was more common. 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 one year.

2.13

Table 2.5 shows the source countries of new residents entering Scotland in 2006 and 2007. Polish migrants formed by far the largest proportion. Whilst the largest numbers are found in the urban areas, migrants have located in all regions in Scotland, with the highest numbers proportionate to the local population being found in Angus, Western Isles, West Lothian, Moray, and Dumfries and Galloway. Thus, 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. It is as yet unclear what effect the economic downturn will have on migrant workers, with some reports suggesting significant numbers have returned to their country of origin since mid-2008.

Table.2.5 Overseas nationals entering Scotland and allocated a National Insurance Number: top twelve countries 2006/07 (Department of Work and Pensions 2007)

Country	Number
Poland	23,140
India	3,460
Slovakia	1,730
Australia	1,690
China	1,590
Ireland	1,250
Pakistan	1,180
France	1,160
Czech Republic	1,120
Lithuania	1,070
Spain	1,070
Nigeria	1,020

Asylum seekers and refugees

2.14

At UK level, the Home Office provides 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 Glasgow (Home Office, 2007). Figures up to the end of 2007 indicate that there were 3,910 asylum seekers in supported accommodation in Scotland, 3,905 of whom were in Glasgow (Home Office, 2008). However, these figures do not provide a reliable guide to the number of asylum seekers since they do not take account of those who subsequently leave or move to other parts of the UK. In addition, the totals do not always include dependants. There are no reliable estimates of the number of illegal immigrants.

2.15

Drawing on Home Office data, the Confederation of Scottish Local Authorities (COSLA) has published a statistical analysis of asylum seekers and refugees in Scotland up to the end of 2006 (COSLA, 2008). This gives information on

the nationality and geographical distribution of asylum seekers in Glasgow and reviews surveys conducted in Glasgow to examine the needs of asylum seekers. The limited information about refugees in Scotland is also summarised. 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 UK (Information Centre, 2008). However, they do not provide any data on where in the UK refugees are located.

2.16

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 three years of its existence, between June 2005 and June 2008, it had 8,475 successful applications. These came from many countries, with the five most numerous being India (2,828), China (2,119), Nigeria (1,027), Pakistan (435) and the USA (382). The results of the scheme were reported in 2008 (Kavenagh *et al*, 2008). The Fresh Talent: Working in Scotland scheme has now been replaced by a UK 'points based scheme'.

Conclusion

2.17

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 2003. 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. The 2011 Census will provide a welcome update of the situation. How we think further improvements can be made will be discussed in more detail in Chapter 6.

Acknowledgement

The material on migrant workers in Scotland was provided by Dr Joanne Morling. We thank Dr Morling and 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' Perspective (Netto *et al*, 2001). 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 between 1991 and 2000. For the present report, the literature search was extended to include the periods 1960 to 1990, and 2001 to 2007. Details of the search strategy for the updated review are given in Appendix 2. We did not include literature reviews or reports, such as NHS Board needs assessments, which did not primarily involve the collection or analysis of local data. Whilst every attempt was made to be inclusive, it is possible that some research reports – submitted, for example, as University dissertations or produced locally by a community organisation – may have escaped our attention.

