

# **Social Care Research Ethics Committee**

**An NRES Research Ethics Committee**

**Annual report**

**1 January 2009 to 30 June 2010**

**(first meeting June 2009)**



social care  
institute for excellence



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Written by the Social Care Research Ethics Committee

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## 1. Introduction

‘The dignity, rights, safety and wellbeing of participants must be the primary consideration in any research study.’

(Research Governance Framework for Health and Social Care, Dept of Health, 2005)

‘Research is defined as any form of disciplined inquiry that aims to contribute to a body of knowledge or theory.’

(Economic and Social Research Council, Framework for Research Ethics, 2010)

The national Social Care Research Ethics Committee (the Social Care REC) reviews adult social care research study proposals from researchers based in England<sup>1</sup>. It is part of the National Research Ethics Service (NRES), and its membership, expertise and procedures have been developed to reflect the social care context. The Social Care REC appointing authority is the Social Care Institute for Excellence (SCIE) and it is funded by the Department of Health (DH). Committee members, recruited through open advertisement, include researchers, ethicists, providers and users of social care.

The aim of the Social Care REC is to complement, not replace, other RECs by addressing gaps in provision, and it will take on specialist roles (see below). No investigator should have to seek ethics review from more than one REC. University RECs and NHS healthcare RECs will continue to review social care proposals where appropriate. For example, student research should normally be channelled through University RECs.

The following principles suggest the type of studies the REC will expect to review:

- a. Social care studies funded by Department of Health.
  - research commissioned directly through the Policy Research Programme.
  - Information Centre (IC) studies (i.e. those to be designed by IC, for implementation by councils with adult social services responsibilities, who do not then individually need to seek additional review).
  - studies commissioned by or through National Institute for Health Research (NIHR) School for Social Care Research.
  - social care studies funded through NIHR.
- b. Social care research that involves people lacking capacity. In England, these MUST be reviewed by a recognised appropriate body under the Mental Capacity Act 2005. The Social Care REC is recognised by the Secretary of State for this purpose. (University RECs cannot review research involving adults lacking capacity.) This includes service evaluations that are ‘intrusive’ as defined under the Act.

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<sup>1</sup> The remit of the Social Care REC was expanded on 1 March 2011 to include proposals for social science studies situated in the NHS. See appendix one for details of the Committee’s current remit.

- c. Social care research that involves sites in England and another United Kingdom country.
- d. 'Own account' research undertaken by councils with social services responsibilities, where the chief investigator feels there are substantial ethical issues.
- e. Studies of integrated services (health and social care), provided that there is no clinical intervention involved and NRES is in agreement.
- f. Studies where investigators do not have access to other review systems. This could include service user-led research. Investigators can contact the coordinator at SCIE for guidance around their specific proposal.

The Social Care REC does not consider any research involving clinical interventions or changes to clinical practice. Such research should be reviewed by another appropriate REC within the NRES. However, some research involving NHS patients may be accepted for review by the Social Care REC where the focus of the research is entirely or substantially social care services, and there is no change to clinical practice. Should such a study take place in an NHS or joint NHS/local authority setting (such as a community mental health team venue), and is required to be registered with an NHS R&D review body, Social Care REC review is equivalent to that of any other NRES REC. Where such applications are accepted for review, they do not then require separate review by another REC within the NRES.

It should be noted that the Social Care REC operates to a wider interpretation of 'research' than may apply in the NHS. For example, most evaluations and certain types of audit would be accepted as suitable for review by the Social Care REC, whereas in the health sector such activity may not be presented in the same way and not considered as research. The purpose of a research study should not be confused with its design and ethical conduct. Neither the health sector nor the Social Care REC would wish to attract studies which have not been designed or presented as research. Neither sector would want to encourage researchers to avoid their responsibilities under the Research Governance Framework. Investigators and sponsors may have a number of reasons for seeking REC review (such as vulnerable participants; wanting advice on consent procedures; ability to reassure publications editors).

The Social Care REC meets monthly (apart from August) and held their first meeting on 5 June 2009.

## 2. Committee information

**Chair:** Professor David Stanley, BPhil PhD AcSS FHEA FRSA

**Vice-Chair:** Susan Harrison, PgDip MA MA MHM

**Alternate Vice-Chair:** Eleanor Grey MA PGCE

**Co-ordinator:** Barbara Cuddon

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**Project Manager  
SCIE** Dr Deborah Rutter  
Senior Research Analyst

### 3. Chair's overview of the operational year June 09–June10: Issues Identified

#### 3.1 Getting the Committee up and running

The genesis of the Social Care REC is recorded elsewhere and is not repeated here. The REC is, of course, an independent committee; it is important first of all, however, to place on record the outstanding support we have received from our sponsor, the Department of Health; our host body, NRES; and our appointing authority, SCIE. Without such support and encouragement we could not have made the progress that has been made in these first 18 months of operation.

