



Principles and Values of UK Research on Ethnicity and Health Tuesday 30th March 2010

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Mark Johnson: UK in a European Context

The UK has a long history of research into ethnicity, migration and health, and this has led to some notable achievements in creating a database of evidence and good practice in relation to services. At the same time, there are acknowledged areas where more is needed, and where we might learn from practice on the mainland. For a long time it could be said that we looked to the USA for leadership in models of policy and practice, while rejecting some of their taken for granted actions such as routine recording of 'race'. Similarly, 'race' and migration researchers on the European mainland watched UK developments for leadership in health issues, with a few exceptions. The balance has now changed significantly. Early UK research did look at migrant health and concentrated on 'port health', threats to public health, imported and 'exotic' disease. Cultural difference was pathologised and assimilation was expected to lead to reduced access barriers; other health inequalities would also then diminish. Struggle (or resistance) by UK BME groups rejected the label of 'migrant' and demanded attention to ethnicity, common diseases and access or exclusion processes affecting health differentials. (But health differentials have not got less, although BME health concerns are now 'core business').

European research has benefited from a presumption of recording much higher levels of personal data centrally while the UK population as a whole has resisted this, but equally, UK is almost alone in recording 'ethnicity' (but not language): mainland research is therefore more advanced in relation to issues of migration. UK policy has now to come to terms with recognition that we have still got (new) migrant populations while mainland policies have to recognise growing diversity among 'settler' populations and a disconnect with 'nationality' as a valid identity marker.

European strengths also include greater recognition of the value or need for migration (e.g. the value of EU internal migrants, and 'workplace health' as an EU priority), less paranoia about health tourism, and an acceptance of a multilingual society - hence translation of HRQoL instruments and research into language support. Policy development around Human Rights agendas and linked initiatives have also increased collaboration: I feel UK research has become sidelined or marginalised at times or not engaged in comparative studies and networks (HfH, COST-HOME etc) That said, the UK still has some advantages in collaborative or minority-led research (e.g. SAHF) and a strong minority community base prepared to support research and developments.

Raj Bhopal: Data Collection/Comparability across the EU

Comparable, routine health data for migrant and ethnic groups have not been collected systematically at a European level. Such data are important for providing clues to disease aetiology and directing public health interventions and health care resources. A major ongoing challenge for the European public health community is to fill in the current gap in the availability of comparable, ethnicity-specific data on the burden of cardiovascular disease (CVD), diabetes (DM) and other major diseases.

The aim of the Migrant and Ethnic Health Observatory – MEHO is to map and analyse routine data from across EU member states with the objective of generating ethnic group-specific health status indicators for five independent health areas, including CVD and DM. Specific tasks included 1) the identification of relevant ethnicity-specific databases on mortality and morbidity from CVD and DM in the EU countries; the analysis of 2) 'within-country' and 3) 'between-country' variation in mortality by country of birth (as a proxy variable for ethnicity) from total and cause-specific CVD in a few selected EU countries.

Generally, EU countries have a relatively weak base for assessing needs and planning health care interventions for its migrant and ethnic minority populations. For a few selected countries, examination of 'within-country' inequalities in CVD mortality shows that mortality risk vary by country of birth in a range of European countries, with substantial excess mortality observed for many migrant populations, particularly women. Mortality comparisons across countries suggest these are possible and potentially valuable. In most cases the observed mortality rates vary in each country, indicating that country-specific context is important to disease outcome. Future work will need to extend the range of countries providing data, and refine the methods to maximise comparability.

Key issues for discussion

- Can existing databases be meaningfully utilised for producing valid and comparable indicators of the burden of CVD/DM in migrant and ethnic minority groups in Europe?
- What immediate and long-term decisions are needed to increase the amount and quality of routine health data, disaggregated by ethnicity, in Europe?

Saffron Karlsen: Ethnicity and Other Determinants of Health

This presentation will present evidence for ethnic and religious inequalities in health and discuss the role of socioeconomic disadvantage and perceptions and experiences of victimisation as drivers of them. While research has traditionally focused on health variations by ethnicity, this work emphasises the need to consider how religious and ethnic identities together lead to particular forms of health experience. While, for many, there is considerable overlap between the ethnic and religious categories used by the census and other quantitative data sources, this work explores the potential for an investigation of religious-within-ethnic and ethnic-within-religious difference to offer insight into the patterning of health and the ways that religion, as well as ethnicity, can provide social locations which offer social resources, as well as identities that are racialised with consequent negative social and economic implications.

