Title: Ethnic diversity in UK social science and public policy research: a consultation and development exercise to produce guidelines for sound scientific and ethical practice

Main proposer: Dr. Sarah Salway, Sheffield Hallam University (SHU)

Research team: Dr. Gina Higginbottom (SHU), Professor George Ellison (St George's, London), Dr. Richard Tutton (University of Nottingham), Dr. Peter Allmark (SHU) and Professor Kate Gerrish (SHU).

Background
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 non-White. The ethnic, religious and linguistic diversity of the UK population is likely to increase in future years. In particular parts of the country (notably certain London boroughs, and parts of the East and West Midlands and Yorkshire and The Humber) individuals of non-White British ethnicity out-number the White British population.

Across a range of social policy and welfare indicators, outcomes for minority ethnic groups continue to be far worse than for the majority White population. In addition, there is great diversity within and between ethnic 'groups', so that generalisation across minorities (and also the majority 'White' population) can be misleading.

The Race Relations (Amendment) Act 2000 has made it unlawful for a public authority to act in a way that constitutes discrimination. The Act further places legal duties upon public bodies, in carrying out their functions, to consider the need to eliminate unlawful discrimination and to promote equality of opportunity and good relations between people of different racial/ethnic groups. Further, most public authorities are also bound by specific duties, such as publishing a race/ethnicity equality scheme or policy setting out how they will meet the general duty (http://www.cre.gov.uk/legal/rra.html), and the Commission for Racial Equality's ongoing formal investigation into the Department of Health clearly indicates its intention to use its powers to identify failures in these duties across a range of public policy arenas (http://www.cre.gov.uk/Default.aspx.LocID-0hgnew0qf.RefLocID-0hg00900c008.Lang-EN.htm).

Given that expectations of evidence-based social policy and practice are now the norm, these duties clearly imply the need for a research evidence base that reflects the ethnic diversity of the population. For example, the need for such an evidence base has been formally acknowledged by the Department of Health in its Research Governance Framework for health and social care in which it sets out general principles that should apply to all research (DH 2001):

'Research, and those pursuing it, should respect the diversity of human society and conditions and the multi-cultural nature of society, Whenever relevant, it should take account of age, disability, gender, sexual orientation, race, culture and religion in its design, undertaking and reporting. The body of research evidence available to policy makers should reflect the diversity of the population' (Para 2.2.7)'

Other government Departments, while not having such explicit general principles, are showing increasing commitment to strengthening the evidence base relating to minority ethnic groups, for instance via specific programmes of research (e.g. the Department for Work and Pensions' work on ethnic minority employment disadvantage) and initiatives to ensure 'ethnic monitoring' (e.g. Department for Education and Skills' work to support schools in this endeavour).

'Effective use of data will help to ensure that disparity of attainment is actively tackled and that pupils can meet their full potential. Effective policies are undermined by lack of data. This has recently been vividly described as "no data no strategy"' (http://www.standards.dfes.gov.uk/ethnicminorities/collecting/).

Some professional bodies (such as the Royal College of Psychiatrists) and voluntary funders of research (including the Joseph Rowntree Foundation) have also expressed their commitment to 'mainstream' ethnic diversity within the research they commission or support.

However, despite the apparent increased awareness of the need for (and right to) inclusion in research that influences knowledge, policy and practice, it is clear that the majority of funded social research that is conducted in the UK focuses predominantly on the majority White British population and fails to consider ethnicity as a variable of analysis. Unlike the US, where, amongst other policy-relevant legislation, the Health Revitalization Act of 1993, now 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.

Furthermore, where research does include samples or participants from minority ethnic 'groups' there is a vast array of approaches and practices to conceptualising ethnicity (including minority and majority ethnicities), and to measuring, analysing and reporting of results, all of which raise practical, methodological and ethical issues.

While it seems without question that, in principle, we should produce evidence that reflects the experience of our diverse population, and thereby informs positive change for all, in practice the ethical and scientific arguments around whether and how to incorporate ethnicity into policy-relevant social research are complex and subject to heated debate.

