

# Publication and disclosure policy

<b>Strategic delivery:</b>	<input checked="" type="checkbox"/> Setting standards	<input type="checkbox"/> Increasing and informing choice	<input type="checkbox"/> Demonstrating efficiency economy and value
Meeting	Authority		
Agenda item	12		
Paper number	HFEA (06/07/2016) 804		
Meeting date	6 July 2016		
Author	Ian Brown, Head of Corporate Governance Jo Triggs, Head of Engagement		
<b>Output:</b>			
For information or decision?	For decision		
Recommendations	<ul style="list-style-type: none"> <li>To consider the Publication and disclosure policy at Annex A</li> <li>To approve the continuation of the current practice not to publish supporting information or research lay summaries.</li> </ul>		
Resource implications	Part of baseline activities of the Communications and Corporate Governance teams		
Implementation date	1 August 2016		
Communication(s)	We will publish the new policy on our website		
Organisational risk	<input checked="" type="checkbox"/> Low	<input type="checkbox"/> Medium	<input type="checkbox"/> High
Annexes	Publication and disclosure policy		

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## 1. Introduction

- 1.1. All public bodies the UK are required to operate in an open and transparent way, so that the public can see that they are well run. A key element of this involves publishing information clear, accessible and easy-to-find information.
- 1.2. The Authority has had a publication policy since 2009, principally covering the publication of Authority and committee papers. This policy has been updated and broadened to include how we will publish all information on the new website and how we disclose information not normally published on the site.
- 1.3. This paper seeks Authority approval of the new policy. In particular, members are asked to consider two issues relating licensing decisions.

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## 2. Publication of licensing decisions

- 2.1. The policy includes our continued commitment to publish inspection reports and minutes relating to treatment and research licences applications. It also includes a continued commitment to publish information about grade A incidents. However, it does *not* include a commitment to publish:
  - supporting information (such as the application form, peer reviewers' comments) relating to licence applications, or
  - lay summaries of research projects before the application is considered by a committee.
- 2.2. As members will know, earlier this year we considered an application to add gene editing to a research licence. There was huge public interest in the application and our decision to approve it, prompting a wider discussion about what information, beyond inspection reports and minutes, we should publish, particularly around licensing matters with high public interest. We committed to reviewing our current practices in time for the launch of the new website.

### Supporting information

- 2.3. Supporting information - such as the application form, comments from a peer reviewer, consent forms, patient information and other papers dependent on the complexity of the application - is not currently published. There are three options for how this could be done in future:
  - Routinely publish all supporting information alongside the inspection report and minutes
  - Only publish documents relating to licence applications which are in the wider public interest
  - Continue to publish only the inspection report and minutes of the decision.

### Lay summaries of research applications

- 2.4.** Applicants for a research licence are asked to provide a lay summary of their proposed research. In the past, this summary was published on the website before the committee considered the application, giving members of the public an opportunity to comment. This service was discontinued but could be reinstated on the new website.

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## **3. Recommendation to the committee**

- 3.1.** We have just started a project to review the end-to-end process for research licensing, inspection and consent and we expect this to conclude early next year. It seems sensible, given this project, to maintain the status quo regarding the publication of supporting information and lay summaries of research applications. These issues will be considered as part of the review and considered by the Authority later in this business year.
- 3.2.** We therefore recommend to the committee:
- To consider the Publication and disclosure policy at Annex A
  - To approve the continuation of the current practice not to publish supporting information or research lay summaries.
- 3.3.** It should be noted that any decision to publish supporting information would affect the licensing of treatment clinics, as well as research laboratories. If the Authority decides to change the approach to research licensing in future, we will consider the implications for treatment clinics too.

# Publication and disclosure policy

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## 1. About this policy

- 1.1.** This policy sets out how the Human Fertilisation and Embryology Authority (HFEA) will be open and transparent about the information we hold, publish and disclose.
- 1.2.** The policy sets out our approach to:
- the publication and disclosure of information relating to regulatory decisions
  - the routine publication of information on our website
  - the routine disclosure of information to interested parties, and
  - how we deal with individual requests for information.

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## 2. Policy statement

- 2.1.** When making decisions on what information to publish we are committed to adhering to the following principles:
- being open and transparent about the processes we adopt and the decisions we make while protecting confidentiality;
  - ensuring that commercially sensitive information is treated confidentially;
  - ensuring that we comply with the legal duties placed upon us with regard to data protection and the common law duty of confidentiality;
  - that any disclosure of information is lawful and proportionate in all circumstances
  - that information is published in an accessible format where possible.

