

Anonymised Register

User Guide

Version 1.0



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1. Introduction

1.1. About the HFEA Register

Information about in vitro fertilisation (IVF) and donor insemination (DI) treatment in the UK has been collected by the HFEA since it was established on 1 August 1991. Since that date, clinics have been required by law to report details of the treatments they carry out to the HFEA. Consequently the HFEA maintains the largest database of infertility treatments in the world.

Information that we currently collect is available at:

www.hfea.gov.uk/fertility-clinic-forms.html

This link shows examples of paper forms. The actual data returned to us is done electronically. We currently process about a quarter of a million forms per year. This information is then held on the HFEA Register.

Changes to the Act & the Register

The original Human Fertilisation & Embryology Act 1990 made it impossible for the HFEA to share this information with anybody outside of the HFEA. Specific enquiries about Register data were answered through the Freedom of Information Act 2000.

The Human Fertilisation & Embryology Act 2008 introduced changes that came into force in October 2009. These changes allow researchers to access the Register.

Find out more at: www.hfea.gov.uk/5447.html

1.2. New anonymised Register

How the anonymised Register works

The anonymised Register aims to allow a broader audience to view, analyse and interpret the information that we hold. We have selected a useful subset of the Register and applied a number of techniques to ensure that none of the information contained can lead to the identification of the individual to whom it relates.

The dataset will be updated in line with the publication of our clinic figures on the Choose a Fertility Clinic service every three months.

Your feedback

It is also our intention to enhance this data over time and we would welcome any suggestions for improvement – email your suggestions to informationssupport@hfea.gov.uk.

1.3. Quality of the data

Over the years, the types of forms, the information that we have collected and the method of data collection have changed since the HFEA started. Up until 2006, information was returned to the HFEA on paper forms which were manually entered on to the Register by double data entry to reduce transcription errors, however there may still be some traces of human error.

The forms that we used to collect information also changed several times so some of the data that we hold is not present across all the years of the Register. As such users may encounter records that appear incongruous or impossible to reconcile.

New quality checks

The HFEA now runs rigorous data checking routines over the information received and requires clinics to correct any incorrect returns. We also ensure the information that we have a statutory obligation to maintain is correct from 1991 to date.

2. Using the anonymised Register

2.1. Accessing the data

The anonymised Register in this release (1.0) is supplied as character delimited data, the delimiter used being the pipe '|' character.

There are 20 files that make up the dataset:

1991-HFEA-AR-V1.0.psv

...

2009- HFEA-AR-V1.0.psv

and

HFEA-AR-V1.0.psv

The latter file contains information from all years of the Register and the others contain the same information divided into annual sections.

Instructions on how to import the information into any particular application is beyond the scope of this document.

2.2. About the data

- ▶ The information covers cycles in the period 01-08-1991 to 30-06-2008.
- ▶ The dataset contains 91 fields of data across 787030 rows of cycle data.
- ▶ The content of each field is described in more detail below and is generally self explanatory.

2.3. Types of data

Number	Numeric Value
Bit	Simple Yes/No Type
Text	Alphanumeric data

2.4. Notes on data values

Text fields – these can include multiple items of information, for example, different types of stimulation used in a cycle. They can also include numerical data that has been split into bands e.g. patient age at treatment.

NULL - the value NULL will also be seen frequently in fields. This indicates that a value for this field has not been captured for the specific cycle. This may be that the clinic did not submit the data or that it wasn't requested by the HFEA at the time.

2.5. Data Dictionary

Field Name	Type	Description
Patient age at treatment	Text	This is a patient's age at treatment, banded as follows: 18-34,35-37,38-39,40-42,43-44,45-50 Where patient age is 999 this indicates a donation cycle
Date patient started trying to become pregnant OR date of last pregnancy	Number	The number of years ago that patient started trying to become pregnant or years since last pregnancy
Total number of previous cycles, both IVF and DI	Number	How many cycles of IVF or DI the patient has previously had. Counts greater than 5 are described as '> 5'
Total number of previous IVF cycles	Number	How many cycles of IVF the patient has previously had. Counts greater than 5 are described as '> 5'
Total number of previous DI cycles	Number	How many cycles of DI the patient has previously had. Counts greater than 5 are described as '> 5'
Total number of previous pregnancies, both IVF and DI	Number	How many times the patient has been pregnant through IVF or DI. Counts greater than 5 are described as '> 5'
Total number of IVF pregnancies		How many times the patient has been pregnant through IVF. Counts greater than 5 are described as '> 5'
Total number of DI pregnancies		How many times the patient has been pregnant through DI. Counts greater than 5 are described as '> 5'

Total number of previous live births – conceived through IVF or DI		How many live births the patient has had subsequent to IVF or DI treatment. Counts greater than 5 are described as '> 5'
Total number of previous live births – conceived through IVF		How many live births the patient has had subsequent to IVF treatment. Counts greater than 5 are described as '> 5'
Total number of previous live births – conceived through DI		How many live births the patient has had subsequent to DI treatment. Counts greater than 5 are described as '> 5'
Type infertility - female primary	Bit	1 if the woman has not been pregnant previously, 0 otherwise
Type of infertility - female secondary	Bit	1 if the woman has been pregnant previously, 0 otherwise
Type of infertility - male primary	Bit	1 if the man has never made a woman pregnant, 0 otherwise
Type infertility - male secondary	Bit	1 if the man has previously made a woman pregnant, 0 otherwise
Type of infertility - couple primary	Bit	1 if the couple have never achieved a pregnancy together, 0 otherwise
Type of infertility - couple secondary	Bit	1 if the couple have previously achieved a pregnancy together, 0 otherwise
Cause of infertility - tubal disease	Bit	1 if the primary cause of infertility is tubal disease, 0 otherwise.
Cause of infertility - ovulatory disorder	Bit	1 if the cause of infertility is ovulatory disorder, 0 otherwise.
Cause of infertility - male factor	Bit	1 if the cause of infertility is a male factor, 0 otherwise.

