

# Strategy 2017-20

**Strategic delivery:**       Setting standards       Increasing and informing choice       Demonstrating efficiency economy and value

## Details:

Meeting                      Authority

Agenda item                7

Paper number              HFEA (11/05/2016) 794

Meeting date                11 May 2016

Author                        Juliet Tizzard, Director of Strategy and Corporate Affairs  
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## Output:

For information or decision?              For decision

Recommendation

Resource implications

Implementation date        1 April 2017

Communication(s)

Organisational risk         Low                               Medium                               High

Annexes

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## 1. Background

- 1.1. Our strategy has been very successful for the HFEA. With the simple and compelling vision of 'high quality care for everyone affected by assisted reproduction', it has focused our minds on that one important goal. Our board, our senior leadership team and our staff have that vision uppermost in their minds when designing services, planning work and carrying out everyday regulatory activities. Our stakeholders, too, understand and support our strategy and rightly hold us to account against its vision and ambitions.
- 1.2. The strategy runs until July 2017 and much of it is already achieved. And the more ambitious service changes, encompassed in Information for Quality, will be completed by the end of this calendar year. Now is the time to think about our next strategy, one which will lead us through to the next general election in 2020.
- 1.3. This paper is designed to prompt an early conversation amongst Authority members about our next strategy, which we would like to launch in April 2017.

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## 2. How have we done so far?

- 2.1. Our ambition in developing our strategy was that a high quality of care for donors, patients and their future children should be central to how we see our role and what we do. Of course IVF services should be safe, lawful and reflect good practice, but clinics must also make the experience of treatment a good one. Patients should feel well prepared, treated with respect and supported throughout and beyond treatment.
- 2.2. Information for Quality is central to that ambition. With slick, efficient systems for engaging with us which play back valuable performance information, clinics can improve their services and spend more time with patients. With clear, helpful information and a balanced assessment of quality in clinics, patients and donors can feel better prepared for treatment and more confident about the decisions they need to make.
- 2.3. We have made great headway in these areas. In summary, we have so far achieved:
  - A great deal of progress through the IfQ programme, towards:
    - Patient ratings through the new, improved, CaFC
    - User research to identify what quality means to patients
    - Publishing more data to encourage better outcomes
    - Wider range of information for patients on the new website
    - Publishing donor gamete availability information on CaFC
  - Regular publication of reports on clinical incidents and fertility trends

- Range of actions to encourage highest possible success rates, including better outcome data presentation and tools to allow clinics to benchmark their performance
- Lifecycle leaflets for donors and recipients
- Information about treatment abroad and unregulated sperm donation
- Best practice guide for clinics about handling donor information
- Introduction of the counselling service pilot
- Savings and efficiencies gained by developing shared services and service level agreements with other ALBs
- HFEA participation in the 'one stop shop' for life sciences, launched in 2014.

**2.4.** In some areas we have more progress to make in:

- addressing the support gap for patients whose treatment has been unsuccessful
- ensuring that clinics fully prepare and support patients and donors, and that they appreciate the importance of their lifelong role as an information provider
- pursuing further work with NHS Commissioners to improve the commissioning of IVF services
- realising the benefits of IfQ, including an improved data submission and verification experience for clinics, more accurate data being submitted to the Register, and efficiency gains for clinics (reduced transactional costs) and for ourselves.

**2.5.** The wider environment in which we work (our sector, society, patient's expectations, political drivers, and so on) is ever changing. When we think about our future strategy, we will need to look outwards and into the future, as well as picking up any pieces of work we would like to conclude, or re-define, based on progress with our strategy. We will need to continue to be an open organisation, and one that constantly seeks improvements and efficiencies and ensures it continues to be an effective and modern regulator.

**2.6.** The focus of our strategic activities is already shifting forward a gear in 2016/17. Having started work in earnest on IfQ in 2015/16, this year we will really see the results. This will change our internal landscape, and enable us to reap the benefits of a better website, better data and better information systems. The next strategy will be situated in a world where IfQ has happened.

**2.7.** What will we need to do next to achieve 'high quality care for everyone affected by assisted reproduction' by 2020?

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### 3. Our strategy to 2020

**3.1.** Set out below are some early thoughts about what our next strategy might focus on. This is not necessarily an exclusive list, but reflects some recent discussions and developing trends, and the increased quality of our information infrastructure and provision after IfQ.

**3.2.** High quality care will remain centre stage. For the next three years we will want to set out new ambitions to ensure that patients, whether treated privately or in the NHS, receive even better care. Some of the following areas of work are new, or emerging, while others would be the natural sequel to previous work.

#### Treatment add ons

**3.3.** One area of work that we have already started is treatment ‘add ons’ which have become a feature of many IVF services. Increasingly, patients are being offered a variety of treatments – including drug regimes, methods for culturing embryos and treatment procedures – with the claim that they improve the chances of a successful pregnancy. Some patient feedback indicates that many now see such treatments as an indicator of a good service. Yet the evidence base for many of these treatments is weak. Our new website will give information about these add ons and we are discussing collaborative work with the professional bodies and patient groups. How might we want to progress this work further in 2017-20?

