

# Research agenda for tackling inequalities related to migration and ethnicity in Europe

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## ABSTRACT

Reducing ethnic inequalities and inequities in health needs to become a higher priority for public health research. Active involvement of migrant and ethnic minority populations in European population health research is necessary, for data show important inequalities but evidence, particularly on effectiveness, is sparse and strategic overviews rarer still. Ethnically disaggregated health surveillance systems are developing slowly, and pragmatically, often using country of birth. The principles to adopt, given the gaps between the ideal and the current reality, need wider discussion. Ethics may provide both principles and impetus. Doing no harm, doing good, respecting the research participants' autonomy are good starting points. More emphasis is needed on justice, fairness and equality, participation and communicating effectively. Ethnic minority groups are willing participants in trials once linguistic and trust-related barriers are overcome, though recruitment costs are higher. Guidelines and strategies by European bodies with research funding or enforcement responsibilities are needed. The research community needs an infrastructure within which to collect and utilize evidence. Research can help migrant and ethnic minority groups to participate more fully in our multi-ethnic societies.

**Keywords** epidemiology, ethnicity, public health, migration, research

## Introduction: Inequalities and inequities in health and health care

Among the highest priorities for public health research, policy and practice is reducing inequalities, not through passive convergence but by improving the health of the worse-off groups so they converge with those in the best-off.<sup>1,2</sup> Migration and ethnicity, two closely interrelated phenomena, are associated with major differences in environment (moving from one country to another) and culture (the core of ethnicity), and some group-level differences in biology (reflecting ancestry). These differences lead to inequalities in health, that are easily demonstrated by relevant epidemiological variables such as country of birth, and self-reported ethnicity and race.<sup>3</sup> The size of such inequalities cannot be matched by most other epidemiological variables (except age group) in within-country statistics.<sup>3</sup> For example, we see 4–6-fold differences in diabetes,<sup>4</sup> 10–20-fold differences in prevalence of smoking<sup>4</sup> and even larger differences in alcohol consumption and alcohol-related diseases.<sup>5</sup> Sometimes the inequalities are in favour of minorities, at other times the opposite.<sup>3</sup> Unlike socio-economic inequalities in the settled White European populations, the

direction of ethnic inequalities are hard to predict and the usual indicators may not be confounding factors.<sup>6–8</sup> So we need research, information, plans and actions to describe accurately and then tackle such inequalities.

The questions addressed in this perspectives paper include the following.

- (1) Why is inclusion of migrant and ethnic minority populations in European population health research important?
- (2) What is the state of such research, particularly on effectiveness of interventions?
- (3) What principles can we adopt given the gaps in evidence?
- (4) What messages are there for setting the future agenda for inequalities research in Europe?

This paper sets out issues for discussion and indicates broad actions that will spur on research. It does not, however, specify the research projects that need to be done.

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Clearly, this more detailed agenda can only be accomplished once broader principles are established and regionally, according to the needs and interests of populations, policy-makers and researchers.

### **Why is inclusion of migrant and ethnic minority populations in European population health research important?**

Policy and law across Europe, and much of the world, requires us to fairly meet the health-care needs of minority migrant and ethnic communities.<sup>9,10</sup> The driving force is the quest for equity and equality in health status. This means that we need to assess the level of inequality, judge whether each inequality is also an inequity meaning there is an element of injustice or unfairness, and both pinpoint and apply effective interventions to resolve matters. The duty imposed by law is usually explicit on public bodies, but unfortunately it is more limited for private ones. In the UK, for example, we have the Race Relations Amendment Act 2000,<sup>11</sup> the DH and Scottish Executive action plans (Fair for All HDL 2002),<sup>12</sup> research governance frameworks (e.g. DH 2001)<sup>13</sup> and the Scottish Strategy for Ethnicity and Health Research, 2009.<sup>14</sup>

From a public health perspective, which drives law and policy in relation to its health applications, data are essential to establish the extent of health inequalities and inequity in health service provision, choose between interventions, i.e. set priorities, monitor the impact of interventions to reduce inequities and inequalities and demonstrate response to laws and policies.<sup>3</sup> It is impossible to demonstrate that new or adapted interventions and services are needed, and equally, that the interventions have redressed inequities, without data.