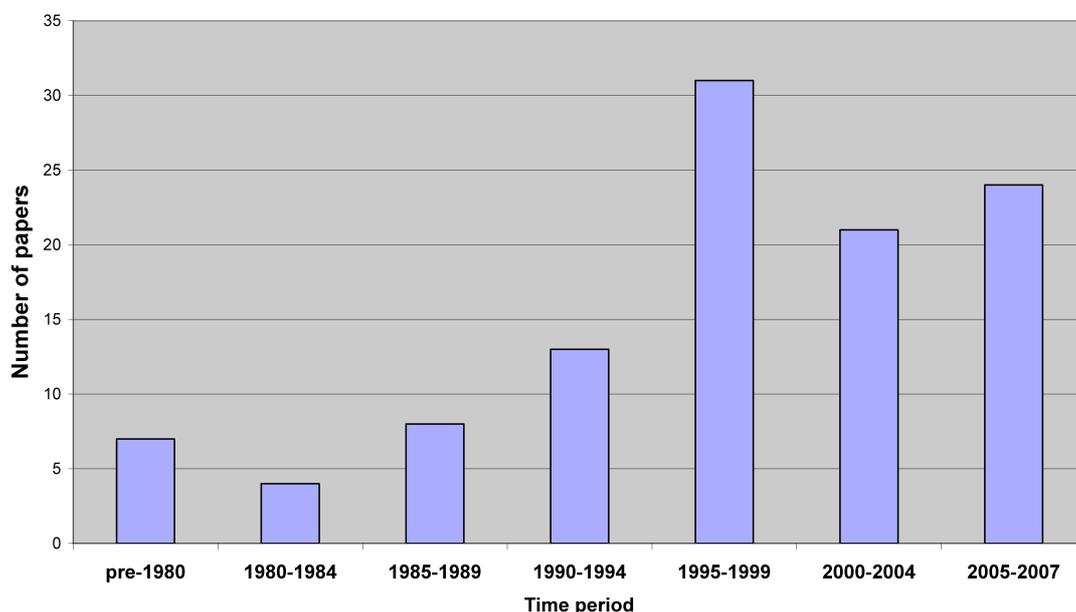
It was beyond the scope of the working group to review the much larger body of research on ethnicity and health carried out in England. Nevertheless, the working group recognises the usefulness and relevance of much of this work. In particular, an excellent regional analysis of inequalities between ethnic groups in health and health care in England was published by the Association of Public Health Observatories (Fitzpatrick *et al*, 2006).

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:

Figure 3.1 Research on ethnicity and health in Scotland: number of research papers in peer reviewed journals



- 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 University of Edinburgh, Department of Public Health Sciences (2001–)

The MRC Social and Public Health Sciences Unit runs an ethnicity and health research programme, currently led by Seeromanie Harding, 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 1962-76 showed a high incidence of rickets and osteomalacia in the Glasgow Pakistani Community (Dunnigan *et al*, 1962; Arneil and Crosbie, 1963; Dunnigan and Smith, 1965; Ford *et al*, 1972a; Ford *et al*, 1972b; Ford *et al*, 1973; Dunnigan *et al*, 1976). This was thought to be due to inadequate exposure to sunlight and a diet deficient in vitamin D. It was not until 1979 that a campaign was launched to provide children in the Glasgow Asian Community with vitamin D

supplements (Dunnigan *et al*, 1981). 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. Further work confirmed the marked north-south gradient in Asian rickets in the UK (Henderson *et al*, 1987). 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.

Diet and Cancers in South Asians

3.4

Dunnigan and his colleagues studied the dietary and smoking patterns of South Asians in the West of Scotland and their relationships with the apparently low rates of colo-rectal, breast and lung cancer compared with the White Scottish population (Dunnigan *et al*, 1982; Robertson *et al*, 1982; Matheson *et al*, 1985).

1986 to 2000

South Asians

3.5

Raj Bhopal and his colleagues initiated the modern era of ethnicity and health research in Scotland with studies of the use of traditional medicine, immunisation, reproductive health, dental health and school-age smoking and drinking among South Asians in Glasgow (Bhopal, 1986a, b, c; Bhopal and Samim, 1988; Firdous and Bhopal, 1989; Kay *et al*, 1989; Kohli, 1989). Rory Williams and colleagues carried out studies comparing a predominantly Punjabi South Asian population, aged 30 to 40 years, with the general population in Scotland. These studies 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 recently 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

3.6

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 (Anderson and Lean, 1995; Anderson *et al*, 2005; Bush *et al*, 1995a, 1995b, 1996a, 1996b, 1998; Williams *et al*, 1996).
- The traditional diet of South Asian people is generally considered healthy in 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 (Bradby, 1997; Munday and Oswald, 2000).
- British-born South Asians were found to approximate the general population more closely than recent South Asian migrants in relation to dietary choices, exercise, body mass and waist measurement. (Williams *et al*, 1996; Shams and Williams, 1997; Lean *et al*, 2001). However, studies by Williams (1993d) and Williams and Shams (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 Asians but this appeared to be developing in the 1990s as a standard of living gradient developed in the South Asian population.

