

Experiences of using the Honest Broker Service for analysis of a maternity dataset and a prescribing dataset to determine the profile of women in Northern Ireland who have accessed maternity services and who have heart conditions

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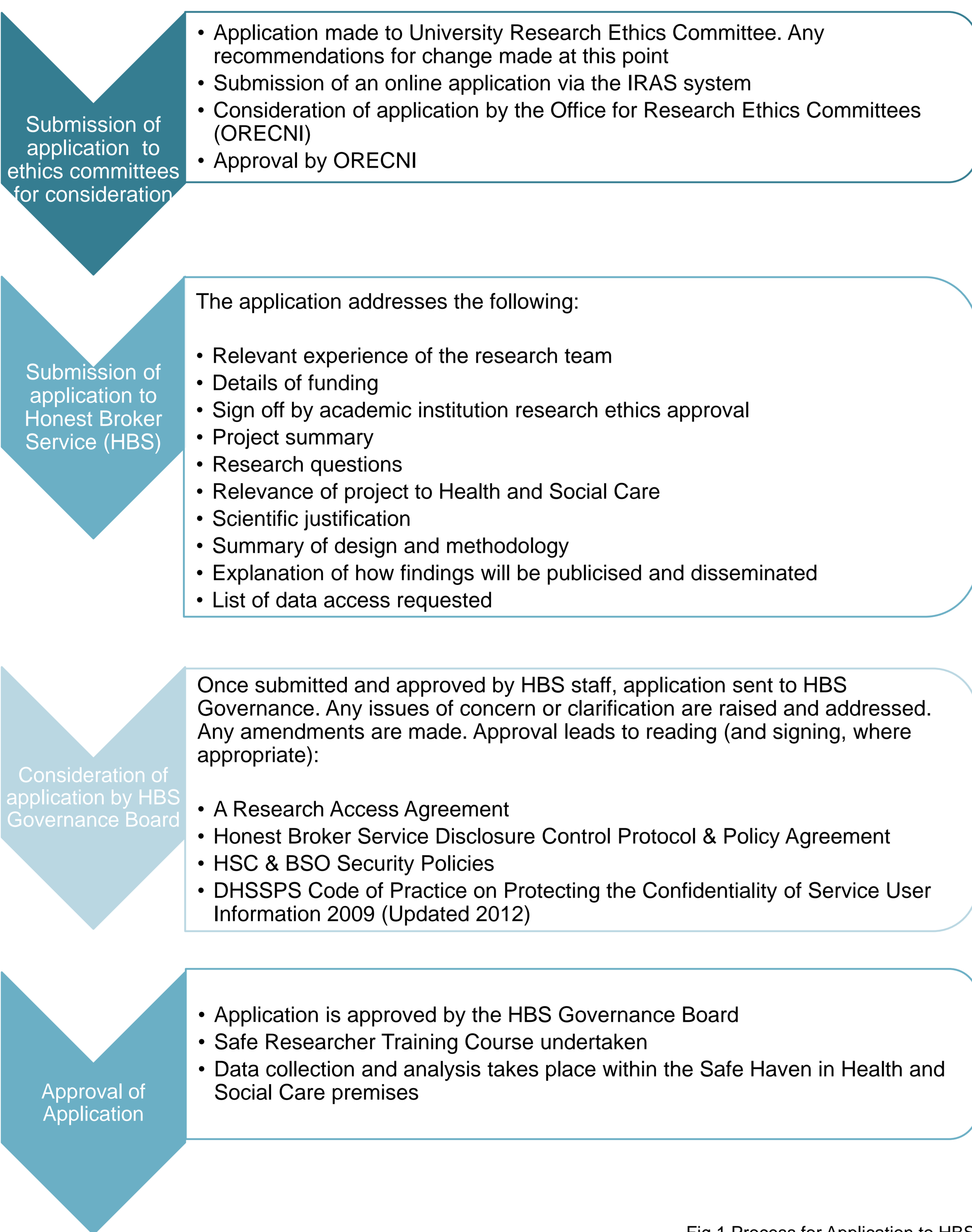
Introduction

There are potential public health benefits to data sharing or linking. As noted by Robinson and Dolk (2016), public confidence in this process is critical. The 2015 Northern Ireland Life and Times (NILT) survey (Economic and Social Research Council, 2016) demonstrated that 72% of the public trusted academic researchers in university to keep data secure. 87% believed that academic researchers should have access to data already linked by a 3rd party. However, 31% agreed that this required specific consent. The Honest Broker Service (HBS) fulfils the role of the '3rd party'.

