JRF Ethnic diversity in social science: ethics and research standards

Consultation with researchers outside universities, ethics committees and scientific review boards.

Introduction

The UK is a multi-ethnic society. The 2001 Census indicated that 13% of the population of England identified themselves as belonging to an ethnic group other than 'White-British' and 9% self-identified as other than one of the 'White' categories. More recent evidence shows that this ethnic, religious and linguistic diversity of the UK population is currently increasing and is likely to do so further in future years (Nazroo 2006; Vertovec 2007). In particular parts of the country (notably certain London boroughs, and parts of the East and West Midlands and Yorkshire and The Humber) individuals reporting other ethnicities outnumber the 'White-British' population. Across a range of social policy and welfare indicators minority ethnic groups continue to fare worse than the majority White-British population (Palmer et al., 2007). Evidence also shows that public policy and practice interventions can have differential effects across ethnic groups (Oakley, 2006; Platt, 2007).

Social science researchers have an important role to play 'in shaping societal attitudes and behaviours, raising issues for public debate, and informing the formulation of social policy and practice' (Salway et al. 2008: 1). Social science research, therefore, has the potential to revolutionise, or propagate, poor welfare outcomes for ethnic minority individuals and groups (Fustinoni & Biller 2000; Garland, et al. 2005) independent of the intentions of the researchers themselves.

Recently government departments have recognized of the importance of generating evidence that includes minority ethnic groups. This can be seen as a response to two factors: the Race Relations (Amendment) Act 2000 and the widespread expectation that developments in social policy and related practice will be evidence-based (Davies, et al. 2000; Thomas and Pring, 2004; Defra, 2006; Davies, 2004). Further, it is increasingly acknowledged that meeting the duties of the RRA requires a body of research knowledge that draws on and is relevant to the ethnic diversity of the whole UK population (Salway et al. 2008). For instance, one of the three building blocks of the 'Delivering Race Equality in Mental Healthcare Programme' current strategy is 'gathering and providing better information' (DRE, no date). In addition to public bodies, some professional organisations have expressed their commitment to 'mainstream' attention to ethnic diversity within the research they commission or support (Salway et al. 2008).

However, despite the apparent increased awareness of the need for (and right to) inclusion and representation of all ethnic groups in research that influences knowledge, policy and practice, the majority of funded social policy relevant research currently conducted in the UK focuses predominantly on the majority 'White-British' population and fails to consider ethnicity as a variable of analysis (Cheesman, 2007). Oakley (2006) describes in detail the processes that act to exclude minority ethnic people from health intervention evaluation, but also cites evidence of similar problems across a wide range of policy domains and social interventions. Unlike the United States, where, amongst other policy-relevant legislation, the Health

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Revitalization Act of 1993, requires that women and members of minority groups be included in all research projects funded by the National Institutes of Health and that a "clear and compelling reason" be given for inadequate representation of these populations (Corbie-Smith et al. 2003), there is currently no explicit *legal* requirement in the UK to include minority ethnic participants in publicly-funded research intended to inform social policy decisions affecting its ethnically-diverse population.

In addition to the question of *whether* social research should pay attention to ethnic diversity, i.e. the volume of research that is (ir) relevant to minority ethnic individuals and groups, it is important also to scrutinize *how* such research is conducted. Where research does include samples or participants from minority ethnic groups there is little evidence of consensus on how best to conceptualise ethnicity (Aspinall, 1997) (including minority and majority ethnicities), or how ethnic data ought to be measured, analysed and reported - all of which raise practical, analytical and ethical issues. While it seems entirely sensible to produce evidence that reflects the experience of the UK's diverse population, and thereby informs improvements in services for all, in practice the ethical and scientific arguments around whether and how to incorporate ethnicity into policy-relevant social research are complex and open to debate.

If social research is to be useful, there are important scientific issues to be addressed in relation to: setting research priorities and the identification of research questions; sampling/recruitment; measurement/ operationalisation (of ethnicity itself and other variables cross-culturally); collecting material and conducting fieldwork; analysis (how to 'unpack' this multi-faceted concept; how to identify routes of causation; whether to focus on inequalities or absolute levels, and so on); as well as reporting and representing the findings of research. Furthermore, significant practical and cost issues may also arise, as evidenced by the fact that recruitment of minorities to clinical trials in the US remains an ongoing struggle for many researchers (Corbie-Smith et al., 2003).

