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### Published version

MIR, Ghazala, SALWAY, Sarah, KAI, Joe, KARLSEN, Saffron, BHOPAL, Raj, ELLISON, George T.H. and SHEIKH, Aziz (2013). Principles for research on ethnicity and health: the Leeds consensus statement. *The European Journal of Public Health*, 23 (3), 504-510.

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*European Journal of Public Health*, Vol. 23, No. 3, 504–510

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doi:10.1093/eurpub/cks028 Advance Access published on 2 May 2012  
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## Principles for research on ethnicity and health: the Leeds Consensus Statement

Ghazala Mir<sup>1</sup>, Sarah Salway<sup>2</sup>, Joe Kai<sup>3</sup>, Saffron Karlsen<sup>4</sup>, Raj Bhopal<sup>5</sup>, George TH Ellison<sup>6</sup>, Aziz Sheikh<sup>5</sup>

1 Leeds Institute of Health Sciences, University of Leeds, UK

2 Faculty of Health and Wellbeing, Centre for Health and Social Care, Sheffield Hallam University, UK

3 Division of Primary Care, School of Community Health Sciences, University of Nottingham, UK

4 Department of Epidemiology and Public Health, University College London, UK

5 Edinburgh Ethnicity and Health Research Group, Centre for Population Health Sciences, University of Edinburgh, UK

6 Leeds Institute for Genetics, Health and Therapeutics, University of Leeds, UK

**Correspondence:** Ghazala Mir, Leeds Institute of Health Sciences, University of Leeds, Charles Thackrah Building, 101 Clarendon Road, Leeds LS2 9LJ, UK, Tel: +44 113 343 4832, fax: +44 0113 343 0862; e-mail: [g.mir@leeds.ac.uk](mailto:g.mir@leeds.ac.uk)

**Background:** There is substantial evidence that health and health-care experiences vary along ethnic lines and the need to understand and tackle ethnic health inequalities has repeatedly been highlighted. Research into ethnicity and health raises ethical, theoretical and methodological issues and, as the volume of research in this area grows, so too do concerns regarding its scientific rigour and reporting, and its contribution to reducing inequalities. Guidance may be helpful in encouraging researchers to adopt standard practices in the design, conduct and reporting of research. However, past efforts at introducing such guidance have had limited impact on research practice, and the diversity of disciplinary perspectives on the key challenges and solutions may undermine attempts to derive and promote guiding principles. **Methods:** A consensus building Delphi exercise—the first of its kind in this area of research practice—was undertaken with leading academics, practitioners and policymakers from a broad range of disciplinary backgrounds to assess whether consensus on key principles could be achieved. **Results:** Ten key principles for conducting research on ethnicity and health emerged, covering: the aims of research in this field; how such research should be framed and focused; key design-related considerations; and the direction of future research. Despite some areas of dispute, participants were united by a common concern that the generation and application of research evidence should contribute to better health-care experiences and health outcomes for minority ethnic people. **Conclusion:** The principles provide a strong foundation to guide future ethnicity-related research and build a broader international consensus.  
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### Introduction

There is now substantial evidence that health and health-care experiences vary along ethnic lines and that minority ethnic groups tend to be at risk of significant disadvantage across a range of indicators<sup>1,2</sup>. The need to understand and tackle such ethnic health inequalities has been repeatedly recognized.<sup>3–6</sup> Health researchers, in generating and disseminating research evidence, play an important role in shaping health policy, practice and debate in ways that can help to ameliorate such inequalities.

Research on ethnicity and health poses significant ethical, conceptual and methodological challenges.<sup>7</sup> In recent years, for example, attention has been drawn to how ethnicity is conceptualized and operationalized,<sup>8–12</sup> inconsistent and inappropriate terminology,<sup>13–15</sup> how researchers engage with minority ethnic individuals and groups,<sup>16,17</sup> how samples are drawn and participants recruited,<sup>18–20</sup> and how comparable data are generated from diverse populations.<sup>20,21</sup>

Many of these challenges have been recognized for some time<sup>22</sup> and there have been several attempts to improve scientific rigour in research on ethnicity and health.<sup>23–26</sup> However, such initiatives have had little impact on practice<sup>26</sup> and as the volume of research in this area grows, so too do concerns regarding its potential to do more harm than good.<sup>27,28</sup>

One factor that appears to undermine the potential to derive and promote guidance in this area is the wide range of disciplinary and

professional perspectives.<sup>29</sup> For example, some disciplines have engaged with the conceptualization and operationalization of ethnicity; others are primarily concerned with the validity and generalizability of diagnostic tools across different linguistic and cultural contexts; and there is ongoing debate around the involvement of service users and the extent to which research in the area of ethnicity can (or should) be ‘value-free’.<sup>29</sup>

This article describes a novel approach to overcoming the challenge of agreeing core principles. It reports the results of a Delphi exercise undertaken with participants from a range of diverse academic and professional disciplines. The aims were to: (i) explore the extent to which it might be possible to derive common inter-disciplinary and inter-professional principles for conducting research on ethnicity and health and (ii) highlight areas where inter-disciplinary and inter-professional differences in ethnicity and health research might warrant further debate.

