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Wither the HFEA and the fate of donor registers?

23 August 2010

By *Professor Eric Blyth, Dr Marilyn Crawshaw, Dr Lucy Frith, Dr Caroline Jones and Dr Jennifer Speirs*

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The UK government's review of Arm's Length Bodies (ALB) in the National Health Service (NHS) (1) has indicated that the Human Fertilisation and Embryology Authority (HFEA) has had its day as a free-standing regulatory body. By the end of the current Parliament, and subject to 'further work ... to examine in greater detail the practicalities involved', including 'particular confidentiality issues', and engagement with 'key stakeholders', the government proposes that its functions will be distributed between the Care Quality Commission, the Health and Social Care Information Centre (IC) and a new research regulator (1).

The review also proposes that responsibility for the HFEA's Register of Information and Donor Sibling Link will be transferred to the IC, a little-known body within the NHS, which claims to be 'England's central, authoritative source of health and social care information for frontline decision makers' (2). Given the UK-wide remit of the HFEA's regulatory activities, the Anglo-centric focus of the IC may be a cause for concern. However, the government proposes the IC will become 'the *national* repository for data across health care' and 'will make data available for use by third parties', thereby relieving other arm's length bodies of this function; and notes that the forthcoming Health Bill will place the IC on a 'firmer statutory footing' (3). For a document with such wide-ranging implications, the paucity of detail in the ALB review would be concern enough, without the rumour circulating since its publication that the HFEA was an eleventh-hour addition to the list of targeted organisations at ministerial request. Suffice to say that the review provides scant evidence that the HFEA should be abolished at all.

The HFEA's Register of Information records details of all licensed fertility procedures undertaken in UK clinics, information about [embryo](#) and [gamete](#) donors, recipients of donated gametes and embryos, and - where the HFEA has been notified - births resulting from licensed procedures using donated gametes or embryos. Any person aged at least 16 who intends to marry, or to enter into a civil partnership or an 'intimate physical relationship' may make a joint request with their intended partner to the HFEA to ascertain whether the Register contains information that they may be genetically related.

A person aged at least 16 may also enquire whether the Register indicates that they are donor-conceived; if so, they may request non-identifying information about their donor and any donor-conceived genetically-related sibling. Anyone conceived after 1 August 1991 aged at least 18 may both register with Donor Sibling Link (DSL) and request identifying information about any donor-

conceived sibling who has already agreed to the disclosure of their identity. Where any subsequent donor conceived siblings join DSL, all existing registered siblings will be notified. In addition, where donation took place before 1 April 2005 and the donor has retrospectively relinquished protection of his or her identity, and in all other cases where donation took place after 1 April 2005, the donor's identity may be provided. In addition, a donor has the right to access non-identifying information regarding the number, sex, and year of birth of anyone born as a result of his or her donation.

Where a request for information from the Register is made, the HFEA is required to provide a 'suitable opportunity to receive proper counselling about the implications of compliance with the request' (formerly s.31(3)(b) Human Fertilisation and Embryology Act 1990; now see s.31ZA(3)(b) regarding information sought about genetic parentage, and s.31ZB(3)(c) for information about an intended partner). In anticipation of the initial requests for information from the Register in 2009, the HFEA decided not to provide or commission counselling services itself. Rather, it advises those seeking information to contact the British Association for Counselling and Psychotherapy or their GP - with added advice that the enquirer 'may also want to contact the British Infertility Counselling Association' or contact The Donor Conception Network or UK Donor Link as 'other places to go for support' (4).

In deciding against commissioning services, it denied people access to the services of UK DonorLink (UKDL), the only specialist expertise available. UKDL, a voluntary sector service funded by the Department of Health is currently only available for those seeking information exchange and contact where the conception took place prior to August 1991 (5,6,7).

The HFE Act 2008 granted the HFEA power to set up or keep a voluntary contact register, or to provide financial assistance to others to do so (s.31ZF and s.31ZG Human Fertilisation and Embryology Act 1990, as amended) (8). One possible outcome was that the HFEA could take over responsibility for, or instead fund, the UK DonorLink register. However, by the time of publication of the ALB review, discussions between the HFEA and UK DonorLink about the future of the register and associated support services were ongoing. Publication of the ALB review raises serious concerns about the future of this register and UK DonorLink's efforts to continue to provide this important service to anyone seeking information exchange.

The current plans to transfer responsibility for the HFEA's Register of Information and Donor Sibling Link to the IC appear not to have considered alternative homes for the Registers, and it is hoped that the proposed consideration of stakeholders' views will be sufficiently unfettered to allow consideration of other solutions, should the proposed abolition of the HFEA proceed. In particular we would urge consideration of the merits of transferring responsibility for the Register to the General Register Offices for England and Wales, Northern Ireland and Scotland (GROs). The GROs already have responsibility for maintaining and overseeing access to adoption and parental order registers. In both New Zealand and the State of Victoria in Australia, the relevant body for registration of Births, Deaths and Marriages has responsibility for the maintenance of births records relating to donor conception (9).

It is crucial that the rights to information of those affected by donor conception are not compromised by ALB Review proposals whose intentions are not primarily concerned with such matters. Consideration of the appropriate home for, and services to support the collection and release of information held on the HFEA Registers and the Voluntary Register must reflect the seriousness of its potential to affect the well-being of those concerned.

SOURCES & REFERENCES

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2) [Health and Social Care Information Centre](#)

emphasis added |

3) [Liberating the NHS: Report of the arm's-length bodies review: para 3.50](#)

emphasis added |

4) [Human Fertilisation and Embryology Authority](#)

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5) [UK DonorLink](#)

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6) [Crawshaw, M. and Marshall, L. \(2008\) Practice experiences of running UK DonorLink, a voluntary information exchange and contact Register for adults related through donor conception](#)

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7) [Opening the Record: Planning the Provision of Counselling to People applying for Information from the HFEA Register Report of the HFEA Register Counselling Project Steering Group](#)

British Infertility Counselling Association (2003) |

8) [Human Fertilisation and Embryology Act 2008](#)

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9) [Blyth, E., Frith, L., Jones, C. and Speirs, J. \(2009\) The role of birth certificates in relation to access to biographical and genetic history in donor conception](#)

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