

# HFEA Register Research Panel Meeting

## 3<sup>rd</sup> November 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

#### Panel Secretary:

Suzanne Hodgson

#### 1. Linkage for Schools Study

The panel discussed whether the project proposed by Scott Nelson to link school census data to the HFEA register should be considered 'medical' research or not. This decision will determine the approvals pathway it will follow. It was noted that the NIGB takes the view that if there is *any* medical element to a project then it should be considered medical research and go through their approvals process.

The study will involve joining the datasets using births certificates which are held by the Registrar General at Somerset House. The study will investigate curricula outcomes (suggested to be at 7, 11, 16 and 18) in children born as a result of assisted reproduction. As previously found in Alastair Sutcliffe's women's cancer study the dataset to be linked to is considerably larger than ours so it is likely that ours will need to be released again. A similar procedure as before should be followed to assess whether this can take place.

It was agreed that there needs to be a process to judge the project merit and the data security of non-medical research to a similar level as the NIGB. ELAC and SCAAC are not in a position to judge these issues but they could assess whether the process proposed for handling non-medical research is suitable.

**Action:** *Draft letter to NIGB to explain the study to the best of our knowledge and ask whether they could reach a view on whether or not this is medical. If necessary, phone Scott Nelson for further information.*

The Panel agreed that some experts need to be recruited to review the project, similar to peer review. An educational statistician could be recruited from the Institute of Education or the Royal Statistical Society. This will be a second step, after first consulting with the NIGB.

#### 2. iART

Scott Nelson's paper predicting live birth outcomes after assisted reproduction has been accepted for publication, having been peer reviewed. He is also intending to produce a website and an i-Phone app which women could use to get a personalised prediction of their own likelihood of having a baby by ART. SMT felt that we should not produce our own predictive tool, but we need to decide whether we should alert Choose a Fertility Clinic users to his site, and whether his website should link back to us. It was noted that linking to his website may be seen as endorsing it. This will be discussed at the December workshop on the anonymous register (see item 3) as Scott Nelson is likely to be attending. Additionally, SN could potentially do a presentation to ELAC or SCAAC.

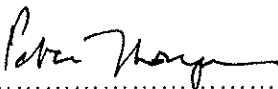
We must ensure that a growth in this kind of online tool doesn't eclipse our own website.

**3. Anonymous register**

A workshop on using and improving the anonymous register (AR) will be held at the HFEA in December. It would be useful for people who have expressed an interest in the AR on the website to attend. However, our website policy states that we will only use their email address to contact them on the matter that they entered it for. In order to contact these people, we need to know when the next AR will be published (waiting on the HFEA ID project to complete) and then ask them if they would be interested in the workshop. The HFEA ID should be completed in 6 weeks time.

**Action:** SH to inform the people who have expressed an interest in the AR that the next version will be available in January with the HFEA ID (which will improve its usability), and then ask them whether they'd be interested in the workshop.

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

Signed.......... Date.....5/11/10.....  
Peter Thompson (Chair)