Irish

3.7

A substantial body of research on the Irish population in Scotland found differences in mortality between those of Irish decent and others. These differences appear to be related to socio-economic factors (Williams, 1992; 1993a, 1993b, 1993c, 1994a, 1994b, 1997; Williams and Ecob, 1999; Walls and Williams, 2004). The role of Catholic–Protestant sectarianism as a contributor to inequalities in Scotland has been explored (Walls and Williams, 2003). However, no significant differences in health behaviours or in illness behaviour between Catholics and non-Catholics were observed (Abbotts *et al*, 1997, 1998, 1999a, 1998b). Mullen and colleagues studied the influence of Irish descent on tobacco and alcohol use (1996) and food consumption (2000).

South Asian and Chinese Women

3.8

A number of studies in the 1990s 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 Domokos, 1992, 1993, 1995a, 1996a, 1996b, 1997b, 1997c, 1998a, 1998b; Baraitser 1999). 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 and

Mcllwaine, 1995). Many preferred a mix of traditional and Western medicine. Studies of disparate groups of ethnic minorities (Zainal *et al*, 2000) 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 requirements, insufficient female doctors and a lack of knowledge of how to access emergency services (Cheung, 2002a, 2002b).

Communication with health professionals

3.9

Communication with health professionals was seen as a key issue (Bowes and Domokos, 1995b, 1996c, 1997a; Hampton, 2000a). Bowes and Domokos pointed out that the preoccupation 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 Domokos, 1996a).

Travellers

3.10

The disadvantages faced by the Scottish travellers' community in accessing health and social care services were described by Lloyd and Morran (1999). These 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.

There have been further limited studies of the health of travellers in Scotland (Smart *et al*, 2003) and their social care needs (Morran, 2002).

Access to services

3.11

Several studies evaluated the role of particular services or projects. (Ahmed *et al*, 1995; Hampton, 1995, 1997; Pershad and Tyrell, 1995; Mackintosh, 1998; Munro, 1996; Chinese Health Force, 1998; Mahmood and Shariff, 2000; Milne *et al*, 1998; Minhas, 1999; Bitel and Ssanyu-Seruma, 2005). 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 recent study of the care experiences of South Asian Sikh and Muslim patients in Scotland with life limiting illness and their families found that service provision was unsatisfactory in many respects (Worth *et al*, 2009). A recurrent theme of these 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.

Mental health

3.12

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 Rigg, 1991; Shams and Williams, 1995; Srivastava and Bowes, 1996; Donachy, 1997; Tyrell, 1998; Austin and Munro, 1997; Fatunmbi and Lee, 1999; Kaifi *et al*, 1995; Shariff, 2000; Bowes and Wilkinson, 2003). An excellent review of existing UK and Scottish research on this subject was published in 2005 (Myers, McCollam and Woodhouse, 2005). This highlighted the complexity of the issues, given the great heterogeneity of ethnic minorities in relation to culture, religion, language, socio-economic circumstances, age and gender – all factors which influence mental health. Refugees and asylum seekers were particularly likely to experience mental health problems as a result of experiences in their country of origin, as well as in the UK where the uncertainty of their status and typically low income made them especially vulnerable. The combination of all these factors can present services with a challenge they may be ill-equipped to meet. Common themes include;

- the importance of valuing individuals' 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
- 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*, 2001b).

2001 to 2009

Linking ethnic identity with death certificates and hospital data

3.13

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*, 2005). 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 among South Asian men and women than non-South Asians but the survival of South Asians was better (Fischbacher *et al*, 2007a, 2007b). This technique provides new opportunities to compare the health status of ethnic minorities with the majority population.

