Using HFEA data effectively to benefit the sector and patients

Annual conference 2018 workshop

Chair: Margaret Gilmore

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Fertility treatment 2014-2016: trends and figures

Past, present and future reporting to benefit the sector and patients

Lisa Whiting
Data and Insights Analyst
15 March 2018
Shifting resource to impact

Impact
Strategy
Analysis
Reports
Data

Impact
Strategy
Analysis
Reports
Data

Resources

Human Fertilisation & Embryology Authority
State of the fertility sector

- 74% of clinics have a five star inspection rating and all 21 research licences show the highest level of performance.
- 86% of clinics met (or were soon to meet) the 10% multiple births target.
- There had been an increase in Grace C incidents from 2015 to 2016, and a decrease in Grade B incidents.
- In 2016 there were:
  - 325 grade C incidents
  - 176 grade B incidents
  - 1 grade A incident.
Fertility treatment 2014-2016

• published on 14 March 2018
• treatment cycles from 2014, 2015 and 2016
• new sections on IUI and surrogacy
• IVF by egg and sperm source
• expanded data on PGD and egg freezing
• more accessible and detailed underlying data tables
• for patients, clinicians, researchers, and the public.
Treatment numbers

- IVF +4% from 2015
- Egg share Surrogacy Egg freeze Egg thaw PGD
  - 2014
  - 2016

- Total
- Fresh
- Frozen

Human Fertilisation & Embryology Authority
In 2016, the IVF birth rate PET was 22% for frozen, and 21% for fresh.

Frozen birth rates overtook fresh for the first time in 2015.

The egg thaw birth rate has increased from 14% PET in 2014, to 19% PET in 2016.

In 2016, the egg thaw birth PET was only 2% below IVF overall.
Future reporting

Fertility trends (Spring 2018)
Donor information (Summer 2018)
Fertility trends (Spring 2019)
Egg sharing (Autumn 2019)

Egg freezing (Spring 2018)
State of the sector (Winter 2018)
'Big picture' review (Summer 2019)
State of the sector (Winter 2019)
Questions to consider

• How can we ensure the data and information we publish is useful for clinics and patients?
• How can we use data to drive improvements in the sector?
• What has been most useful in reports published to date?

Please feel free to email us at intelligenceteam@hfea.gov.uk or chat to us throughout the day.
Why do we need to use our data effectively?

Jessica Hepburn

15 March 2018

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Using data effectively: A case study of egg freezing

HFEA Annual Conference
15 March 2018, London

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Chair’s Foreword

“This year we have published figures on the emerging area of egg freezing for the first time. Freezing techniques are relatively new, and were very rare only five or six years ago. Interest from patients and the media has grown considerably in recent years, however, and we felt it was time to provide more clarity.”

Sally Cheshire

Two main questions:
1. How many patients are storing their eggs?
2. How many patients are thawing eggs for treatment?
In 2014, 816 women started treatment aiming to freeze their own eggs for future treatment.

Reasons for freezing are not recorded in great detail but include women who:

- Have a condition or are facing medical treatment for a condition that may affect their fertility (e.g. chemotherapy for cancer)
- Are concerned about age-related fertility decline but not currently in a position to have a child
- Are at risk of injury or death (e.g. Armed Forces deployment)
- Are about to undergo gender reassignment
Figures are presented in two age groups: 37 years and under and 38 and over.

Two-thirds of the women freezing eggs are 37 and younger, and a third are 38 and older.

54.1% of 38< group and 36.4% of <37 group recorded “no male partner” as reason for freezing eggs. What were the other reasons?

“In both groups, the second most common reason was ‘other’. Further given reasons are unexplained infertility and low sperm count.”
So, we decided to look at our figures at the LWC

The HFEA reported that 65 clinics had frozen and stored eggs in 2014, but eight clinics performed half of the cycles.

Compared to the 816 women who started treatment nationally in 2014, at the LWC we had 71 women starting 91 cycles of treatment.

This suggests that the LWC has a very large proportion of egg freezing, and thus makes our data quite significant.