In particular, it is important to highlight the various ways in which untheorized or insensitive inclusion can have negative implications (Ellison and Jones, 2002). For example, in the area of biomedical and health research, Richard Tutton and George Ellison have drawn attention to the dangers of biomedical/genetic research where 'linking genetic information to socially defined categories has the potential to reinforce crude biological notions of race/ethnicity and for the research to be misused in political, scientific or clinical contexts' (Project Update 2006). In

social science, there are also numerous examples of 'adverse incorporation' of minority ethnic groups into research resulting in the creation/perpetuation of damaging stereotypes, exaggeration of differences between 'groups', the 'othering' of minority groups, and the production of culturalist explanations that ignore socioeconomic and political factors (Hall 1997; Karlsen 2004). Historically, gross abuses of human rights have occurred in the name of scientific enquiry where minority groups have been exploited as the subjects of research, including the infamous Tuskegee Syphilis Experiment in the US.

In addition, if social research is to be useful, there are important scientific issues to be addressed in relation to: research priority setting / research question identification; 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); and reporting and representation. For instance, in quantitative, statistical studies important questions include:

- How should ethnicity be conceptualised and measured? Under what circumstances should ethnicity be conceptualised as a categorical variable capturing discrete social and/or biological differences, or as 'proxy variables' for related (behavioural, biological or socioeconomic) variables?

- When is it unnecessary to collect data on ethnicity, and what sorts of study design warrant representative, 'exclusive' or 'boosted' samples? When and how should data be disaggregated by ethnicity in subsequent analyses?

- How might the different sample sizes generated by representative sampling influence the power of any analytical 'signals' observed in disaggregated analyses comparing different ethnic groups?

- How might the differential heterogeneity of the ethnic categories applied influence the clarity of any 'signals' observed in disaggregated analyses comparing different ethnic groups?

And in qualitative work, key issues include:

- How to manage the tensions between the need to challenge essentialism of ethnic labelling in the research process, while also engaging with the ways in which different forms of essentialism can be part of the experience and narratives of research participants.

- How to mediate between the need to 'fix' ethnic categories at various points in the research cycle while also creating space for understanding the fluid and contingent nature of individual and collective identities.

- How to design inclusive studies that provide meaningful opportunities for marginalised people to co-produce policy-relevant findings and the implications of such ways of working for what we consider as 'evidence'.

Legal mandates, such as those in force in the USA, provide no guidance on these complex methodological issues. Furthermore, significant practical and economic issues 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).

Opportunities for increasing the quality and quantity of social science and policy-relevant research that is inclusive of minority ethnic populations
There are four critical junctures in the research cycle at which there is the potential to significantly increase both the quantity and quality of research that incorporates ethnic diversity: (1) Scoping and commissioning of research; (2) Independent Scientific Review (ISR) or equivalent prior to receiving funding; (3) Ethics Approval prior to commencing a study; and (4) Peer-review at publication stage. At all stages, other academics, and in the case of (1), (2) and (3) members of the public or 'lay' readers too, may act as gate-keepers and can therefore potentially challenge researchers on whether and how ethnicity has been taken into consideration in the work.

Ongoing work by Richard Tutton and George Ellison has identified around 35 different guidelines on the use of race/ethnicity that are in existence for health and biomedical journals. However, these guidelines are varied (Tutton et al. in press; Smart et al. 2006; Outram and Ellison 2006) and largely not enforced (Ellison and Rosato 2002). Key journals that publish social policy-relevant research including Ethnicity & Health, Ethnic and Racial Studies, and Journal of Marriage & the Family, do not currently employ any specific guidelines for reviewers or authors.