#### Treatment costs

**3.4.** We are not an economic regulator, and have no direct levers to pull around the cost of treatment, but this is one of patients’ top concerns. Although our new website won’t list prices for each clinic, it will give patients information about the range of costs across UK clinics. It will also give patients a chance to give feedback on the patient ratings feature about whether they paid what the clinic estimated treatment would cost.

#### Capitalising on IfQ

**3.5.** The new clinic portal, website and Choose a Fertility Clinic will make a huge difference to patients and to clinics. For the first time patients will have a fully rounded picture of each clinic, making it much easier to make an informed decision. The new portal will make data submission for clinics much more straightforward, freeing up time to treat patients and reducing costs. It will also allow clinics to compare their performance against the national average and will, we hope, help drive an improvement in service quality over time.

**3.6.** But the launch of those services will be just the beginning. We will need to encourage and monitor use – and refine things over time in response to feedback. And we will need to see whether the changes we want to see happen are actually happening.

- 3.7.** We also want to use our improved data systems to assess practices in clinics or challenge treatments being offered or the basis on which they are being offered. We can use our data more effectively to provide more/better information on the website and clinic portal. Our data holds the potential to identify poor areas of sector/clinic performance, to create more empowered consumers, and to support innovation and research. And we want to ensure that data submitted by clinics really is more accurate and easier to submit.
- 3.8.** IfQ will also make a significant shift in greater transparency with easier access to inspection reports, new patient feedback mechanisms and other information on the new website and CaFC. We view transparency not as an end in itself but also as a driver of both patients' and professionals' behaviours, both of which are crucial to motivating higher quality care.

#### NHS commissioning

- 3.9.** NHS commissioning of IVF is patchy and a constant source of complaints from patients across England. The issue has four principal elements. There is a widespread mismatch between supply and demand such that patients find it difficult to access treatment. Access varies across the UK depending on the decisions of individual CCGs (with some withdrawing the service altogether). Many CCGs lack the information or knowledge to make well evidenced commissioning decisions. And there is no wider knowledge among CCGs of the right price to pay for these services. Access and geographical variability are an inevitable consequence of local commissioning but we can make progress on information and price, if there is the will to do so among the relevant organisations in the health system.

#### Technological developments

- 3.10.** Genetics and genomics are an area of focus for the Government and the Department of Health. Embryo testing technology and the associated genetics knowledge are developing at a fast pace which shows no signs of slowing. Tests are getting faster, cheaper and more accurate. Last year we approved more than 50 new conditions for PGD, about one a week. Most of the conditions are rare but the PGD tests offer hope, where there previously was none, that families can avoid passing on a serious inherited condition. We also expect more applications for research involving genome editing in the future and some are calling for a wider debate about the use of such techniques in treatment.
- 3.11.** This is clearly a growth area and will lead to an increase in the availability of and demand for these services, people's level of awareness and understanding of what is possible, and their knowledge about their own genetic make-up.

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## 4. Next steps

**4.1.** In developing our strategy for 2014-2017, we consulted widely and took our time. Because the strategy was such a step change for us and because the vision of high quality care for everyone affected by assisted reproduction is still central to our approach, we feel that more 'low-key' consultation on the strategy to 2020 will be sufficient. We will use existing stakeholder groups and forums and we may focus on particular narrow areas with different stakeholder groups, rather than engage all of them with the whole document.

**4.2.** A rough timetable might be:

May 2016	Early discussion with Authority members and staff
June 2016	Draft strategy themes and activities
July 2016	Authority workshop to discuss
August 2016	CMG item to coincide with business planning for 2017/18
September 2016	Authority agree draft strategy
October 2016	Engagement with stakeholders, staff and wider?
November 2016	Authority workshop on early engagement feedback
December 2016	Continued engagement/follow-up as needed
January 2017	Authority agree new strategy
March 2017	Annual conference launch
April 2017	Publication

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## 5. Recommendation

The Authority's views are sought on the ideas outlined in this paper. It is early days, and we would appreciate members' input in shaping this process, as well as thoughts about our future vision as we move towards the next strategic period.

# Information for Quality programme: update

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## Details:

Meeting	Authority
Agenda item	9
Paper number	HFEA (11/05/2016) 795
Meeting date	11 May 2016
Author	Nick Jones, Director of Compliance and Information

## Output:

For information or decision?	For information
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Recommendation	<p>The Authority is asked to note:</p> <ul style="list-style-type: none"> <li>• The forthcoming approvals processes to proceed to 'public beta' phase and later to 'live'</li> <li>• Progress since the HFEA annual conference</li> <li>• Data migration and cleansing</li> <li>• Programme timelines and budget.</li> </ul>
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Resource implications	Nil, albeit a larger than anticipated budget carry-over to 2016/17
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Implementation date	During 2016–17 business year
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Communication(s)	Regular, range of mechanisms
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Organisational risk	<input type="checkbox"/> Low <input type="checkbox"/> Medium <input checked="" type="checkbox"/> High
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Annexes