

Using data – The UK Experience: Disadvantages / Advantages



Belgium Society of Reproductive medicine

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Summary

The Human Fertilisation and Embryology Authority

- Our regulatory remit

The HFEA Register

- What we collect and why
- How we use the data

Using UK Register data (developing CAFC)...

- ...as a reliable source of information for patients
- ...to help patients make informed decisions

Appraisal of UK system

- Disadvantages / Advantages



Human Fertilisation & Embryology Authority

Human Fertilisation and Embryology Authority (HFEA)

- UK independent regulator responsible for licensing UK fertility treatment centres and research using human embryos
- Formed in 1991 following the introduction of the Human Fertilisation and Embryology Act 1990
- UK fertility clinics **required by law** to submit data about fertility treatment to the HFEA

HFEA Register



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How the HFEA makes Register data available

- Data and research publications, which include underlying datasets
- Publicly available anonymised register (cycle-level data)
- Enquiries or Freedom of Information requests
- Research applications for patient identifiable data or de-personalised datasets
- Choose a Fertility Clinic

Publications: <https://www.hfea.gov.uk/about-us/publications/research-and-data/>

Anonymised register: <https://www.hfea.gov.uk/about-us/our-data/guide-to-the-anonymised-register/>

Choose a fertility clinic: <https://www.hfea.gov.uk/choose-a-clinic/>



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Sector Oversight



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Data and research publications

- Use register data to analyse trends in fertility treatment use or to investigate specific topics
- Published for lay audience accessibility (patients, clinicians, researchers and general public)
- Gain wide media coverage in the UK and some internationally
- Publish flagship publication '**Fertility treatment: trends and figures**' annually in May/June
- Other recent publications: '**State of the Sector 23/24**', '**Ethnic Diversity in Fertility Treatment 21**'



Dashboard instructional video

HFEA dashboard Instructional video



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All cycles



[Return to menu](#)



Human
Fertilisation &
Embryology
Authority

Please filter:

[Reset filters](#)

Cycle type
All

Patient age
All

Funding
All

Partner type
All

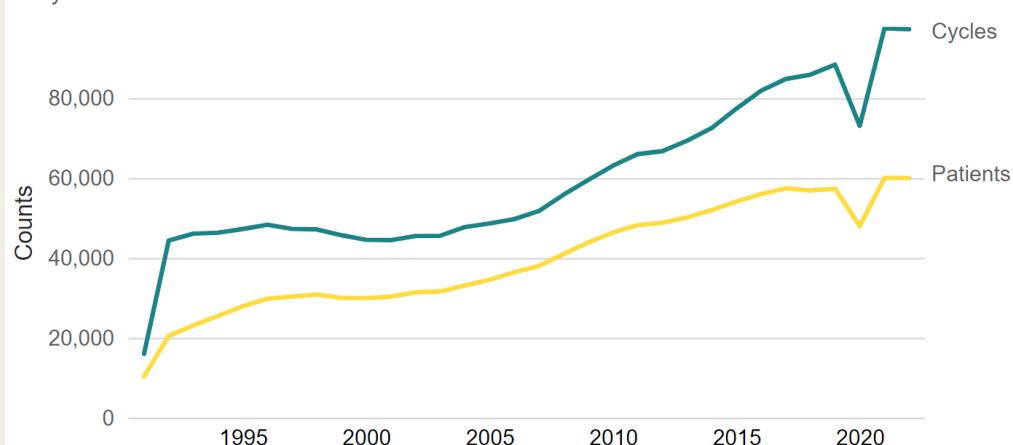
Patient ethnicity
All

Year
1991 2022

[Return to menu](#)

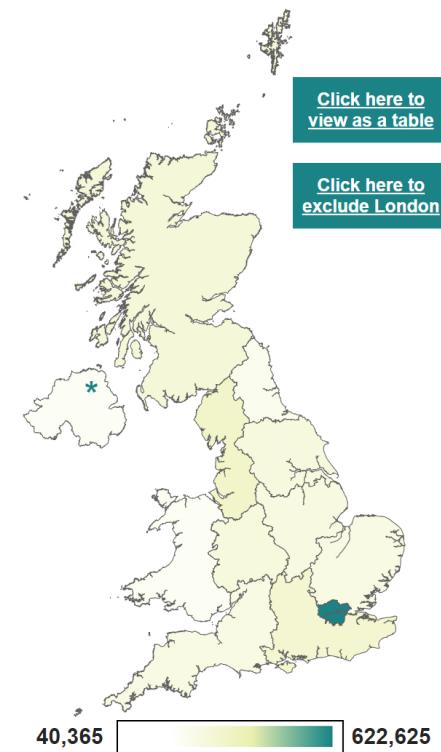
Cycles and patients by year

● Cycles ● Patients



[Click here to view as a table](#)

