

Terms of Reference – Register Research Panel

Functions of the Register Research Panel

1. The functions of the Register Research Panel shall be to:-
 - a) Authorise or refuse to grant applications to access HFEA Register data made under the Human Fertilisation and Embryology (Disclosure of Information for Research Purposes) Regulations 2010 or under section 33A(2)(h) of the Human Fertilisation and Embryology Act 1990 (as amended by the 2008 Act).
 - b) Suspend, revoke, vary or place conditions upon authorisation to access Register data.
 - c) Review annual reports submitted by research establishments.
 - d) Publish lay summaries of research projects involving the use of HFEA Register data.
 - e) Submit a report to the HFEA's Oversight Committee about the work of the Register Research Panel not less than once a year.
 - f) Refer appeals against the decisions of the Register Research Panel to the Register Research Review Panel (comprised of the Chief Executive and the Director of Finance and Facilities).
 - g) Liaise and collaborate with the National Information Governance Board and any other bodies in the UK with an interest in the safeguarding of personal data and the oversight of research studies involving the linkage of complex datasets.

Membership of the Register Research Panel

2. The membership of the Register Research Panel shall include the Director of Strategy and Information, who will serve as Chair of the Panel, the HFEA's Caldicott Guardian and the Head of IT.

Meetings of the Register Research Panel

3. The quorum for a meeting of the Register Research Panel shall be three.
4. Meetings of the Register Research Panel will be scheduled to follow the timetable of the National Information Governance Board's Ethics and Confidentiality Committee as set out in the Memorandum of Understanding between the two organisations.

Attendance at meetings of the Register Research Panel

5. In addition to the members of the Register Research Panel, the following persons may attend meetings at the invitation of the Panel Chair:-
 - a) Administrative support personnel
 - b) Legal advisers
 - c) Specialists in the field of non-medical research.

Powers delegated by the Authority to the Register Research Panel

6. The Authority delegates to the Register Research Panel the following powers:-
 - a) Authorise access to Register data for the purposes of medical or non-medical research.
 - b) Deny, suspend, revoke, vary or impose conditions upon authorisation to access Register data.

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Document control

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