

Transparency Team
Cabinet Office
4/W2
1 Horse Guards Road
London
SW1A 2AS

14 October 2011

Dear Sir/Madam,

re: Making Open Data Real: A Public Consultation

I am responding to your above consultation as Chief Executive of the Human Fertilisation and Embryology Authority (HFEA), a non-departmental public body.

The HFEA is the UK's independent regulator of treatment using eggs and sperm, and of treatment and research involving human embryos. This response is based on our experience as a public body covered by the Freedom of Information Act 2000 (FOIA) and as a proactive provider of information to healthcare researchers, people seeking treatment, donor-conceived people and donors.

There are three key points I would like to make:

1. Transparency for its own sake is not necessarily a good thing and data released without consideration of quality, context or meaning can be misleading and harmful. The complexity of data presentation is demonstrated in our online directory of licensed centers, which includes information for patients about licensed clinic activities (<http://guide.hfea.gov.uk/guide/AllClinics.aspx?x=A&y=T>). In developing this directory we did much policy work and user testing to make concepts like success rates, confidence intervals, observed and predicted outcomes etc understandable.
2. A large amount of data held by the HFEA is published via this directory for people seeking treatment. Further publications have been designed for healthcare researchers (<http://www.hfea.gov.uk/5874.html>). We believe that proactive publication of information like this, although it involves significant work on, for example, user requirements, is a more efficient use of resource than bespoke information disclosures to individuals under the FOIA.

Roughly a third of FOI requests dealt with by the Authority relate to the HFEA's register of treatments and require expert analyst skills to carry out unique extracts. These are also resource intensive yet result in less regular and even disclosure of information than planned proactive publications.

3. Lastly, we urge caution before increasing the existing burden of the FOIA at a time when resources are being cut. It is arguable that accountability and transparency are better served by organisations releasing structured, contextualised and quality assured information than disclosure under the FOIA.

Yours faithfully,



Alan Doran CB

