

Beyond fertility trends: the role of intelligence

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

Details:

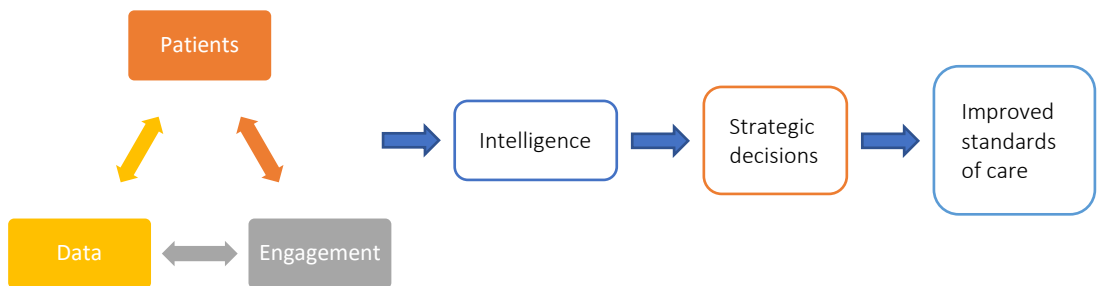
Meeting	Authority
Agenda item	10
Paper number	HFEA (14/03/2018) 874
Meeting date	14 March 2018
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Output:

For information or decision?	For information
Recommendation	The Authority is asked to: <ul style="list-style-type: none"> Note the key outcomes of the fertility trends 2018 report Comment on possible future areas of work to explore
Resource implications	None
Implementation date	Ongoing
Communication(s)	Full press and stakeholder communication plan for Fertility Trends report
Organisational risk	<input type="checkbox"/> Low <input checked="" type="checkbox"/> Medium <input type="checkbox"/> High
Annexes	None

1. Our intelligence strategy

- 1.1. Our intelligence strategy, approved by Authority on 24 January 2018, set us on a trajectory to ensure that our information is used to inform strategic decisions which result in improved standards of care.
- 1.2. The January Authority paper focused on the patient-led proposals, whereas this paper focuses on the way we will utilise our Register and other information to improve standards.
- 1.3. Using multiple sources of data, intelligence enables the discovery of new relationships and exploration of new possibilities. This new knowledge will, in turn, help us to use the wealth of information that we hold to improve standards of care. The 'standards of care' we aim to improve relate to the complete breadth of technological advances, public health research, patient care, birth rates, and many others.



- 1.4. We have done work like this in the past. Our 'Fertility Treatment in 2014-2016, Trends and Figures' report is an example of the mechanism we have previously used to assess our outcomes, and how we perform as a sector each year.
- 1.5. This paper aims to take this report one step further, commenting on both our current outcomes and performance, and indicating areas that intelligence could identify for future work.