Meanwhile, a preliminary search and consultation exercise suggests that there is little in the way of guidelines for use either by researchers or reviewers of proposals at the levels of commissioning, ISR and Ethics Approval. In several cases examined, the review forms and guides available include no mention of ethnicity or ethnic diversity at all, in others reviewers are simply asked to check a box to indicate that "issues concerning racial and ethnic diversity have been considered" (or similar). The Social Research Association's latest ethics guidelines (SRA 2003) alert social researchers to their responsibility to ensure *'the inclusion in research projects of individuals and groups who might otherwise be excluded'* (p38), but the guidance talks only about the need to pay attention to the ethnic background of interviewers and the need to produce materials in minority ethnic languages *'where relevant'*. Nor does the Department of Health Research Governance Framework provide any detailed guidelines as to how research practice should address the complex issues that arise in researching in multi-ethnic settings. While some funding agencies, including the JRF, give explicit indication to applicants that they expect research to be inclusive of minorities wherever appropriate, many more do not.

In short, though social researchers are encouraged to consider the importance of making their research inclusive of minority ethnic populations, there is a dearth of guidance on appropriate study design and little in the way of quality assurance checks within the research cycle. The present project aims to fill this gap in guidance by developing, piloting and disseminating a set of guidelines. This will

be done taking into consideration the complex scientific and ethical issues and the overall desire to promote, rather than stifle, good social research that contributes to well-being.

Aims and objectives
This project will build upon and expand the work of Richard Tutton and George Ellison in the field of biomedical and genetics research to examine the complex issue of addressing ethnic diversity in social science research, in order to:

Develop, pilot and disseminate a set of guidelines that will help commissioners of research, investigators, applicants and peer reviewers consider when and how ethnic diversity should be included in social policy-relevant research projects, and to make appropriate decisions and recommendations regarding research design to ensure that ethnic diversity is appropriately, effectively and sensitively incorporated into such research.

The project will produce a number of related outputs that aim to meet the needs of the Joseph Rowntree Foundation's own programme of work, as well as contributing to a shift in the working practices of the social science research community more broadly.

The guidelines will aim to increase the quality and quantity of research that effectively and sensitively includes minority ethnic populations by:

- Supporting those researchers who are already considering ethnic diversity as a central dimension in the design and execution of their research projects.

- Encouraging other researchers actively to consider whether and how their research can more adequately represent the ethnic diversity of the population.

- Providing guidance for research commissioners and reviewers to design and evaluate research protocols that generate evidence appropriate for ethnically diverse populations.

Methodology
The project will follow a consultation and development approach ensuring that we draw on the expertise and perspectives of a wide range of stake-holders including researchers, funders, commissioners, reviewers, researchers, partners, and users of research including members of the public.

1) Review of existing guidelines, texts and papers.
Building on the work carried out by Richard Tutton and George Ellison in the area of biomedical/genetics research, a review of existing guidelines, texts and papers that relate to addressing ethnic diversity in social policy-relevant research will be undertaken. The review will be multidisciplinary (focusing primarily on sociology, social policy, social geography, education, social work, public health, social

psychology and economics) and will aim to extract key issues/central themes identified in relation to scientific rigour and ethical practice in social science research that addresses race/ethnicity. The review will focus on consolidating key messages in relation to the different elements of study design including: engagement/participation; conceptualisation; inclusion and sampling; measurement/operationalisation; analysis and interpretation. Particular attention will be given to how guidance on each of these dimensions of study design should link clearly to project aims.

We will seek information from:

a) Existing guidance in use by ISR and Ethics panels across a range of institutions (including: university level ethics committees, faculty level ethics committees, health and social care Research Governance panels, local authority research ethics panels etc.)
b) Journal guides to authors and reviewers (spanning a range of social science and social policy areas).
c) Existing guidance in use by professional bodies (e.g. SRA, BSA, BPA), funding agencies (including the JRF's own documentation) and commissioners of research.
d) Key texts and papers (spanning a range of social science and social policy areas).
e) A review of past proposals submitted to JRF for funding.

2) Delphi and Consumer Panel techniques.
In order to elicit diverse perspectives, opinions, lessons learnt and examples of best practice we will use a range of techniques to consult with significant stake-holders as follows:

a) Ethics/Governance panel members - via a web-based survey and questionnaire.

b) Academics/researchers - via a web-based survey and questionnaire.

