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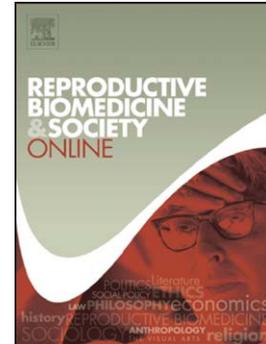
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Short title: UK birth registration reform

Can the UK's birth registration system better serve the interests of those born following collaborative assisted reproduction?

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Abstract

Current birth registration systems fail to serve adequately the interests of those born as a result of gamete and embryo donation and surrogacy. In the UK, changes to the birth registration system have been piecemeal, reactive and situation-specific and no information is recorded about gamete donors. Birth registration has thereby become a statement of legal parentage and citizenship only, without debate as to whether it should serve any wider functions. This sits uneasily with the increasingly accepted human right to know one's genetic and gestational as well as legal parents, and the duty of the State to facilitate that right. This commentary sets out one possible model for reform to better ensure that those affected become aware of, and/or have access to, knowledge about their origins and that such information is stored and released effectively without compromising individual privacy. Among other features, our proposal links the birth registration system and the information stored in the Human Fertilization and Embryology Authority's Register of Information, although further work than we have been able to undertake here is necessary to ensure a better fit where cross-border treatment services or informal arrangements have been involved. The time for debate and reform is well overdue.

Keywords: *birth certificates, birth registration, donor conception, gamete donation, surrogacy*

The advent and increasing prevalence of gamete and embryo donation and surrogacy – or collaborative assisted reproduction – call into question the ability of the UK's birth registration system to serve adequately the interests of those born as a result of such procedures. Although time has witnessed both policy shifts and legislative reform, these have been piecemeal, reactive and situation-specific. Wider debate about the purpose and significance of birth registration has been lacking, as in the White Paper *Joint Birth Registration: Recording Responsibility* (Department for Work and Pensions, 2008) which was

driven primarily by policy intentions to engage more unmarried genetic fathers in financial and other support for their children (for a useful summary see Clapton, 2014). In this commentary, we argue that systematic reform is now both necessary and achievable.

The UK's birth registration system retains much of its original mid-nineteenth century characteristics but has shown itself capable of adaptation, for example to take account of adoption, surrogacy arrangements, civil partnerships and re-registration for transgender individuals. It also enables paternity details to be altered, added or removed following the original registration (Bainham, 2008) including for donor-conceived individuals in limited circumstances (Crawshaw and Wallbank, 2014), and allows the posthumous naming of an intended parent (Human Fertilization and Embryology Act, 2008). In the process, birth registration has become a record of citizenship and legal parentage alone, obscuring additional functions as a source of information about one's progenitors through recording biological facts (Bainham, 2008) and as a public health record (Brumberg *et al.*, 2012). While earlier records were not a guarantee that the named father was also the genetic parent, the law assumed this to be the case. Thus, it was a criminal offence for a husband to be registered as father if the registrant knew him not to be the genetic father, including where donor insemination had been used. When this offence was removed in the case of donor insemination in the 1987 Family Law Reform Act there was, again, no discussion about the implications of removing the record of assumed biological facts.

For individuals conceived following donor-assisted reproduction, the birth registration system fails to record details of their genetic parents where one or both of these is a gamete donor or where multi-parenting arrangements prevail, for example where two female parents and a genetic father share child-rearing responsibilities. In our view this sits uneasily, first with increasingly accepted views that individuals should have the right to know their parents (United Nations Convention on the Rights of the Child; European Convention on Human Rights). Although neither Convention is explicit in who should be defined as a parent, the UN Committee on the Rights of the Child has frequently expressed a view that this should include gamete donors (Blyth and Farrand, 2004) while, in the *UNICEF Implementation Handbook for the Convention on the Rights of the Child*, Hodgkin and Newell (2007) argue that this should include:

genetic parents (for medical reasons alone this knowledge is of increasing importance to the child) and birth parents, that is the mother who gave birth and the father who claimed paternity through partnership with the mother at the time of birth (or whatever the social definition of father is within the culture). (Hodgkin and Newell, 2007: 105)

Whilst acknowledging that terminology in collaborative assisted reproduction is complex and contested in its everyday use within and by the families and individuals affected, the principle for these purposes is therefore that 'parents' should include:

- those with a linear genetic relationship to the child (i.e. the genetic 'parents' who may variously be the surrogate, the intending/commissioning 'parents' in a surrogacy arrangement, or an embryo or gamete donor);

- those who carried the pregnancy and gave birth even if they are not raising the child (i.e. the birth/gestational 'parent')
- those raising the child or who are otherwise the child's legal 'parents'.

