

HFEA Register Research Panel Meeting

2nd August 2011

Finsbury Tower, 103-105 Bunhill Row, EC1Y 8HF

MINUTES

Members of the Panel:

Peter Thompson (PT), Director of Strategy and Information (Chair)
David Moysen (DM), Head of IT
Comments received in writing from Richard Martin (RM), Head of Corporate and Quality Projects

Panel Secretary:

Suzanne Hodgson

Not in attendance:

Charlotte Augst (CA), Head of Business Intelligence. CA, as the HFEA's Caldicott Guardian provided Caldicott approval for the study and has therefore not been involved in its review as a member of the Register Research Panel.

Documents considered

Project protocol, version 2 dated 20/06/2011
Data flow sheet, version 3 dated 20/06/2011
NIGB application form, dated 24/06/2011
Caldicott Guardian's letter of approval, dated 22/06/2011

1. Review of Application

A new application has been received via the NIGB Ethics and Confidentiality Committee (ECC) requesting access to identifying data from the HFEA register.

1.1. The lead investigator is Dr Alastair Sutcliffe of the UCL Institute of Child Health. The study aims to address the question of whether children born after assisted reproduction are at a significantly different risk of mortality. The study will link data from the HFEA register to birth registration records held by the Office for National Statistics (ONS). These records held by the ONS are automatically linked to death registrations, so it should be straightforward to ascertain whether a child conceived via ART subsequently died and therefore calculate the cohort's mortality rate. This will be compared with the expected mortality rate based on population statistics. Only non-donor cycles performed in 2001 in England and Wales will be used.

1.2. The applicants have requested access to the following fields to perform their linkage:

- Date of birth
- Birth weight
- Sex of child
- Mother's names (including previous names, if applicable)
- Mother's date of birth
- Birth order

Additionally, the Panel noted that the applicants may request access to father's name if the match rate is found to be unacceptably low.

1.3. The data required by the applicants is held by the HFEA and is disclosable under section 33D and cannot be obtained elsewhere.

1.4. The application has been reviewed recently by the NIGB ECC who have given a provisionally positive opinion. The applicants have advised the ECC that they have received Research Ethics Committee approval though this has not yet been received. The ECC also noted they had not yet received a Systems Level Security Policy (SLSP) from the ONS.

- 1.5. The Panel noted that UCL staff will never themselves have sight of identifiable data, and the data flow has been designed to ensure that no one organisation ever have all of the data (i.e. identifiers, fertility data and death data).
- 1.6. Aggregated data will be held for 15 years by UCL; the data file will be held here for 6 years (which can be extended if necessary).

2. Location of linkage

The applicants have proposed that the HFEA data be sent to the ONS for the linkage to be performed. While it is preferred that HFEA data is not sent off-site, the Panel agreed that in this case this will be acceptable. If the linkage were to be performed here, a disproportionately greater amount of data would need to be transferred from the ONS and this would go against the principles of the Data Protection Act. The Panel agreed that the ONS can be considered a trustworthy organisation. The linkage will be performed by a small, restricted team who are experienced in handling sensitive data of this kind. The ONS SLSP will need to be submitted to the Panel, as well as the ECC.

3. Opinion

The Panel felt happy to give a provisional indication that we would grant access to the data based on the documents reviewed.

The access is conditional on receiving the following documents:

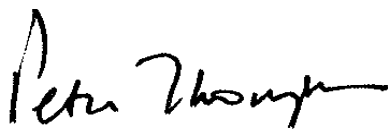
- REC approval letter
- ONS and UCL SLSPs
- Data Sharing Agreement (if required)
- Updated data flow sheet reflecting all of the data being transferred out of the HFEA.

The Panel also suggested that the additional field of father's name be included in this application, as it had proved useful during the recent pilot match and will save time to do this now rather than as an amendment.

Action: PT to write to the Chair of ECC to advise of this decision - **Done**

RM confirmed in writing his agreement with the above decisions.

I confirm this to be a true and accurate record of the meeting.



Signed.....Date.....14/09/2011.....
Peter Thompson (Chair)