

Voluntary Contact Register

Strategic delivery: Safe, ethical, effective treatment Consistent outcomes and support Improving standards through intelligence

Details:

Meeting	Authority
Agenda item	9
Paper number	HFEA (27/06/18) 886
Meeting date	27 June 2018
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Output:

For information or decision?	For information
Recommendation	<p>The Authority is asked to note:</p> <ul style="list-style-type: none"> the update on progress made to establish a new Voluntary Contact Register service the update on consultation, engagement and dialogue with stakeholders, including DCR the proposed timeline for the implementation of the new service how performance of the new service will be reviewed and monitored
Resource implications	Within budget
Implementation date	To be agreed following consultation
Communication(s)	As required
Organisational risk	<input type="checkbox"/> Low <input checked="" type="checkbox"/> Medium <input type="checkbox"/> High

1. Introduction

- 1.1. Donor Conceived people are important to the HFEA. This paper provides a progress update on ongoing work to develop a new vision and approach for the voluntary contact register, known as the Donor Conceived Register (DCR).
- 1.2. Following a review of options, we are seeking to implement a stable, long term and high-quality service, with funding guaranteed for a period of five years, developing this in partnership with the DCR, with the major components of the service delivered by sector leading specialists.
- 1.3. Significant progress has been made in developing the new service and this paper signals the vision and direction of travel as agreed to date. It is expected that this work will be finalised over the coming months, and the new service will be in operation later in 2018.

2. Background

- 2.1. The DCR enables people conceived through donated sperm or eggs, their donors and siblings to identify each other through DNA matching. Where they wish, they are able to use the register to contact each other. The register is intended for use for anyone who donated or who was conceived before August 1991 (i.e. before the HFEA was established). The DCR also includes a small number of people conceived after August 1991 who may have siblings on the register. Around 400 people are registered on the DCR, an on-line forum exists via social media and members are invited to meet around twice a year (in practice a meeting might typically involve 10-20 people).
- 2.2. In April 2017, at the request of the Department of Health, responsibility for the DCR transferred from the DH to the HFEA. At that time the DCR was serviced by the National Gamete Donation Trust (NGDT) under a rolling 12 month contract, which is still in place.
- 2.3. The Authority last received an update on the DCR in May 2017. It was agreed that to ensure the service was high-quality and offered value for money, we should investigate retendering it. The clear priority was to maintain a high-quality service for donors and donor-conceived people and it was felt that this could be best achieved by contracting out the entire service to a suitable organisation. It was agreed that the HFEA should retain oversight of the service to ensure service users' needs are met. It was also agreed that a range of performance metrics and a formal feedback mechanism would be implemented for the new service.
- 2.4. We published a tender later in 2017 and we received just one bid in response. The single bid was from the current provider, the NGDT. However, their bid failed to meet our quality and price criteria and on that basis the contract was not awarded.
- 2.5. We have subsequently explored other options for delivery of the service in partnership with DCR and other stakeholders. This paper provides an outline of our thinking on the components of the service, how we expect they will be delivered and how we will support a smooth and seamless transition.

3. Service summary

- 3.1. The service comprises three main parts: a) administration, b) DNA testing and matching, and c) counselling.

3.2. Administration includes:

- Providing guidance and information to existing and new DCR members through a telephone advice line
- Managing the co-ordination of DNA tests with the agreed supplier
- Providing support and guidance to individuals before, during and after DNA testing
- Maintaining the register (in line with industry standards) and confirming register matches with individuals
- Processing the results of matching sensitively
- Funding the regular meetings of the DCR (see paragraph 2 above) and all other support it requires, such as raising awareness, publicity and supporting the website and Facebook group

3.3. DNA testing includes:

- DNA sampling to industry standards with appropriate accreditation, analysing against an appropriate quantity of polymorphic autosomal DNA markers, along with holding securely the DNA data associated with this
- Forwarding the results to the administration service with details of results so contact can be made with the registrant

3.4. Counselling includes:

- Counselling sessions to be provided, where necessary through the registration or linking process/mediation, to registrants. This will usually be via telephone

3.5. The service operates as follows:

- Registrant joins the DCR and requests the DNA test via the administrative support service. Advice and guidance is provided by the admin service, as is specialist counselling. The administrative support service is responsible for maintaining the register
- The DNA test takes place and the information is checked against the DC register – for example whether a link exists and the quality. The administration service then communicates the outcome, along with the options the registrant has for sharing contact details relating to the link(s). Counselling is offered throughout the process

4. Review of options and initial feedback

- 4.1.** We are committed to seeking a long term high quality service for donor conceived people and those who wish to join the DCR. In addition to this, we are seeking a service which is more efficient, as measured through a range of performance metrics which will be regularly monitored. We also wish to introduce further improvements, such as to the security of information held and clear protocols will exist relating to information access, transfer and governance. These will be regularly audited.
- 4.2.** It is acknowledged that there are very few providers with the specialised and detailed knowledge necessary to run this service.
- 4.3.** We have carefully considered several options; as follows:

Option 1	Re-engage the market	We considered retendering for the service . This option was discounted given our understanding of the availability of suitable providers along with the lack of interest we received when we tendered for the service in December 2017.
Option 2	Long term extension of the NGDT contract	We considered extending the NGDT contract . This option was discounted for several reasons which include; the score the bid received when evaluated and longevity / sustainability of the service. It is also unclear whether this service would meet the long-term requirements of registrants' from the DCR.
Option 3	Fully managed and run in-house	We considered fully managing and running the service in-house . This option was discounted because the HFEA is a regulator and we do not possess the specialist and detailed skills required for full running of this service in-house.
Option 4	New service delivered via sector / industry leading suppliers	We considered a new service funded by the HFEA and delivered via several sector / industry leading organisations , with oversight provided by the HFEA. This is the preferred option and further details are set out below.