Personal networks and email listings (JISCMAIL MINORITY-ETHNIC-HEALTH and SOCIAL POLICY) will be used to convene a panel of at least 50 experts willing to participate.

c) Consumer/user groups and community-based organisations - via a series of four face-to-face workshops (London (2), Sheffield/Leeds, Leicester/Birmingham).

We will draw on established networks with which we have existing links to convene four workshops in which we will gather experiences and opinions of community representatives, service users and members of the public including SUMEHR, East London, ETN Leeds, and Voluntary Action Sheffield.

We will seek ethical approval for conducting this data gathering exercise from the Faculty of Health & Wellbeing Research Ethics Committee at SHU in order to protect the interests of both participants and the research team.

3) Development of a series of linked draft guidelines for use in commissioning, designing and reviewing of social policy-relevant research projects

Drawing on the information yielded from phases (1) and (2) above, we will undertake a synthesis of key principles and practices in order to develop a series of linked draft guidelines for:

a) JRF internal use (to guide applicants in their study design and internal reviewers in their assessment of proposal quality).
b) Research commissioners.
c) Independent Scientific Review (to guide applicants in their study design and independent academic reviewers in their assessment of proposal scientific rigour).
d) Ethical review & research governance (to guide applicants' consideration of the ethical dimensions of their study design and lay and professional reviewers in their assessment of ethical standards pertaining to both study participants and wider society).
e) Peer-review of academic papers (to guide authors in the conduct and presentation of studies and reviewers in their assessment of paper quality).

4) Development of measures/tools for use during the piloting of guidelines.

Here we will identify measures and tools that can be used to assess the appropriateness and feasibility of the guidelines. It is anticipated that we will elicit information on both the perceptions of those asked to use the guidelines, and those receiving feedback on the basis of the guidelines. Research governance bodies keep extensive records regarding all projects and it is likely that journals (particularly those administered electronically) would also be able to provide information to allow us to examine how the process of implementing the guidelines operates in practice (see 5 below).

Thought will also be given to whether any measures of 'impact' on the quality and/or quantity of research projects being approved and/or published can be designed and collected. This, however, may require a retrospective investigation or a longer time period for prospective evaluation.

5) Piloting of guidelines and eliciting of feedback (over a 12 month period)

We will arrange for the guidelines to be introduced to a small number of (1) Organisations commissioning social policy-relevant research (including JRF and internal University funding schemes); (2) Independent Scientific Review boards (3) Ethics/Governance review panels and (4) Academic Journals. In addition, in (1) above, the JRF guidelines will be piloted with internal staff and applicants.

For categories (2) and (3) we will aim to cover a range of 'settings' since there will be variation across geographical areas and sectors in the extent to which issues of race/ethnicity are considered pertinent and are already being addressed. An orientation to the guidelines will be provided to the Chairs/Editors and assurance gained that they will be distributed to reviewers/applicants on a pilot basis. The guides themselves should be self-explanatory and therefore be used by reviewers as part of their normal review process without the need for any additional

orientation (though this will of course be one of the dimensions we will seek feedback on). Since many journals now use electronic submission and tracking procedures, it will be necessary to work with the editors to re-configure their system settings. Professor Kate Gerrish is Joint Editor and Sarah Salway and Gina Higginbottom are members of the Editorial Team for *Ethnicity & Health*, while George Ellison is Associate Editor of *Critical Public Health* and we therefore anticipate being able to use these as two of the pilot journals. Kate Gerrish is also a member of the Taylor & Francis Editors network offering the possibility of accessing a wide range of social science journals. The Research Team are also members of several review boards themselves and have links with a number of Chairs of review boards, including the Association of Research Ethics Committees (AREC), as well as journal editors. Our networks will ensure that we are able to identify sufficient 'pilot sites' to gain useful feedback on the guidelines.

The measures/tools developed (4 above) will be used to evaluate the guidelines.