Diabetes and heart disease among South Asians

3.14

A number of studies have focused on the higher incidence of diabetes and coronary heart disease among South Asians than in the general population. A survey of diabetic patients from ethnic minorities in Glasgow found levels of knowledge about diabetes was poor (Baradaran and Knill-Jones, 2004). A detailed needs assessment of diabetes among ethnic minority groups and current service provision provided much valuable information (NRCEMH, 2004). A subsequent controlled trial of an education programme found it was feasible and able to improve knowledge and attitudes. However, there was no net benefit compared with a control group (Baradaran *et al*, 2006a). 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 GPs, and 80% did not monitor trends of complications of diabetes by ethnic group (Baradaran *et al*, 2006b). 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). Their attitudes to specialist diabetic services were generally positive (Lawton *et al*, 2006a). 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 (the Khush Dil project) found modest reductions in cholesterol, blood pressure and weight after a six month follow-up (Matthews *et al*, 2007). A study of diabetic patients in Tayside showed that the care received by South Asian patients was equitable with that of the majority population (Fischbacher, 2009).

Greater Glasgow surveys

3.15

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 (FMR Research, 2004). 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

3.16

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 as other studies have shown a high prevalence of use of alternative tobacco products, particularly in the Pakistani and Bangladeshi communities (Bakshi *et al*, 2002). 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). The available information on alcohol consumption in minority ethnic groups has recently been reviewed (Jarvis, 2009).

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

3.17

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 African-Caribbean	64
Chinese	63
Indian	57
General Population	30

A report by Heim and colleagues (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 (Khan *et al*, 1998a, 1998b; Ross *et al*, 2004; Bradby and Williams, 2006; Bradby, 2007).

Diet and physical activity

3.18

Around half the Chinese, African and African-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 and 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 African-Caribbeans, the average number of days of moderate activity decreased with age. 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*, 2006b).

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 or vegetables daily
Chinese	53
African and African-Caribbean	47
General Population	34
Indian	33
Pakistani	19

Oral and dental health

3.19

Chinese, African and African-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 African-Caribbeans were most likely to have all their own teeth but least likely to have visited a dentist in the last six months. Conway and colleagues (2007) have studied the interacting effects of ethnicity and socioeconomic circumstances on dental health in children. Mullen *et al* (2007) explored the attitudes to dental health of second generation ethnic groups.

Sexual health

3.20

There has been relatively little focus on sexual health, with only small-scale local studies being conducted (Bradby and Williams, 1999). Abstinence from sexual behaviour 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).

Asylum seekers and refugees

3.21

Reports 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, poverty, racism, lack of interpreting services and limited health services were highlighted (Marsden *et al.* 2005; Green, 2006). Studies of 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 UK (Ferguson and Barclay, 2002; Barclay *et al.*, 2003; Mojee *et al.*, 2003). 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. In a study of socially isolated refugees in Edinburgh, over half had symptoms compatible with a diagnosis of anxiety disorder and 40% with a diagnosis of depression (Ager *et al.*, 2002). Although likely to be a biased sample, the study provides useful pointers to refugees' experience and the scope for supportive action.

Major gaps in our knowledge about ethnicity and health in Scotland

3.22

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:

- 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.
- There has been very little research on the relationship between ethnicity and socio-economic status in Scotland and how they combine to influence health.
- Very little research has been undertaken to evaluate the appropriateness and effectiveness of statutory mental health services for minority ethnic communities.
- 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.

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
- 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 (2005) 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.

Patterns of Mortality

Ethnicity

4.4

The death certificate does not record ethnicity so direct analyses by ethnic group are impossible. This needs to be rectified. Fischbacher and colleagues (2007) 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). 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 certificate. There are a number of other problems with country of birth analyses discussed by Bhopal (2007). For example, in the first half of the twentieth 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 a result, of all the people aged over 70, living in Scotland but born in India, most are White and only a minority have Indian ethnic origins. Despite these problems, country of birth analyses have provided interesting and useful information: 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 with 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 notably 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 to 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 those of the same age living in England and 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 Pakistan, Bangladesh, China 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, which hospital staff are recommended to complete, it is currently only being completed on 24% of hospital admission and day-case records. This renders it useless, at present, for studies by ethnic group (ISD Scotland 2009).