2. Fertility trends

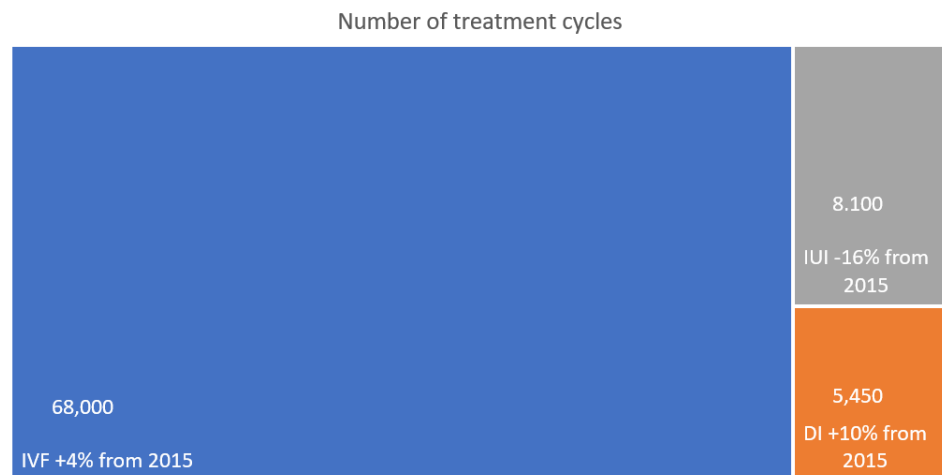
Learning from feedback

- 2.1. Our 'Fertility Treatment in 2014-2016, Trends and Figures' report launched today provides information on birth outcomes for 2014, 2015 and 2016. We have expanded the scope of the report to:
 - Make a greater range of statistics (including surrogacy and IUI data for the first time) available in as much detail as is reliable and practicable
 - Make more current statistics available to inform patients

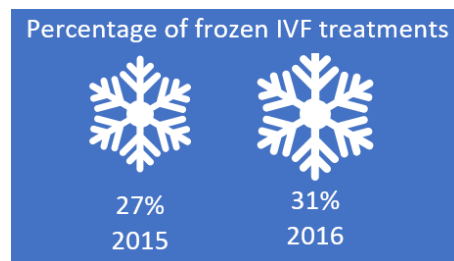
- Provide more commentary and analysis that aids interpretation – particularly with regards to our new definitions (such as per embryo transfer)
- Provide additional detail on outcomes by couple status (in response to frequent PQs on this topic)
- Provide IVF treatment rates for all combinations of donor/own egg, donor/partner sperm and fresh/frozen treatment cycles (in response to patient feedback saying they would like more specific categories)
- Ensure more information about the data we collect is available on our website (in response to feedback from researchers)

What have we learned: key statistics?

2.2. In 2016, there were a total number of 81,550 treatment cycles, the majority of which were IVF.

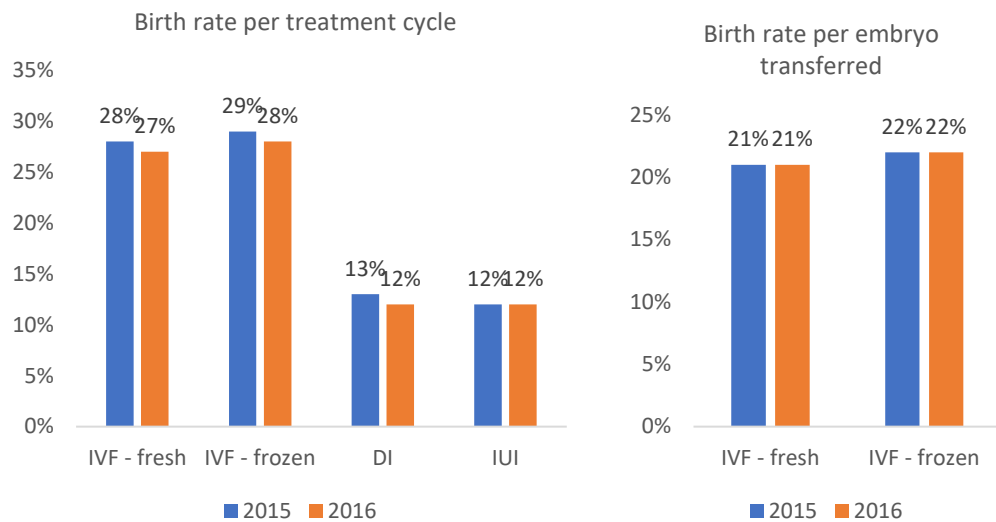


2.3. The proportion of IVF treatments that used frozen embryos increased to 31% of all IVF treatment cycles in 2016.



2.4. Frozen embryo transfer birth rates were above fresh IVF birth rates for the first time in 2015.

2.5. Birth rates for all treatment types remained broadly the same between 2015 and 2016.



Identifying future strategic priorities

- 2.6.** Reports show us what has happened so far and what the current performance is. Intelligence can show us why things happened, identify future areas of work, and adapt our strategic and policy responses to deliver the changes we want to see.
- 2.7.** The remainder of this paper highlights areas of work that could be explored to identify changes in the way that we respond to developments in the sector and to drive improvements in standards. This is not the time for a detailed discussion of the issues raised but any comments at this stage would be useful in helping us to prioritise next steps.