We created a database and performed a 5-year analysis on all 514 cycles of own egg freezing treatments undertaken by 342 women at the LWC between 2012-2017.
What did we find out?

1. There were four distinct categories of egg freezers among our patients, and each category had a very distinct average patient profile.
What did we find out?

- **Social Egg Freezers**
  - Single, 37.4 years old. 1 cycle of egg freezing, 7 eggs frozen. Eggs still in storage.

- **Medical Egg Freezers**
  - Single, 27.3 years old. 1 cycle of egg freezing, 11 eggs frozen. Eggs will be in storage for considerable time.

- **Clinical Egg Freezers**
  - In a heterosexual relationship, 39.2 years old. At least 2 cycles, 4 or 5 eggs frozen per cycle. Large proportion of eggs thawed for treatment.

- **Incidental Egg Freezers**
  - In a heterosexual relationship, 35.5 years old. 1 (unintended) cycle of egg freezing, 9 eggs frozen. Eggs thawed for treatment if sperm was subsequently available.

4.3% IEF
100% All Egg Freezers
Average age 37.5; undertaken 1.5 cycles of egg freezing; frozen 7 eggs per cycle

- **75.7% SEF**
  - Single, 37.4 years old. 1 cycle of egg freezing, 7 eggs frozen. Eggs still in storage.

- **2.1% MEF**
  - Single, 27.3 years old. 1 cycle of egg freezing, 11 eggs frozen. Eggs will be in storage for considerable time.

- **17.9% CEF**
  - In a heterosexual relationship, 39.2 years old. At least 2 cycles, 4 or 5 eggs frozen per cycle. Large proportion of eggs thawed for treatment.

- **4.3% IEF**
  - In a heterosexual relationship, 35.5 years old. 1 (unintended) cycle of egg freezing, 9 eggs frozen. Eggs thawed for treatment if sperm subsequently available.
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1. There were four distinct categories of egg freezers among our patients, and each category had a very distinct average patient profile.

2. Women freezing their eggs for social reasons were the largest category, but there were also a significant number of Clinical Egg Freezers, as well as smaller numbers of patients who were freezing eggs incidentally (for unexpected reasons), or for medical reasons.
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3. These different categories of egg freezing became particularly significant when we looked at the thaw data.
“Of the thawed egg cycles performed, well over half used eggs which had been frozen for less than a year. These are unlikely to be those of women freezing in order to preserve their fertility in the longer term, but maybe those that had to put their treatment on hold for unexpected reasons, for instance, if donor or partner sperm was not available at the right time.”
Eggs frozen at the LWC

- In Storage: 386 (271) - 75.1%
- Thawed: 114 (60) - 22.2%
- Moved: 9 (7) - 1.8%
- Discarded: 5 (4) - 1.0%

SEF Cycles: 361 (93.5%)
MEF Cycles: 10 (2.6%)
CEF Cycles: 83 (72.8%)
IEF Cycles: 8 (2.1%)

SEF Cycles: 17 (14.9%)
MEF Cycles: 0 (0%)
CEF Cycles: 83 (72.8%)
IEF Cycles: 14 (12.3%)
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4. Most “social freezers” still have their eggs in storage, and the great majority of thaw cycles are undertaken by women who frozen their eggs not for social, but for clinical or unexpected reasons. Thus, to date, the majority of children born from frozen eggs, are not actually born to women intentionally “postponing” motherhood via egg freezing.
It is very important to...

• Ask the right questions of the data – particularly when trying to understand a newly-emerging and fast-developing phenomenon.

• Think critically about what the data may cover or obscure, as well as what they reveal.

• Record as much relevant detail as possible at the stage of data collection (both by clinics and by the HFEA), so that a variety of questions may be asked (and answered!) in the future.

• Include social scientists in the conversation about clinical and regulatory practice!
THANK YOU

Research performed in collaboration with:
Trina Shah, Jinjun Wang and Dr Kamal Ahuja at the London Women’s Clinic
and Professor Susan Golombok at Centre for Family Research, University of Cambridge
Questions and discussion