Cycles by clinic nation and region



1,905,500

Total cycles between 1991
and 2022

693,965

Total patients between 1991
and 2022



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Using UK Register data to help patients make informed decisions



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Releasing clinic level data

- HFEA started to release clinic level data from mid 90s (through a document called 'The Patient's Guide')
- Paper guide, success rates per cycle, easily presented as a league table
- Criticism and push back from the sector
- Early searchable clinic function 2009
- Detailed information, including inspections details, patient feedback and move towards success rate headline per embryo transferred with underlying detailed stats

Developing Choose a fertility Clinic

Autumn 2014:
Information for Quality consultation

Feb/March 2017:
'Live' version of CaFC tested and launched

Annual refresh until new register data migration 2021:

Today:
Awaiting refresh



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Choose a fertility clinic

Ready?

Use our Choose a Fertility Clinic service to find the clinic that's right for you. If you're an NHS patient, use it to research the clinic you'll be having treatment at.

Choose a Fertility Clinic is the only tool that publishes comparable information about all fertility clinics in the UK. That's because we collect data from clinics about all the treatments they carry out. And we inspect each clinic at least every two years to check their standards.

Choose a Fertility Clinic

Data we publish

We collect data from fertility clinics and publish much of it on our website, including individual clinic success rates.

Individual clinic rates can't tell you how likely you are to have a baby. Look instead at the national rate on Choose a Fertility Clinic or visit our research and data page for the latest statistics.

Using the data on our website you can view the success rates for different clinics safe in the knowledge that they've been calculated in exactly the same way. Please note, we don't publish figures for clinics performing very small numbers of cycles as the results can be misleading.

If you're looking for clinic data, head to the bottom of this page to search for a clinic and view: how inspectors rate the clinic; how patients rate the clinic; pregnancy and birth rates from different fertility treatments, multiple birth rates and waiting times for donated eggs, sperm or embryos.

Clinics rates vary in reporting so used HFEA to facilitate comparison across clinics

From National Patient Survey 2021

We found the data from the HFEA website was the biggest factor in choosing our clinic

From National Patient Survey 2021

Find out more here: <https://www.hfea.gov.uk/choose-a-clinic/>



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Choose a fertility clinic

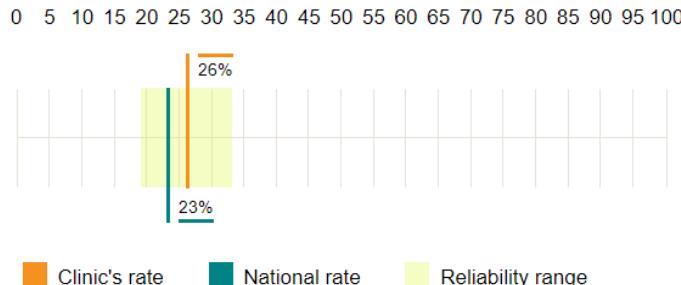
Leicester Fertility Centre

Leicester Fertility Centre has been licensed by us since 1992. It is a medium-sized clinic offering all fertility treatments, including embryo testing.



Births per embryo transferred

01/01/2018 to 31/12/2018



 Births per embryo transferred

Under 38 38 and over
 All

 Births per egg collection

 Multiple birth rate

 Consistent with national average 

[The clinic birth rate is based on 388 embryos transferred](#)

- Patient Rating**
- How likely are you to recommend this clinic to friends and family if they needed similar care or treatment?
- To what extent did you feel you were treated with privacy and dignity?
- To what extent did you feel you understood everything that was happening throughout your treatment?
- Was the level of empathy and understanding shown towards you by the clinic team?
- Did you pay what you expected?