In the absence of explicit legal requirements for social policy relevant research to reflect and be relevant to the UK's multiethnic population, decisions as to whether, and how, research topics and research designs include attention to ethnic diversity lie predominantly with individual researchers and the commissioners/funders of research. Recent years have seen the publication of important texts that offer guidance to social scientists researching in multi-ethnic contexts (Stanfield and Dennis, 1993; Gunaratnam, 2003; Nazroo, 2006). However, it is of interest to explore the extent to which UK social scientists more generally have begun to engage with and tackle these complex issues. To what extent do social scientists have access to advice and direction on when and how they should incorporate attention to ethnic diversity within their research work? The present paper begins to address this important area by reporting on an exploration of the current practice undertaken by government departments, UK based voluntary and private organisations and ethics committees.

The specific aims of the current investigation were to:

1. Examine the procedures and policies which government departments, UK based voluntary and private organisations and ethics committees have in place to ensure ethical scrutiny and scientific rigour.

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- 2. Examine the extent to which ethnic diversity (and/or related issues such as culture, inclusion, and discrimination) is explicitly or implicitly given attention within such guidance.
- 3. To explore whether there is any basis for consensus in this area by examining similarities and differences across and between the groups.
- 4. To identify whether guidance on these issues is need and if so what form and content this should take.

The investigation forms part of a larger project funded by the Joseph Rowntree Foundation in which a series of review and consultation exercises are being used to consolidate expert opinion and to explore the feasibility and desirability of developing guidance to support commissioners of research, investigators and peer reviewers to consider when and how ethnic diversity should be included in social policy-relevant research projects (http://research.shu.ac.uk/ethics-ethnicity/). This paper documents the consultation part of the wider project.

<u>Methods</u>

JRF identified key stakeholders in government departments and private and voluntary research agencies that they wanted us to consult with. In total we approached the twelve government departments who are most active in producing social policy relevant research (both in-house and commissioned) and fifteen key research agencies. The following table shows our response rates:

	Government departments	Private research agencies
Sample size	12	15
No. of responses received	6	8
No. of responses promised	2	2
No. unable to participate	1	1
No. of non-responses	3	4

The following departments and organisations responded:

Government departments and Section (where relevant)	Private Research Agencies
National Audit Office	New Policy Institute
Scottish Government - Children Young	
People and Social Care	Institute for Public Policy Research
Home Office - Research and Statistics	Shared Intelligence
Department for Work and Pensions	Policy Students Institute
New Local Government Network	Ipsor MORI
Welsh Assembly	Ecotec
	Involve
	Community and Organisations: Growth and Support

Interview schedules were designed for government and private research agencies covering questions common to both as well as questions specific to each context i.e. the government departments questionnaire covered sections on in-house research

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as well as commissioning research while the private research agencies questionnaire focussed purely on in-house research.

Once the lists of contacts and participant information sheets had been developed the interviews were piloted (July - August 2008). After the pilot some small amendments to the interview schedule were made and it was decided that we would offer participants the choice of participating in the exercise via a telephone interview or paper questionnaire. The interviews/distribution of paper copies were conducted from September through to November. Apart from chasing up some remainder paper questionnaires that organisations are currently completing this stage of data collection has now been completed.

A representative from each organisation took part in a telephone interview or completed a paper questionnaire. All of the private research agency participants responded on behalf of their organisation. The Scottish Government and Home Office responded on behalf of their section within the department. It should be noted that while participants responded on behalf of their respective organisations that the views expressed are those of the respondent and not necessarily of the department or organisation that they represent.

A separate sampling strategy was developed for our consultancy with ethics committees based on geographical areas. The areas, all cities, were primarily selected on the basis of having a relatively high minority ethnic population as it was felt that research ethics and Independent Scientific Review (ISR) committees in these areas would consider ethnic diversity to be a relevant issue and to have developed procedures to deal with it. The aim of the exercise was not to provide a comprehensive scoping of whether and how ethics and ISR committees are dealing with ethnic diversity, but rather to (i) identify any examples of processes or tools that have been developed; and (ii) assess the receptiveness of such committees to potential guidance. The following regions were selected: Manchester; Bradford, Birmingham; London - Tower Hamlets; London - Tooting; and Leeds. Sheffield was also included given our local connections and relative ease of inclusion. The questionnaire and participant information sheets have also been designed. The intention is to contact and gather information from all the ethics and ISR committees within a region to which a piece of social science research could be referred for review - i.e. NHS committees; University committees, and Local Authority committees. We do not intend to include local private research organisations. At present we are in the process of compiling a list of contacts in each of the geographical areas identified. However this is proving to be difficult as there is no harmonised procedure for research that takes place outside the NHS.