- 4.4.** Following the options appraisal, we are seeking a new service to be provided by industry and sector leading suppliers. This approach has formed the basis for initial discussions with both providers and registrants' from the DCR.
- 4.1.** We are now at the stage where we can prepare for a wider consultation on an outline service model (see section 6 below). We recognise that discussions with proposed suppliers will evolve over the coming weeks. This paper focusses on the direction of travel and signals how we currently envisage core components of the service functioning in the future.
- 4.2.** To support a smooth and seamless transition we have agreed a four-month rolling contract with NGDT until we agree and formally approve the new service model. As outlined in the timeline below, we are proposing a soft-launch of the new service with a staged handover. We are also working closely with registrants' from the DCR to ensure the new service meets their requirements.

5. Progress and initial feedback

- 5.1.** We met with a group of DCR registrants' first on 14 April to gather feedback on how the service could operate in the future. We met again with largely the same group of people on 9 June to discuss our initial proposals and received further feedback.
- 5.2.** For the administration service, we approached the Donor Conception Network given their background in providing support to people involved in donor conception. The DCN have signalled their agreement in principle to providing this component of the service. This aspect of our proposal was not supported by members of the DCR present at the meeting on 9 June due to registrants' view that the DCN's principle focus is on parents rather than children. We understand that other registrants' have a different view. We propose to seek wider feedback on the merits of this aspect of our proposed model during consultation and to explore alternative providers as part of this work. We can revisit the DCN option in the light of these wider views.
- 5.3.** For the DNA service, we have approached two leading UK pathology laboratories and we feel this component of the service would be best delivered by one of them. We also believe that this will lead to improvements in terms of turnaround times (from 14 weeks to less than 3) and quality to be realised against the current service. This was well received by the registrants from the DCR and we are agreed in principle to move forward on that basis.
- 5.4.** At present, applicants are asked to make £100 contribution towards the cost of DNA testing. Those who are unable to pay (e.g. students, income support, financial hardship) the DNA testing is fully funded. We have decided to maintain this position in the new service.
- 5.5.** For the counselling service, we have approached PAC-UK, who we currently use to provide counselling for individuals using our Opening The Register (OTR) service. Our Register contains information about donors and treatments involving the use of donor gametes and embryos in the UK for those conceived after August 1991 and our OTR service enables donor-conceived individuals, donors and parents to access the information we hold. Our proposal is that the current counselling contract is extended to include the counselling service for DCR registrants. We recognise a degree of training will be necessary. PAC-UK have signalled they agree in principle to providing this component of the service. This was well received by registrants from the DCR and we are agreed in principle to move forward on that basis.

6. Timeline

Date	Summary	Details
16 July 2018	Consultation starts	Updated proposal issued to DCR registrants' and other interested stakeholders.
31 August 2018	Consultation closes	This allows for a comprehensive review by all stakeholders over a seven week period.
1 – 14 September 2018	Review of feedback	Review of consultation feedback by HFEA
Week commencing 17	Discussions with Chair of DCR and communication of	Should the preferred model be agreed, the NGDT contract will run to allow a smooth transition - expected to be a further 4-5 months, to end-January

September 2018	preferred model to stakeholders DCR registrants meeting	19 allowing a smooth and managed handover. Transition progress will be closely monitored. DCR registrants meeting during September to review progress and provide feedback. HFEA decision on new model will be taken in the light of this meeting.
October / November 2018	New service start date – soft launch including parallel running	Start date for new service including detailed handover from NGDT during this period.
February 2019	Initial review	Review of transition and service evaluation of all aspects of new service between HFEA and DCR
April 2019 and onwards	Ongoing review	Regular measurement and reporting of all aspects of the new service through KPIs and appropriate performance reviews involving the DCR

7. Next steps

- 7.1.** It is recommended that a new service is commissioned as outlined above, overseen and fully funded by the HFEA, and delivered by sector leading specialists. This will allow a stable future for the DCR for at least the next five years. It brings together experts delivering a seamless and professional service to registrants.
- 7.2.** During July and August 2018, we will continue to have collaborative conversations with DCR and others about the likely final design of the service to include the administration service, the DNA testing service and the counselling service.
- 7.3.** It is proposed that following a period of consultation, the new service commences during October / November 2018 with a period of transition where the new service runs alongside the existing service provided by NGDT – this approach will ensure a smooth handover and transition. The launch date will be agreed in due course.

8. Recommendations

- 8.1.** The Authority is asked to note:
- The update on progress made to establish a new Voluntary Contact Register service
 - The update on consultation, engagement and dialogue with stakeholders, including DCR
 - The proposed timeline for the implementation of the new service
 - How performance of the new service will be reviewed and monitored.