Key questions for discussion:

- (How) can we engage with the dynamic nature of 'ethnicity' and 'ethnic awareness' in research?
- What is the best way to determine which of the different drivers of ethnic inequalities in health are the most important/require most immediate focus – in terms of their relative contribution to health inequality, potential cost-effectiveness, wider relevance etc?
- Given the finite nature of available resources, is it more important to establish ways to remove/reduce racism in society or to remove/reduce its impact on health, or both?

Aziz Sheikh: Religious Identity and Ethnicity

Religious/faith identity is frequently overlooked in the context of epidemiological and health services research, despite the fact that this is for many people the key defining characteristic of their identity. This is problematic for a number of reasons, these including the fact that religious beliefs and practices can impact on health belief models and patterns of behaviour, which may in turn impact on health status and access to care. Overlooking this aspect of identity can sometimes also limit the opportunity to work with communities and their social and organisational structures. My central point is that, where relevant, the faith dimension needs to be considered as an integral aspect of ethnic identity; it is currently at the margins, which in turn inadvertently may result in our marginalising some minority ethnic communities.

Key question for discussion:

Can this be done in an inclusive way without exacerbating existing social tensions?

Sarah Salway: Enhancing the Quality and Quantity of Ethnicity Research

This paper describes some of the findings from a Joseph Rowntree funded project in which we used a series of review and consultation exercises to explore the feasibility and desirability of developing guidance for researchers and research commissioners aimed at enhancing the scientific and ethical rigour of social research that engages with ethnicity. The starting point for the project was a two-fold concern that (i) much social research that aims to inform policy and practice development in the UK continues to overlook the ethnic diversity of the population *and* (ii) that where research does include attention to ethnicity the ethical and scientific rigour of the work is often poor. Indeed, as the volume of research addressing ethnicity and aspects of wellbeing expands, so too do concerns regarding the *quality* of this research, its contribution to changes in policy and practice that benefit minority ethnic individuals and communities, and its potential role in stereotyping and stigmatising minoritised groups. The project focus was not restricted to health-related research but findings have applicability to social researchers working in the field of health and those who seek to commission and/or apply research evidence in this area.

Key issues for discussion

- What should be the criteria for identifying when ethnicity is 'relevant' and should therefore be a focus of investigation in any particular study? And, under what

circumstances can ethnicity reasonably be ignored? If ethnicity is not a focus, what principles should be followed in assessing and maximising the usefulness/applicability of study findings to our multiethnic context (e.g. via linked knowledge translation work; via reference to other relevant evidence etc.?)

- What mechanisms are needed, to i) ensure that ethnicity is included in studies where it should be? ii) enhance the quality of (published) research on ethnicity?
- Is there a convincing argument that ethnicity should be exceptionalised? How can a concern for other dimensions of diversity and (in) equality be pursued alongside efforts to enhance quality and quantity in ethnicity research?

Ghazala Mir: Participatory Research, 'Bridging' and Health

Studies exploring health inequalities often demonstrate inappropriate engagement between service providers and disadvantaged communities. However, research methods used to explore such issues have been subject to less scrutiny. Attitudes towards research within minority ethnic groups can include disengagement and cynicism about the research process, along with feelings of being vulnerable to exploitation and abuse of trust. This raises questions about the acceptability of current research methodologies to people from minority ethnic groups. Participatory approaches that engage individuals, offer reciprocity and contribute to understanding about how needs can be met are suggested as relevant to the priorities of these populations and a way of modelling the social change needed to address structural determinants of health.

Key issues for discussion:

- What are the opportunities and barriers to using participatory approaches in research on ethnicity and health?
- How can research design contribute to reducing social inequalities rather than simply describing these?

George Ellison: Ethnically Representative, Comparative and Inclusive Samples

Ethnic disparities in health and health care utilisation have encouraged policy makers and researchers to press for ethnically inclusive sampling frames that are both: (i) representative (so that their findings are generalisable and applicable to the population as a whole); and (ii) comparative (so that any ethnic disparities can be exposed, examined, understood and addressed).