Following a highly successful open recruitment campaign which attracted over 80 applications, 30 high calibre applicants were interviewed at the end of January 2009. Of these, 15 were appointed and brief biographies can be viewed on the website. We were extremely satisfied with the range of experience and background represented. Since then one member has resigned to live abroad and another, Daphne Obang, sadly died in June 2010 after a long illness. An appointment has been made to replace Daphne's valuable expertise in diversity and equality.

Following recruitment, custom designed induction and training was undertaken by our members and co-ordinator. The full Committee attended a two day residential induction event which was planned with a range of targeted inputs as well as providing opportunities for members to get to know one another. Ongoing updating and training is undertaken by individual members and co-ordinator to meet NRES requirements. Additionally, there have been two full committee training sessions. The first was in respect of the Mental Capacity Act (MCA), led by David Neal (Head of Policy and Deputy Director, NRES), and leading to the formal recognition of the Social Care REC as an appropriate body under the Act (authorising it to review research concerning adults who may lack capacity to give their consent to participate). The second, led by Dennis L Carney (freelance trainer and consultant), concerned diversity and equality with a focus on improving service delivery and ensuring an understanding of the relevant law. One outcome of our first annual self-evaluation was a request for advanced ethics training and plans are under way for this to be provided in 2011 by two of the Committee members who are professional ethicists.

As a national Committee with members drawn from across England, we make considerable use of teleconferencing for members who are available but unable to make the journey. For similar reasons we also conduct a number of interviews with applicants by teleconference. It is our experience that not only is this a satisfactory way of conducting Committee business but, in view of the necessary discipline of a conference call, it can often be more efficient, quite apart from saving applicants having to make lengthy and tortuous journeys in some instances (for example, from the far south west). NRES SOPs do not currently formally recognise teleconference

attendance but we expect them to do so in future revisions to further support this flexibility that has been demonstrated to be of value by the Social Care REC.

On one occasion in the Chair's absence the Committee has been chaired by the vice Chair. Every meeting is started with a call for declarations of interest. There has been a very small number of occasions where individual applications have been chaired by a member where the meeting Chair has declared a conflict of interest. Where there is a declaration, the Committee's decision is either that the interest is not material, is material but minor and of an order that the member may remain in the meeting but does not participate in the discussion, or is substantive and the member is required to leave the meeting whilst it addresses that particular application. Decisions are fully minuted. A lead and second reviewer system is operated for initiating discussion, and the Committee's questions are put to the applicant by the Chair, with contributions from other members which are managed through the Chair.

### 3.2 Reactions from the social care research community

Substantial effort has gone into publicising the existence and purpose of the REC including national presentations (see list of meetings and conferences appended on page 19), the development of a dedicated website and the distribution of flyers. SCIE as the appointing authority, and Dr Deborah Rutter as the project manager, have been extremely supportive and facilitative in this respect. In addition, all members take on a role as publicists.

Social care researchers who have submitted to the Committee have responded positively in meeting the requirements of our opinions. Initially the community had not only to learn about our existence, but also to understand our function and, in some circumstances, become accustomed to mandatory ethical review. Some applicants have been unaware of the requirement or process of ethical review and they have been on a steep learning curve. We believe that applicants are more responsive, or less resistant, once they appreciate that the Committee rigorously pursues a proportionate approach to its review. It is clear that some repeat applicants actively use their attendance at Committee to enhance their own understanding of research ethics.

Whilst we see very competent and impressively sophisticated submissions, we have also seen some with poor understanding of research ethics, and substantial misunderstanding of the Mental Capacity Act, from amongst applicants across all sectors including universities, national organisations and government departments.

In some instances there has been a degree of resistance to the review process, with attempts by applicants to undermine the authority of the Committee. Some of these situations arise where applicants are unfamiliar with the standard requirements of ethical review, and the need to consider areas such as voluntary recruitment, informed consent and the potential for offence in wording

questionnaires. In responding to such situations we have stuck strictly to the ethical issues in question but also taken the opportunity to update and inform applicants when deemed appropriate.

Having now been operational for 18 months, there is sufficient evidence from significant sectors that the community not only has accepted the role of the Social Care REC, but finds it an important and positive innovation. The evidence submitted by the Academy of Social Sciences to the Rawlins review (September 2010) includes some very supportive comments (eg section 28. ‘contributors to the AcSS submission have reiterated the value of a separately constituted Social Care Research Ethics Committee’) as does feedback from the online survey for the ‘State of social care research’ update (October 2010).

### 3.3 The complexity of the studies reviewed

Committee members have, collectively, extensive experience of sitting on NRES and other RECs and substantial relevant expertise. At least five have previously sat for a number of years on other NRES RECs and two continue to so. Whilst we have no wish to plead a special case, it is our firm view that the complexity of the studies and the issues which we review, coupled with researchers who are frequently unfamiliar with the process, and the relatively uncharted waters of complex social care research ethics review, make for complex discussion and decision making which typically takes longer than it does in our experience of other RECs. Issues include: design, methods (qualitative, data collection measures, ethnographic, large scale surveys), recruitment practices, consultee arrangements, variety of settings (care homes, LA, own home of participants), and working with professionals from, for example, the performing arts who have never previously engaged with research ethics.

