Chronic diseases in Europe’s migrant and ethnic minorities: challenges, solutions and a vision

Raj Bhopal

The pattern of chronic disease varies hugely internationally, and this is now reflected in Europe’s multi-ethnic populations. This is creating challenges for epidemiology, public health and clinical care. Human rights legislation and health policies are mandating equity of service i.e. equal needs being met equally well. Indicators of race and ethnicity demonstrate important variations in health and health care, but the data are sparse, especially in Southern and Eastern Europe, and for some ethnic groups across the continent. Ethnic coding of routine health databases is required. The task will best succeed as a national one, with European level coordination and guidance on concepts. Pending this achievement, data linkage techniques can help fill the information gap. One of many ongoing debates that need resolution across Europe is on the preferred indicator of ethnicity, related terminology and mode of measurement. Original research also needs expansion, especially in relation to cohort studies and trials and boosted samples of ethnic minority groups in large scale European health surveys. Such work may require European legislation of the kind that has been effective in the United States (NIH Revitalisation Act 1993). A dialogue between policy makers, funders, researchers and practitioners is needed urgently as a precursor to engaging the public.

Introduction: ethnic diversity in Europe and its relevance to chronic diseases

The pattern of chronic diseases, including cardiovascular problems such as stroke and myocardial infarction, and cancers, varies across the world, demonstrably for environmental reasons, and mostly theoretically, for genetic ones. These risks and patterns accompany migrant populations, and even their descendents, creating further complexity and new patterns in the countries of migration. Europe is still tiring to adjust to its role as a recipient of immigrants rather than a source of emigrants. As a part of this adjustment, it needs to assess the challenge of chronic disease among its now ethnically diverse populations. These challenges include the legacies of history, particularly racism and inequality. Johann Blumenbach’s landmark book ‘On the Natural Varieties of Mankind’, first published in Germany in 1775, concluded that despite its diversity there was unity of the human species. Blumenbach recognized the importance of this then controversial conclusion i.e. equal potential and equal worth of all human races. Europe was to undergo much turmoil, founded on the principle of European superiority, including the horrors of slavery, colonization, eugenics and then Nazism, before there was to be a consensus, prepared by UNESCO, on the essential equality of human beings. Europe has now become a multi-ethnic, multicultural continent that is founded on equality and human rights. A multi-ethnic continent presents vast social and scientific opportunities and challenges that are increasingly recognized, particularly by the law. European law and policy requires Member States to meet the health care needs of minority ethnic communities.

Why give specific attention to migrant and ethnic minorities’ needs in relation to chronic diseases?

Migration, ethnicity and race imply major differences in environment and culture, and some differences in biology, which inevitably lead to inequalities in health. These inequalities are often stark and are easily demonstrated by variables, such as country of birth, ethnicity and race. Data by indicators of ethnic group are required to establish the extent of health inequalities and inequity in health service provision, choose between interventions i.e. set priorities, monitor the impact of efforts to reduce these inequalities and demonstrate our response to law, health policy, research governance and research ethics. There are, however, incredibly little data by ethnicity. The European Migrant and Ethnic Health Observatory (MEHO) is mapping the data landscape (http://meho.eu.com/ accessed third of September 2008). The landscape shows patches of green but is largely barren. European information, although limited, shows major variations in social and lifestyle risk factors and disease outcomes when analysed by ethnic group, country of birth, name and other proxy indicators of ethnicity. The 2- to 5-fold variations are common, and even bigger ones occur.

The most difficult questions are: what are we to do, what are our priorities, what resources are needed, how shall we target services and how shall we evaluate cost-effectiveness? The concepts that help us answer these questions are equity and inequity. An inequality or a difference that is unfair or unjust is inequity (equity being fairness).
Ethnic variations in smoking prevalence, which can be 20-fold in the same city,\textsuperscript{13,14} give insights into why information is needed. The differences are massive and far larger than seen in relation to sex, social class and other common epidemiological variables. But are these differences simply inequalities or are they inequities too? Mostly, White men and women have the highest prevalence of smoking. Is this unjust? If European institutions had systematically engineered this situation that would be unjust, but some 50 years of anti-tobacco education and smoking cessation services have been designed and targeted at the general population, effectively the White population. The high prevalence in Bangladeshi men (40–50%),\textsuperscript{13,15} in contrast, is an inequity for very little effort has been made to reduce smoking in this community.