This paper explores the potential consequences of policies that have sought to impose ethnically inclusive sampling frames that are both representative and comparative. Since the statistical requirements of representative and comparative samples are very different, the conflation of these two sampling frames under the imperative of inclusivity often leads to inadequately powered comparative analyses, particularly those involving the comparatively smaller samples of minority ethnic groups. Likewise, since the denominators required to assess the ethnic inclusivity of research samples are usually provided by statutory agencies, and since these agencies increasingly use socially-constructed and context-specific ethnic categories based on self-reported identity, researchers are obliged to use the very same categories when calculating their studies' enumerators. In the process these categories become standardised within scientific

practice, and used therein as (if they were) reliable, valid, discrete and generalisable markers of wholesale and fundamental difference. Thus, when the types of samples and data required to address and assess ethnic inclusivity, are subsequently used in comparative analyses, these are predisposed towards the production of statistically underpowered, analytically flawed, aetiologicaly imprecise and potentially misleading findings.

This paper argues that the analytical and aetiological requirements of representative and comparative research designs are often incompatible, and that different research questions might benefit from: representative, exclusive and/or boosted sampling frames; and from statutory and/or bespoke ethnic categories. It seems unlikely that the sampling frames required for research that is *both* representative and comparative are possible, necessary or cost-effective given their requirement for inclusive and boosted sample sizes and disproportionate levels of participation amongst minority ethnic groups.

Key questions for discussion

- How should ethnicity be operationalised and sampled to generate findings that are applicable to the population as a whole?
- How should ethnicity be operationalised and sampled to support analytically robust and aetiologicaly useful comparative analyses?
- Is it necessary, possible or appropriate to use research designs that are both inclusive and comparative?
- When is it ethically appropriate to adopt representative, exclusive and/or boosted sampling frames?

Joe Kai: Workforce Development

The presentation will include an outline of debates on facilitating 'cultural competence' for health care practice and whether 'culturally informed practice' improves health and quality of health care in ethnically diverse contexts. These debates include the challenges of:

- Defining what we mean
- Identifying and developing appropriate interventions
- Testing intervention effectiveness
- Establishing what is effective for delivery and implementation in the real world

Key questions for discussion

- Prioritising and addressing research questions concerning the above.
- If we get there - Generating evidence on effectiveness of interventions does not mean they will then be used (commissioned) in policy or practice. What can be done to build evidence on the *business case* for improving quality of care and reducing ethnic inequalities?
- Anticipating and addressing the gaps in evidence on how interventions developed in research settings can be implemented in the messy world of practice.

Jan Cambridge: Principles of Cross-Cultural Communication

Human beings construct the world of thought and practical reality through language; interpreters and translators operate in the interstices between other people's world views. Any human interaction that crosses ethnic boundaries is likely to encounter cross-cultural and cross-linguistic difficulties to some extent. These are not always immediately evident and the longer they go unnoticed the longer it takes to repair them. Interpreting Translation and Language Support (ITALS) research needs improvement and far greater interdisciplinary collaboration. ITALS *in* research need greater understanding and care in their application. The fundamental principle that I would highlight is that finding out about multiethnic populations and how best to serve them cannot be effective without properly planned ITALS at its core. I will discuss the main elements of language that affect interpreting in practice.

Key questions for discussion

- When ITALS input is needed in research, who should supply it?
- Is there a need to agree a standard nomenclature for ITALS personnel and practices (skill sets?)
- At what stage and how would a research team address potential problems or influences of local bilingualism?

Mark Exworthy: Influencing Policy

Understanding the process of health policy is essential if action on various health issues are to be addressed effectively. Yet, despite improving evidence and political will in many areas, 'improvement' is often not apparent. This session uses the example of health equity to explain some of these factors and offers ways of conceptualising the policy process.

Key questions for discussion

- What factors shape the development of health policy in the field of 'ethnicity and health'?
- What (local or national) contextual factors mediate the implementation of policies? How can we learn from other countries?
- How far do conceptual models help explain the trade-offs and compromises that are evident in the policy process?