### 3.4 Diversity and dignity

We repeatedly see statements in applications that research is not funded to a level which permits special arrangements to be made for translation and interpretation. Either funded research does not cover the cost of involving minority ethnic populations or researchers do not factor them in, or both. We believe that one of our functions as a committee is to draw this to the attention of both commissioners and applicants. It is not acceptable that substantial, usually black and minority ethnic (BME), communities remain outside of the research environment, particularly when the possibility exists that their needs may be different from the traditional research populations. There may be circumstances in which the Committee might consider equality and diversity limitations in study design as a justification for delivering an unfavourable opinion.

Another issue which arises regularly concerns the use of particular instruments which the Committee finds unacceptable (for example, too intrusive for the purposes and an affront to personal dignity; or just simply poor research design) but which are characteristically defended by researchers as being validated, the only reliable measuring tool, etc. With some of these tools we are aware, through the direct experience of our members and from correspondence from Association of Directors of Adult Social Services (ADASS) research governance groups, that others find them unacceptable to the extent that some local authorities will not host studies which use particular instruments. Researchers can sometimes appear more concerned to find a usable tool than to reject it on ethical grounds: as with time pressures, it seems that the imperative to win and complete a research contract can compromise ethical considerations. Nevertheless, we encourage researchers to consider applying for funding to develop more acceptable tools. We would likewise set this challenge for commissioners and service providers too.

### 3.5 Tight timescales

Funders' tight timescales for delivery (and this includes both DH and SCIE) place enormous pressure on researchers to submit applications for review before the methodology has been finalised. In some cases, the incremental aspect of the research – e.g. a survey informs the interview topic guides – makes it impossible to know at the start precisely what data collection tools will be used. Researchers argue to us that they cannot meet the Committee's requirements in the time available and there are occasions where the Committee comes under considerable pressure to compromise ethical standards. It should be added that it does not do so. It is important that researchers understand the place of ethical review in the process of designing and undertaking research. However, where the content of later research tools or topic guides is determined during earlier stages of enquiry, the submission of these tools to the REC at a later date as an amendment is an option.

### 3.6 Quality of applications

With the usual caveat that there are notable exceptions, there is considerable work yet to do to encourage and enable applicants to submit well written IRAS Forms. Applicants new to IRAS struggle with the idea of it as much as with their actual use of it: the process is not yet, unlike the case with most healthcare research, embedded in the organisational research culture of most of our applicants. Key sections in applications submitted are not written in lay language, there are multiple typos, sections not completed, version numbers etc not put on attached documentation; information sheets and consent forms are inadequate, using language which is not written with the needs of the respondent in mind. Reviews of the basic science by university or organisational research committees are rarely included with applications. Whilst much work has gone into developing the Social Care REC filter version of the IRAS form, there remain some fundamental

problems, most notably, from the proposers' point of view, a lack of capacity to search or spell check the full document.

A major function of the Social Care REC website is to provide initial advice to applicants and to refer via links to NRES, IRAS and DH advice and information.

### 3.7 Misunderstandings about the Mental Capacity Act (MCA)

Whilst the implementation of the MCA is still relatively recent, and there is an increasing number of researchers with a competent working knowledge of the research sections, it remains one of our most substantial concerns and the single area on which we spend most time giving advice before, during, and after review. Amongst the issues that arise are:

1. Failing to make an acceptable case for including the person who lacks capacity.
2. Confusing the overall 'best interests' test approach of the Act with the specific requirements for research approval.
3. Misunderstanding the role of consultees.
4. Having difficulty in differentiating between proxy responses and including the person who lacks capacity in the research (though we acknowledge that this is a grey area in relation to the Act).
5. Failing to appreciate that the Social Care REC has a duty to deliver an ethical opinion within a legal framework in order to ensure that research under the Act is conducted lawfully.
6. A University REC reviewing a research proposal involving those lacking capacity to consent and giving approval to proceed without being aware that it has no lawful powers to do so.
7. And, from time to time, applicants telling us that they have been advised by experts who could not possibly be wrong.

### 3.8 Use of sub-committees

Whilst in our self-evaluation one member expressed a concern about our relatively limited use of the sub-committee option in the consideration of amendments, the reality is that none of our studies is likely to involve the degree of physical risk that some healthcare interventions might pose. We therefore take a relatively low key approach to amendments, related to our approach to proportionality in general. Our experience is that CIs are diligent in referring amendments to us and, if in doubt, will seek advice as to whether it should be minor or substantial. Although we have a designated standing sub- committee, in most instances Chair's action is taken in confirming a minor amendment. Sub-committees are occasionally held, both in terms of a consideration of major amendment or in finalising an opinion.

### 3.9 Report to SCIE Board

Dr Rutter and Professor Stanley presented a progress report to SCIE's Board in September 2009. Its purpose was to update members on the development and functioning of the Social Care REC. The key issues flagged at the time were: a brief description of the steps taken to form and equip the Committee and initiate the review process; a brief comment on SCIE's function as the appointing authority; a recommendation to re-establish an advisory group (see below).