When ethnic differences in major risk factors are so large, chronic diseases cannot be managed without ethnically disaggregated data. For example, we need to implement and evaluate interventions to reduce the high prevalence of smoking both to reduce smoking in specific groups (e.g. Bangladeshi and Pakistani men) and to maintain the low prevalence of smoking in relevant groups e.g. all South Asian women who provide a challenging and achievable goal for the rest of the population to reach. Such challenges cannot be met without data.\textsuperscript{1,1–16}

**What do we need to do to build up an evidence base for chronic diseases and their risk factors by ethnic group in Europe?**

**Routine statistics and linkage**

Vital statistics on general populations i.e. births, deaths, marriages, migrations and hospitalization, need to include ethnic group to provide an accurate picture of modern Europe’s health. Doing this reliably will be a long-term, multimillion pound endeavour. As each country has its own information systems this is probably best undertaken as a national exercise, with European co-operation especially on basic concepts and terminology. High-quality, complete, ethnic coding in routine information systems is unavailable anywhere in Europe. It is very difficult to achieve even with top level commitment. Though it has been firm NHS policy since 1995 in England the nation is still struggling to produce useful information with slow but steady progress.\textsuperscript{7,18}

Fortunately, there are some faster, albeit interim, solutions based on exact (ideal) or probability linkage methods. Computerized probability matching techniques can link hospital discharge and mortality to census records.\textsuperscript{19,20} Linkage methods are rapidly developing in Scotland and England,\textsuperscript{20,21} with linkage of primary and secondary care data sets to the census being the next challenge. The potential for European linkage studies is considerable. Already huge advances have been made in using linkage to explore ethnicity and health in Scandinavia,\textsuperscript{22} Holland\textsuperscript{23} and elsewhere in the world, especially New Zealand.\textsuperscript{24} Linkage methods, however, requires a census or population register that contains valid ethnic group codes. Most European countries have only nationality or country of birth, either in a census, or in a civic register.\textsuperscript{25,26} In the long term neither of these proxies for ethnicity will do.\textsuperscript{1}

**Original research**

The European record on investigator-led research on ethnic variations in chronic diseases is variable across countries, but even in the best circumstances in the North Western countries (United Kingdom, Holland, Scandinavia) the output is modest in relation to need. Mostly, we see cross-sectional surveys and analyses of existing medical records. There is, however, a scarcity of large-scale research e.g. cohort studies and trials. Ranganathan and Bhopal showed that 15 of 31 North American cardiovascular cohort studies provided data by ethnic group, but in Europe the figure was 0 out of 41.\textsuperscript{27} There is only one large scale, multi-ethnic cardiovascular study designed as a cohort in the United Kingdom, almost certainly the only one in Europe, that has almost completed recruitment—it is led by Kooner in West London\textsuperscript{28} and should have outcome data in about 5 years.

A similar picture emerges for virtually all large-scale research—especially trials.\textsuperscript{29,30} Experience of trials is building up in the health care setting, as in the Asian Diabetes Study in the Midlands of the United Kingdom.\textsuperscript{31} There are two major, funded European trials of diabetes prevention, focusing on South Asians—PODOSA in Scotland (recruiting from 2007 \textsuperscript{32}http://www.podosa.org/index.html); and Dhiaan in The Hague, Holland (recruiting planned from 2009; \textsuperscript{33}http://www.amc.nl/?sid=1415). The challenges of such trials are formidable, though they are achievable, albeit at higher cost than in trials on White populations. The United States has spurred recruitment of ethnic minorities groups with the NIH Revitalisation Act of 1993 with policy implementation in 1994, with amendments in 2000.\textsuperscript{34} This Act requires investigators to include ethnic minority populations and women unless there are scientific reason not to do so. Costs are higher for recruitment\textsuperscript{35} but this is not legally, ethically or scientifically acceptable as a reason for exclusion of minorities in the United States, at least for grants from the National Institutes of Health. Europe has no equivalent laws or policies but they need to be considered.