6) Modification / fine-tuning of guidelines and dissemination of guidelines for wider peer-review and uptake via publication in print and web-based media.
Following the pilot period, the research team will modify and fine-tune the set of guidelines. The guidelines will then be made available via a website on which we will elicit feedback comments from users of the guidelines. We will also disseminate the lessons learnt and outline guidelines via a published paper and one or more dissemination events. We will also produce a 'briefing pack' that will be sent to journal editors, ISR and ethics review committees, professional bodies and scientific societies, and funding bodies (including, but not limited to, The Nuffield Foundation, The Leverhulme Trust, and the ESRC), commissioners, partners and users of research. Again, the extensive academic and practice networks of the research team (and their respective research centres) will be utilised to ensure wide distribution of the results of the exercise. In addition, the Enterprise Centre at SHU will provide support to identifying relevant recipients through its extensive databases.

References

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Corbie-Smith, G., Viscoli, C.M., Kernan, W.N., Brass, L.M., Sarrel, P. and Horwitz, R.I. (2003) 'Influence of race, clinical, and other socio-demographic features on trial participation' *Journal of Clinical Epidemiology* , Volume 56, Issue 4 , April 2003, Pages 304-309.

Commisssion for Racial Equality (2007) *The Race Relations Act* http://www.cre.gov.uk/legal/rra.html

Department of Health (2005) *Research governance framework for health and social care: second edition* DH: London

Ellison, G.T.H. and Rosato, M. (2002) 'The impact of editorial guidelines on the classification of race/ethnicity in the British Medical Journal'. *Journal of Epidemiology and Community Health* 56: 45A

Ellison, G.T.H. and Rees Jones' I. (2002) 'Social identities and the 'new genetics': scientific and social consequences'. *Critical Public Health* 12: 265-282.

Gotay' C.C. (1991) 'Accrual to cancer clinical trials: directions from the research literature'. *Soc Sci Med* **33**, pp. 569–577.

Hall S. (1997) 'The spectacle of the other' in Hall S. (ed.) *Cultural representations and signifying practices* London: Sage.

ONS (2001) *Census 2001 - Ethnicity and religion in England and Wales* http://www.statistics.gov.uk/census2001/profiles/commentaries/ethnicity.asp#ethni c

Outram, S.M., Ellison, G.T.H. (2006). Improving the use of race/ethnicity in genetic research: a survey of instructions to authors in genetics journals. *Science Editor* 29: 78-81.

Smart, S., Tutton R., Ashcroft R., Martin P.A., Ellison G.T.H. (2006). Can science alone improve the measurement and communication of race and ethnicity in genetic research? Exploring the strategies proposed by Nature Genetics. *BioSocieties* 1: 307-318.

Tutton R., Smart, A., Ellison, G.T.H., Ashcroft, R., Martin, P. (2006) *Race/ethnicity and genetics in science and health* Project Update, Autumn 2006.University of Nottingham: Nottingham.

The research team

Sarah Salway is Principal Research Fellow in the Centre for Health & Social Care Research, Sheffield Hallam University. With a background in sociology and public health, she has extensive experience of conducting both quantitative and qualitative social science research. Her work on race/ethnicity has spanned the social welfare and health arenas. She has lived and worked for extended periods in South Asia, speaks Bengali and has a particular interest in the experiences of British Bangladeshis. She recently convened an ESRC-funded two-year seminar programme, 'Understanding and tackling ethnic inequalities in health'. She is a member of the Sheffield Health and Social Research Consortium Scientific Review Board and is currently Assistant Editor of the Routledge journal *Ethnicity & Health*. Sarah will act as PI for the project providing academic direction and coordinating all activities. With Gina Higginbottom, she will undertake the bulk of the review and consultation work. She will take the lead on developing and piloting the

guidelines while also eliciting and incorporating critical input from the other team members. Sarah will contribute 40% FTE in year one and 10% in year two.

Relevant publications:
Salway S., L. Platt, P. Chowbey, K. Harriss and E. Bayliss (2007) <u>Long-term ill-health, poverty and ethnicity</u> Joseph Rowntree Foundation: York and The Policy Press: Bristol.