### Methods

Ethical clearance was provided by The University of Edinburgh’s School of Health in Social Science Research Ethics Committee.

Researchers, policymakers and practitioners with substantial experience in ethnicity and health research, were invited to a UK Department of Health sponsored workshop to discuss the principles they believed should inform such research. Presentations and group discussion focused on: the importance of research on ethnicity and

health; appropriate methodological approaches; and mechanisms for translating such research into policy and practice (Further details of the programme and presentations are available at: <http://www.etn.leeds.ac.uk/newspage.htm>). Potential workshop participants, including international participants and those with international research experience, were identified through professional networks and from responses to a general invitation sent to members of the JISCmail Minority Ethnic Health and Health Equity e-lists (JISCMAIL is an academic mailing service which supports over a million people from academic, policy and practice backgrounds within the UK and internationally to collaborate through specialist online groups. Further details of the professional and disciplinary backgrounds of workshop delegates is available at <http://www.etn.leeds.ac.uk/document/dohworkshop/WorkshopParticipants.pdf>). The key aim of the workshop was to attempt to achieve consensus on the most important principles underpinning research on ethnicity and health. A formal consensus-building technique, the Delphi exercise,<sup>30</sup> was selected as the mechanism through which those invited to the workshop (who would comprise the Delphi Panel) might identify and agree on these key principles, as summarized in table 1.

In Round 1 of the Delphi exercise, all Panel members were invited to provide statements on the most important principles they felt should be applied to ethnicity and health research. These initial statements were emailed to the Delphi Panel coordinator (G.M.) to minimize any risk that peer group pressure might influence individual responses. The Panel coordinator then organized the statements under themed headings, disaggregated multi-faceted principles and ensured that there was no unnecessary duplication. This process was subsequently reviewed by a member of the Panel (A.S.) to ensure that no salient principles had been misinterpreted or lost.

In Round 2, all Delphi Panel members were asked to anonymously score each of the statements from Round 1 on a 5-point Likert scale ranging from '1 = unimportant' to '5 = very important', with an opportunity to make additional free-text comments on each statement. Responses were collated and statements revised and reduced to 32 in response to the free-text comments received. These revised statements were then circulated to Panel members during Round 3 of the exercise. Individual Panel members received their original score for each statement along with an overview showing the percentage of Panel members who had scored the statement 4 or 5 (i.e. 'important' or 'very important'). Where statements from the previous Round had been combined, original statement numbers and percentage scores were provided separately. Panel members were then invited, in light of this information, to provide a single score for each revised statement, allowing each Panel member to re-evaluate their position and take account of the controlled feedback from the Panel as a whole.

Consensus was defined as >80% of respondents ranking the statement as '4' or '5',<sup>30,31</sup>—the final selection and format of the consensus principles is based on the results of Round 3. At this stage, free-text comments were collated for each statement. These comments were used to provide explanations for any consensus, or lack thereof, on each specific statement. Finally, to highlight areas where differences in perspectives across different disciplines and professions appear to warrant further debate, free-text comments were combined with an analysis of numerical scores to explore

similarities and differences between Panel members from different disciplinary and professional backgrounds.

## Results

Of the 38 potential workshop participants, 21 attended the workshop and a further 12 responded to an invitation to take part in the Delphi Panel, providing a total of 33 Panel members. Nine Panel members were from policy/practice backgrounds and 24 from research institutions (table 2). Researchers included specialists in quantitative and qualitative research, clinicians, social scientists, epidemiologists and statisticians. Panel members were roughly balanced in terms of gender and around a third were from minority ethnic backgrounds. A total of 17 Panel members (52%) responded to the Round 1 invitation, providing a total of 84 statements that were then reduced to 44 in Round 2 and 32 in Round 3 of the Delphi exercise. Almost all Round 1 participants had attended the workshop and this appears to have increased their confidence and willingness to actively contribute statements.<sup>30</sup> Subsequent response rates were 91% ( $n=30$ ) for Round 2 and 94% ( $n=31$ ) for Round 3 (Figure 1). Scores for each of the 32 statements generated following Round 3 are presented in table 3, and the 10 statements for which consensus was reached are presented in table 4. These 10 principles are discussed in the context of feedback from Panel members, below.

### Importance and purpose

Regardless of disciplinary/professional background, there was a high level of agreement among Panel members that researchers in the field of health inequalities had a responsibility to address ethnicity within their research (90% of respondents ranking Principle 1 as 'important' or 'very important'). An even higher level of agreement was reached on the need to ensure that inclusivity did not replicate discriminatory processes, but aimed instead to improve the condition of populations experiencing disadvantage (93%—Principle 2). Free-text feedback emphasized the multi-dimensional nature of ethnicity and highlighted the importance of identifying underlying causal processes linking particular ethnic identities to health outcomes. Researchers were seen as having an important role in ensuring that discriminatory processes were avoided, and that research both modelled and promoted the social change necessary to reduce disadvantage.

