

HFEA Register Research Panel Meeting

13th September 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

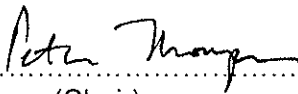
Panel Secretary:

Suzanne Hodgson

1. Alastair Sutcliffe (AS) at the Institute of Child Health, UCL has proposed two studies requiring access to identifiable Register data. For one of the studies no specific security issues with the data linkage were identified but for the second, in women's cancer, the researchers have proposed that the linkage is performed off site, which is against agreed policy. At a meeting on 16th July the researchers agreed to supply a letter explaining why the linkage could not occur at the HFEA and what security would be put in place to protect the data. This letter was received on 24th August.
2. Their letter explains that NHS Information Centre (IC) policy means that their data cannot be released or accessed remotely. It can only be accessed by NHS IC staff at their site.
 - 2.1. The Panel agreed that sufficient information on location and security should be provided in order for them to allow the release of Register data off site. The letter does not fully provide this information.
 - 2.2. The Panel will write to AS to explain that some concerns have been addressed but others have not. It will be made clear that this is not in order to put up barriers to research but is required to justify to the Authority why our policy has not been followed.
 - 2.3. The researchers should write again and explain that data held by the NHS IC is collected on the understanding that it does not leave the premises and would constitute a breach if it did. They must also confirm that the linkage will be performed retrospectively and updated at the relevant point in the study and no flag will be placed on patients' NHS records identifying them as fertility patients. Flagging would constitute a breach for the HFEA.
Action: CA to draft response to AS. **Done.**
 - 2.4. The researchers also need to be aware that if anyone outside their research team views the Register data it will constitute a breach.
 - 2.5. If the researchers take responsibility for the encryption we will need to give them the terms for looking after it.
 - 2.6. Other actions outstanding from the July meeting still need to be addressed, mock data has not been provided to DM for the children's cancer study.
Action: DM to draft security policy by the end of this week.
3. **Other projects**
 - 3.1. Judith Rankin, who has carried out research on congenital abnormalities in IVF babies in the northern region, is seeking funding to continue her research on national data.
4. **Anonymous register (AR)**
 - 4.1. An RP has asked for a bespoke version of the AR including the first part of the patients' post codes. The Panel agreed that if it set a precedent of providing bespoke ARs to researchers identification could become possible by piecing these together.
Action: CA to advise the RP of the decision.

- 4.2. It was agreed it may be useful to aggregate the ages in the AR differently, allowing more detailed analysis in women under 35.
- 4.3. In order to improve the usability of the AR interested parties will be invited to discuss it and inform us what level of detail is a priority to them.
Action: DM to give CA the names of those who have expressed an interest.
- 4.4. The Panel agreed that it is vital that researchers build in to their grant applications the cost of actually getting the data.

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

Signed.....  Date..... 16 / 9 / 10

Peter Thompson (Chair)