Salway S. (2007) 'Young Bangladeshi men in the UK labour market: inclusion, exclusion and identity' <u>Ethnic and Racial Studies.</u> *forthcoming*

Salway S., L. Platt, P. Chowbey and K. Harriss (2007) 'Long-term health conditions and Disability Living Allowance: exploring ethnic differences and similarities in access' *forthcoming* in the 13th Sociology of Health & Illness monograph <u>Ethnicity, health and healthcare: understanding diversity, tackling disadvantage</u>.

Salway S. (2007) 'Patterns of labour market participation among Bangladeshi and Pakistani women in the UK: evidence from the Family Resources Survey' <u>Journal of Ethnic and Migration Studies.</u> 33(5)

Gina Higginbottom is Principal Research Fellow at Sheffield Hallam University and a former National Primary Care Research Fellow. Her expertise is within the fields of medical sociology and public health. She has a substantial portfolio of policy relevant research within the domain of ethnicity and health conducted in partnership with a number of population groups in the UK, utilising participatory models of research. Gina is founder and convenor of Transcultural Research Group in Health and Social Care (TRG) and is a member of the Sheffield Health and Social Care Consortium's (Research Governance body) Scientific Review Panel. Gina is Assistant Editor of Ethnicity and Health and a member of a number of funding committee research proposal review panels e.g. DOH Research for Patient Benefit, Mary Seacole Leadership Awards. Gina will work with SS in conducting the review and consultation process and will also contribute to the development, piloting and refinement of the guidelines. Gina will contribute 10% FTE in year one and 5% in year two.

Relevant publications:
Higginbottom**,** GMA (2006) Pressure of Life': Ethnicity as a mediating factor in mid-life and older peoples' experience of high blood pressure *Sociology of Health and Illness* 28(5):1-2

Higginbottom GMA, Mathers N, Marsh P, Kirkham M. Owen, JM (2006) The experience of early parenthood amongst young people of minority ethnic origin in England: young parents, grandmothers and service providers' views *Social Science and Medicine* 63(4):858-870

Higginbottom, GMA & Mathers, N. (2006) The use of herbal remedies in self care and the promotion of general well-being by individuals of African Caribbean origin with hypertension. *Diversity in Health and Social Care* 3(2) 99-110

Higginbottom, GMA (2006) African Caribbean hypertensive patients' perceptions and utilization of Primary Health Care Services in England *Primary Health Care, Research and Development* 7:25-36

George Ellison, Richard Tutton, Kate Gerrish and Peter Allmark each bring to the project different expertise and networks that will ensure the work incorporates diverse perspectives and reaches a wide audience. Acting as expert consultants, they will contribute to the project by: giving critical comment on the review work (both in writing and via participation in team meetings); inputting into the design of the consultation exercise and survey tools; contributing to the writing/preparation of the guidelines for different audiences; providing links/networks that will facilitate the identification of 'sites' for piloting of guidelines; contributing to the development of the measures/tools for evaluation of the pilot phase; contributing to the analysis and consolidation of feedback from the pilot phase; contributing to the redrafting of the guidelines and advising on and contributing to the production of varied dissemination products. Each has been costed into the proposal for 9 days in year one and 4 days in year two.

George Ellison is Professor of Health Sciences in the Faculty of Health and Social Care Sciences at St George's, University of London. With a background in natural science and public health, he has developed an extensive programme of work examining the operationalisation of race/ethnicity in public policy and biomedical research. He has lived and worked for extensive periods in South Africa, speaks Afrikaans and has a particular interest in the way race/ethnicity was conceptualised and applied in pre- and post-apartheid legislation, and in research into disparities in health and social wellbeing. Together with Alan Goodman (president of the American Anthropological Association) he recently published an edited volume of papers exploring the role of 'difference' within human biology (*The Nature of Difference: Science, Society and Human Biology*, Taylor & Francis, 2006) and is currently preparing a second volume examining the development of interdisciplinary approaches for exploring variation in health and social care. He was co-applicant on two grants from the Welcome Trust research programme on biomedical ethics involving projects studying the editorial review of studies using race/ethnicity in genetics journal articles, and its use in biobanks and pharmacogenetics research. He has also recently been awarded a British Council grant with Jo Chataway (Open University) to explore the ethical, legal and social implications of the new genetics and biotechnology throughout Africa. George is a co-applicant on the proposed project and, together with Richard Tutton, will bring expertise in the development of guidelines for academic journals, research ethics committees and institutional review boards to evaluate the inclusion of racial/ethnic data in research proposals. George will bring his extensive experience and contacts to support the project across its life-cycle.

