The Social Care Research Ethics Committee

What RECs do –
and how to keep on the right side of them

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REC convenor for SCIE
Some Key Principles of Ethics Review of Social Care Research in England

* No investigator should have to seek ethics review from more than one REC.
* Social care community accepts a wider definition of what constitutes research e.g. most service evaluations would be accepted as suitable for review by the Social Care REC.
* Social care community may operate a different concept of ‘risk’ or potential damage from that pertaining to invasive health studies.
Who decides if referral to REC for review is necessary?

- GAfREC (2011, amended Feb 2012) outlines legal and statutory requirements for review of particular types of research
- The chief investigator and/or the sponsor can decide if criteria for review are met – and if the case is uncertain, seek advice from NRES queries line or from Social Care REC
- Social Care REC does see borderline cases where there are motives for review: Chair can give formal opinion on need for review (contact coordinator)
Sources of ethical review in adult social care research

National Research Ethics Service (NRES):
- NRES RECs have own Governance Arrangements (GAfREC) & are funded by DH
- Key plank in NIHR funding & support for (mainly health) research in UK (UK a world leader)
- Social Care REC is an NRES specialist REC

University RECs (most HEIs should have one)
Local Authority Governance consortia
Origins of the Social Care REC

Social care researchers dissatisfied with NRES provision – design, methods, contexts not understood

Funded by Department of Health via NRES

Social Care REC operates to all SOPs of National Research Ethics Service (NRES);

IRAS form version redesigned (within limits) to include SC REC

First monthly meeting held in June 2009: we meet 11 times per year, on first Friday of month (except August)
Developments of Social Care REC

1. Accredited by NRES as meeting their QA systems
2. Trained, and approved by Sec of State for Health to review research with adults lacking capacity (under Mental Capacity Act, 2005)
3. Enlarged our remit, into NHS (joint/integrated services or topics; social science methods in NHS settings)
4. While NRES has cut back number of its Committees 200 RECs (2004) to 81 (2011) in England, we have maintained the case for specialist social care provision
What are RECs for? GAfREC


Harmonised as includes (with some exceptions) health *and social care services* covered by all UK health departments.
What are NRES RECs?

“A research ethics committee is a group of people appointed to review research proposals to assess formally if the research is ethical. This means the research must conform to recognised ethical standards, which includes respecting the dignity, rights, safety and well-being of the people who take part.” (GAfREC, 2011, 1.1)
What NRES RECs cover

Among other categories, research involving:

(a) people identified from, or because of, their past or present use of the services for which UK Health Depts are responsible (including health & social care services provided under contract with the private or voluntary sectors),

(b) potential research participants identified because of their status as relatives or carers of above.

Note: research involving staff of services are NO LONGER automatically included in cover

GAfREC 2011

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What makes a ‘good’ application?

1. Clarity of aims and process;
2. Accessible information and consent;
3. Thought-through strategy for recruiting people without offending Data Protection and confidentiality;
4. Consideration of how to impose least possible burden on participants;
5. Additional support/debriefing for participants;
6. Social inclusion in research for all those in a diverse community (including those with communication deficits);
7. Understanding of ‘confidentiality’ – deconstruct it!

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What else will help?

Being clear about ethical issues & difficulties – the REC will be reassured by your recognition of them.

Don’t exaggerate the impact or benefit of the research – even in health, it is unusual for participants to benefit (though later ones may).

Fill in the IRAS form thoughtfully: it is long and comprehensive because it must describe your research aims, methods and arrangements to the members. This is your only opportunity to ‘speak’ with members, other than to clarify queries if you attend the meeting, or by mail if you cannot attend.
Common deficiencies in applications

1. Information and consent not fit for purpose
2. Uncertain (illegal?) arrangements for recruiting people:
   a. who has right to contact them?
   b. ‘opting out’ recruitment is not normally acceptable strategy for frail people
3. Disproportionate burden on people (service users, carers, staff)
4. May need strategies for disclosure of abuse in information sheet;
5. May need further support for interviewee after data collection
More common deficiencies

6. Social inclusion in research: some topic areas particularly need translation/multilingual researchers

7. Confidentiality:
   - What is anonymisation?
   - When is data coded and linked or unlinked?

8. Lack of transparency, honesty, clarity for participant

9. No access to social care (only to health) record under s.251 of NHS Act without person’s consent (joint records?)

10. NEVER assume staff will collect & anonymise data.

11. Student supervisors should review applications before signing!
REC review may be good for you!

- Statutory requirement (e.g., Mental Capacity Act) or requirement by funder (e.g., SSCR)
- Publication – journals may require it
- Host organisations may be reassured
- Your approach – e.g., to recruitment – will be thought through in detail (the forms!) and may even be improved

If you don’t use us, you will lose us!
Further information and help

- Barbara Cuddon:
  Social Care REC Co-ordinator
- email screc@scie.org.uk
- www.screc.org.uk
- www.scie.org.uk
- Deborah.Rutter@scie.org.uk