The questionnaires to ethics committees were piloted at the beginning of October and some small amendments to the questionnaire were made. The timing of our pilots was delayed due to a query over whether or not we needed NRES approval. Once we had received confirmation that this was not required we proceeded with recruiting participants. As before respondents were given the choice of participating in the exercise via a telephone interview or paper questionnaire. The interviews/distribution of paper copies were conducted from October through to November. Apart from chasing up some remainder paper questionnaires that committees are in the process of completing we feel that we have come to the end of

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this stage of the review as we have been unable to make contact with the remaining contacts on our list despite numerous attempts by email and telephone. Unfortunately the response rate was not as successful as we had hoped:

	NHS ethics committees
Sample size	14
No. of responses received	3
No. of responses promised	2
No. committees do not review social policy relevant	1
proposals	
No. unable to participate	4
No. of non-responses	4

Due to the small response rate the following sections are designed to only give a flavour of the data collected from NHS ethics committees.

The research context and need for guidance

Government departments:

All of the government departments consulted conduct in-house research with five of also commissioning research. Four have specific programmes of research focusing on the needs and experiences of minority ethnic groups. The remaining two are involved in some projects that pay attention to ethnic diversity. Only one respondent mentioned specific plans for increasing the amount of research it does with ethnic minority groups. This particular focus is on research with new migrants.

Four respondents stated that they saw no challenges for their organisation regarding when and how to take ethnic diversity into account as they consider themselves to be experts in the field. The other two respondents stated that they felt there were many challenges e.g. resources, researcher experience, sample sizes, awareness issues. Both of these respondents also stated that these challenges were ongoing as the issues surrounding researching ethnic diversity are complex and fluid.

Two respondents stated that their department had a process of ethical scrutiny in place; two that they were in the process of developing a process and the remaining two that they had no process in place. Interestingly respondents viewed peer review in different ways. One department saw this as constituting their ethical review process while another regarded this as part of the process for developing ethical scrutiny procedures but not a sufficient procedure in its own right.

Three departments who have or are developing a process of ethical scrutiny do not have a race/ethnicity specialist involved in this process. One respondent envisages having a race/ethnicity specialist once their process has been fully developed (along with specialists in other areas, e.g. children and young people).

Three respondents reported that their department follows the Government Social Research (GSR) code of research ethics complemented by guidance taken from Social Research Association (SRA) and Market Research Society (MRS). One respondent commented that the GSR code is very generic and not prescriptive. Out of the remaining three, two do not have any code of research ethics but rely on

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researchers to follow the code of ethics employed by the organisation undertaking the project for their commissioned work. One respondent reported that their organisation envisages developing a code in the future.

Three departments have a process in place for ensuring scientific rigour and one is looking to develop this. All respondents reported that no race/ethnicity specialist is involved in this process.

Four respondents reported that their department has processes in place for deciding whether a piece of research should include attention to ethnic diversity. Of the remaining two, one reported that their work always includes attention to ethnic diversity and the other that no procedure is currently in place. Out of the four reporting procedures, two of these are informal review processes; one department consults GSR guidance and another has produced its own diversity guide. Four departments stated that researcher and/or stakeholder knowledge and experience dictated how attention should be paid to ethnic diversity. One has produced a diversity document.

Two of the five departments who commission research provide ethical scrutiny and scientific rigour guidance to researchers in tenders. This is done on a case-by-case basis.

Four of the five departments who commission research have an ethical and scientific review process in place for reviewing proposals i.e. tender assessment form, detailed framework, steering group. The remaining department is looking to develop such a process both for ethical and scientific review which they see as interrelated. The same four representatives who commission research and have an ethical and scientific review process in place stated that they would not consider a proposal if they felt that the researchers' approach to ethnic diversity was not appropriate. The other is unsure of their response.