### Framing and focus of research

The consensus principles also reflected a concern that researchers should be transparent about the concepts, theories and assumptions that underpin their work (90%—Principle 3). Transparency was sought to overcome disciplinary divides and require researchers to think more clearly about the taken-for-granted assumptions that may underpin their work (and result in stereotyping or stigmatizing the populations involved).

The highest level of agreement (97%—Principle 4) was achieved on the need to recognize diversity within ethnic group categories. This was driven by a concern that ethnic identities are often presented as fixed and homogenous, and that researchers should recognize and explicitly examine the various social factors that might explain associations between ethnicity and health outcomes,

**Table 1** Main steps in undertaking the Delphi exercise<sup>31</sup>

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Expert panel: Constructing a panel and obtaining agreement to participate.
Round 1: Experts contribute their ideas and these are summarized and circulated amongst the panel, typically in the form of a questionnaire.
Round 2: Panel members individually rank their level of agreement with each statement and individual responses are summarized and circulated to the panel with a repeat questionnaire.
Round 3: Panel members revise their opinions in the light of findings from the previous round; results are again summarized and fed back to the panel.
Reaching agreement: Three rounds are usually sufficient to allow an acceptable degree of agreement to emerge amongst most panel members but, if not, a final fourth round can be conducted.

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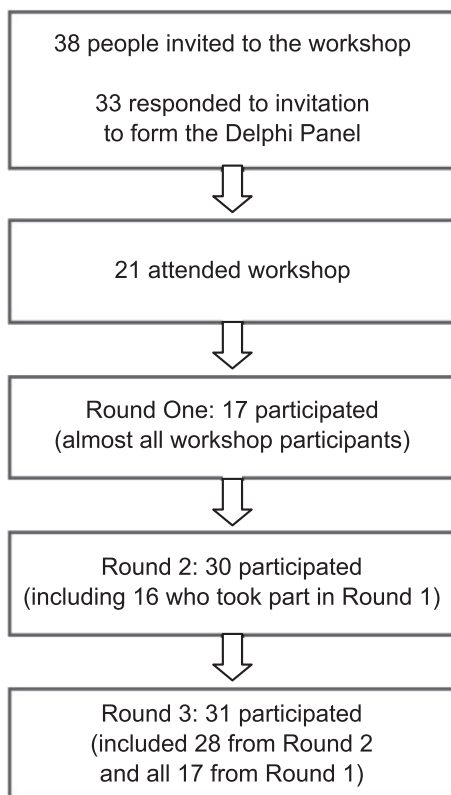
**Table 2** Participation by professional background and discipline

Stage of Delphi exercise	Academic researchers <sup>a</sup>	Researchers with clinical backgrounds <sup>b</sup>	Health service practitioners/managers <sup>c</sup>	Total (international participants) (%)
Delphi Panel	18	6	9	33 (3=9%)
Workshop	11	6	4	21 (0)
Round 1	10	4	3	17 (0)
Round 2	17	6	7	30 (3=10%)
Round 3	19	4	8	31 (3=10%)

a: Researchers based solely in universities or other research institutions.

b: Researchers with clinical training based in universities or other research settings.

c: Panel members working only in health service settings.

**Figure 1** Delphi participants at each stage

including socio-economic position, language, religious identity, experiences of discrimination, migration history and cultural preferences and behaviours.

There was a high degree of consensus on the need to involve people from minority ethnic communities in the research process and support them to define appropriate participatory practices for themselves (90%—Principle 5). The strong support for this principle arose from recognition of the power imbalances in research relationships. Participatory approaches that could empower people from these populations, both to define research questions and suggest solutions to be evaluated, were considered important to making studies meaningful and effective for tackling inequalities.

### Data collection and analysis

The most contentious area for developing consensus related to data collection, where conflicting principles were in evidence about the

kinds of data that should be gathered (table 3). Nonetheless, a high level of agreement was reached on the need for ethnic categories and labels to be meaningful in terms of the specific research questions explored (87%—Principle 6). Feedback indicated that researchers should recognize that ethnic categories are neither natural nor neutral and should not be employed without reflection on their meaning and utility. In particular, there was agreement that while ethnic categories such as those used in UK censuses<sup>32</sup> are useful for exposing disadvantage (80%—Principle 7), they offer limited insight into the causes of disadvantage and there is a need to develop additional categories and measures that might be more helpful in explaining inequalities and identifying suitable interventions.

However, there remained inter-disciplinary differences of opinion as to how this might be achieved, with panel members from clinical or health service backgrounds favouring more prescriptive statements. Almost all practitioners/policymakers and researchers with clinical backgrounds advocated the collection of a number of additional measures (including nationality, language, religious affiliation and experience of discrimination). Consensus was not reached on this approach (60% agreement—table 3, Statement 22 and see table 5) and feedback revealed disagreement about the burden of data collection and the risk that researchers might infer causal relationships between such measures and disadvantage without first seeking evidence of causality.

