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.\(^1,2\) The need to understand and tackle such ethnic health inequalities has repeatedly been recognized.\(^3–6\) 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.\(^7\) In recent years, for example, attention has been drawn to how ethnicity is conceptualized and operationalized;\(^8–12\) inconsistent and inappropriate terminology;\(^13–15\) how researchers engage with minority ethnic individuals and groups;\(^16,17\) how samples are drawn and participants recruited;\(^18–20\) and how comparable data are generated from diverse populations.\(^20,21\)

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

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.\(^29\) 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’.\(^29\)

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,30
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 op-
portunity 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’.30,31—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, epi-
demiologists 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.30 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 homogeneous, 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 exercise31

| 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. |
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 the 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 censuses12 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 ≤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
The purpose of research on ethnicity and health should be for the well-being and betterment of populations being studied. 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. 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. A better understanding of similarities and differences between ethnic groups can potentially improve the health of the entire population.

Framing and focus of research

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. It is important to be explicit about the assumptions and theories that underlie research on ethnic health inequalities.

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. Where quantitative data are lacking, such as in the case of asylum seekers and refugees, qualitative studies are an important means of generating knowledge. 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. 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.

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. There is a need to establish the cost-effectiveness of interventions while not neglecting other principles of ethnic health research. Single-discipline and inter-disciplinary research along with overarching reviews of evidence are needed to improve the evidence base for reducing ethnic health inequalities. Researcher-led models for developing research should be integrated with those led by service users. Methodologies for ethnic health research will vary across disciplines and inter-disciplinary approaches should be flexible enough to recognize differences.

Framing and focus of research

The use of ethnic categories and labels should be meaningful in relation to the particular experiences and outcomes being explored. Census categories are useful for exposing disadvantage but additional measures may be needed to explore the processes through which disadvantage is created. 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.

Where possible, researchers should draw on terms and categories that are understood and agreed within the existing literature on ethnicity and health.

Research samples should be appropriate for the aim of the research:

- Representative samples of diverse ethnic groups should be used where the aim of the research is to produce representative research findings
- 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
- In quantitative studies representative samples of diverse ethnic groups should not be used for comparative analyses unless the sample sizes meet a minimum threshold

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) 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. 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). New categories for exploring the causes of disadvantage and ways to address these should be developed with the input of minority ethnic communities.

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.
### Future directions

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.

**Data analysis**

28. 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 principle. Researchers must be alert to the dangers of discriminatory thinking and behaviour and guard against actual and potential harm resulting from their research.

29. 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.

30. 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.

**Consensus Principles**

Table 3 Continued

<table>
<thead>
<tr>
<th>Data analysis</th>
<th>Number of scored responses</th>
<th>Mean score</th>
<th>Number &gt;4</th>
<th>&gt;4 of total responses (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Analysis of health inequalities should pay attention to the social context in which ethnic differences in health outcomes are measured and health behaviours occur.</td>
<td>30</td>
<td>4.50</td>
<td>27</td>
<td>90.0</td>
</tr>
<tr>
<td>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?</td>
<td>30</td>
<td>4.05</td>
<td>23</td>
<td>76.7</td>
</tr>
<tr>
<td>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.</td>
<td>30</td>
<td>3.72</td>
<td>17</td>
<td>56.7</td>
</tr>
</tbody>
</table>

**Future priorities**

29. There is a need to focus on intervention studies that help identify effective ways of reducing inequalities.

30. 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 4 The Leeds Consensus Principles for research on ethnicity and health**

**Importance and purpose**

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.

**Framing and focus**

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.

**Data collection and analysis**

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.

**Future priorities**

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)**

<table>
<thead>
<tr>
<th>Score</th>
<th>Academic researchers</th>
<th>Researchers with clinical backgrounds</th>
<th>Health Service Practitioners/Managers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Score 4 or 5</td>
<td>11</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Scores 0–3</td>
<td>8</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>19</td>
<td>4</td>
<td>8</td>
</tr>
</tbody>
</table>

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 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).
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.39 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.33

Building on previous guidance

The Leeds Consensus Principles show continuity with earlier guidance generated by and for the research community. Smart et al.’s26 review of editorials from biomedical journals32 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,23,24 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.75

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,23,24 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.6,16,36

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 and should instead contribute to better health-care interventions. Panel members identified 10 key principles for framing, undertaking and using ethnicity and health research.8,16

Key points
- A consensus-building interdisciplinary Delphi exercise involving academic researchers, practitioners and policymakers 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 uniting 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


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34. ICMJE. Uniform Requirements for Manuscripts Submitted to Biomedical Journals, 2010. Available at: http://wwwicmjeorg/urm_mainhtml (1 November 2010, date last accessed).