Four respondents said that they would find guidance on when and how research should pay attention to ethnic diversity helpful. The other two consider themselves to be experts in this area and would either consider being involved in developing guidance or consider using the guidance to train other departments.

In several of the interviews, respondents raised the issue of whether ethnic diversity should be considered separately from other equality strands. In particular, some respondents referred to their organisation's need to work within a single equality framework and therefore the need to consider all axes of diversity and potential inequality simultaneously.

Private research agencies:

Four respondents stated that their organisation had a specific 'programme of research' or 'research theme' that focussed on ethnic diversity. Only one respondent mentioned that their organisation was looking to increase the amount of research that it conducts with ethnic minority groups although another organisation emphasised that one of their primary goals this year was to sustain the amount of work that they do in this area. Interestingly, two other participants stated that rather

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than increasing the amount of work, they would like to focus on improving the work that they do in this area.

Four respondents revealed that their organisations do not have their own process of ethical scrutiny. Two of these follow the guidance of the commissioner or their partner researchers. The other two organisations do not have a process in place at the moment but are looking to develop one in the near future. One of these envisages having a race/ethnicity specialist within their ethical scrutiny process. Three of the four respondents who stated that their organisation does have a process of ethical scrutiny have an informal process involving peer review and staff workshops. One of these organisations is looking at present to formalise this process and two have a race/ethnicity specialist within their process. The remaining organisation has a formalised process of a research board which reviews all projects. There are a number of race/ethnicity specialists on this board.

Only two of the organisations have their own code of research ethics, two use the code of the commissioner/ partner organisation, one follows the SRA code, two follow the MRS code and the remainder organisation is in the process of developing a code based on SRA and MRS guidance. In two cases the organisational representative reported that they follow the code of ethics in use by the commissioner of the study in question. This may be problematic since we know from our government department interviews that the commissioner might not have such a code in place.

Five out of the eight organisational representatives reported that their organisation has a procedure for reviewing the scientific rigour of the research that it undertakes i.e. internal peer review. Interestingly two of these five respondents do not see peer review as constituting a sufficient quality control measure to ensure scientific rigour due to its informal nature, while the remaining three do. Three out of these five organisations have a race/ethnicity specialist involved in their scientific review process. One of these three also stated that as well as asking their race/ethnicity specialist to review a project looking at ethnic diversity they always try to have the project reviewed by a second reviewer who has no expertise in the area to give a differing viewpoint.

Three participants stated that there were challenges in deciding when and how to include reference to ethnic diversity; four stated that this was in part the case i.e. challenges for how but not for when; difficulties for some colleagues. The other respondent stated that this was not a problem. One respondent emphasised that this should always be a challenge for organisations as 'it requires constant re-thinking.' Another stated that it is difficult to explain why there is a need to include reference to ethnic diversity to commissioners.

No organisations have any explicit procedures in place for deciding when to include reference to ethnic diversity though one is looking to do this in the future. Five stated that they base this decision on knowledge and experience and the remaining two follow the procedures recommended by commissioners/ partner organisations. No organisations have any explicit written guidance regarding how to include attention to ethnic diversity though the same organisation as mentioned above is looking to develop this guidance in the future. Four stated that they base these

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decisions on knowledge and experience and one reported that they follow guidance recommended by commissioners.

When asked how the organisation would respond to a proposal that does not include reference to ethnic diversity though they feel that it should, all stated that they would include reference to ethnic diversity in their tender and view it as 'added value.'

The response to the question how would the organisation respond to a proposal that includes reference to ethnic diversity though they feel that it should not was not as unanimous. Two respondents stated that they would argue their own case, one that they would not respond to the call and five stated that it is always appropriate to include reference to ethnic diversity.

In regard to disagreements with funders over the approach to ethnic diversity one stated that they would do what the funder asked, one that they would write the tender as they saw appropriate and let the commissioner decide who to tender it to and the remaining six said that it would depend on a number of factors e.g. how integral the disagreement is to the overall issue, previous relationship with funder. Only two stated that financial considerations may influence this decision. One respondent stated that they would undertake a project only if they felt they could steer the findings in a positive way for the participants/ minority groups involved.