### 3.10 Stakeholder reference group

A SCIE advisory group was established to facilitate the initial stages of the Social Care REC implementation plan and was stood down in February 2009 following completion of arrangements to appoint Committee members. Whilst the Social Care REC reports to SCIE, and is accountable in governance terms to NRES, there was identified a continuing need for an intermediate level of stakeholder involvement as in the report to SCIE's Board referred to above. This was not a proposal to reconvene the previous group but to create a new body with terms of reference, its purpose to be to:

- develop and maintain links with key stakeholders
- provide the social Care REC with direct feedback from the social care research community
- provide a capacity that is competent to advise the Social Care REC and NRES in the event of appeals and disputes
- provide social care expertise to the panel of National Research Ethics Advisors.

The proposal arose partly as a result of discussions with DH and NRES concerning, in particular, the development of social care focused support for assisting in dealing with contested appeals; and partly there was an expectation from the sector following the closure of the original group. SCIE's Board approved the proposal which has, however, remained unimplemented. To a certain extent this is because it has been overtaken by events: the review of arms length bodies, the Rawlins Review, and general recessionary pressures including the unlikelihood of securing a budget. A virtual group was considered as an alternative. Furthermore, after the SCIE Board meeting there was some discussion about how the proposal might fit with the Committee's independence. Whilst the matter remains in abeyance it is arguable that there are other ways of obtaining feedback from the sector, as previously described above. However there continues arguably to be a gap in terms of appeals process which requires to be addressed.

The potential for developing informal links with the National Research Ethics Advisors Panel is under consideration.

### 3.11 Proportionality

It is important for the Committee's integrity for its decisions to be accepted as reputable within the social care research community. We strive to ensure that our approach is one of making ethical decisions within a legal framework which are proportionate to the type of study.

As a new REC, we work constantly for our ethical opinions to be seen as authoritative as those of other NRES RECs, particularly in relation to trust R&D departments, where there continues to be only a partial understanding of both our existence and our authority. This is certainly not for lack of support within NRES and the DH research directorate, with whom we have engaged in this respect. We have contributed to consultations on the revisions of NRES Standard Operating Procedures, and the governance arrangements for research ethics committees, which we hope will spell this out clearly, and have drafted an annexe to the former to aid understanding and promulgation. Section 5 below lists the range of events at which there has been a presence to promote the work of the Committee.

Following publication of the NRES pilot and consultative paper on proportionate review, in November 2010 the full Committee considered whether to set up a separate proportionate review committee. It decided not to do so, on the grounds that the criteria were essentially health, rather than social care, related and that as a national Committee there were constraints on our resources. The decision will be reviewed in 12 months time. However, the Committee will consider whether there are some proposals – such as repeat large-scale national surveys – which it might deal with in a more proportionate way.

### 3.12 The boundaries of adult social care

For as long as there continues to be no children and families equivalent to the Social Care REC we continue to come under pressure to review research which involves children. We have agreed with NRES that we will accept studies which are adult-focused but which include some respondents under 16 years. Similarly we occasionally accept studies where the focus may be on children but all respondents are adults. To be competent in reviewing these studies we have identified members who also have expertise and research ethics training in matters relating to children. Where we do review the ethics of research involving children we give non-binding advice rather than an ethical opinion.

### 3.13 Deciding who should review studies when there is NHS involvement

Initially, we did not accept for review studies which involved NHS staff or premises. However, with the blurring of health and social care boundaries, the increasing development of new types of workers, and the clarification of our authority, we began to accept, on a case-by-case basis and in consultation with NRES, studies where no clinical intervention was involved which included NHS staff, NHS patients and NHS premises. Following this experience we now make decisions without routine referral to NRES but would refer in cases where we deemed it to be necessary. This development trajectory demonstrates both the growing maturity of the Committee and the confidence that NRES places in us.

## 4. User feedback

As a new Committee, the Social Care REC was very keen to ensure that the service it is providing meets the needs of researchers. All those whose projects were reviewed between 1 April 2009 to 31 March 2010 were contacted and asked to complete a user feedback form which is now part of the Social Care REC website. All researchers will be encouraged to complete this form following the review of the application. The results are detailed below.

Rating guideline 1=poor, 5=excellent

### Application process

Please rate your experience of:

Question	Average	Range	Mode (most frequent)	No of Respondents
Using the Social Care REC website to find information	3.6	2-5	4	18
Contacting the Social Care REC Co-ordinator to seek advice	4.9	4-5	5	18
Downloading and completing the IRAS Form	3.1	1–4	3	18
Using the online guidance/advice when completing the IRAS Form	3.3	2–5	3	18
Submitting your form to the Social Care REC	3.6	1–5	4	18

## Social Care REC meeting

Did you attend the Social Care REC meeting either in person or via telephone?  
16 people said yes, 1 no and 1 did not respond but answered the questions.