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## 3. Legislative framework

- 3.1.** We will take into account the following non-exhaustive list when making decisions about disclosing the information that we hold:
- the Human Fertilisation and Embryology Act 1990 (as amended)
  - the relevant provisions of other legislation, such as the Freedom of Information Act 2000, Data Protection Act 1998 and the Human Rights Act 1998

- the Environmental Information Regulations 2004 ('EIR')
- relevant case law.

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## 4. Freedom of Information

**4.1.** Under the Freedom of Information (FoI) Act 2000, we are required to give information we hold to anyone who asks for it, except in circumstances where the disclosure requested is exempt. We have a model publication scheme, available on our website, which details the information we publish and the retention period for certain classes of information. Anything not included within our publications scheme or in our committee and authority minutes can be requested under the Act.

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## 5. HFEA model publication scheme

**5.1.** Our model publication scheme is based on the Information Commissioner's Office guide for non-departmental public bodies. As part of our publication scheme we publish information relating to the following areas.

### Who we are and what we do

**5.2.** We publish information about our people and our activities, including:

- an explanation of our internal structure and roles and responsibilities within it
- senior executives and board members
- an explanation of the legislative basis of our activities
- lists of, and information relating to, partner organisations
- details of meetings of the Chief Executive or board members with Ministers and external organisations (including meetings with newspaper and other media proprietors, editors and senior executives)
- organisational information and structure
- staff roles and responsibilities
- locations and contacts.

### What we spend and how

**5.3.** We publish financial information for the current and previous two financial years, including:

- details of expenditure over £25,000 (monthly)
- details of contracts and tenders worth over £10,000
- details of government procurement card expenditure over £500
- senior staff and board members' allowances and expenses (senior staff are defined as those earning at least £58,200 per annum)
- pay and grading structures
- procurement and tendering procedures
- financial statements for projects and events
- internal financial regulations.

## **Our priorities and progress**

**5.4.** We publish information for the current and previous two years on:

- strategic plans
- annual business plan
- annual report
- internal and external performance reviews
- reports to Parliament
- privacy impact assessments (in full or summary format)
- service standards
- statistics produced in accordance with the HFEA's requirements
- public service agreements.

## **Policies and procedures**

**5.5.** We publish current written policies and procedures relating to:

- the conduct of HFEA business
- the provision of services
- the recruitment and employment of staff
- making enquiries and complaints
- records management and personal data.

## **Lists and registers**

**5.6.** We publish:

- a list of information that has been provided in response to FoI requests
- a register of gifts and hospitality provided to board members and senior staff.

## **The services we offer**

**5.7.** We publish information about our services, including:

- printed information
- subscription services
- information access services.

## **How we make decisions**

**5.8.** We publish details of major policy and service decisions and how we arrived at those decisions, including information relating to:

- public consultations and other engagement exercises
- stakeholder groups
- scientific reviews.

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## 6. Corporate and licensing decisions

### Agendas and minutes

**6.1.** We publish the agenda, papers and minutes of the following committees:

- The Authority
- Appeals Committee
- Appointments Committee
- Audit and Governance Committee (AGC)
- Executive Licensing Panel (ELP)
- Licence Committee
- Oversight Committee
- Remuneration Committee
- Scientific and Clinical Advances Advisory Committee (SCAAC)
- Statutory Approvals Committee (SAC)
- Register Research Panel
- Register Research Review Panel.

### Authority meetings

**6.2.** Subject to section 7, the following documents will normally be published on the website two working days in advance of any Authority meeting:

- agenda
- papers to be relied on at the meeting.

**6.3.** Subject to section 7, tabled papers considered at the Authority meeting which were not published in advance of the meeting will normally be published on the website within two working days of the Authority meeting.

**6.4.** A note of the decisions taken at the Authority meeting will normally be published on the website within two working days of the Authority meeting.

**6.5.** The minutes of the Authority meeting will normally be considered at the next meeting of the Authority and, subject to section 7, the approved minutes will normally be published on the website within eight working days of the day on which the minutes were ratified by the Chair.

**6.6.** An audio recording of the Authority meeting will normally be published on our website within 10 working days of the Authority meeting.

### Committees not concerned with licensing

**6.7.** Subject to section 7, the following documents will normally be published on the website two working days before of any committee meeting not concerned with licensing:

- agenda
- papers to be relied on at the meeting
- signed minutes of the previous meeting.

- 6.8.** The publication of papers and presentations made to the Scientific and Clinical Advances Advisory Committee are considered on a case-by-case basis as there may be legitimate concerns about the confidential nature of research.
- 6.9.** Subject to section 7, tabled papers considered at the committee meeting which were not published in advance of the meeting will normally be published on the website within eight working days of the meeting at which they were considered.