Hodgkin and Newell (2007) state further that in relation to Article 8 of the UN Convention ('right to identity'):

The concept of 'children's identity' has tended to focus on the child's immediate family, but it is increasingly recognized that children have a remarkable capacity to embrace multiple relationships. From the secure foundation of an established family environment, children can enjoy complex and subtle relationships with other adults and with a range of cultures, to a much larger degree than may be recognized. Thus children's best interests and senses of identity may be sustained without having to deny them knowledge of their origins, for example after reception into state care, through 'secret' adoptions or anonymous egg/sperm donations and so forth. (Hodgkin and Newell, 2007: 142).

This is supported by research suggesting that for some donor-conceived individuals, their best interests and sense of identity may even be enhanced rather than threatened by having information about the donor, with or without any ongoing relationship (Blyth *et al.*, 2012). Further, given that all these 'parents' are potentially significant to offspring throughout their lifetime – variously for medical reasons, to better understand their social, cultural and biographical heritage, to satisfy their curiosity, to complete their identity and so on—they arguably have the right to know them all (Blyth *et al.*, 2009).

Our second concern regarding the UK's system lies in its incongruity with recent UK practice, policy and legislative developments. These promote the rights of individuals to discover information about genetic parents and others genetically related through gamete or embryo donation (including through surrogacy) via the Human Fertilization and Embryology Authority (HFEA) registers and the government-funded DNA-based voluntary pre-1991 Donor Conceived Register. The UK's current birth registration system increases the likelihood that some of those individuals eligible to exercise these rights may never learn of their entitlement through the failure to allow it to be part of the machinery for meeting what we argue to be the State's human rights obligations to record and provide full parentage information.

The possibility of reforming birth registration is far from a novel concept. Almost a decade ago, a joint Committee of the House of Lords and House of Commons:

.... recognize[d] the force of the argument that the fact of donor conception should be registered on a person's birth certificate. This would create the incentive for the parent(s) to tell the child of the fact of his or her donor conception and would go some way to address the value of knowledge of genetic history for medical purposes. Moreover, unlike where children are born through natural conception, assisted conception by its nature involves the authorities and we are deeply concerned about the idea that the authorities may be colluding in a deception. However, we also recognize that this is a complicated area involving

the important issue of privacy, as well as issues of human rights and data protection. We therefore recommend that, as a matter of urgency, the Government should give this matter further consideration (House of Lords and House of Commons Committee on the Human Tissue and Embryos [Draft] Bill, 2007: 276).

Although the Committee's sense of urgency has never been reflected in the policies promoted by the three subsequent administrations (Labour 2007–2010; Coalition 2010–2015; Conservative 2015–present), other jurisdictions, such as Argentina, British Columbia (Canada), New Zealand, the Republic of Ireland and Victoria (Australia), have done so. These have introduced formal changes to take account of collaborative assisted conception and the reality that a child may have more than two parents (as defined above), while individual court cases resulting in similar outcomes have been reported in Florida and changes are actively under consideration in Germany, South Australia and New South Wales (Australia). These developments are discussed in more detail by Rundle and Hardy (2012), Allan (2016) and Collins (2016). Pressure is also growing in the UK and internationally from donor-conceived and adopted people (see for example Coalition for Accurate Birth Records <https://www.facebook.com/groups/1697052370542414>; Kramer 2015).

Although reforms in other jurisdictions have been implemented too recently to provide any real policy or practice guidance, we nevertheless consider that that birth registration reform is feasible in the UK. We acknowledge that it should ensure that:

- individual privacy is not compromised
- any additional bureaucracy is proportionate
- any additional public expense is proportionate.

Key to any reform is effective linking of the registration systems of the HFEA and the three UK General Register Offices (GRO). Most radically this could be achieved by transferring the HFEA's responsibilities for keeping relevant Register information to the GRO – as occurred (temporarily) in Victoria where the ill-fated transfer of the Infertility Treatment Authority's Register to Births, Deaths and Marriages has recently been reversed.

If separate HFEA and GRO registration systems were retained, it should be possible to institute effective collaboration to enable links to be made between GRO records and the HFEA Register of Information. Below, we set out one possible model, building on previous proposals advanced by Blyth *et al.* (2009), PROGAR (2012) and the Birth Registration Campaign (2013).