Seven out of eight respondents said that they felt that their organisation would find guidance on when and how research should include attention to ethnic diversity helpful. The respondent who stated that s/he did not think guidance would be particularly helpful explained that this was because the organisation already had a number of experts in this field but that they could see how other organisations might find guidance helpful.

Issues and challenges: possible form and content of guidance

Government departments:

A number of issues were highlighted as being areas in which guidance was needed including:

- a) when to include attention to ethnic diversity:
- b) examples of bad practice to inform good practice;
- c) examples of common problems/ issues to be aware of;
- d) introductory training for new researchers;
- e) sampling and questionnaire design;
- f) language translation;
- g) research with 'invisible minorities' / new immigrants;
- h) patterns of changing migration;
- i) cross-cultural researcher competence;

Different ideas were also suggested for the form that guidance should take:

a) a database of non-research feeds e.g. documents published by charities and lobby groups;

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- b) website with general information complemented with a way that people can get answers to specific questions which in turn are made available to other researchers via the website:
- c) checklists supported by more detailed guidance;
- d) a graded approach with minimum and higher levels of attainment (so that people aren't put off if goal seems unachievable);
- e) self-assessment tool for individuals and departments so people can see how they are currently doing and areas they need to improve on;
- f) case studies with detailed, practical suggestions.

Several respondents were concerned that any guidance developed should not only address ethnic diversity but rather diversity and equality issues as a whole. This would mean the guidance was in line with the single equality agenda and the single equality schemes that government departments must now develop.

A number of respondents also noted that guidance needs to somehow reach those researchers who are not aware that they need to consider issues surrounding ethnic diversity. As one respondent stated 'Those who need to learn more often than that are not aware that they need to learn.'

Private research agencies:

A number of issues were highlighted as being areas in which guidance was needed including:

- a) diversity within certain groups: Somalians Northern and Southern;
- b) umbrella terms if ever appropriate to use;
- c) interaction of different characteristics e.g. ethnicity and gender, ethnicity and age;
- d) community researchers and interpreters;
- e) methodological approaches;
- f) why to include reference to ethnic diversity as well as when and how;
- g) research with new/ hidden communities i.e. Eastern European immigrants, gypsies.
- h) hierarchy within race equality needs to be addressed i.e. gypsies and travellers are often forgotten.

Different ideas were also noted for the form that research guidance should take:

- a) a piece of research dealing with some of these issues;
- b) web based resource complemented by tailored consultancy e.g. face-to-face workshops, email or telephone support;
- c) examples of good research papers;
- d) an addition to JRF's current guidance attached to tenders;
- e) brief bullet points

Three respondents stated that a website with a tailored consultancy resource would be helpful.

Three stated that researchers may feel patronised by guidance especially if they do a lot of work in this field and therefore guidance should take a non-personal form such as on a website rather than face-to-face consultancy.

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As with the government department representatives, issues of whether it is legitimate to look at ethnic diversity separately from diversity issues more widely were raised.

The importance of ethnic representation in research team make-up was raised by one respondent.

2. Research Ethics committees and ISR:

a) Method

A sampling strategy has been developed for this stage of our consultancy exercise based on geographical areas. The areas, all cities, were primarily selected on the basis of having a relatively high minority ethnic population so that it was felt more likely that research ethics and ISR committees would consider ethnic diversity to be a relevant issue and to have developed procedures to deal with it. The aim of the exercise was not to provide a comprehensive scoping of whether and how ethics and ISR committees are dealing with ethnic diversity, but rather to (i) identify any examples of processes or tools that have been developed; and (ii) assess the receptiveness of such committees to potential guidance. The following regions were selected: Manchester; Bradford, Birmingham; London _Tower Hamlets; London Tooting; and Leeds. Sheffield was also included given our local connections and relative ease of inclusion. The questionnaire and participant information sheets have also been designed. The intention is to contact and gather information from all the ethics and ISR committees within a region to which a piece of social science research could be referred for review - i.e. NHS committees; University committees, and Local Authority committees. We do not intend to include local private research organisations. At present we are in the process of compiling a list of contacts in each of the geographical areas identified. However this is proving to be difficult as there is no harmonised procedure for research that takes place outside the NHS.