If 'yes' rate your experience of:

Question	Average	Range	Mode (most frequent)	No of Respondents
The timekeeping of the meeting	3.9	1–5	5	17
The venue where the meeting was held, including where you were asked to wait	4.1	3–5	5	14
The way the committee approached and treated you	4.1	3–5	5	17
Understanding the issues raised by the Committee at the meeting	3.8	2–5	4	17
Asking the REC for clarification on issues of importance to you or your research	3.8	1–5	4	16

## Communicating with the Social Care REC

Question	Average	Range	Mode (most frequent)	No of Respondents
The time taken to confirm your application was valid and would be reviewed at the next meeting of the REC	4.8	3–5	5	17
The time taken to advise you of the decision of the Committee after reviewing your application	4.6	2–5	5	18
Understanding the issues raised in the letter from the REC	4.1	1–5	5	18
Understanding what you had to do to address the issues raised in the letter from the REC	4.1	2–5	4	18
Getting clarification and answers to questions you were unsure about, arising from the letter	4.3	2–5	5	14

### If your application was rejected:

Question	Average	Range	Mode (most frequent)	No of Respondents
Understanding what you needed to do to take forward your application	4.3	3–5	5	4
Understanding the options open to you	4.3	3–5	5	4
The ease of taking this process forward	3.7	2–5	None	3

## Free text comments:

### Social Care REC remit (interface of research design and ethics)

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| 1. 'Several of us feel this survey is not asking relevant questions. The venue of the REC meeting is surely less important than the fact that some committee members did not seem to understand the point of a REC and asked questions that were not relevant or useful or that improved the study for potential participants. We felt the committee members would benefit from a briefing on the role of a REC and the ethical issues related to research; rather than other research issues. Also, the committee seems to withdraw an application, when minor amendments would have been an adequate solution'.  |
| 2. 'The position of proxies and consultees could be better clarified. I was not impressed by one member of the SREC being on the other end of the telephone. I think the Committee is far too large in size. I think the Committee was inclined to re-review the research - which is not their job when it has already been peer reviewed. I think that the questions about translation and interpreting were a little adversarial. I am not convinced that the SREC is being proportionate in taking too much trouble over things that the NHS would see as audit. It is a shame that I am being advised to go to NHS rather than SREC as it is easier to deal with issues of mental capacity'. |

### Co-ordinator support

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| 3. 'The support provided by the SCREC Administrator/Coordinator is excellent'.  |
| 4. 'The REC Coordinator Mrs Cuddon was personable and provided an excellent interface between the committee and myself. Overall I am very satisfied with the service provided.' |
| 5. 'The co-ordinator was very helpful'.   |

### Meetings

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| 6. 'I preferred the venue on Portland Place to the new one'.  |
| 7. 'Overall, the communication with the social care REC was good, the committee gave good feedback and advice. My only minor criticism is that, when attending the committee meeting, we were not offered a drink; all committee members had refreshments; - this did not help with feeling at ease in front of such a large group, particularly as a fairly new researcher'. |

### Process of application

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| 8. 'The REC operated in a fully professional way, was supportive and gave useful and relevant guidance. The REC co-ordinator was very supportive when completing and submitting the form'. |
| 9. 'The process was very bureaucratic and time-consuming, and furthermore allowed for no flexibility in the research plan'.  |

10. 'The issues raised were sensible, and I felt it was a rigorous examination. Barbara Cuddon was extremely helpful in smoothing the process. The IRAS Form is fine in terms of logic and content now and it is reliable in terms of saving etc. It is still a bit slow and clunky. An overarching spell check would be a great help, also speeding up moving on from page to page and the saving, which seems to take a while would make the experience better'.

## 5. Publicity/raising awareness

To raise awareness of the Committee an A5 leaflet was produced and distributed to a wide range of organisations including universities, and local authority adults social services and research governance departments. A website has been developed, which is continually being updated with useful information.

### Meetings/conferences attended

<b>Name</b>	<b>Date</b>	<b>Title of conference/meeting</b>	<b>Presentation</b>
Professor David Stanley	March 2009	Midlands Research Group study day	Introducing the national Social Care Research Ethics Committee
Professor David Stanley	March 2009	AREC Conference	A national Social Care Research Ethics Committee
Barbara Cuddon	30 June 2009	NRES South London Network Co-ordinators meeting	Overview of the Social Care REC
Dr Deborah Rutter and Barbara Cuddon	16 November 2009	Social Service Research Group	Ethical review of user surveys and other research
Professor David Stanley and Dr Deborah Rutter	24 November 2009	NRES Conference 2009	Making it work: addressing ambiguities and uncertainties in social care research ethics review'
Barbara Cuddon	6 December 2009	Research Governance Panel in Adult, Culture and Community Services at Haringey Council	Overview of the Social Care REC
Professor David Stanley	February 2010	York Making Research Count – adult care conference	Introducing the national Social Care Research Ethics Committee

Professor David Stanley	February 2010	JUC SWEC research committee	A briefing on the national Social Care Research Ethics Committee
Dr Michael Dunn	22 March 2010	AREC/Academy of Social Sciences/SRA meeting to explore the possibility of developing some general principles of ethical research practice to which all social scientists are able to subscribe.	
Dr Deborah Rutter and Barbara Cuddon	30 March 2010	School for Social Care Research Launch	Ethics and research governance workshop
Professor David Stanley	May 2010	Ethics and Welfare Conference, Sheffield Hallam University	Interprofessional ethics