Inspection rating linked to length of licence

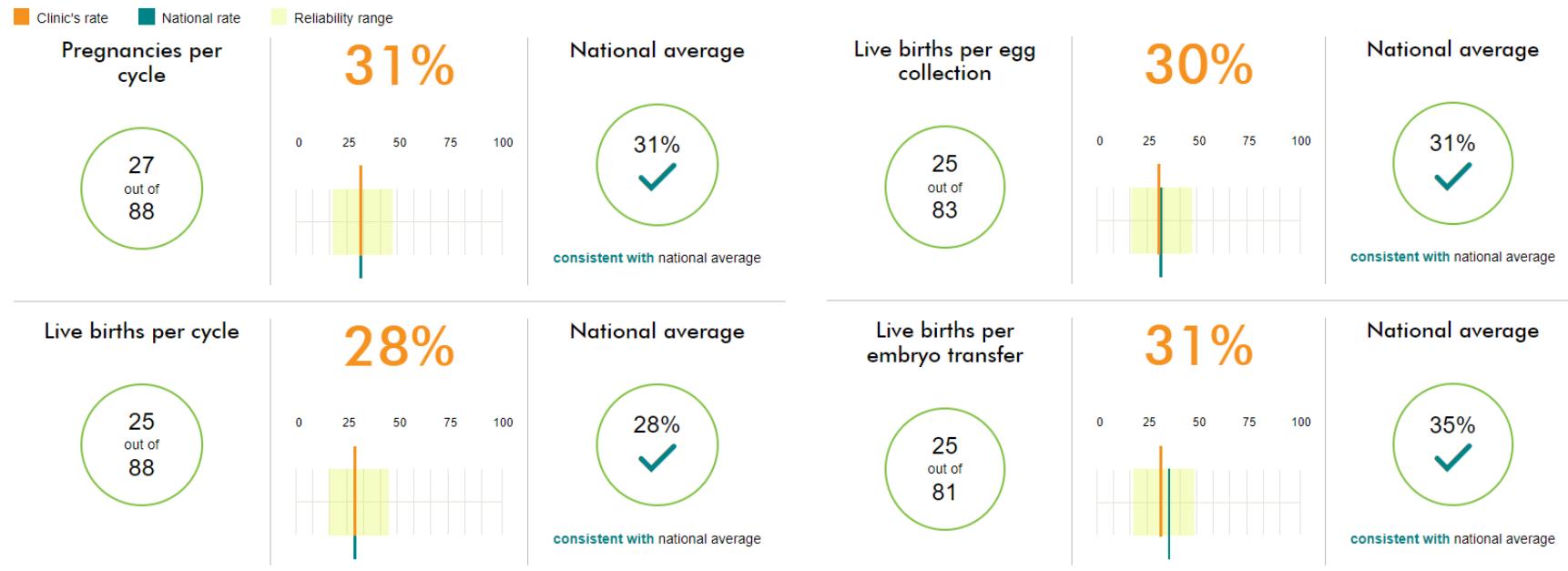


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Choose a fertility clinic – detailed statistics