3. NHS Ethics committees:

a) Method

As for the other parts of our consultation exercise, questionnaires and participant information sheets have been developed for NHS Ethics committees. Sampling was based on the same geographical regions as for Research Ethics committees and ISR.

The questionnaires were piloted at the beginning of October and some small amendments to the questionnaire were made. The timing of our pilots was delayed due to a query over whether or not we needed NRES approval. Once we had received confirmation that this was not required we proceeded with recruiting participants. Respondents were given the choice of participating in the exercise via a telephone interview or paper questionnaire. The interviews/distribution of paper copies were conducted from October through to November. Apart from chasing up some remainder paper questionnaires that committees are in the process of completing we feel that we have come to the end of this stage of the review as we

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have been unable to make contact with the remaining contacts on our list despite numerous attempts by email and telephone. Unfortunately the response rate was not as successful as we had hoped:

	NHS ethics committees
Sample size	14
No. of responses received	3
No. of responses promised	2
No. committees do not review social policy relevant	1
proposals	
No. unable to participate	4
No. of non-responses	4

Due to the small response rate the following sections are designed to only give a flavour of the data collected.

b) Findings

The research context: the need for guidance

Two committees were city-wide independent review boards with the third being a district research ethics committee. Both of the city-wide independent review boards reviewed proposals mainly from students and academic staff while the district research committee reviewed proposals from a number of different researchers i.e. consultants, registrars, nurses, students, academic staff, public-sector organisations, support groups

All three committee representatives stated that their committee was only supposed to scrutinise the proposals for ethics as they had already been examined and signed off by an independent scientific advisor. However, all felt that unofficially their role was also to review the scientific rigour of applications as scientific rigour has a direct impact on ethics. The Helsinki Declaration code of ethics was referred to by one committee representative. All submissions must be completed alongside the NRES Integrated Research Application form.

All of the respondents reported that their committee paid attention to whether and how ethnic diversity was taken into account in the study proposals reviewed. Respondents mentioned the following as issues that are given attention by their committee: researcher matching by gender for certain ethnic groups; timing of research i.e. not during Ramadam; stratification to include minority groups; language and translation; geographical location i.e. if there is a large ethnic minority population in the studied area these should be represented in the sample.

However none of the committees had any guidance for reviewers in relation to ethnic diversity or a race /ethnicity specialist.

The respondents indicated that it is not common for their committees to reject a proposal because it has not included attention to ethnic diversity through the committee feels that it should have. In one case though the respondent reported that researchers are regularly asked to review their proposal and re-submit it based on

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this issue. No formal procedures are in place to respond to proposals that need further work though all committees stated that informally they offer guidance.

Similarly, respondents indicated that it is not common for a proposal to be rejected because it has paid insufficient attention to ethnic diversity, though it may be referred for further work. However, responses were divided on whether proposals are rejected/referred for further work because they have included attention to ethnic diversity though the committee feels it is not appropriate: one stated that this has never happened, one that it is always appropriate to include reference to ethnic diversity and the other that the committee at present is divided on whether it is always appropriate or not. Two committees stated that issues regarding whether and how ethnic diversity should be taken into account were not problematic for their committee. The third stated that these issues were problematic as it is important to constantly think about these complex issues.

Two respondents felt that their committee would find guidance helpful. The committee that said it would not pointed out the need to ensure that any guidance is in line with the legal requirements of the Clinical Trials Act. This committee refers applicants to the guidance on the IRAS website.

The committee that rejected guidance would consider the following for each study:

- 1. The location of the study.
- 2. The background of the respondents.
- 3. The background of the researcher conducting the study e.g. a student or contract researcher.

The respondent stated that they had developed a common-sense approach to taking these considerations into account. These issues are then discussed each year at the Chairs' meeting.

Issues and Challenges: possible form and content of guidance

A number of issues were highlighted as areas being in need of guidance, including:

- a) timing i.e. if appropriate to conduct research during religious festivals;
- b) translation and language;
- c) power dynamics in the home in different cultural contexts and the impact this has on informed consent:
- d) gender matching;
- e) cultural taboos and sensitivities;
- f) the need to pilot with minority as well as majority groups;
- g) intersection of ethnic diversity with other variables i.e. ethnicity and disability;
- h) harm individual and group;
- i) how to decide whether a project/issues should be a focus for a particular ethnic group

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Form of guidance (both suggestions were made by two of the respondents):

- a) not prescriptive but rather a list of prompts/ issues to be aware of;
- b) flow chart of main areas to consider

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4. Summary of key findings

Responsiveness of organisations to guidance.