The typical fertility patient

- 2.8.** Our data shows that a significant majority of fertility patients are women with a male partner, undertaking IVF using their own eggs and partner sperm (OEPS). This demographic makes up 88% of around 68,000 IVF treatment cycles. The next most common treatment after OEPS IVF, is IUI at around 8,100 treatments a year. It is important to maintain this context in discussions of more specialist treatments such as egg freezing and PGD which have treatment numbers around 1,170 and 700 cycles respectively.
- 2.9.** Given the bulk of our patient cohort undertake standard IVF using OEPS, we might want to assess whether our policy and communications focus sufficiently on these fertility service users, as well as those who often receive more media coverage, e.g. surrogates, lesbian couples, transgender patients and where policy and practice may be more complex.

Multiple birth rate and frozen embryo transfer

- 2.10.** In 2008 around one in four IVF births were multiples compared to about 2% from natural conception. Over the last decade, we have worked with the sector to reduce the multiple birth rate with the goal of reaching 10%.

- 2.11.** The multiple birth rate has decreased substantially since 2008 for both fresh and frozen cycles, with no reduction in the pregnancy rate. In 2016, 11% of births from IVF treatment cycles were multiple births, down from 13% in 2015.
- 2.12.** Given the continuous downwards trends, it seems sensible to predict that the 10% target will be met in 2017 or 2018. The data prompts us to consider the policy implications for what to do when the target is met; whether we would want to introduce a lower target, or whether we are happy that the 10% goal is the signal that sufficient progress has been made¹. We might also explore further how the frozen outcome data impacts upon the ambition of any future target we set

Egg freezing

- 2.13.** We know more women are freezing their eggs and more women are using previously frozen eggs in treatment, even though overall numbers are still relatively small. Success rates are also improving and, given the public interest in egg freezing, this is valuable information for the public and patients.
- 2.14.** Furthermore, now that there are more patients undertaking egg freezing cycles and using frozen eggs in treatment, it will be possible to begin robust analysis of which factors may influence success rates. Our upcoming egg freezing report (due Spring 2018) will explore these questions in more detail to help inform patients, the public and clinics.
- 2.15.** The emergence of changing messages from the outcome data prompts us to consider reviewing our processes for how we communicate key changes and emerging evidence in developing areas of fertility treatment across our stakeholders.

Success rates for older women

- 2.16.** Currently, NICE recommendations for IVF funding distinguish between women aged up to the age of 40, who are recommended to receive three full cycles of IVF, and women aged 40-42 who are recommended one.² The NICE guidance states this is because “age was found to be the only robust factor in determining IVF success”.
- 2.17.** We know this to be true for older patients using their own eggs. However, when looking at patients using just donor eggs our data demonstrates that age does not influence success rates. This may have implications for funding recommendations or the information we provide to patients around success.
- 2.18.** This prompts us to consider reviewing our processes for how we communicate these significantly different outcomes with all stakeholders, and to explore if we have any responsibility to encourage this emerging evidence to be reflected in

¹ The lowest multiple birth rate in Europe can be found in Sweden at 4.9%:
<https://academic.oup.com/humrep/article/31/2/233/2380245>

² In England individual Clinical Commissioning Groups may then introduce their own eligibility criteria

national commissioning guidance and decisions in which, where donor eggs are used, there is minimal evidence to suggest older women should be denied access to treatment.