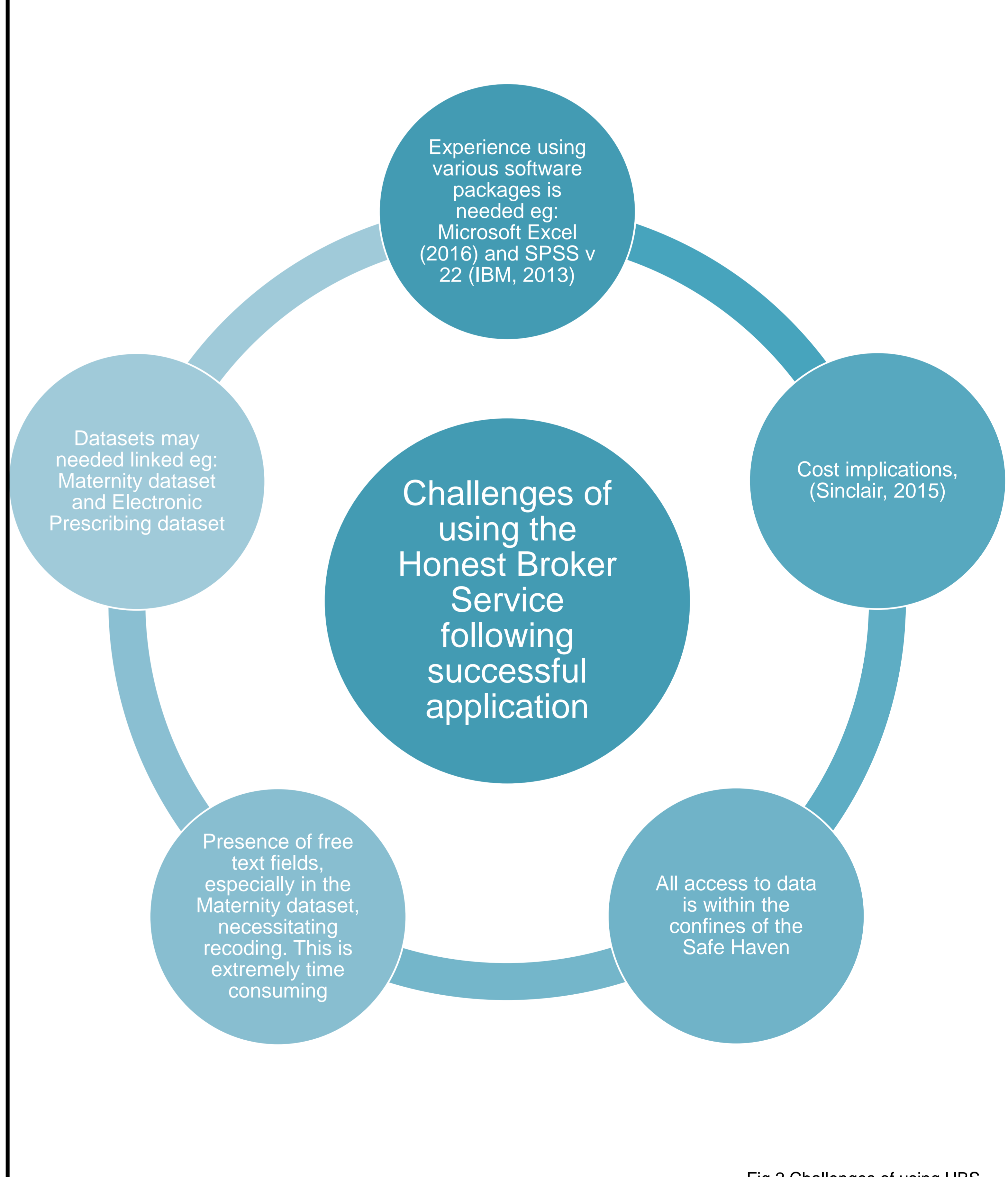
The Honest Broker Service, offered by the Health and Social Care Business Services Organisation, facilitates access to anonymised (and at times pseudonymised) health and social care data. It aims to:

- Provide good information governance
- Provide data in line with the Information Commissioner's Office Codes of Practice, data protection and confidentiality requirements
- Enable sharing of non-identifiable data to enable planning and commissioning of services and public health monitoring
- Import datasets to the data warehouse where they are pseudonymised, anonymised and linked to other datasets, if requested
- Join data from different Health Care Trusts to gain a fuller understanding of the population served
- Deliver high quality, cutting-edge research potential by enabling the linking of electronic datasets to enhance health informatics research
- Facilitate and support the safe use of non-identifiable patient data for medical research through the provision of a research safe haven (Morgan, 2016)

Process for HBS Application



Challenges



Lessons learned from experiences using the Honest Broker Service

- The application process can take a considerable length of time (Fig 1). Do not underestimate this
- Anyone working on the raw data must be named on the application. This can be amended as necessary as new personnel become involved (Fig 1)
- Be very specific about variables requested – what the requestor means will not necessarily be what is understood by those managing the data, especially if the requestor is from a clinical background and does not have extensive statistical or computer software knowledge (Fig 1)
- Use of the Honest Broker Service is charged at a daily rate. It can be difficult to estimate how many days work are involved at the outset (Fig 2)
- The data are not necessarily presented in a format suitable for analysis. Changing the data to a format suitable for analysis can be time consuming and may involve further training, expertise of others and possibly a cost implication (Fig 2)
- Raw data cannot be taken out of the Safe Haven. All analysis must be undertaken on site, necessitating travel and parking. It can be difficult to access assistance for specific issues which may arise while working in the Safe Haven. No internet access is permitted, to preserve anonymity and confidentiality and ensure no data can be removed without prior approval (Fig 2)

References

Economic and Social Research Council. (2016) *Northern Ireland Life and Times Survey 2015*. Available at: <http://www.ark.ac.uk/nilt/2015/index.html>. Accessed: 20/03/17.

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Morgan, S. (2016) *HSCNI Honest Broker Service*. [PowerPoint Presentation]. HSCNI Honest Broker Service. Belfast: Business Services Organisation.

Robinson, G and Dolk, H. (2016) Public Attitudes to Data Sharing in Northern Ireland. Available at: <http://www.ark.ac.uk/publications/updates/update108.pdf>. Accessed 09/03/17.

Sinclair, M. (2015) Accessing data from safe havens and warehouses: pinnacles and pitfalls. *Evidence Based Midwifery*. Vol13 (4): p1.