A statement on sampling criteria also failed to achieve consensus (67% agreement—table 3, Statement 20). This was partly due to concerns across professions and disciplines that stringent principles on sample sizes and sampling schemes (particularly in terms of minimum sampling thresholds) could provide an excuse for *not* including minority ethnic communities in research. While some Panel members emphasized the importance of raising issues affecting people from minority ethnic communities in whatever way possible, others were concerned that findings based on inadequate data could serve to reinforce unhelpful stereotypes and discriminatory practices.

Nonetheless, a high level of consensus was reached on the need to account for social context in explaining research findings (90%—Principle 8). Comments highlighted the importance of structural factors in explaining health inequalities and the risk that analyses that focused solely on behaviour or genetics might replicate social relations that blamed minority ethnic groups for the health disadvantages they experience. Consensus was, however, not achieved on the need to focus specifically on racial discrimination in ethnicity and health research (57%—table 3, Statement 28). While most researchers, including those with clinical backgrounds, agreed with this statement, almost all health service practitioners and policymakers scored it  $\leq 3$ . Free-text feedback suggested that these and other Panel members who disagreed with the statement considered racial discrimination difficult to determine and only one of a range of factors that led to disadvantage.

### Future priorities

There was a shared concern that researchers needed to move on from increasingly sophisticated descriptions of ethnic inequalities in health and focus instead on *how* such inequalities might be reduced, by identifying effective interventions and defining best practice (83%—Principle 9). While Panel members across professional and disciplinary boundaries felt that a focus on establishing the cost-effectiveness of interventions was also appropriate, consensus was not achieved on this approach as a principle (67%—table 3, Statement 12). Those who disagreed argued that a pre-occupation with developing ‘business cases’ for interventions might obscure the social justice arguments for reducing ethnic health inequalities.

Finally, there was consensus on the importance of developing better models for involving minority ethnic communities in research (83%—Principle 10). Participatory models that

Table 3 Summary of final (Round 3) scores

<i>Consensus statements are indicated in bold font</i>	Number of scored responses	Mean score	Number >4	>4 of total responses (%)
<b>Importance and purpose</b>				
1 <b>The purpose of research on ethnicity and health should be for the well-being and betterment of populations being studied.</b>	30	4.50	28	93.3
2 <b>Ethnicity is significantly correlated with disadvantage and ill-health and researchers in the field of health inequalities have both a professional and ethical responsibility to incorporate evidence on ethnicity into their work and recommendations</b>	30	4.52	27	90.0
3 <b>Equity should be the guiding ethical principle for ethnic health research; researchers must be alert to the dangers of discriminatory thinking and behaviour and guard against actual and potential harm</b>	30	4.22	24	80.0
4 A better understanding of similarities and differences between ethnic groups can potentially improve the health of the entire population.	30	3.93	20	66.7
<b>Framing and focus of research</b>				
5 <b>There is a need to examine diversity within ethnic groups and avoid homogenization. For example, age, gender, religion, education, socio-economic position, geography or periodicity of migration will all impact on the generation of ethnic health inequalities. Investigation of ethnic health inequalities should pay due regard to the ways in which ethnicity intersects with other forms of difference in order to understand how and why it may be relevant.</b>	30	4.69	29	96.7
6 <b>It is important to be explicit about the assumptions and theories that underlie research on ethnic health inequalities</b>	30	4.40	27	90.0
7 <b>There is a need to improve the participation of minority ethnic communities in all stages of the research process. Appropriate participation should be defined by these communities then promoted by researchers and statutory agencies and resourced by funding bodies.</b>	30	4.28	27	90.0
8 Where quantitative data are lacking, such as in the case of asylum seekers and refugees, qualitative studies are an important means of generating knowledge	30	3.93	23	76.7
9 All research involving minority ethnic communities should use (and publish) validation techniques to ensure that research tools, especially those developed as diagnostic or quality of life measures, operate similarly across participants regardless of ethnic/linguistic background.	29	4.02	22	73.3
10 Research must engage more effectively with the inter-related issues of migration, ethnicity and religion, as separate and interlinked social factors that impact on health inequalities	29	4.00	21	70.0
11 The role of racism in perpetuating ethnic health inequalities should be taken as given and more energy devoted to exploring its forms and the means by which it can be addressed.	30	3.83	21	70.0
12 There is a need to establish the cost-effectiveness of interventions while not neglecting other principles of ethnic health research.	29	3.88	20	66.7
13 Single-discipline and inter-disciplinary research along with overarching reviews of evidence are needed to improve the evidence base for reducing ethnic health inequalities.	30	3.83	19	63.3
14 Researcher-led models for developing research should be integrated with those led by service users	29	3.86	18	60.0
15 Methodologies for ethnic health research will vary across disciplines and inter-disciplinary approaches should be flexible enough to recognize differences	29	3.43	16	53.3
<b>Data collection</b>				
16 <b>The use of ethnic categories and labels should be meaningful in relation to the particular experiences and outcomes being explored</b>	30	4.38	26	86.7
17 <b>Census categories are useful for exposing disadvantage but additional measures may be needed to explore the processes through which disadvantage is created</b>	30	4.23	24	80
18 Ethnic monitoring records should wherever possible include use of self-assigned Census categories. This would enable researchers to draw on data that is consistent at a national level.	30	3.95	22	73.3
19 Where possible, researchers should draw on terms and categories that are understood and agreed within the existing literature on ethnicity and health	29	3.91	21	70.0
20 Research samples should be appropriate for the aim of the research: <ul style="list-style-type: none"> <li>• Representative samples of diverse ethnic groups should be used where the aim of the research is to produce representative research findings</li> <li>• Exclusive samples that do not include all ethnic groups should only be used when either there are good grounds for supposing (i) that there is no ethnic variation in the outcome being explored or (ii) there is a need to extend existing research to include under-researched groups within the sample</li> <li>• In quantitative studies representative samples of diverse ethnic groups should not be used for comparative analyses unless the sample sizes meet a minimum threshold</li> </ul>	29	3.97	20	66.7
21 It is important to balance the potential benefits of including ethnicity in research design (i.e. to expose, explore and reduce ethnic disadvantage) alongside the potential negative impact (e.g. in stereotyping and stigmatizing ethnic groups)	30	3.90	19	63.3
22 Data that would be useful for research include: place of birth; parent's place of birth; national identity; language/need for interpreter; religious affiliation/practice; and experience of discrimination	29	3.71	18	60.0
23 Researchers should explore the processes through which ethnic identification occurs and the acceptability of collecting a wider range of ethnicity-related markers and characteristics (including religious affiliation, national identity, language and observer-ascribed ethnicity)	30	3.43	16	53.3
24 New categories for exploring the causes of disadvantage and ways to address these should be developed with the input of minority ethnic communities	29	3.59	15	50.0
25 The concept of ethnicity is dynamic and self-assignment to ethnic groups can vary depending on situation and context. Measures such as family ethnic origins and ancestry have a weak evidence base but may be useful where stability/reproducibility of data is an important issue.	29	3.09	10	33.3

