# Keeping It Confidential: Public Attitudes Towards The Use Of Personal Health Information In Med...

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Keeping It Confidential: Public Attitudes Towards The Use Of Personal Health Information In Medical ResearchÂ

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It is well established in the medical research community that research on the personal health records of large numbers of people can provide important insights and help make medical advances. However, to date, little work has been done to investigage how the public feel about the use of their personal health information.

Therefore, the Medical Research Council commissioned Ipsos MORI to look at public attitudes to and awareness of the use of personal health information (note 1) in medical research.

The Ipsos MORI survey of 2,106 people and qualitative research (involving Saturday workshops and in-depth interviews) found that if the public is informed about what medical research entails, they are generally positive towards it, and more likely to take part. Specifically, if the public had more information (note 2) about the purposes of medical research, they are likely to be more inclined to allow their personal health information to be used for that purpose.

Public awareness of the use of personal health information for the purposes of medical research is low. They know that medical research is undertaken, but few have a good understanding of what it entails, who does it, and for what purpose. The two key pillars of confidentiality and consent feature highly in the debate over what information should be available, to whom, and in what circumstances and these two themes are central to building trust. This research indicates that communications are key to building public trust - if the public is informed about what medical research entails, they are generally positive towards it. The key to effective communication with the public on the subject is the need to keep terminology simple and tailor communications for a lay audience.

The survey also found that seven in ten people were likely to allow their personal health information to be used in medical research. Of those that were not happy for their information to be used, 28% cited concerns about privacy. Other common concerns focused on potential abuse and loss of control, information 'falling into the wrong hands'.

The survey shows that attitudes to medical research are generally positive and if communications are handled well, this might increase propensity for agreement to use personal health information for medical research purposes. This includes communicating the value of such use of medical records (possibly by giving examples of research that could not have been done without such access and the adverse effect of such an eventuality on public health).

Notes
- The phrase 'personal health information' was deliberately not defined for respondents, in order to gauge the spontaneous associations they had with it. Most commonly the public associates the phrase with GP records or with medical records.

- Areas of information they are likely to require include: whether they would have control of the information and its potential uses and confidentiality of the information.

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Links
The Use of Personal Health Information in Medical Research General Public Consultation (pdf, 560KB)
Keeping it on the record:Â A review of the research by Mark Henderson (Times Science Editor) (Times Website)
Speaking out and winning trust: MRC press release (MRC Website)

Technical details
This programme of research involved both qualitative and quantitative research among the UK general public. The details of each stage of the research project are as follows:

General Public Qualitative Research: three workshops were conducted between 29 July and 5 August 2006 at three

locations across the UK, supplemented by six in-depth telephone interviews.

General Public Quantitative Research: Questions were placed on the Ipsos MORI Social Issues Omnibus. A nationally representative quota sample of 2,106 adults (aged 15 and over) was interviewed in 212 sampling points throughout Great Britain and Northern Ireland. Interviews were carried out face-to-face in respondents' homes. Fieldwork was conducted between 14 and 18 September 2006. Data are weighted to match the profile of the UK population