

Department of Health Consultation: Protecting Health and Care Information

Response from the Nuffield Council on Bioethics

Background

The Nuffield Council on Bioethics is an independent body that informs policy and supports public discussion by identifying, exploring and reporting on ethical issues in science and medicine. The Council aims to help ensure that policy is informed by the best possible consideration of ethical implications through carefully reasoned analysis of important current issues arising out of bioscientific research.

By responding to this consultation we therefore wish to ensure that you are aware that, in 2013, the Council established a Working Party of experts to explore and report on the ethical issues raised by the linking and use of biological and health data: <http://www.nuffieldbioethics.org/biodata>. The Council's Assistant Director Dr Peter Mills (pmills@nuffieldbioethics.org) is leading this work.

The findings of this inquiry are due to be published in late 2014. The response to the present consultation is limited, given the stage of our own work and the limited opportunity to respond. Whilst we are not (yet) in a position to address the specific consultation questions, we hope that the comments below will nonetheless be taken into consideration.

General comments on the consultation paper

We endorse the recognition in the consultation paper that individual-level data with no obvious identifiers is not simply 'anonymous' (this was a key theme to emerge in the responses to our own public consultation). This raises important issues in the context of new drivers and techniques for knowledge extraction (which we are taking forward in our report).

We would have found more detail about the wording and scope of the regulations for Accredited Safe Havens useful in order to understand exactly what will be addressed. We therefore think it is important that a further in-depth consultation, including a full Privacy Impact Assessment, should be conducted before new regulations are laid before Parliament.

General comments about the consultation process

We note that this consultation does not appear to have been widely publicised (e.g. it is not listed under announcements on the Department website, no notice was received through mail updates from the Department, no obvious promotion through social media channels). We also suggest that giving people only 6 weeks to respond to the consultation is an inadequate amount of time given the importance of the issues it raises, for example, controls on the release of potentially identifying information from ASHs and HSCIC. The suggestion made above for further consultation on this issue is again relevant, bearing in mind both of these concerns.

We strongly urge that the further promised regulations on safeguards and the role of CAG in advising on HSCIC disclosures (paragraph 52) should be subject to a more open process that provides greater opportunity for input, especially given the apparent level of public concern about these matters and the stated expectation¹ that they will resolve important and still controversial questions about the secondary use of personal health information.

Hugh Whittall
Director, Nuffield Council on Bioethics

¹ Evidence from the NHS England National Director for Patients and Information to the HC Health Select Committee, 1 July 2014 (Q490)