(continued)

**Table 3** Continued

<i>Consensus statements are indicated in bold font</i>	Number of scored responses	Mean score	Number >4	>4 of total responses (%)
<b>Data analysis</b>				
<b>26 Analysis of health inequalities should pay attention to the social context in which ethnic differences in health outcomes are measured and health behaviours occur.</b>	30	4.50	27	90.0
27 Research on ethnicity and health should always make clear how the relationship between ethnicity and health outcomes is being framed, for example, is a causal relationship suggested and if so, is the cause linked to behaviour or genetics?	30	4.05	23	76.7
28 Researchers should seek to determine the impact of racial discrimination on the health of people from minority ethnic groups. This is potentially very important in understanding the relationships between ethnicity and health.	30	3.72	17	56.7
<b>Future directions</b>				
<b>29 There is a need to focus on intervention studies that help identify effective ways of reducing inequalities.</b>	30	4.38	25	83.3
<b>30 More research is needed on appropriate models for involving minority ethnic communities in research. For example, models for community capacity building, empowerment, representativeness and continuity of engagement</b>	28	4.25	25	83.3
31 The research community for ethnicity and health needs to target a diverse community of practice and establish the next generation of researchers in this field	30	4.13	23	76.7
32 International collaborations exploring the feasibility of ethnic monitoring/data collection (and collection on some of the other equality dimensions protected by law in the UK) are helpful for the development of research on ethnic health inequalities and for comparative studies.	30	3.90	20	66.7

**Table 4** The Leeds Consensus Principles for research on ethnicity and health

<b>Importance and purpose</b>
1. Ethnicity is often associated with disadvantage and ill-health. Researchers consequently have both a professional and ethical responsibility to incorporate evidence on ethnicity into their work and recommendations.
2. The purpose of research on ethnicity and health should be for the well-being and betterment of populations being studied and equity should be the guiding ethical principle. Researchers must be alert to the dangers of discriminatory thinking and behaviour and guard against actual and potential harm resulting from their research.
<b>Framing and focus.</b>
3. It is important to be explicit about the assumptions and theories that underlie research on ethnicity and health.
4. There is a need for research to, where appropriate, examine diversity within ethnic groups and avoid homogenization. For example, age, gender, religion, education, socio-economic position, geography or time of migration may all impact on the generation of ethnic health inequalities. Investigation of ethnic health inequalities should pay due regard to the ways in which ethnicity intersects with other forms of difference in order to understand how and why it may be relevant.
5. There is a need to improve the participation of minority ethnic communities in all stages of the research process. Appropriate participation should be defined by these communities, then promoted by researchers and statutory agencies and resourced by funding bodies.
<b>Data collection and analysis</b>
6. The use of ethnic categories and labels should be meaningful in relation to the particular experiences and outcomes being explored.
7. Census categories are often useful for exposing disadvantage, but additional measures may be needed to explore the processes through which disadvantage is created.
8. Analysis of health inequalities should pay attention to the social context in which ethnic differences in health outcomes are measured and health behaviours occur.
<b>Future priorities</b>
9. There is a need to focus on intervention studies that help identify effective ways of reducing inequalities.
10. More research is needed on appropriate models for involving minority ethnic communities throughout the research process. For example, models for community capacity building, empowerment, representativeness and continuity of engagement.