### Journal articles

Name	Journal	Title	Reference
Professor David Stanley	The Journal of The Association of Research Ethics Committees	Introducing the national Social Care Research Ethics Committee	Research Ethics Review (2009) Vol 5, NO 2, 45-47

## 6. REC workload and activity during the reporting period

### Committee membership and training

#### Social Care REC membership

<b>Name</b>	<b>Occupation</b>	<b>Date appointed</b>	<b>Date membership ended</b>
Professor David Stanley – Chair	Professor of Social Care	01/01/2009	
Sandra Andrews	Police Officer	12/02/2009	
Samantha Clemens	Social Researcher	12/02/2009	
Professor Malcolm Cowburn	Professor of Applied Social Science at Sheffield Hallam University	12/02/2009	
Professor David Croisdale-Appleby	Wolfson Research Inst. & Chair, Skills for Care	12/02/2009	
Rachel Dittrich	Research Manager	12/02/2009	
Dr Michael Dunn	Senior Researcher in Health and Social Care Ethics	12/02/2009	
Eleanor Grey – Alternate Vice-Chair	Independent	12/02/2009	
Susan Harrison – Vice Chair	Consultant and Interim Manager in Adult Social Services	12/02/2009	
Claire Hopkins	Independent	12/02/2009	
Valerie Lang	Retired	12/02/2009	
Irene Linder	Semi-retired	12/02/2009	
Craig Moss	Head of Research and Information	12/02/2009	
Daphne Obang	Independent	03/09/2009	June 2010
Bridget Penhale	Reader in Gerontology	12/02/2009	
Dr Suzanne Shale	Independent Ethicist	12/02/2009	

Member's personal profiles can be viewed on the Social Care REC website – [www.screc.org.uk](http://www.screc.org.uk)

## Co-opted members

<b>Name</b>	<b>Occupation</b>	<b>Meeting date attended</b>
Professor Mary Gilhooly	Deputy Head of School for Research, School of Health Sciences and Social Care, Executive Director, Brunel Institute for Ageing Studies	08/01/2010

### Social Care REC members declaration of interests

Name	Declaration of Interest
Professor David Stanley - Chair	Director, Skills for Care. Director, Strategic Solutions Ltd. Chair in Social Care, Northumbria University.
Samantha Clemens	Employed by the National Centre for Social Research. Member of Social Research Association.
Professor Malcolm Cowburn	I have a dormant consultancy relationship with workers at St Luke’s Hospice Sheffield, in relation to a group work programme for bereaved relations of St Luke’s patients. The group work is not currently running. I am a GSCC registered practitioner. I am a member of the ESRC Peer Review College. I am a member of the Faculty of Development & society, Sheffield Hallam University Research Ethics Committee. I am a research-active academic.
Professor David Croisdale-Appleby	Chair of Skills for Care. Chair of Skills for Care & Development. Member of SCIE Partners’ Council. Chairman of Hft. Professor at the Wolfson Research Institute. Professor at the School of Medicine & Health at the University of Durham. Expert Lay Social Science Member of the South East Research Ethics Committee (Medical REC).
Rachel Dittrich	Research Manager at Hampshire County Council & Chair of the Research Development & Governance Panel in Hampshire Adult Services.

Dr Michael Dunn	Senior researchers in a university department involved in undertaking health and social care research. Peer reviewer for Journal of Applied Research in Intellectual Disabilities
Susan Harrison	Owner and Director of Harrison Consultants Ltd. Trustee of Cuba Medical electives. Member of the Research Council of Changing Faces. I am currently a doctoral student at the Tavistock & Portman NHS Foundation Trust and the University of East London.
Valerie Lang	Governor at Whittington Hospital. Member of scope Assembly (advisory only). Trustee, Mobility Choice.
Craig Moss	Assistant Director of Research and Information at Addaction. Currently completing a MSc at City University in the Sociology Department.
Bridget Penhale	Member of Action on Elder Abuse. Member of PASA (Practitioner Alliance for Safeguarding Adults). Member Ann Craft Trust .
Suzanne Shale	I consult in Research Ethics – most clients are NRES Committees. I teach at Kings College London and University of Oxford. Trustee of Compassion in Dying. Director of Learning and Teaching, Health Experiences Research Group, University of Oxford/Healthtalkonline. I Provide training in research ethics to NRES Committees.

Meetings for Full Ethical Review 01 April 2009–31 March 2010:

<b>Month</b>	<b>Date</b>	<b>Number of members present at meeting</b>
June	05/06/2009	14
July	03/07/2009	10
August	07/08/2009	9
September	04/09/2009	11
October	02/10/2009	13
November	06/11/2009	10
December	04/12/2009	10
January	08/01/2010	11
February	05/02/2010	12
March	05/03/2010	13
April	09/04/2010	10
May	07/05/2010	10
June	04/05/2010	10

13 full committee meetings were held during the reporting period. All meetings held were quorate.