Show data for: Births over 3 years, IVF | 35-37, Fresh embryo, patients' eggs

Pregnancies and births per treatment cycle



Find out more here: <https://www.hfea.gov.uk/choose-a-clinic/>

Outcomes published

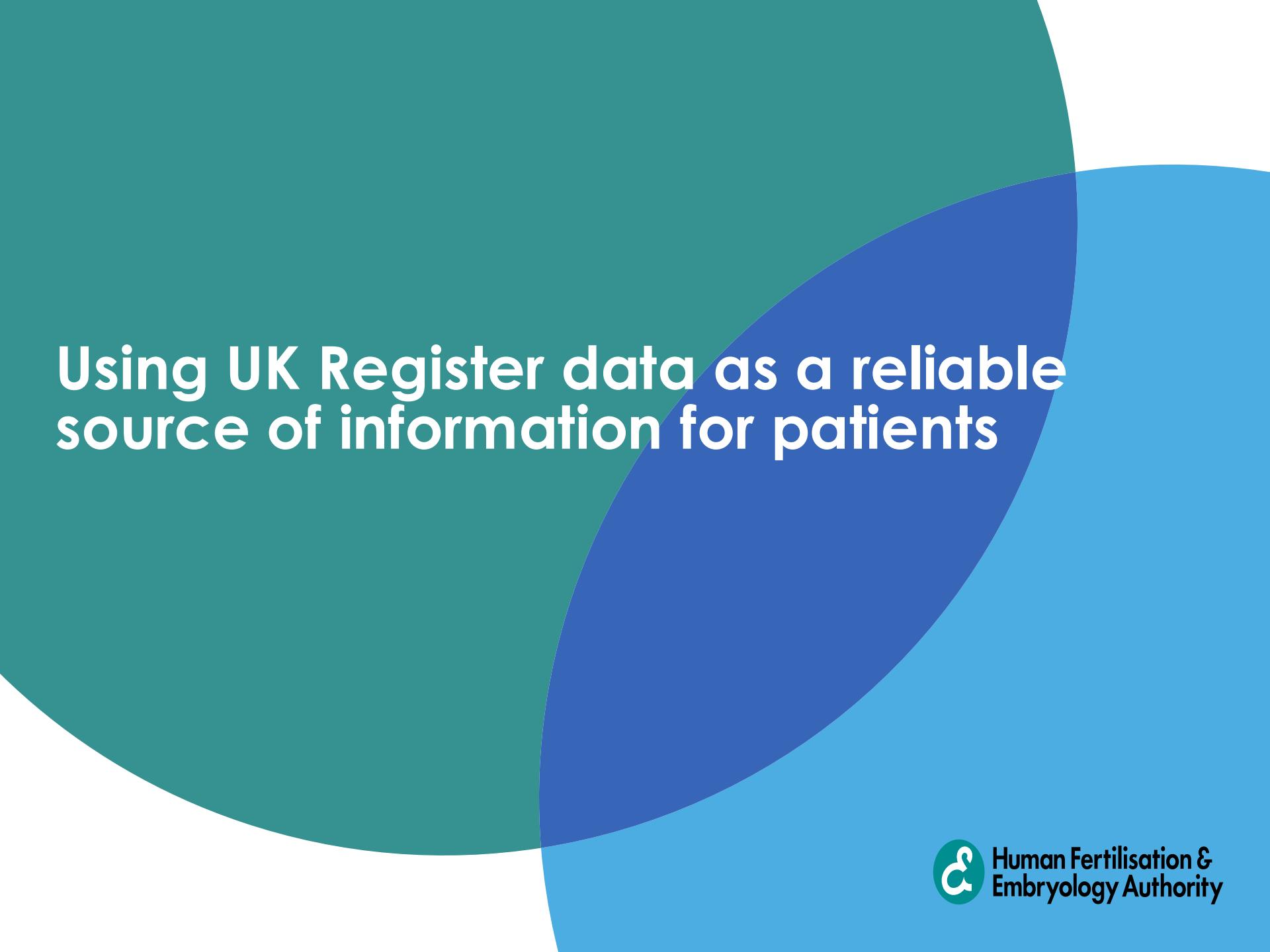
Search functions

- Births per embryo transferred
- Births per egg collection
- Multiple Births
- Births / pregnancies
 - DI
 - IVF
 - ICSI
 - IVF / ICSI
 - Natural IVF
 - PGT-M

- Ages
 - Under 25
 - 35 – 37
 - 38 – 39
 - 40 – 42
 - 43 – 44
 - Over 44
- Type
 - Fresh - donated eggs
 - Fresh - patient eggs
 - Frozen - donated eggs
 - Fresh - patient eggs
- Pregnancies for IUI with partner sperm



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Using UK Register data as a reliable source of information for patients



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How patients use HFEA Register data

Source of impartial, unbiased information (Patient survey)

A non-biased point of information for patients [o]f UK fertility services

Impartial information for patients

Provides statistical information on clinics to patients

Provide unbiased and factual information regarding services and clinics

Provide reliable information

Provides objective fact-based information

Unpublished data from National Patient Survey 2021

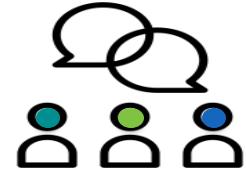


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Appraisal of UK system



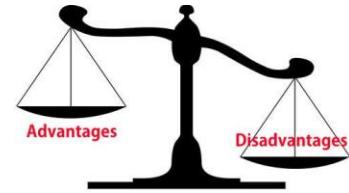
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Advantages

- Single source of accurate information for patients, especially important in UK where majority of cycles are self-funded
- Headline figure of births per embryo transferred promotes good practice around embryos transfer
- Underlying more detailed statistics provide in depth statistics for treatments and age ranges
- Reference to the national average helps compare a clinic without making a league table
- Data validation exercise with clinics
- Clinics like the fact it displays statistics on a level playing field (prevents false advertising!)
- Drives good practice
- CAFC value is that the success rate data is not held in isolation – inspection reports, patient feedback, clinic information all in one place

Disadvantages



- HFEA data currently out of date as a new register and submission system has been developed (refresh by end of the year and more frequent updates)
- Even when updating frequently birth data is over 1 year old
- Difficulties inherent in publishing outcome data for small clinics
- Some clinics do publish their own 'questionable' rates even though we provide guidance
- Clinics have to submit data (considered burdensome, although this is UK law)
- Validation and correction of errors can be time consuming
- Clinics may 'select' better prognosis patients
- Concern that CAFC is used to publish league tables in press, clinics often say they treat difficult patient populations with poorer prognosis (??)

To conclude...

- The HFEA holds over 30 years worth of fertility treatment data
- We use Register data in various ways to improve patient care, via research and information on fertility treatment
- Choose a fertility clinic webpages help patients make informed choices about where to have treatment
- We work with patients to ensure the information we publish is relevant and easy to understand
- We believe publishing statistics is of benefit to both clinics and patients