**Table 5** Inter-disciplinary/inter-professional diversity in responses to Statement 22 (Data that would be useful for research)

Score	Academic researchers	Researchers with clinical backgrounds	Health Service Practitioners/Managers
Score 4 or 5	11	3	8
Scores 0–3	8	1	0
Total	19	4	8

empowered and developed capacity within disadvantaged communities were strongly supported by Panel members, whereas models integrating researcher-led and user-led approaches received substantially less support (60%—table 3, Statement 14).

## Discussion

### *Consensus and disagreement*

Despite differing disciplinary perspectives across Delphi Panel members, it was possible to arrive at consensus on a number of key principles for ethnicity and health research. The 10 Leeds Consensus Principles encompass many of the key generic dimensions of research and should provide sufficient direction to inform decisions by those commissioning, undertaking and publishing ethnicity-related studies.

Areas in which consensus was not achieved relate most notably to specific aspects of research design and data generation, and reflect the disciplinary diversity of Panel members. This appears to reflect a lack of shared understanding on methodological details, such as how more 'meaningful' data categories and measures might best be developed to improve causal understanding or the targeting of

interventions. Panel members acknowledged that study design and data collection decisions are shaped by disciplinary paradigms and the practical constraints within which researchers work. Broad principles might therefore be preferable to tight prescriptions that are potentially counter-productive if they alienate researchers and dissuade them from actively reflecting on research practice.<sup>29</sup> Thus, while the Leeds Consensus Principles do not provide specific guidance on research design, they do encourage researchers across all disciplines to be explicit, transparent, reflective and critical about the methodological choices they make (Principle 3).

Disagreement about whether research should specifically explore the relationship between racial discrimination and health warrants further debate, since objections conflict with a growing body of literature suggesting a central role for racism in producing ethnic health inequalities.<sup>33</sup>

### *Building on previous guidance*

The Leeds Consensus Principles show continuity with earlier guidance generated by and for the research community. Smart *et al.*'s<sup>26</sup> review of editorials from biomedical journals<sup>34</sup> notes the trend over time away from prescriptive standardization towards more generic guidance. Other areas of continuity include: the recognition that research may perpetuate negative stereotypes of minority ethnic people;<sup>23,24</sup> the multidimensional nature of ethnicity and its link with socio-economic disadvantage; the internal diversity of ethnic groups; and the need to collect information on dimensions other than fixed, statutory ethnic categories.<sup>35</sup>

The Leeds Consensus Principles also extend beyond previous guidance to highlight the need to focus on intervention studies investigating how ethnic health inequalities might be reduced. Furthermore, the Principles emphasize the importance of involving members of minority ethnic communities in the research process. Although this has been highlighted previously,<sup>23,24</sup> it has been presented as an 'ethical' consideration, rather than guidance on scientific rigour. Involving members of minority ethnic communities in decisions about the kind of data that should be collected could, for example, challenge researchers' ideas about the value or risk of collecting certain types of data and contribute to resolving the conflicting approaches currently in operation. Principle 10 thereby responds to recent commentary on the urgent need for more empirical work on different ways to effectively engage minority ethnic communities in research.<sup>10,36</sup>

Finally, Principle 1 argues that health researchers have an overriding professional and ethical responsibility to incorporate attention to ethnicity within their work. In this respect, the principles move beyond guidance for those who are already engaged in ethnicity and health research, to the wider community of health researchers who might not normally consider ethnicity. Given the sustained policy and research interest in health inequalities yet disappointing attention to ethnicity within these international agendas,<sup>37</sup> Principle 1 is clearly of paramount importance.

### *Strengths and limitations*

The Delphi exercise presented here successfully elicited the views of a substantial number of researchers, policymakers and practitioners from a range of disciplinary backgrounds, each with substantial experience in ethnicity and health research. Although Panel members were not randomly selected, the commonalities between our findings and guidelines developed elsewhere<sup>24,28</sup> suggest that the consensus achieved is likely to be more widely identified. Nonetheless, in light of the variations between health-care systems and ethnic populations in different national contexts, there is scope for this exercise to be replicated with a broader range of participants from outside the UK. That said, the broad nature of the principles established should provide a firm foundation for exploring whether further consensus, particularly across European contexts, is possible.

