

Supplementary Submission to the DH consultation on Accredited Safe Havens, and Protecting Personal Health and Care Data: The context of the Farr Institutes

“The Farr Institute aims to deliver high-quality, cutting-edge research linking electronic health data with other forms of research and routinely collected data, as well as build capacity in health informatics research. The Farr Institute aims to provide the physical and electronic infrastructure to facilitate collaboration across the four nodes, support their safe use of patient and research data for medical research, and enable partnerships by providing a physical structure to co-locate NHS organizations, industry, and other UK academic centres.”¹

The Farr Institute is supported by £37m of Research Council support², including £20m for buildings, designed to include specific capabilities to meet the Information Governance standards required for the data they wish to use.

We understand that the Farr Institutes have been designed to meet the same standards as will be applied to HSCIC itself. Approval for hosting of an entire safe setting might apply to an Institute of such public standing, with suitable IG competencies, procedures and designs, if it requests data for the purposes of a public mission and patients have consented to those purposes. Consent is vital for research.

The work of the Farr Institute is of a very different nature to that of commissioning health services for patients. Research use must be considered entirely separately to Commissioning. Where it is not, both suffer³.

Given the conflation of purposes in the original consultation, and unclear suggestions made about Accredited Safe Havens, it may be that each Farr site would (also) be required to become an ASH in order to process the data required.

Given the IG design of such facilities, we see no reason why each Farr site would not be able to become a host for both a safe setting venue, and also a host for research data itself where permitted, given the construction work already underway to construct facilities where that can be done safely.

Were such a scenario to arise, however unlikely this may be, the suggestions in the Farr submission to the consultation would have to be considered in order for the Farr Institute, and its distributed nature, to be able to be accredited.

¹ From the front page of <http://www.farrinstitute.org>

² https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/332767/bis-14-750-science-research-funding-allocations-2015-2016-corrected.pdf

³ One possible resolution to the care.data conflation is discussed in detail here:

<https://medconfidential.org/wp-content/uploads/2014/06/2014-06-11-Achieving-local-choice-and-consensual-research-use.pdf>