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 carried out 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 to Mar 2003). Results arranged by country of birth and sex, with standardised mortality ratios (SMR) (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				
Scotland	171488	171488	100	100–100
UK (other)	12827	15634	82***	81–83
N. Ireland	1336	1430	94*	89–99
Ireland	1716	1688	102	97–107
India	419	431	97	88–107
Pakistan	110	156	71***	58–85
Bangladesh	5	11	44	14–103
China	71	95	75*	58–94
Hong Kong	93	108	86	69–105
Rest of the world	2760	3332	83***	80–86
Men				
Scotland	152456	152456	100	99–101
UK (other)	11889	15766	75***	74–77
N. Ireland	1204	1201	100	95–106
Ireland	1507	1393	108**	103–114
India	473	535	88**	81–97
Pakistan	171	272	63***	54–73
Bangladesh	9	21	44**	20–83
China	67	93	72**	56–91
Hong Kong	103	148	69***	57–84
Rest of the world	3325	3848	86***	83–89

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

Table 4.2 Observed and expected deaths among Scottish residents (25 to 69 years) from coronary heart disease for 6.25 years (Jan 1997 to Mar 2003). Results arranged 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				
England & Wales	38017	38018	100	99–101
Scotland	5466	3526	155***	151–159
UK (other)	282	317	89	79–100
N. Ireland	36	25	143*	100–198
Ireland	54	33	166***	124–216
India	23	11	210**	133–315
Pakistan	19	7	258***	156–404
Bangladesh	2	0	742	90–2680
China	1	2	50	1–279
Hong Kong	3	3	88	18–257
Rest of the world	66	68	97	75–123
Men				
Eng/Wales(ref)	118464	118462	100	99–101
Scotland	13944	10255	136***	134–138
UK (other)	967	1045	93*	87–99
N. Ireland	111	75	148***	122–179
Ireland	100	76	132**	107–160
India	61	44	138*	105–177
Pakistan	49	31	160**	118–211
Bangladesh	1	3	38	1–210
China	3	6	49	10–142
Hong Kong	8	16	51	22–101
Rest of the world	209	182	115	100–131

(*) Two sided test $p < .05$ (**) 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.

Exploring the potential for linkage and the value of the information so obtained is part of 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 proportion stating they were not in good health varied from about 4% in people of Chinese and African origin to 15% among White people of Irish origin. The cross-cultural validity of such self-reported data is unknown.

Scottish Health Survey and other surveys

4.14

This survey collects ethnicity data but there is no targeting of minority ethnic 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 made to ensure cross-cultural validity of questions and measurements. This needs to be assessed more systematically, particularly to see whether data from the four 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 only large enough to permit a limited analysis of South Asian pupils. There is a lack of usable ethnicity information in surveys such as the Scottish Household Survey, the Health Education Population Surveys and the Health Behaviour of School Children surveys.

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, as well as maternal and child health. Reports on cancer and mental health will be prepared in 2010. There are positive developments in the ethnic coding of diabetes registers. However, unless a means can be found to record ethnicity consistently in primary care, and on hospital databases and death certificates, our ability to assess the health of ethnic minorities in Scotland will remain extremely limited.

Chapter 5

Research Ethics and Methods

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. A more detailed discussion of these issues can be obtained in Bhopal (2007).

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:

1. **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). Research has also been used to perpetuate racist stereotypes (for example, that certain races are less intelligent than others) (Bhopal, 1998). 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.
2. **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 healthcare 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.

- 3. 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 men of African origin. 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.
- 4. 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. 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.

- 6. 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. As a result, ethnic minority groups have been largely bypassed in the larger scale and expensive kinds of research such as trials and cohort studies. Thus, if ethnicity is to be treated as an important issue in health and healthcare 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.
- 7. 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

5.4

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) 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

5.5

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 they are 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.

5.6

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 upon, 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. A new ethnicity classification has been proposed by the Scottish Government for Scotland's 2011 Census. This was developed using a wide range of evidence from research, consultation and question testing (Scottish Government and GROS, 2008). It is designed to enable everyone completing the census to define their own ethnic group or background in a way that will allow the resulting data to be analysed both by broad categories of group (e.g. White, Asian, African or Mixed) and, when needed, in much more detail (e.g. Polish, Bangladeshi or Arab) with well over 100 separate identities being available.

5.7

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.