Relevant publications:

Ellison GTH (2007) <u>Health, wealth and IQ in sub-Saharan Africa: Challenges facing the `Savanna Principle' as an explanation for global inequalities in health</u>. *Britsih Journal of Health Psychology* 12: 191-227.

Ellison GTH (2006) Medicine in black and white: BiDil®, race and the limits of evidence-based medicine. *Significance* 3: 118-121.

Outram SM, Ellison GTH (2006). Improving the use of race/ethnicity in genetic research: a survey of instructions to authors in genetics journals. *Science Editor* 29:78-81.

Ellison GTH (2005). 'Population profiling' and public health risk: when and how should we use race/ethnicity? *Critical Public Health* 15: 65-74.

Richard Tutton is Senior Research Fellow in the Institute for Science and Society at the University of Nottingham. His academic training is in literary and cultural studies and sociology, and has experience of conducting qualitative research with both diverse professional and public groups. His long-standing research interests are in exploring how developments in science, technology and medicine are implicated in changing social and cultural practices of identity, ethnicity and citizenship. For the last three years he has been engaged on a Wellcome Trust project that examined the use of race and ethnicity in genetics-based research and medicine.

Relevant Publications:
Tutton, R. (2007) 'Opening the White Box: Exploring Categories of Whiteness in Contemporary Genetics Research', *Ethnic and Racial Studies*, 30 (4): 557-569

Tutton, R. (in press, 2007) 'Biobanks and the Biopolitics of Inclusion and Representation' in H. Gottweis and A. Petersen (eds) *Monitoring Bodies: The New Politics of Biobanks*, London: Routledge

Smart, A.; R. Tutton, R. Ashcroft, P. Martin and G.T.H. Ellison (2006) 'Can Science alone improve the Measurement and Communication of Race and Ethnicity in Genetic Research? Exploring the Strategies proposed by *Nature Genetics*', *BioSocieties* 1 (3): 307-18

Tutton, R. (2004) 'Race and Medicine in the Twenty-first Century', *British Journal of General Practice* 54 (506): 716-7

Peter Allmark is Principal Lecturer on secondment to the Centre for Health & Social Care Research, Sheffield Hallam University. His research interests and expertise focus on the philosophy and ethics of health and social research. He is a member of a NHS Research Ethics Committee and a peer reviewer for the *Journal of Medical Ethics*, amongst others. He has published one article on the ethics of the inclusion of minorities in research.

Relevant publications:
Allmark P. (2004) Should research samples reflect the diversity of the population? *Journal of Medical Ethics*; 30(2),185-9.

Kate Gerrish
Kate Gerrish is Professor Nursing in the Faculty of Health and Wellbeing at Sheffield Hallam University and Sheffield Teaching Hospitals NHS Foundation Trust. With a professional background in nursing, she has developed a programme of research which has focused on the experiences and perspectives of different ethnic groups in relation to their access to and passage through health services and the health care practitioner's role in supporting these groups, in understanding cultural conflicts that can arise, the cultural congruence of services and how these affect the performance of health care professionals. In recognition of her contribution to this field, in 2006 she was appointed Adjunct Professor of Trans-cultural Nursing at the Karolinska Institute in Sweden. For the past 5 years she has co-edited the international journal, *Ethnicity and Health* with Professor James Nazroo, University of Manchester. As Chair of the Research Society of the Royal College of Nursing of the United Kingdom and through a joint appointment in the NHS she is actively involved in a broad range of committee work relating to research governance policy and procedures and scientific review in health and social care. Kate is a co-applicant on the proposed project and will bring expertise in the development of the proposed guidelines for research ethics committees and scientific review panels and academic journals As an editor of a journal published by Taylor and Francis Informa she is well positioned to facilitate the piloting, evaluation and subsequent dissemination of guidelines to a number of international journals in the social sciences, social policy and health fields.