### **What is the state of evolution of such research in Europe, particularly on effectiveness of interventions?**

While European data are sufficient to establish that important inequalities exist,<sup>15</sup> they are patchy, inconsistent, incomplete and insufficiently accurate to meet the needs of public health policy or health-care provision.<sup>16,17</sup> Existing data do not usually provide a national perspective as they are mostly from local studies. We are distant from the goal of a pan-European perspective, though there is clear evidence of both interest and need.<sup>18</sup>

More broadly, we also find a limited strategic overview of research. Research is mostly driven by the interests of a few academics/institutions, and the often highly specific and local concerns of voluntary organizations representing migrant and ethnic minority groups. There is also a shortage

of evaluative research of health services relating to accessibility and use of health services by minority migrant and ethnic groups, appropriateness of health services and patterns of employment in the health service.<sup>19</sup>

There are few data on minority ethnic groups' use of the full range of health services. (primary, secondary and support), and this raises continuing and awkward questions related to accessibility of health services, and patterns of referral and use of health services, and possible discrimination.<sup>19,20</sup> In the UK, but little elsewhere in Europe, there is sparse but quickly growing ethnically disaggregated morbidity surveillance data.<sup>21</sup> Death and birth certification data that underpin public health surveillance are generally not available by ethnic group but country of birth is often available.<sup>16,22</sup>

There is a rarity of ethnically disaggregated data in large-scale surveys in Europe, with the Health surveys for England 1999 and 2004 being exceptional.<sup>23,24</sup> Unsurprisingly, therefore, there is a shortage of major trials and cohort studies providing data by ethnic group and migration status.<sup>25</sup> Ranganathan and Bhopal<sup>26</sup> showed that while 15 of 31 North American cardiovascular cohort studies provided data by ethnic group, the corresponding figures in Europe were 0 out of 41. Bartlett *et al.*<sup>27</sup> reported that 8 of 47 trials on statins were specific about ethnicity—all eight were USA based. Several other similar studies have come to the same conclusion.<sup>28</sup> In the absence of such work whether health promotion and prevention interventions in Europe are effective across migrant and ethnic groups, whether adapted (rarely so) or not, is generally unknown.<sup>29</sup>

The contrast between the research record in this field in USA and Europe is stark. Why might it be so? The USA is a country forged by in-migration, whereas, until recently Europe was forged by out-migration.<sup>30</sup> The USA has been a multi-ethnic nation for hundreds of years. Race, closely allied to ethnicity, has been and remains a powerful issue in USA politics and national life.<sup>31</sup> The passing of a law in 1993 that required researchers to design their research so as to include racial and ethnic minorities, and women, as a prerequisite for National Institutes of Health funding has been highly influential.<sup>32</sup> Europe has no equivalent requirement and even a debate on the matter seems difficult for researchers.<sup>33</sup>

### **What principles can we adopt given the gaps?**

#### **Information systems**

It is encouraging that there is a clear policy commitment even though currently information across the European

Region specifically,<sup>16</sup> and more generally globally,<sup>34</sup> is poor. Country of birth is widely used as a substitute for migrant and ethnic group and while it is not ideal, it offers a pragmatic short-to-medium term route to progress in Europe as high quality, complete, migrant status, and ethnic group coding in routine information systems is not imminent (with the exception of the UK).<sup>16,22</sup> Recording ethnicity on birth and death certificates is under renewed debate, for example with a launch of a consultation on the matter in Scotland as recommended by the Scottish research strategy.<sup>14</sup> The proposal to do this in England and Wales, where it requires government approval, was overturned by the House of Lords. As the consultation was supportive Scotland introduced this in 2012.

### Interventions, trials and recruitment

The question of what interventions work across a range of ethnic groups is problematic.<sup>35</sup> The placebo-controlled, randomized, double-blind trial is the gold standard but such trials are difficult to conduct, particularly for complex interventions. Do we need evidence from such studies to recommend an initiative in minority migrant and ethnic groups? If so, do such studies exist? What do we do when there are no specific relevant studies, or the evidence is sparse?<sup>29,35</sup> We need a vision for the future and principles that will help us now.

Clearly there is a large gap between the ideal and the current reality. The ideal research programme would be comprehensive in tackling the major health issues of the populations under study, including having high response rates, providing comparable data across a range of ethnic groups, collecting information on various facets of ethnicity, adjusting for confounding variables, and being analysed and interpreted to advance science, improve health status and develop better health care.<sup>3</sup> In practice, many of these ideals are sacrificed to make studies feasible given the limitations of funding and human resources, but researchers should take care to outline the limitations arising from such sacrifices. One of the key issues is recruitment of participants into studies, particularly large-scale ones involving cohorts and trials.<sup>36</sup>