NHS funding

- 2.19.** Although regulation of fertility services is UK-wide, commissioning is devolved to the national level. The trend over the past few years has seen a divergence in commissioning policy across the four nations of the UK. Although the picture in Scotland has improved markedly in recent years, many English Clinical Commissioning Groups (CCGs) have reduced their fertility service over the same period. Given the fact the England accounts for the bulk of the UK population, we might expect this to come through in UK-wide trends, however in 2016 41% of IVF treatments were funded by the NHS, a figure which has remained broadly stable since around 2010.
- 2.20.** The obvious explanation for this apparent contradiction is a delay in the impact of commissioning decisions filtering through to the experience of patients. It may therefore be worth exploring the funding data further to help patients and the public better understand the current picture.

3. Intelligence driving our future analysis

- 3.1.** We have developed a timeframe for future reports utilising our intelligence of the types of issues raised through enquiries, PQs, FOIs, and engagement with patients. We have profiled the reports and analysis taking into account both the level of interest and current resource expended on ad-hoc analysis with the resource needed to develop a more thorough publication.

Strategic review of outcomes

- 3.2.** We recognise that our inspection team have significant expertise in making decisions that drive standards at a local (clinic) level, however, in today's complex operating environment, making sound strategic decisions is more important – and more difficult – than ever, if we aim to account for the full range of demographic, regulatory, market and other factors, and to do this fast enough so there is still time to act.
- 3.3.** The intelligence strategy included an aim to deliver a regular review of enquiries, complaints, FOIs, PQs, incidents, inspection reports, and other qualitative feedback alongside key indicators. This would be used for a sector-level review of outcomes.
- 3.4.** This offers a 'big picture' review of our information to create a solid basis for analysing potential strategic options and guiding effective action across policy, compliance, licensing and communications. We will do this by synthesising information from a wide range of sources to identify the key factors and interactions affecting performance from across the organisation. Importantly, we plan to combine readily captured metrics and quantitative data with softer, more

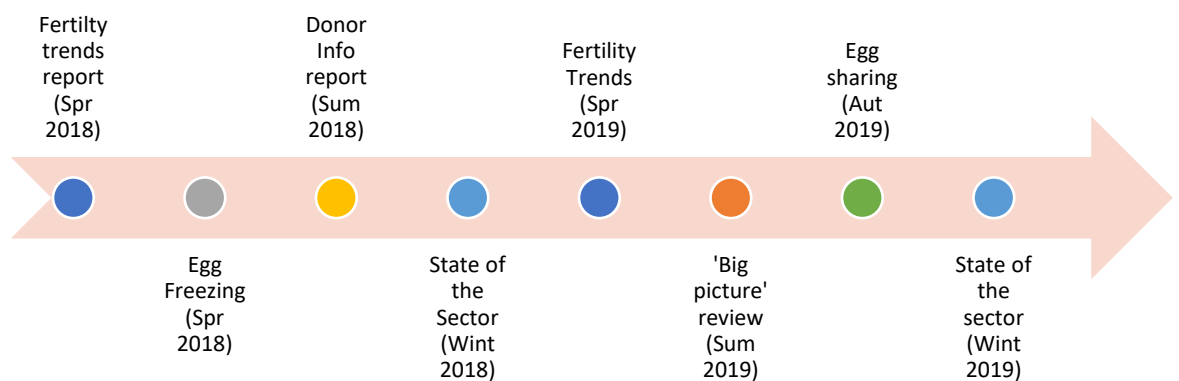
qualitative information (patient feedback, enquiries, research) that is typically excluded from other analyses.

3.5. This will make it possible to explain the forces driving performance, understand how our current performance was established, and to explore what policies and actions will increase standards in the future.

3.6. We can also use this knowledge to review and build on the early intervention approaches we have developed, such as using the risk tool to provide early warning alerts where performance drops below the expected level. This will enable us to gain the best value from our information on an ongoing basis.

Future reporting timeframe

3.7. Our proposed analysis and reporting timeline to the end of the 2019/20 strategy:



4. Recommendation

4.1. The Authority is asked to:

- Note the key outcomes of the fertility trends 2018 report
- Comment on possible future areas of work to explore