

## **Supplementary Submission on Longitudinal Studies, to the DH consultation on Accredited Safe Havens, and Protecting Personal Health and Care Data**

Longitudinal studies are methodologically designed to follow the same group of people throughout their lives, charting changes and attempting to understand the reasons for them.

There are many different types of longitudinal study<sup>1</sup> but they are all systematic, substantive and are fundamentally long term projects. Longitudinal studies are a wholly different activity to Commissioning. Individuals, properly informed, will have chosen to contribute to the long term benefit of all, partially because they have consented to what data is being used, what it will be used for, and how it will be protected.

Cohort studies routinely build up close bonds of trust with the individuals within their cohort and study managers take pains to ensure this trust is not damaged, which may include the use of some data exclusively via safe settings.

A large scale academic longitudinal study looking at the effects of Commissioning or other health interventions or changes would not, on the face of it, be objectionable. However, any such study would need to have a substantive justification and a proper research design methodology around data collection and use.

This is not what was proposed - or at least strongly implied - in the consultation. A longitudinal study is not something to be left to the whim of an individual ASH. In fact ASHs may best be considered as data processors, rather than data controllers in their own right.

A longitudinal study is not simply a collection of data that happened to be passed to, or through, a particular service and was retained 'just in case', for possible future study. Such a process would not involve obtaining patients' informed consent and would in fact be arbitrary retention. This is unlikely to be seen as legal under the Data Protection Act, nor would it meet the requirements of research ethics, nor will the subjective collection of arbitrary data.

Presentations from NHS England are clear that "all answers" do not lie in a single particular dataset, but in linkage, beyond data needed for direct commissioning purposes. However, with the high level of ambiguity on data set design and need within the consultation, it is unsurprising that such confusion could also be used as a justification for more data for vague purposes.

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<sup>1</sup> <http://www.closerprogramme.co.uk>

Though the primary purpose of care.data is commissioning, it has mainly been sold for research. Given the linkage required and long-term retention of data in longitudinal studies, HSCIC is a far more secure, appropriate and independent location for such studies to be based than individual ASHs based in CCGs or commercial contexts where local pressures may provide incentives other than highest quality independent research.

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