Finally, these consensus statements did not identify ways in which such guidance might translate into improvements in health-care policy and practice, beyond the provision of more pertinent, robust and intervention-focused research. There may therefore be benefit in adopting a similar Delphi method to explore consensus on the effective translation of such research evidence into health-care policies and practice.

## Conclusions

There is ongoing concern that health research is not serving the interests of minority ethnic communities as well as it should. The Leeds Consensus Principles are intended to encourage researchers to consider how much their work might better contribute to improving the health of minority ethnic communities. These principles complement recent European-level policy statements on the principles and values informing research, policy and practice on migrant and ethnic health.<sup>38,39</sup> They also engage with debates within the USA about the (inappropriate) use of ethnic health research in policy development.<sup>40</sup> Given the perceived challenges of incorporating attention to ethnicity within health research, and the need to develop shared perspectives internationally and between disciplines, there is clearly a need to develop these principles further in collaboration with researchers, policymakers and practitioners beyond the UK context.

## Acknowledgements

The authors thank the Department of Health for funding the workshop and Delphi exercise. The authors are also grateful to Delphi Panel members who gave generously of their time and to Jeanette Moore who carried out quantitative analysis of Delphi scores. Initial findings from the Delphi exercise were presented at the 3rd Migrant Health Conference in Pécs, Hungary in May 2010.

## Funding

The UK Department of Health funded the workshop and Delphi exercise on which the consensus principles presented in this article are based.

*Conflicts of interest:* None declared

### Key points

- A consensus-building interdisciplinary Delphi exercise involving academic researchers, practitioners and policy-makers identified 10 key principles for framing, undertaking and using ethnicity and health research.
- Achieving consensus about the kinds of data that should be gathered was challenging, and reflected differing clinical and non-clinical research and practice imperatives.
- It was acknowledged that particular study design and data collection decisions will be shaped by disciplinary paradigms and practical constraints within which all researchers work.
- A unifying and common concern was that the generation and application of research evidence should not replicate patterns of social exclusion, stereotyping and stigmatization, and should instead contribute to better health-care experiences and health outcomes for ethnic minority populations.
- Decisions about the kind of research to best inform migrant and ethnic health policy and practice might usefully draw on the 10 Leeds Consensus Principles presented here.

