

FROM: NATIONAL RESEARCH ETHICS ADVISORS' PANEL

TO: REC Chairs

Document Reference: NREAP / 01

Type of document: Letter from NREAP Chair, NRES Research Ethics Advisor and NREAP Manager

Date of document: 22 April 2010

Title of document: (I) Disclosing Information about a Research Participant without consent and (II) Appropriate action for a researcher when seeing poor practice

Background: In the last three months a series of enquiries have been received from applicants concerning the decisions of RECs around the above two contentious issues.

To help researchers and RECs, NRES is collecting published guidance that can be found on these issues. (See letter below)

Dear Chair,

Re: (I) Disclosing Information about a Research Participant without Consent and (II) Appropriate Action for a Researcher When Seeing Poor Practice.

In the last three months there has been a series of enquiries from applicants concerning the decisions of RECs around these two contentious issues. To help researchers and RECs NRES is collecting published guidance that can be found on these issues. These will be discussed by the National Research Ethics Advisors' (NREA) Panel who will then issue guidance. In the meantime RECs are asked to be sensitive to the issue, and if they have concerns with a particular study to initially discuss with Dr Hugh Davis, the NRES Research Ethics Advisor, by email. We would also welcome any guidance you know of and your committee's views on these issues. Again send these to Hugh Davis or Clive Collett who is the NREA Panel Manager.

Clive Collett has identified the following guidance on disclosure that might be of use to you, depending on the nature of the research project:

For Clinicians:

The General Medical Council:

http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality.asp

“53. Disclosure of personal information about a patient without consent may be justified in the public interest if failure to disclose may expose others to a risk of death or serious harm. You should still seek the patient’s consent to disclosure if practicable and consider any reasons given for refusal.

54. Such a situation might arise, for example, when a disclosure would be likely to assist in the prevention, detection or prosecution of serious crime, especially crimes against the person. When victims of violence refuse police assistance, disclosure may still be justified if others remain at risk, for example, from someone who is prepared to use weapons, or from domestic violence when children or others may be at risk.”

Re social research and disclosure:

The British Psychological Society Professional Practice Guidelines are quite comprehensive on disclosure:

http://www.bps.org.uk/downloadfile.asp?file_uuid=092B7E1C-1143-DFD0-7EA4-6235165A3BA8&ext=pdf&randomID=FA945E60-DF03-0CED-C4DF00ECBF348BDF

“Disclosure in the public interest
...In exceptional circumstances, disclosure without consent, or against the client’s expressed wish may be necessary in situations in which failure to disclose appropriate information would expose the client, or someone else, to a risk of serious harm (including physical or sexual abuse) or death.”

Also the **British Sociological Association** have issued the following (Statement of Ethical Practice for the British Sociological Association (March 2002 - http://www.britisoc.co.uk/equality/Statement+Ethical+Practice.htm#_anon):

“37) Guarantees of confidentiality and anonymity given to research participants must be honoured, unless there are clear and overriding reasons to do otherwise, for example in relation to the abuse of children.

38) Research data given in confidence do not enjoy legal privilege, that is they may be liable to subpoena by a court and research participants should be informed of this.”

Also of use is the **UK Data Archive** (funded by ESRC) FAQs (<http://www.data-archive.ac.uk/sharing/confidfaq.asp#illegal>):

“If a researcher obtains information on illegal or criminal activities (e.g. child abuse), is there a legal obligation or moral duty to disclose this to the relevant authorities?”

Exceptions to the duty of confidentiality occur where there is a legal compulsion, for example, the information may be subpoenaed by relevant police investigations or court proceedings, or where there is a disclosure of the information made 'in the public interest', as defined by the courts. There are no mandatory reporting laws in the UK but guidance issued by professional bodies and local safeguarding children boards emphasises the need to make a referral where there is a reasonable belief that a child is at risk of significant harm. There are thus ethical obligations on researchers working with children to make provision for the required actions to be taken in cases of disclosure of e.g. child abuse. Under the Children Act 1989 (England and Wales), the Children (Scotland) Act 1995 and the Children (Northern Ireland) Order 1995, the local authority has a duty to make enquiries about any allegation of abuse (is suffering, or is likely to suffer, significant harm). Additionally, some researchers are members of professional groups such as teachers and social workers who have a legal duty to report suspected child abuse.”

Yours Sincerely,

Andrew George
Chair NREA Panel

Hugh Davies
NRES Research
Ethics Advisor

Clive Collett
NREA Panel
Manager

The National Research Ethics Advisors' Panel is an independent panel hosted and appointed by NRES. It was established under direction of the four UK Health Departments and the United Kingdom Ethics Committee Authority.