5.8

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

5.9

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.

5.10

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 (Vettini *et al*, 2001; Hanna *et al*, 2004, 2006, 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 adaptation is to be done adequately. If not, however, the validity of the results may be seriously diminished. In future Scottish research involving more than one ethnic group or language, all standardized questions and their translations should be prepared with the help of interpreters and validated before use in the field.

5.11

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 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 the meaning and acceptability of the translations, as well as the appropriateness of the response options, and instructions and modifications 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

5.12

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

5.13

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* highlighted the worldwide dearth of studies of health promotion interventions involving ethnic minorities (Netto *et al*, 2008; Netto *et al*, forthcoming).

Conclusions

5.14

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 weaknesses 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 would add 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 is 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 the 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 and 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. Large family size and close family links (including consanguinity in some populations) make 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 the action we consider is needed if useful research on ethnicity and health in Scotland is to be fostered. We then suggest what the future research priorities should be.

6.2

As described in Chapter 1, the Scotland Act 1998 gave the new Scottish Parliament the power to encourage equal opportunities and the Race Relations (Amendment) Act 2000 charged public bodies with the responsibility of eliminating 'unlawful racial discrimination and promoting equality of opportunity and good relations between people of different racial groups'. In the Scottish Government's Equality Strategy: Working Together for Equality (2000) there was a commitment to 'developing better statistics that provide information for different equality groups'. The strategy recognised the importance of research to 'identify issues to be addressed, provide the evidence to support action and help to signpost solutions to problems'. Among other things, it proposed conducting a survey on ethnic minorities in Scotland.

6.3

In the 10 years since the Scottish Parliament was established, the diversity of the Scottish population and the proportion of the population who belong to ethnic minorities have been growing rapidly. Our understanding of the implications of these unprecedented developments for health and healthcare services has not kept up. Despite these clear commitments and the growing need for information, relatively little practical action has been taken. There continues to be no explicit encouragement for health researchers to focus on issues related to ethnicity or 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.

6.4

How can such a commitment to equality of opportunity be put into effect in a way that safeguards and improves the health and wellbeing 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 the Scottish 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

6.5

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 otherwise (National Institutes of Health, 2001). 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

6.6

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.

6.7

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 wellbeing, 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 research and development project and programme steering and advisory structures
- improving representation of minority ethnic communities in the research and development workforce.

We support this action plan and think something similar should be adopted in Scotland.

Policies of other bodies

6.8

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 (MRC) nor the Wellcome Foundation have a published policy, although we were told the MRC is developing one.

Priorities for future research in Scotland

6.9

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

6.10

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 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 particular 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.

6.11

Whilst there has for some time been a requirement upon NHS Boards routinely to record ethnicity for hospital admissions and new out-patient appointments, a recent report from ISD Scotland showed that recording of ethnicity remains very low, although there have been distinct improvements in some NHS Board areas (ISD Scotland, 2009). The overall level of ethnic coding for hospital admissions was 24%. The highest levels were 66% and 58% in two Boards but six Boards achieved less than 1%. For outpatients, the overall level was 10% with six Boards recording less than 1%. The seriousness of this issue has been recognised by the Scottish Government. The Director of the Healthcare Policy and Planning Directorate wrote to all NHS Boards in December 2008 highlighting the unacceptably low levels of recording of ethnicity¹. The issue was discussed at the January meeting of the Mutuality, Equality and Human Rights Board. At the time of publication of the present report, Government proposals for action to improve recording were awaited.

6.12

In this respect, England is well ahead of Scotland, with over 90% of hospital admissions now being ethnically coded. This did not happen overnight. 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.

¹ Letter from the Director of the Healthcare Policy and Planning Directorate 15 December 2008
<http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/MEHRB/EthicsData>

6.13

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. Such a system should be as simple as possible and avoid duplication of effort. We have highlighted in Chapter 5 the new ethnic classification proposed for use in the 2011 Census (para 5.13). We **recommend** that this classification is adopted by all organisations and researchers as the standard for routine use. It will provide a consistent denominator against which other data, e.g. mortality and hospital admissions, can be compared over time. If the circumstances of particular research dictate otherwise, a different classification could be devised to suit the study.