Ethnic minorities groups are willing participants in trials with consent and response rates on a par with the population as a whole but only once linguistic and trust-related barriers are removed.<sup>4,37</sup> Costs are higher for recruitment but costs in themselves are not ethically or scientifically acceptable as a reason for exclusion.<sup>38</sup> To quote Sheikh 'What is now needed is less blame directed at already marginalized people. Instead, those with the power to change the way in

which research is conducted should translate the important insights provided by Wendler *et al.*'s study into significantly more invitations extended to minority ethnic and racial groups to participate in the research endeavour'.<sup>39</sup>

### Ethics

Ethics of research may provide principles necessary to move forward. The ethics of research generally are applicable to migrant and ethnic minority groups, indeed, ethical codes are usually written following the abuse of minorities, e.g. the Nuremberg Code following the Nazi atrocities of the Second World War, and the adoption of Institutional Review Boards (ethics committees) following the Belmont Inquiry on the infamous Tuskegee Syphilis Study.<sup>40</sup> Ethical codes may need to be modified to have the desired effects, e.g. not bypassing migrant and ethnic minorities in the interests of expedience. Ethical codes on confidentiality and informed consent may also need modification, e.g. in some communities consent is likely to be a family, if not communal, matter.

The classical ethical principles of doing no harm, doing good, respecting the research participant or patient, and offering autonomy in decision-making are a good starting point. In the context of migration, ethnicity and health research these need to be augmented with more emphasis on justice, fairness and equality, inclusivity and participation and communicating effectively, e.g. oral communications in general preference to written ones. If a person does not read, at least arguably, it is unethical (as a waste of resources), to send written information. Arguably, it is ethical to telephone or even call at the doorstep of such a person before writing. Currently, however, ethical discourage contact prior to written consent.<sup>40</sup>

The head of the household (usually but not always male) or the whole family may decide on participation. Thus, individual informed consent is not always workable or in some circumstances may not be desirable on its own. Clarification that it is unethical to bypass migrant and ethnic minority groups in trials and cohort studies is a necessary, though not sufficient, prerequisite to progress. Ethics committees are in a powerful position to do this.<sup>40</sup> Bypassing minority ethnic groups might reflect institutional racism<sup>41</sup> in the research world. There are some statements on ethics of research in relation to ethnic minority groups but, with the key exception of the USA,<sup>32</sup> not usually by bodies with funding or enforcement authority.<sup>42</sup> For example, there is an Ethical Code for Researching 'Race', Racism and Anti-racism in Scotland (SABRE). Published in 2001 by the Scottish Association of Black Researchers (SABRE), it emphasizes social justice and human rights; commitment to

anti-racism and to promoting social inclusion; empowering and actively including black and minority ethnic peoples' perspectives and addressing the complex and problematic nature of concepts of 'race', racism and ethnicity. It also requests that research does not pathologize, stereotype or exploit, black and minority migrant and ethnic people, and that research values diversity within the black and minority migrant and ethnic populations. SABRE recommends that researchers should acknowledge the power relations inherent in social research processes, e.g. between White and Black, researchers and researched and families and communities.

Unfortunately, as is likely with informal actions the guidelines are no longer on the internet but I have published a summary.<sup>3</sup>

### Filling gaps and setting the foundation for the future in Europe: the example of Scotland

Scotland, as with much of Europe, has a shortage of research data by ethnic group. The way it has made progress, particularly using retrospective approaches, might be helpful for other countries. Other countries across Europe which have made a great deal of progress that would be worth sharing in articles similar to this one include, in particular, The Netherlands with a ground-breaking prospective cohort study,<sup>43</sup> Denmark with its strong emphasis on health-care utilization research<sup>44</sup> and Germany, which has been leading the way in relation to cancer.<sup>17</sup> To my knowledge, however, Scotland is unique in Europe for having a documented research strategy in this field.

Filling data gaps retrospectively is possible as shown in Scotland using census, place of birth, name search and data linkage methods.<sup>45</sup> The findings have been powerful in altering thinking, not least in guiding Scotland's ethnicity and health research strategy.<sup>14</sup>

Using census population data and death data we found that compared with White Scottish men and women, all-cause mortality was unexpectedly lower among those born in England and Wales, Pakistan, Bangladesh, India (men), China and rest of world.<sup>46</sup> Linking census records to hospitalizations and deaths showed that South Asians' incidence of heart attack, however, was higher but survival was better.<sup>47</sup> Name search methods showed that diabetes care for South Asians was equitable but key glycaemia-related outcomes were poorer.<sup>48</sup> More work is being done on cardiovascular disease, cancer, maternal and child health and mental health using linkage methods.<sup>45</sup>