- Whenever the HFEA is notified of a donor-conceived birth (including where surrogacy arrangements were involved) either by a parent or by a treating clinic, this information is provided to the GRO.
- The GRO notes a link between its own birth registration and HFEA records and informs the parent(s) (here we mean those raising the child or who subsequently become the legal parents) in writing that this is in place.

- The format of all birth certificates regardless of whether or not the individual is donor-conceived or born following a surrogacy arrangement, is annotated to make clear that it is a certificate of legal parentage only and that further information may be available about genetic and gestational parentage (we explain this in more detail below). The exact details to be included on such a certificate will require further debate.
- When an application is made to the GRO either for a birth record or to see if any additional information is available and the GRO is satisfied that the applicant is the individual to whom the information relates or his or her legal parent – and those persons only – the GRO will indicate to the applicant that the HFEA has information regarding the conception.
- If the individual then chooses to contact the HFEA, the measures that exist with regard to applications to the HFEA Register will come into operation (i.e. age limits relating to information disclosure and the provision of counselling).
- Arrangements for releasing information to anyone with a Parental Order in place continue as now.

The provision of information and advice concerning birth registration to persons undergoing a donor or surrogacy procedure would become mandatory as part of the responsibilities of licensed treatment centres and specified as such in the HFEA *Code of Practice*.

The situation is undoubtedly more complex where donor-assisted treatment services have been provided overseas or through informal arrangements in the UK or overseas. Further discussion is required about the feasibility of linking GRO systems to overseas systems where they exist. For intended/commissioning parents in surrogacy arrangements there could be a requirement to supply such information as is available to them as part of a Parental Order application. There could also be the facility for anyone who has used either informal arrangements or overseas treatment to voluntarily submit the information that they hold to the GRO.

Privacy concerns can be addressed by recognizing that the ‘background’ information of those born following third party assisted conception merits ‘special treatment’ by not being accessible to public inspection or search. There is precedent here through restrictions on public access to the Parental Order Register (for births resulting from a surrogacy arrangement), the Adopted Children Register, the Stillbirth Register and the Gender Recognition Register. We suggest that there should be informed debate as to whether any restrictions should be lifted following the person’s death, for example to enable those wishing to identify genetic as well as legal forebears or for other historical research purposes.

Finally, and importantly, we suggest that there are no good reasons for retaining the current ‘short’ and ‘long’ birth certificates to which all UK citizens are entitled – and perhaps not even the current Parental Order and Adoption certificates. One certificate – called a

certificate of legal parentage or similar – could be introduced for all official purposes which shows the date on which it is issued (storing the original certificate in the case of adoption, surrogacy and so on). This should include a statement that it is a record of legal parentage only and that information about any additional records concerning genetic and/or gestational parentage will be provided on request. The GRO would then be required to inform any enquirers as to where any additional information is available and either supply it or signpost to the relevant agency, whichever applies. They would need to make clear that: (i) where surrogacy was involved then a gamete donor may also have been used; and (ii) that where the enquirer had been born overseas or through informal arrangements then information may be lacking. The GRO should also advise enquirers not to assume their legal parents are their genetic or gestational parents if additional information is not available.

Annotation of the birth certificate itself to make explicit donor conception provides the most direct form of certification for donor-conceived people. However, given the wide-ranging purposes for which a birth certificate is used and the range of individuals and organisations requesting sight of one for identification purposes, such an overt disclosure poses privacy risks to both donor-conceived people and to their parents. This further strengthens the argument for the introduction of a certificate of legal parentage for all citizens, including not only donor-conceived people but also those who are adopted and surrogate-born.

Annotation of the birth certificate itself may also prove self-defeating if it led to reduced levels of disclosure by recipient parents or increased their recourse to services overseas in order to avoid using this system (Blyth *et al.*, 2009). Further research and debate is needed to consider how great a risk this may be. However, we are not persuaded by opposition to reform on the grounds that the decision for disclosure should remain a private family matter – in other words parental discretion – and that the State therefore carries no responsibilities beyond allowing access to the HFEA Register (Nuffield, 2013).

In summary, we believe that this proposal should receive detailed consideration. It safeguards privacy rights so that no-one other than the donor-conceived person or his or her legal parents will be able to access information disclosing the donor-conceived person's status. It would not establish any provisions that are different from current provisions for public access to birth records that would alert an enquirer who is not the donor-conceived person him/herself to the possibility of donor-conception and avoids setting up a completely separate registration system. It does involve additional resources insofar as the GRO and the HFEA will have to establish systems for the recording of this new information. However, the limited numbers of individuals involved indicate that any such resource requirements are proportionate.

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