## References

- Gill PS, Kai J, Bhopal RS, Wild S. Health Care Needs Assessment: Black and Minority Ethnic Groups. In: Raftery J, editor. *Health Care Needs Assessment: The Epidemiologically Based needs Assessment Reviews*. Abingdon: Radcliffe Medical Press Ltd, 2007.
- Nazroo JY, Jackson J, Karlsen S, Torres M. The black diaspora and health inequalities in the US and England: does where you go and how you get there make a difference? *Soc Health Illness* 2007;29:811–30.
- Black Sir Douglas (Chair). *Inequalities in Health: Report of a Research Working Group*. London: Department of Health and Social Services, 1980.
- Acheson Sir Donald (Chair). *Independent Inquiry into Inequalities in Health*. London: The Stationery Office, 1998.
- Department of Health. *Tackling Health Inequalities*. London: HMSO, 2003.
- Department of Health. *Health Inequalities - Progress and Next Steps*. London: Department of Health, 2008.
- Salway S, Ellison G. Nursing research for a multiethnic society. In: Gerrish K, Lacey A, editors. *Nursing Research*. Oxford: Wiley-Blackwell, 2010.
- Rafnsson B, Bhopal R. Large-scale epidemiological data on cardiovascular diseases and diabetes in migrant and ethnic minority groups in Europe. *Eur J Public Health* 2009;19:484–91.
- Aspinall P, Chinouya M. Is the standardised term Black African useful in demographic and health research in the United Kingdom? *Ethnicity & Health* 2008;13:183–202.
- Gerrish K. Researching ethnic diversity in the British NHS: methodological and practical concerns. *J Journal of Advanced Nursing* 2000;31:918–25.
- Mir G, Sheikh A. 'Fasting and prayer don't concern the doctors . . . they don't even know what it is': Pakistani Muslim patients with long-term illnesses. *Ethn Health* 2010;15:327–42.
- Davidson E, Liu JJ, Sheikh A. The impact of ethnicity on asthma care. *Prim Care Respir J* 2010;19:202–8.
- Afshari R, Bhopal R. Ethnicity has overtaken race in medical science: MEDLINE-based comparison of trends in the USA and the rest of the world 1965–2005. *Int J Epidemiol* 2010;39:1–3.
- Aspinall P. Approaches to developing an improved cross-national understanding of concepts and terms relating to ethnicity and race sociology. *Int Sociol* 2007;22:141–70.
- Bhopal R. Glossary of terms relating to ethnicity and race: for reflection and debate. *J Epidemiol Commun Health* 2003;58:441–5.
- Johnson M. Engaging communities and users: health and social care research with ethnic minority communities. In: Nazroo J, editor. *Health and Social Research in Multiethnic Populations*. London: Routledge, 2006.
- Mir G. Researching inequalities: lessons from an ethnographic study. In: Williamson A, Desouza R, editors. *Researching with Communities: Grounded Perspectives on Engaging Communities in Research*. New Zealand: Muddy Creek Press, 2008:285–300.
- McClellan C, Campbell C. Locating research informants in a multi-ethnic community: ethnic identities social networks and recruitment methods. *Ethnicity Health* 2003;8:41–61.
- Ellison GTH. Population profiling and public health risk: when and how should we use race/ethnicity? *Critical Public Health* 2005;15:65–74.
- Nazroo J, editor. *Health and Social Research in Multiethnic Populations*. London: Routledge, 2006.
- Bhopal R, Vettini A, Hunt S, et al. Review of prevalence data in and evaluation of methods for cross cultural adaptation of UK surveys on tobacco and alcohol in ethnic minority groups. *BMJ* 2004;328:76.
- Colledge M, van Geuns HA, Svensson PG. *Migration and Health: Towards an Understanding of the Health Care Needs of Ethnic Minorities*. Copenhagen: World Health Organisation Regional Office for Europe, 1983.
- Patel N. *Getting the Evidence: Guidelines for Ethical Mental Health Research Involving Issues of Race Ethnicity and Culture*. London: TCPS and MIND, 1999.
- SABRE. An Ethical Code for Researching Race, Racism and Anti-racism in Scotland Scottish Government, 2001. Available at: <http://www.scotland.gov.uk/Publications/2005/03/mepess/15> (22 September 2010, date last accessed).
- McKenzie K, Crowcroft NS. Describing race, ethnicity and culture in medical research. *BMJ* 1996;312:1054.
- Smart A, Tutton R, Martin P, et al. The standardization of race and ethnicity in biomedical science editorials and UK biobanks. *Soc Stud Sci* 2008;38:407–23.
- Gunaratnam Y. Complexity and complicity in researching ethnicity and health. In: Douglas J, Earle S, Handsley S, et al, editors. *A Reader in Promoting Public Health: Challenge and Controversy*. Basingstoke: Palgrave, 2007:147–56.
- Bhopal R. Ethical issues in health research on ethnic minority populations: focusing on inclusion and exclusion. *Research Ethics Rev* 2008;4:15–9.
- Salway S, Allmark P, Barley R, et al. Social research for a multiethnic society: an exploration of current guidance and future possible directions. *21st Century Soc* 2009;4:53–81.
- Keeney S, Hasson F, McKenna H. Consulting the Oracle: ten lessons from using the Delphi technique in nursing research. *J Adv Nurs* 2006;53:205–12.
- Worth A, Nurmatov U, Sheikh A. Key components of anaphylaxis management plans: consensus findings from a national electronic Delphi study. *J Royal Soc Med Sh Rep* 2010;1:42.
- Office for National Statistics. Census 2001: Definitions - Output classifications part 1, 2010. Available at: [http://www.statistics.gov.uk/downloads/census2001/definitions\\_chapter\\_6\\_part\\_1.pdf](http://www.statistics.gov.uk/downloads/census2001/definitions_chapter_6_part_1.pdf) (1 November 2010, date last accessed).
- Becares L, Stafford M, Nazroo J. Fear of racism, employment and expected organisational racism: their association with health. *Eur J Public Health* 2009;19:504–10.
- ICMJE. *Uniform Requirements for Manuscripts Submitted to Biomedical Journals*, 2010. Available at: [http://www.icmje.org/urm\\_main.html](http://www.icmje.org/urm_main.html) (1 November 2010, date last accessed).
- McKenzie K, Crowcroft NS. Describing race, ethnicity and culture in medical research. *BMJ* 1996;312:1054.
- Sheikh A. Why are ethnic minorities under-represented in US research studies? *PLoS Med* 2006;3:e49.
- Exworthy M, Bindman A, Davies H, Washington E. Evidence into policy and practice? Measuring the progress of US and UK policies to tackle disparities and inequalities in US and UK health and healthcare. *Milbank Quarterly* 2006;84:75–109.
- Commission of the European Communities. Solidarity In Health: Reducing Health Inequalities In The EU Com (2009) 567, 2009. Available at: [http://ec.europa.eu/health/ph\\_determinants/socio\\_economics/documents/com2009\\_enpdf](http://ec.europa.eu/health/ph_determinants/socio_economics/documents/com2009_enpdf) (16 August 2010, date last accessed).
- Xavier A, Price C, von Nordheim F. Solidarity in health: the European Commission sets out new actions on health inequalities. *EuroHealth* 2009;15:1–4.
- Kaufman JS, Nguyen TT, Cooper RS. Race medicine and the science behind BiDiL: how ACE-inhibition took the fall for the first ethnic drug. *Rev Black Political Econ* 2010;37:115–30.