Relevant publications
Gerrish K & Guillaume L (2006) Whither survey research: the challenges of undertaking postal surveys within the UK research governance framework. *Journal of Nursing Research* 11:6 485-497
Jirwe M, Gerrish K & Emami A (2006) The theoretical framework of cultural competence. *Journal of Multicultural Nursing and Health*, 12:3 6-16
Gerrish K. & Griffith V. (2004) Integration of overseas Registered Nurses: evaluation of an adaptation programme. *Journal of Advanced Nursing* 45:6 579–587
Gerrish K Chau R, Sobowale A, Birks, E (2004) Bridging the language barrier: the use of interpreters in primary care nursing. *Health and Social Care in the Community* 12:5 407-413
Gerrish K (2003) Self and others: the rigor and ethics of self-reflexive ethnography. In J. Latimer (ed) *Advanced Qualitative Research for Nursing*. Blackwell Science Oxford 77-94
Gerrish K (2001) The nature and effect of communication difficulties arising from interactions between district nurses and South Asian patients and their carers. *Journal of Advanced Nursing* 33: 5, 566-574

Budget Justification

Consultancy fees
George Ellison and Richard Tutton's inputs to the project have been costed at the nominal daily rate of £300. They will each contribute 13 days of paid input to the project as detailed on the enclosed quotations. However, since the project fits closely with George Ellison's wider programme of work, it is anticipated that he will contribute additional time free of cost to this project.

(Note: As SHU members of staff, the contributions of Kate Gerrish and Peter Allmark, also 13 days each, have been translated into % time equivalent)

Online survey fees
Technical support to the online consultation exercises will be provided by the Centre for Research & Evaluation at Sheffield Hallam University (CRE). CRE have a number of staff who specialise in this type of work and we will require 7 days input at £200 per day to design, implement and analyse the online consultations.

Administration
We have budgeted for administrative support to the project at 10% FTE over the two year period. Due the nature of the project, involving a high level of networking and liaison, administrative support will be important. The administrator will support SS in setting up and maintaining systems for cataloguing the review material; take responsibility for the logistics of the consultation exercises (both online and workshops); liaise with project partners and stakeholders; and contribute to the preparation of project documents and outputs.

Travel and subsistence
We have budgeted for standard class train travel for team members to attend team meetings and also for the workshop participants to attend the consultation workshops. We also include costs of 6 journeys to JRF in York for team members. Cheapest fares will be purchased. We have estimated travel costs as follows:

For workshops:
3 medium distance fares X 4 workshops @ £60 per journey = £720
20 local fares X 4 workshops @ £20= £1,600
For team meetings:
3 London-Sheffield X 6 meetings @ £90 = £1,620
For visits to JRF:
6 Sheffield-York journeys @ £30 = £180

Total travel and subsistence= £4,120 (year 1: £3,520; year 2: £600)

Workshops
4 consultation workshops are planned.
We have budgeted for:
1/2 day room hire X 4 @ £300 = £1,200
Refreshments for 24 people X 4 @ £10 = £960
Materials for 24 people X 4 @ £5 = £480

Total for workshops= £2,640

Direct office expenses
The project will make relatively light use of office equipment and stationery. We have budgeted £400 for computer use and support, and, based on notional monthly charges per full-time staff member (£17.50 telephone, £15 stationery, £15 computer consumable and £20 photocopying) we have budgeted £324 for SS and £81 for GH in year 1 and £81 for SS and £40 for GH in year 2.
Total direct office expenses= £926.