### **Committees, panels and decisions concerned with licensing and authorisations**

- 6.10.** Subject to section 7, the following documents will normally be published on the website within 15 working days of the meeting of a committee concerned with licensing, or decision of a Licensing Officer:
- a note of the decision of a Licensing Officer to make any administrative variation of a licence, and any accompanying supporting documentation
  - minutes of the meeting where the panel or committee considered an initial or renewal licence application, or an interim inspection report
  - minutes of the meeting where the panel or committee considered whether to vary, suspend or revoke a licence
  - minutes of meetings relating to consideration by the panel or committee of grade A incidents, serious adverse events or serious adverse reactions
  - minutes of meetings where the panel or committee considered applications for embryo testing
  - minutes of meetings where the panel or committee considered applications for the import/export of gametes
  - any inspection report relating to an initial inspection or a renewal or interim inspection which was considered by the panel or committee, or any other type of inspection report on which the panel or committee made its decision to vary, suspend or revoke a licence
  - subject to ensuring patient and commercial confidentiality, supporting paperwork relating to grade A or grade B incidents or serious adverse reactions considered by the panel or committee.
- 6.11.** The documents above are redacted where necessary to preserve the anonymity of any patients concerned and, in the case of papers relating to applications for research, redacted to preserve any commercially sensitive information or sensitive personal data relating to clinic staff, which is exempt from publication in accordance with the provisions of the Freedom of Information Act 2000.
- 6.12.** Other documents considered by the Licence Committee and Executive Licensing Panel, such as the application form, comments from peer reviewers, consent forms and patient information, are not published on our website but can be requested under the Freedom of Information Act 2000.
- 6.13.** In the case of sensitive decisions (including, but not only, those relating to applications for HLA testing, or the import/export of gametes) the executive may take steps to ensure the patient is aware of the decision, before publishing the minutes on the website.
- 6.14.** When hearing representations under section 19(4) of the Act, publication of the relevant documentation and minutes are at the discretion of the Chair of the Licence Committee, subject to the relevant regulations.
- 6.15.** Publication of the relevant documentation and minutes of proceedings of the Appeals Committee are at the discretion of the chair, subject to the relevant regulations.

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## **7. Documents that are not published on the Authority's website**

**7.1.** The following documents and information are not normally published on our website:

- information that is in draft form
- information that has been archived
- confidential reports and unpublished papers relating to ongoing research presented to the Scientific and Clinical Advances Advisory Committee
- confidential and/or sensitive personal information considered by Remuneration Committee or Appointments Committee
- certain confidential or sensitive material relating to grade A or grade B incidents, serious adverse events or serious adverse reactions or relating to embryo testing
- material that is covered by copyright not held by the Authority. In instances where the publication of papers on the Authority's website is prohibited by copyright the full title and reference of the paper will be provided
- information which is exempt from disclosure under the Data Protection Act 1998 or Part II of the Freedom of Information Act 2000
- information, the disclosure of which would be a breach of section 33A of the Human Fertilisation and Embryology Act 1990 (as amended)
- transcripts of representations hearings. The resource implications of redacting the transcript before publication would be disproportionate. However, requests for copies of any transcripts that are held by the Authority would be considered for disclosure under the Freedom of Information Act 2000.

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## **8. Roles and responsibilities**

**8.1.** All of the information in our publication scheme is available on our website. The website also contains comprehensive information about treatment types and all licensed centres.

**8.2.** The communications team has overall responsibility for the website. Each team within the HFEA has access to the Content Management System (CMS) so they can make amendments to their content on the website. Any changes required should be actioned within five working days to make sure the information is always up to date.

**8.3.** The secretary to the Authority or relevant committee or panel is responsible for ensuring that documents, which include the agenda, any papers and presentations, and minutes, are published on the website in accordance with this document.

**8.4.** Where there is an issue as to whether documents, or parts of documents, should be redacted or withheld from publication, the secretary will refer the matter to the Chair of the Authority or Chair of the relevant committee or panel for decision.

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## **9. Retention periods and updating**

**9.1.** All information on the website is retained for three years from the date of publication, with the following exceptions:

- Information relating to centre licensing, which will be kept for five years to accommodate the standard length of licence.

- 9.2.** Any information which has been removed after the relevant retention period will be made available on request.
  - 9.3.** Any request for inspection reports and minutes of committees concerned with licensing before 2004 would be considered for disclosure under the Freedom of Information Act 2000.
  - 9.4.** We have internal processes to ensure that information published on the website is kept up to date. Each page has a date stamp indicating when it was last updated.
  - 9.5.** Clinic statistics on Choose a Fertility Clinic are updated every six months.
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## **10. Translation of information into different formats**

- 10.1.** Upon request we will translate our information into braille, audio. We will also translate it into a foreign language if that is specifically requested.
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## **11. Information access policy**

- 11.1.** This policy should be viewed in conjunction with the information access policy which gives details of the information we make available to members of the public and how they can access it.