## Sub-Committee meetings held 01 April 2009–31 March 2010:

Month	Date	Number of members present at meeting
July	03/07/2009	5
August	12/08/2009	3
October	05/10/2009	7
January	05/01/2010	4
March	22/03/2010	3
April	09/04/2010	5
April	27/04/2010	3

A Chair's Action meeting was held on 4 January 2010

## Training 01 April 2009–31 March 2010:

Training/Event	Date	Name of member (s) who attended
Induction Training for Social Care Members, NRES and SCIE	27/04/2009–28/04/2009	Professor David Stanley Sandra Andrews Samantha Clemens Professor Malcolm Cowburn Professor David Croisdale-Appleby Rachel Dittrich Dr Michael Dunn Eleanor Grey Susan Harrison Claire Hopkins Valerie Lang Irene Linder Craig Moss Bridget Penhale Dr Suzanne Shale
Half-day Mental Capacity Act Training, NRES	05/06/2009–05/06/2009	Professor David Stanley Sandra Andrews Samantha Clemens Professor Malcolm Cowburn Professor David Croisdale-Appleby Rachel Dittrich Dr Michael Dunn Eleanor Grey Susan Harrison Claire Hopkins

		Valerie Lang Irene Linder Craig Moss Bridget Penhale
Equality and Diversity Training (Half-day), SCIE	02/10/2009–02/10/2009	Professor David Stanley Sandra Andrews Samantha Clemens Professor Malcolm Cowburn Professor David Croisdale-Appleby Rachel Dittrich Dr Michael Dunn Susan Harrison Claire Hopkins Valerie Lang Irene Linder Daphne Obang Craig Moss Dr Suzanne Shale
Qualitative Methodologies, NRES	27/10/2009–27/10/2009	Craig Moss
NRES Annual Conference , NRES	23/11/2009–24/11/2009	Professor David Stanley Susan Harrison Daphne Obang
NRES Advanced Ethics, NRES	20/01/2010	Craig Moss
NRES Southern Conference,	11/02/2010	Eleanor Grey Claire Hopkins
NRES Children’s Research Ethics	04/4/2010	Claire Hopkins
NRES, Chairing Skills	17/04/2010–18/04/2010	Eleanor Grey Susan Harrison
NRES Training Workshop on Consent for Use of Samples and Related Data in Research	18/04/2010	Dr Suzanne Shale
Nowgen, Genetic Research and the REC review	11/05/2010	Samantha Clemens

## 7. REC workload and activity during the reporting period (June 2009 – June 2010).

*35 studies were reviewed*

3 withdrawn after meeting = 32 studies

Table 1: Applications assigned to a full committee meeting held within the reporting period:

<b>Applications for full ethical review – Type</b>	<b>Number</b>	<b>%</b>
Mental Capacity Act	13	37.14
Others	22	62.86
<b>Total applications reviewed</b>	<b>35</b>	<b>100.0</b>

Table 2: Other REC activity during the reporting period:

Number of applications ruled invalid by co-ordinator	0
Number of studies withdrawn after the meeting	3
Site-specific assessment	0
Number of student applications reviewed	3
Number of substantial amendments reviewed	0
Number of Mental Capacity Act (Section 30) applications reviewed	13
Number of modified amendments reviewed	0

Table 3: Decisions given at meetings held within the reporting period:

<b>Decisions taken at meetings following review of applications</b>	<b>Number</b>	<b>%</b>
Favourable opinion with standard conditions	1	2.86
Favourable opinion with additional conditions	16	45.71
Unfavourable opinion	3	8.57
Provisional opinion	12	34.29
Invalid	0	0.00
No opinion pending consultation with referee	0	0.00
Not requiring review by NHS REC	0	0.00
Number of studies withdrawn after the meeting	3	8.57
<b>Total</b>	<b>35</b>	<b>100%</b>

Table 4: Summary of current status (as at 30.06.10) of applications reviewed during the reporting period:

<b>Status of applications at date of generation of report</b>	<b>Number</b>	<b>%</b>
Further information favourable opinion with standard conditions	9	25.71
Further information favourable opinion with additional conditions	3	8.57
Further information unfavourable opinion	0	0.0
Favourable opinion with standard conditions	1	2.86
Favourable opinion with additional conditions	16	45.71
Unfavourable opinion	3	8.57
Provisional opinion	0	0.00
Number of studies withdrawn after the meeting	3	8.57
<b>Total</b>	<b>35</b>	<b>100%</b>

Table 5: Other management Information for the reporting period:

Average number of applications reviewed per full meeting	2.70
Number of applications for full ethical review over 60 days	0
Number of applications over 60 days as a % of total	0.00%
Number of days taken to final decision – average	30.97
Number of days taken to final decision – mode	22

Table 6: Applications reviewed within the reporting period:

REC Reference	Application short title	Number of days on clock
09/IEC08/1	LA Experience Survey of Equipment and Minor Adaptations Users: 2009-10	35
09/IEC08/2	Personalised Budgets in Leicestershire	36
09/IEC08/4	INTO THE WORKFORCE	47
09/IEC08/5	Pathways into care: prevention and early intervention in Oxfordshire	53
09/IEC08/6	Development of the Putting People First User Experience Survey	24
09/IEC08/7	Local Authority User Experience Survey of Carers 2009-10	28
09/IEC08/8	Everyday decision-making by people with dementia and their spouses.	41
09/IEC08/9	Investigating Vetting and Barring Schemes	39
09/IEC08/10	EviDEM Mental Capacity Act Study	22
09/IEC08/11	Rethinking Multiple Exclusion Homelessness	36
09/IEC08/12	The Friendship Matters Study	27
09/IEC08/13	Outcomes of Social Care for Adults (OSCA)	26
09/IEC08/14	Evaluation of the Generations Together Programme	42
09/IEC08/15	Personal budgets - experiences of older people/people with MH problems	41
09/IEC08/16	A Pilot Diary Study Investigating the Effects of Seasonal Affective Disorder (SAD)	38
09/IEC08/17	EviDEM Mental Capacity Act study	32
09/IEC08/18	Recovery and Resilience: African, African-Caribbean and South Asian Women's Narratives about Recovering from Mental Distress	31
09/IEC08/19	Safeguarding Adults Boards and Self Neglect	31
10/IEC08/1	Music Therapy in Dementia Care: Profiling, Stabilising & Evaluating v1	34
10/IEC08/2	Why Music? Music Therapy and Adults with Learning Disabilities v.1	33
10/IEC08/3	Evaluation of the Generations Together Programme: Case Studies	24
10/IEC08/4	Investigation into the effects of Seasonal Affective Disorder (SAD)	21

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10/IEC08/5	Work In Progress 1	41
10/IEC08/6	Learning Disabilities Employment & OT	22
10/IEC08/7	African, Caribbean and South Asian Women's Stories of Recovery v2	22
10/IEC08/8	Personalisation of Services - A Scoping Study	22
10/IEC08/9	Personalisation and severe mental illness	22
10/IEC08/10	Pilot for National Adult Social Care User Experience Survey	18
10/IEC08/11	A pilot study of the Strengthening Families model of child protection conferences to examine interagency working, family partnership and outcomes for children at risk.	54
10/IEC08/12	Living in Fear – promoting better outcomes for people with disabilities	35
10/IEC08/13	HEALTHBRIDGE	16
10/IEC08/14	Research about the impact of the Independent Mental Capacity Advocacy (IMCA) Service – Stages 1 and 2	24
10/IEC08/15	Housing Services for People with Mental Health Problems in England	19
10/IEC08/16	Living in Fear – promoting better outcomes for people with disabilities	27
10/IEC08/17	Research about the impact of the Independent Mental Capacity Advocacy (IMCA) Service – Stage 3	21

## Appendix One: Expanded remit of the national Social Care REC from 1 March 2011

The Social Care REC reviews adult social care research study proposals, and some proposals for social science studies situated in the NHS (see item 6 below), from researchers based in England. It is part of the **National Research Ethics Service (NRES)**, and its membership, expertise and procedures have been developed to reflect the social care context. The appointing authority is the Social Care Institute for Excellence (SCIE). Committee members, recruited through open advertisement, include researchers, ethicists, providers and users of social care.

The Social Care REC reviews applications involving the social care sector (e.g. in local authority, private and voluntary care settings) that would not otherwise have access to ethical review, or which cross sector boundaries. It generally expects to review the following types of study:

1. Social care studies funded by Department of Health.
  - Research commissioned directly through the Policy Research Programme.
  - Information Centre (IC) studies (i.e. those to be designed by IC for implementation by Councils with Adult Social Services Responsibilities, who do not then individually need to seek additional review).
  - Studies commissioned by or through National Institute for Health Research (NIHR) School for Social Care Research.
  - Social care studies funded (in rare cases) through NIHR.
2. Social care research that involves people lacking capacity in England and Wales and requires approval under the Mental Capacity Act 2005. The Social Care REC is recognised by the Secretary of State as an Appropriate Body for this purpose.
3. Social care research involving sites in England and another United Kingdom country.
4. 'Own account' research undertaken by Councils with social services responsibilities, where the Chief Investigator and/or sponsor feels there are substantial ethical issues.
5. Studies where investigators do not have access to other review systems. This could include service user-led research.
6. Studies taking place in NHS settings with NHS patients or staff where the approach to data collection uses social science or qualitative methods, provided that the research does not involve any change in treatment or clinical practice. A study collecting patients' views of care and treatment through structured questionnaires or qualitative interviews would be an example of this type of study. Studies taking place in joint health and social care settings (such as a

community mental health team venue) may also be reviewed within this category.

7. Student research within the field of social care should ordinarily be reviewed by a university REC, rather than by the Social Care REC. If such review is not available to the applicant, they are requested to contact the Social Care REC Co-ordinator. If student research requires NRES REC review, uses social science methods and takes place in NHS contexts but does not involve change in clinical practice, it can be reviewed by the Social Care REC.