

# HFEA Register Research Panel Meeting 16<sup>th</sup> July 2010

21 Bloomsbury Street London WC1B 3HF

## MINUTES

### Members of the Panel:

Peter Thompson (PT), Director of Strategy and Information (Chair)

David Moysen (DM), Head of IT

Charlotte Augst (CA), Head of Business Intelligence (Minutes)

**For the research project:** Kathryn Bunch, Jackie Gallagher, Diane Pryce, Alastair Sutcliffe, Carrie Williams

### 1. *Children's Cancer Study*

1.1 The only outstanding issue here was the System Level Security Policy.

**Action:** David to provide an SLSP within a week.

1.2 The anticipated start date for this study is the 1 February 2011, two researchers will need access to the Register for linkage purposes for a few weeks. Technical and process issues to be sorted out before then.

1.3 David confirmed that donor treatment data could be included in this study if identifiers were removed.

**Action:** Kathryn to provide 'mock data' to David identify any issues and solutions.

### 2. *Women's Cancer Study*

#### 2.1 Longitudinal study

It was agreed that the HFEA approval currently only covers the retrospective part of the study, but that this initial linkage should be conducted in such a way as to enable a further, later linkage, without incurring the same costs/ effort.

#### 2.2 Linkage

The HFEA set out that permanent or even time limited flagging of patients who had received fertility treatment on the NHS data base was not permissible under the governing legislation. It was also agreed that simply re-running the whole linkage process again in 5 years time was not (cost) effective.

Different ways to enable the linkage of the two data sets (with a view to a later update in 5 years time) were explored (unique study numbers and NHS numbers being stored at HFEA, unique study numbers and NHS numbers stored at the NHS IC). The researchers and the NHS Information Centre will contact the ECC (NIGB) to find out what option is acceptable to them. Both sides agreed that a way to benefit from the efforts of the first very elaborate linkage will be found, that doesn't constitute permanent 'flagging' on an NHS data base.

**Action: Jackie, Diane and Carrie** to approach Natasha at the ECC to explore options for recording the outcomes of the initial linkage in a way that was acceptable under governing legislation and cost-effective.

**Action: HFEA Register Research Panel** to consider these options afterwards.

### 2.3 Location

NHS IC set out that it wasn't possible to move their data sets, or parts thereof, to the HFEA.

**Action: Jackie and Diane, together with Alastair**, to set out in a letter the reasons for why the relevant data for linkage to the HFEA data set could not be moved over to the HFEA (by end of July).

**Action: Register Research Panel** to reconvene in the first half of August in order to consider the question of location for linkage in light of this letter.

### 2.4 Security policies

**Action: NHS IC** to provide HFEA with security policy and any other standard information on information governance, for the record.

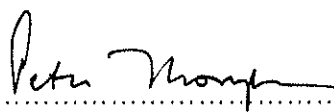
## **3. Lay summaries**

**Action: Carrie and Alastair** to provide Charlotte with lay summaries for the two studies.

## **4. Information sharing**

It was discussed and agreed that the HFEA would be made aware of any possible findings or publications before these were made public.

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

Signed..........Date.....21/7/10.....  
Peter Thompson (Chair)