6.14

If ethnic identity is to be related to death rates from specific diseases then it must be recorded on or easily linked to the death certificate. At present, only the deceased's country of birth is recorded. As discussed in Chapter 4, this has severe limitations as it does not provide any information about the ethnic origins of people born in the UK and it may include people who happen to be born in a country but have no ethnic link to it. We therefore **recommend** that the death certificate in Scotland is amended to enable ethnic identity to be recorded using the same ethnic classification as for the census. This recommendation is fully supported in principle by the Registrar General, but a number of practical issues will need to be addressed to ensure successful implementation.

6.15

If ethnic identity is to be related to hospital admissions or primary care contacts then it should be recorded on or easily linked to the databases which record this information. Ideally, information about ethnic identity should thus 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. Ethnic identity is a suitable piece of information for inclusion on the CHI as it should not vary over time. 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. We therefore **recommend** that the Scottish Government should require ethnic identity to be one of the items recorded and should develop an action plan to achieve this by 2015. This should be carried out with the individual's consent – or in the case of a child, the consent of a parent or guardian – on the Community Health Index for every person registered with the NHS. The same classification as for the 2011 Census should be used. Given the potentially sensitive nature of the information, access to the full CHI database would require to be subject to strict security procedures. Once consistent ethnic recording is in place, it will enable the extent of ethnic inequalities in health to be fully appreciated and will provide a sound basis for taking action to address them.

6.16

Achieving linkage to the CHI will take time and how it will be done will require further consideration. As the vast majority of the population is registered with a GP whom they visit at least once a year, doing this through primary care is one option. As should already happen, patients should be routinely asked about their ethnic identity when being admitted to hospital or registering for a new hospital clinic appointment. With the individual's consent, this information could then be added to the CHI. Given the current very low rates in most NHS Boards, 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, e.g. HEAT, NHS Scotland would make faster progress. Progress could be evaluated through board accountability reviews. 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 collects 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.

Once ethnic identity is linked to the CHI, then more time will be available to admitting-staff to ask hospital patients about other less permanent (but no less important) information such as disabilities, religion and, where appropriate, sexual orientation.

Priority 2: Making the best use of data linkage methods

6.17

In the current circumstances, and for at least several years to come, ethnic identity will not be readily linked to death certificates, hospital admissions or other health service databases. Consequently, our 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, as well as 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 and is being planned for Phase 3. This will allow analyses of ethnic variations in morbidity and service use and give an indication of variations in the quality of care by ethnic group. We therefore **recommend** that the Scottish Government gives full support to the research programme which links the ethnic coding on the Census to a range of health-related databases. Once ethnicity is recorded on death certificates and the CHI, the need for this approach will cease.

Priority 3: A health survey of ethnic minorities in Scotland

6.18

The third priority is to conduct a survey on a sufficiently large sample of ethnic minorities in Scotland which can provide information about a wide range of health behaviours and risk factors, such as the prevalence of smoking, alcohol consumption, eating behaviour, levels of physical activity, obesity, etc. and compare the findings with those for the population as a whole. One approach considered was to extend the revised Scottish Health Survey to include an ethnically boosted sample of the population. However, the Scottish Health Survey Review Group and the Scottish Centre for Social Research concluded in 2008 that using the Scottish Health Survey for this purpose would be neither practical nor cost-effective: screening ethnic minority groups on a very large scale would be needed to yield a reasonable number of potential participants. Many of the questions would have to be modified, translated and validated for use with different ethnic groups. They concluded that 'survey assessment of minority ethnic health was best achieved by an independent survey designed specifically for that purpose'.