**Towards evidence-based interventions**

The effectiveness of chronic disease interventions in migrant and ethnic health needs to be established. The question of what works is problematic particularly for complex interventions, and in multi-ethnic populations the complexities are increased. Placebo-controlled, randomized, double blind trials are difficult to conduct, particularly for complex interventions. Do we always need evidence from such studies before we recommend an initiative in migrant and ethnic minority groups? If so, what do we do when there is no such evidence? Inaction is, surely, unjustifiable.

The biggest chronic problem facing Europe’s ethnic minority populations is coronary heart disease. What is the impact in Europe of cardiovascular risk factor control interventions in South Asians, who have the highest rates of disease? There are no trials. The only published data come from a pragmatic in-service evaluation of Khush Dil, a small project in Edinburgh, Scotland.\textsuperscript{36} That sparsity of evidence provides a stark reminder of how much research we need to do.

If studies on general populations included people from minority ethnic groups, either in proportion to their presence in the population or with boosted samples, in time, meta-analyses will be possible but only if populations are clearly described and a common nomenclature is used. Building up a database of this kind will be a major and expensive endeavour, will take many years and will need to be a European exercise. Trials and other major studies in Europe may need to be focused on minority populations to help build experience and set up infrastructures.

Meanwhile, we need to utilize descriptive data, pragmatic evaluations and general principles of what works. For simple interventions, e.g. folic acid supplementation for pregnant women to prevent congenital abnormalities, evidence of
effectiveness will probably be transferable across ethnic groups, although minor amendments such as dosing schedule may need changing. We can evaluate the impact by monitoring uptake and outcome if data are coded by ethnic group. Specific randomized trials are probably unnecessary for such simple interventions. If the proposed intervention is more complex, e.g. brief advice from the general practitioner to help Bangladeshi or Turkish smokers to quit, we almost certainly need to do a trial. We also need research on how to modify interventions to make them cross-culturally effective. The Health Technology Assessment Board in the United Kingdom has funded a project to explore this issue (commencing October 2008 principal investigator Aziz Sheikh with me as a coinvestigator; see http://www.nchta.org/project/1745.asp).

Conclusions and a vision
Health policy, research and health care should deliver work of equal quality and value to all ethnic groups. Otherwise our work may be inequitable, unethical and institutionally racist, if not illegal and it may perpetuate if not widen inequalities. Involvement of policymakers, researchers, practitioners and funders is essential to achieve this goal. Europe needs to consider legislation on research as in the United States, to prevent, control or manage chronic diseases in Europe’s ethnic minority groups but with or without this the following needs to be achieved:

- Ethnic minority populations should be active and energetic participants, and that requires a vigorous public engagement programme.
- Policies, strategies and health care plans, without exception, need to incorporate the ethnic dimension. Such actions should be evaluated for their impact on ethnic inequalities and adjusted accordingly before they are published and implemented.
- We need to sustain the beneficial aspects of minority ethnic group cultures (e.g. taboo on smoking in Sikhs). Where minorities exhibit the lowest rates of disease or risk factors they should provide the goal for other groups to emulate.
- More research—cohort and trial data especially—is vital to develop methods, and provide data.

By paying attention to migration and ethnicity, we improve the health and healthcare of the entire population. Europe has seen the challenge of chronic diseases in its multi-ethnic population and now needs to tackle it.8

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References
5 Bos V. Ethnic inequalities in mortality in the Netherlands and the role of socioeconomic status. Rotterdam: University Medical Center Rotterdam, 2005.
14 Nierkens V. Smoking in a multicultural society: implications for prevention. Academic Medical Center, University of Amsterdam, 2006.


