

This response was submitted to the consultation held by the Nuffield Council on Bioethics on *The linking and use of biological and health data* between 17 October 2013 and 10 January 2014. The views expressed are solely those of the respondent(s) and not those of the Council.

Dear Jo and colleagues,

I am a psychiatrist (MRCPsych) and also a MA Philosophy student (Open University) with an active interest in personal identity and the issue of sharing e-health identities. I am currently working up a PhD proposal in this area too, hoping to begin in Autumn 2014.

My research/search for the proposal highlights the paucity of UK large scale empirical research in this area – normative and empirical problems abound. What it means to people to share aspects of their medical records or histories, whether they should have ownership of a record, what may be termed sensitive data and why, and whether people can really understand any of the implications of data sharing at the clinical interface are all questions yet to be addressed. GP/primary care based work that I have reviewed have very flawed methodology but are a start( small studies, conflicts of interest, lack of operational definitions etc).

Conclusion: I do not believe that the necessary cost benefit analysis of data sharing (especially 'care.data') is achievable in any sense which makes the concept of informed consent viable at this stage. This is very much a worry concerning the clinical interface rather than any one individual's decision to support research by sharing their data and histories at the individual level.

Yours sincerely,

Jo Bowen (Dr.)

P.S. I will complete the respondent's sheet separately.