6.19

Information relevant to ethnic minorities living in Scotland will be available from the Understanding Society Survey being led by the Institute of Social and Economic Research at the University of Essex². This will have a total sample size of 40,000 households containing around 100,000 individuals from throughout the UK. The survey will include an ethnic minority boost sample of 3,000 households with at least 8,000 individuals. The study will interview each participant every 12 months. It will cover a wide range of topics including health, disability, education, origins and nationality, family and partnerships, income, earnings, wealth, savings and expenditures, current employment, transport and communication access, child care and other care responsibilities, life satisfaction, community, leisure, and political participation. Although only a small proportion of the ethnic minority households in the survey will be Scottish residents, much of the information about ethnic minority groups across the UK will be of relevance to those in Scotland. Careful consideration of the first wave of results from the survey, due out in 2010, would provide a good basis for determining the scale and content of a Scottish survey. Using some of the questionnaire modules from the UK survey would also allow direct comparison with the same ethnic minorities in other parts of the UK. The Understanding Society survey and a complementary Scottish survey would be particularly useful for enabling the relationships between ethnic identity, socio-economic status and health to be better understood.

6.20

In order to achieve information of acceptable representativeness from a Scottish survey, a sample of around 500 would be needed for each ethnic group. Based on information from similar surveys, the estimated overall cost per interviewed subject would be about £1,000. If there were to be six ethnic groups, e.g. Indian, Pakistani, Chinese, African and African-Caribbean, Polish

² Further information available at www.understandingsociety.org.uk

and Italian, this would amount to a total sample of 3,000 at a cost of around £3m. Conducting such a survey might be more efficiently done if it was restricted to the Glasgow area where a similar survey was conducted a few years ago. Savings could also be made by using previously validated questionnaires from the Understanding Society survey. We therefore **recommend** that a survey of ethnic minorities living in Scotland is conducted between 2011 and 2012 with the aim of adding significantly to the information obtained from the Understanding Society survey.

Priority 4: Coordinated research on major health problems and issues

6.21

The fourth priority is to conduct health-related research with two main aims. The first is to focus on the evaluation of larger scale interventions designed to address major preventable or treatable contemporary health problems such as diabetes, heart disease, cancer, obesity and depression. Such interventions need not be exclusively focused on ethnic minorities but should involve them in ways that can allow meaningful conclusions to be reached. They also need not be conducted wholly in Scotland: opportunities for collaboration with researchers in other parts of the UK and elsewhere should be taken to the full. Decisions on what to study should be based on a thorough understanding of existing research. For example, a recent report by Netto *et al* (2008) reviewed the international research literature on interventions which aimed to prevent cardiovascular disease and cancer in Pakistani, Chinese and Indian communities. It showed very little relevant research has been done. This review has led on to a new programme of research aimed at identifying the adaptations in mainstream health improvement interventions which need to be made to make them suitable for different ethnic minorities (Netto *et al*, forthcoming).

6.22

The second aim is to facilitate smaller-scale qualitative studies of key related issues such as understanding of and attitudes towards mental illness, HIV infection or terminal illness; barriers to behaviour change in relation to diet, physical activity or tobacco use; and of the perceptions and experience of ethnic minorities in the use of health and social care services. These should be carried out to a sufficiently high standard to yield results and insights that can be published in peer-reviewed journals and have the potential to influence policy.

6.23

Achieving both aims will require the following:

- 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.

We therefore **recommend** that the Scottish Government should encourage and support

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

Priority 5: Catalysing, coordinating and using research

6.24

Until now, research on ethnicity and health in Scotland has lacked a focal point through which ideas can be stimulated and supported, the overall research effort can be coordinated, and the findings disseminated and channelled into policy and service delivery as appropriate. We think this could best be achieved by establishing a new multi-disciplinary steering group. We therefore **recommend** the establishment of a Scottish Ethnicity and Health Research Group to catalyse and coordinate high-quality relevant research and make the best use of the findings. As well as overseeing research conducted in Scotland, it should also maintain a watching brief over relevant research in the rest of the UK and, where relevant and practical, other parts of the world. Given the role of its new Equality and Planning Directorate, we **recommend** that the new Group is hosted by NHS Health Scotland.

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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) Scotland
Dr Dermot Gorman	Lothian NHS Board
Dr Imelda Hametz	Analytical Services Division, Scottish Government
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

Literature search strategy for the period 2001–2007

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 year period 1991–2001. The audit was conducted by Dr Gina Netto and colleagues (Netto et al 2001). 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 the 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 the period 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, Gujerati, 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