Conclusions by a recent strategic review of Scottish research on ethnicity and health to date include that: too little is known about health status of minority ethnic

groups due to lack of ethnic coding on health and death records; the research focus has often been on diseases commoner among such populations but not on the most common diseases; little attention has been paid to evaluation of health promotion strategies; there has been little research on effectiveness of mental health services; few of known findings have been acted upon and even when data available, opportunities to analyse have not been taken.<sup>14</sup> The Scottish strategy on ethnicity and health research, created by a multi-disciplinary, multi-sectoral group with considerable consultation, has noted that defining ethnicity is not easy, so research should be based on the Scottish census classification. It recommended that quantitative studies should be designed, wherever appropriate, to ensure that sample sizes are sufficient to produce accurate analyses by ethnic group. As questionnaires need to capture cross-culturally valid information, the strategy recommends that translations are prepared with the help of interpreters and validated before use. Qualitative methods need to be complemented with quantitative data on representative populations. The strategy<sup>14</sup> identified only two evaluations of interventions in Scotland to date (Vit D<sup>49</sup> and Khush Dil<sup>50</sup>) and one in progress (PODOSA<sup>51</sup>). Priorities for laying the foundations for future Scottish research are given in Box 1. The strategy outlines broad approaches that will promote a wide range of research projects but it does not attempt to direct research to specific research questions, though that could be a useful next step.

#### Box 1. Six priorities in the Scottish ethnicity and health strategy<sup>14</sup>

1. Good ethnic coding of health information systems is essential  
Recommend >80% by 2013
2. Data linkage—considerable scope for further study  
Recommend this work is taken further
3. Ethnically boosted health survey, possibly within
  - UK Longitudinal Health Survey
  - Scottish Health Survey
 Recommend at least one is supported
4. Coordinated research on major health problems  
Recommend focus on evaluations of interventions, e.g. on heart disease, cancer, obesity and depression
5. Audit of local health and social care services  
Recommend each NHS Board should carry out regular audits of range and quality of services for ethnic minorities
6. Coordinating and monitoring research by implementation group  
Recommend it is hosted by Health Scotland



## Conclusions

European health initiatives need to cater for the migrant and ethnic minority populations with work of equal potential effectiveness and sensitivity. To do otherwise promotes inequality, maintains inequity and is unethical and institutionally racist, if not illegal. We need institutional structures including pro-active strategies, scrutiny by ethics committees and stringent requirements of researchers. Data need to be demonstrably used for increasing awareness and stimulating policy and action to improve the health of migrant and ethnic minority groups. We need, in particular, to strengthen the evidence base showing effectiveness of interventions by migrant and ethnic group. Legislative and policy imperatives are already integrated and symbiotic, but very often they are not implemented.

Ethnicity and health work needs embedding within wider diversity and social justice goals. Ethnicity reflects social circumstances more than biology, and as such it fits well both in the World Health Organization Social Determinants of Disease programme,<sup>52</sup> and within the diversity and health movement.<sup>53</sup> Progress in socio-economic inequalities and health research has been greater than in ethnic inequalities. This is partly historical, as the former has been a central concern of public health in Europe since the 19th century, whereas ethnicity has only elicited serious interest in the last two or three decades. Other reasons include the misguided over-emphasis on biology as the dominant underlying reason for racial and ethnic variations in disease—a perspective that dominated the field until well after the Second World War.<sup>54</sup> The understanding that through the study of ethnic variations we can potentially benefit the entire populations, and not just the minorities is rare, but necessary to bring the subject into the mainstream of research.<sup>3,8</sup> Socio-economic inequalities/social determinants of health work tend to emphasize financial and material resources, whereas the diversity agenda, whether on ethnicity, gender, sexual orientation or disability, puts as much if not even more emphasis on cultural matters. By combining perspectives we create a more powerful 'equity lens'.<sup>55</sup>

For example, in ethnic minority groups differences between men and women, particularly in health-related behaviours and employment, tend to be larger than in the settled White European populations. Pakistani women, for example, are much less likely to smoke cigarettes or be employed than either Pakistani men or White European women.<sup>24</sup> By analysing such observations from ethnicity, socio-economic, cultural and gender perspectives, we are likely to reach more valid and valuable conclusions than from any one of these perspectives. The research

community needs infrastructures within which to collect and utilize such evidence.

Research is needed for migrant and ethnic minority groups to move from the shadows and participate more fully in a vibrant, healthy, multi-ethnic Europe.

## Meanings of some terms as used in this paper

- Ethnicity (subsuming race): the group you belong to, or are perceived to belong to, because of culture, ancestry and physical features.
- Migrant: someone who leaves one country to take up residence in another.
- Inequality: difference.
- Inequity: a difference that is potentially unjust.

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