Respondents differed in their responsiveness to guidance. Thirteen out of the seventeen respondents stated that they would find guidance helpful. There responses are recorded by category below:

- Four respondents from government departments said that they would find guidance helpful.
- The other two consider themselves to be experts in this area and would either consider being involved in developing guidance or consider using the guidance to train other departments.
- Seven respondents from the private research agencies said that they felt that their organisation would find quidance helpful.
- The one respondent who stated that s/he did not think guidance would be particularly helpful explained that this was because the organisation already had a number of experts in this field but that they could see how other organisations might find guidance helpful.
- Two NHS respondents felt that their committee would find guidance helpful.

Content of guidance.

The following issues were highlighted as being in need of guidance.

- when to include attention to ethnic diversity (Government)
- examples of bad practice to inform good practice (Government)
- examples of common problems/ issues to be aware of (Government)
- introductory training for new researchers (Government)
- sampling and questionnaire design (Government)
- language translation and community researchers (Government, Private Research Agencies [PRA], NHS)
- research with 'invisible minorities' / new immigrants i.e. Eastern European immigrants, gypsies (Government, PRA)
- patterns of changing migration (Government)
- cross-cultural researcher competence (Government)
- diversity issues as a whole not just a focus on ethnic minority diversity in line with the single equality agenda and the single equality schemes that government departments must now develop. (Government)
- diversity within certain groups e.g.. Somalians Northern and Southern (PRA)
- umbrella terms if ever appropriate to use (PRA)
- interaction of different characteristics e.g. ethnicity and gender, ethnicity and age (PRA, NHS)
- methodological approaches (PRA)
- why to include reference to ethnic diversity (PRA)
- timing i.e. if appropriate to conduct research during religious festivals (NHS)

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- power dynamics in the home in different cultural contexts and the impact this has on informed consent (NHS)
- gender matching (NHS)
- cultural taboos and sensitivities(NHS)
- the need to pilot with minority as well as majority groups(NHS)
- harm individual and group (NHS)
- how to decide whether a project/issues should be a focus for a particular ethnic group (NHS)

Format of guidance.

The following forms of guidance were recommended.

Government departments:

- a database of non-research feeds e.g. documents published by charities and lobby groups
- website with general information complemented with a way that people can get answers to specific questions which in turn are made available to other researchers via the website
- checklists supported by more detailed guidance
- a graded approach with minimum and higher levels of attainment (so that people aren't put off if goal seems unachievable)
- self-assessment tool for individuals and departments so people can see how they are currently doing and areas they need to improve on
- case studies with detailed, practical suggestions

Private research agencies:

- piece of research dealing with some of these issues;
- web based resource complimented by tailored consultancy e.g. face-to-face workshops, email or telephone support;
- examples of good research papers;
- addition to JRF's current guidance attached to tenders;
- brief bullet points

NHS ethics committees:

- not prescriptive but rather a list of prompts/ issues to be aware of;
- flow chart of main areas to consider

5. Issues arising

There appears to be some discrepancy regarding where the responsibility of having and employing a code of research ethics lies i.e. on the commissioner or the researcher. This responsibility needs to be addressed in guidance so that the relevant parties are aware of their duties and how to implement the agreed code.

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Peer review is viewed differently by respondents who took part in both the government and private research agencies in relation to both ethical scrutiny and scientific rigour. The role of peer review needs to be explored and addressed in the guidance.

Particularly in the government department interviews some respondents considered themselves to be experts but were unable to discuss these issues in depth/ deal with the complexities of the issues i.e. would say 'We know all about that' but then could not elaborate. Guidance needs to find ways to respond sensitively to this as well as to the assertion made by private researchers that some researchers may find guidance patronising. Guidance therefore needs to be written in a way that makes it as accessible as possible to the widest possible audience and in a form that is appropriate to the diversity of this audience e.g. researchers, commissioners and ethics committees. Three tailored sets of guidance could be produced to support each of these groups.

In addition guidance needs to somehow reach those researchers who aren't aware that they need to be aware of issues surrounding ethnic diversity.

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