Cause of infertility - patient unexplained	Bit	1 if the cause of infertility is unexplained, 0 otherwise
Cause of infertility - endometriosis	Bit	1 if the cause of infertility is endometriosis, 0 otherwise
Cause of infertility - cervical factors	Bit	1 if the cause of infertility is cervical factors, 0 otherwise
Cause of infertility - female factors	Bit	1 if the cause of infertility is an unexplained female factor, 0 otherwise
Cause of infertility - partner sperm concentration	Bit	1 if the cause of infertility is due to low partner sperm concentration, 0 otherwise
Cause of infertility - partner sperm morphology	Bit	1 if the cause of infertility is due to abnormal partner sperm morphology, 0 otherwise
Cause of infertility - partner sperm motility	Bit	1 if the cause of infertility is due to poor partner sperm motility, 0 otherwise
Cause of infertility - partner sperm immunological factors	Bit	1 if the cause of infertility is due to immunological factors affecting partner sperm viability, 0 otherwise
Main reason for producing embryos storing eggs	Text	A comma separated list of the main reason for carrying out this cycle which can include: treatment now ,for donation , for storing eggs, for storing embryos, for research
Stimulation used	Bit	1 if this was a stimulated cycle, 0 if not
Type of ovulation induction	Text	A comma separated list of the types of stimulation used
Egg donor age at registration	Text	If donor eggs were used, the donor's age at registration banded as follows: <=20,21-25,26-30,31-35

Sperm donor age at registration	Text	If donor sperm was used, the donor's age at registration banded as follows: <=20,21-25,26-30,31-35,36-40,41-45,>45
Donated embryo	Bit	1 if this cycle used a donated embryo, 0 otherwise
Patient acting as surrogate	Bit	1 if the patient was acting as a surrogate in this cycle, 0 otherwise
Treatment type - IVF or DI	Text	Either IVF or DI
Specific treatment type	Text	A comma separated list of specific treatment types used in this cycle - see www.hfea.gov.uk/glossary.html for an explanation of the terms
PGD	Bit	1 if this cycle involved the use of preimplantation genetic diagnosis/screening, 0 if not
Elective single embryo transfer	Bit	1 if this cycle involved the deliberate use of only one embryo
Egg source	Text	Indicates whether the eggs used in this cycle came from the patient or a donor
Sperm from	Text	Indicates whether the sperm used in this cycle came from the patient or donor
Fresh cycle	Bit	1 if this cycle used fresh embryos
Frozen cycle	Bit	1 if this cycle used frozen embryos
Eggs thawed	Number	If this cycle used frozen eggs, the number of eggs thawed, all numbers >50 are banded
Fresh eggs collected	Number	The number of eggs collected in this cycle, all numbers >50 are banded
Fresh eggs stored	Number	The number of eggs collected in this cycle and subsequently frozen, all numbers >50 are banded
Total eggs mixed	Number	The number of eggs mixed with sperm, all numbers >50 are banded
Eggs mixed with partner sperm	Number	The number of eggs mixed with sperm from the partner, all numbers >50 are banded
Eggs mixed with donor sperm	Number	The number of eggs mixed with sperm from a donor, all numbers >50 are banded
Total embryos created	Number	The total number of embryos created in this cycle, all numbers >50 are banded
Eggs micro-injected	Number	The number of eggs that were injected with sperm e.g. by ICSI, all numbers >50 are banded

Embryos from eggs micro-injected	Number	The number of embryos that developed from injected eggs, all numbers >50 are banded
Total embryos thawed	Number	If this was a frozen cycle, the total number of embryos that were thawed, all numbers >50 are banded
Embryos transferred	Number	The number of embryos transferred into the patient in this cycle, all numbers >50 are banded
Embryos transferred from eggs micro-injected	Number	The number of embryos transferred into the patient in this cycle that were created by injecting sperm, all numbers >50 are banded
Embryos stored for use by patient	Number	The number of embryos that were created in this cycle and then frozen for subsequent use by the patient, all numbers >50 are banded
Embryos (from eggs micro-injected) stored for use by patient	Number	The number of embryos that were created in this cycle by injecting sperm and then frozen for subsequent use by the patient, all numbers >50 are banded
Date of egg collection	Number	These 5 fields are based on the first date given on the form which is represented by 0 and NULL if there is no date given. All subsequent dates are given as the number of days following the first date. If 999 this means that the date given was > 7.0 if eggs were collected, NULL if no eggs were collected
Date of egg thawing	Number	
Date of egg mixing	Number	
Date of embryo thawing	Number	
Date of embryo transfer	Number	
Year of treatment	Date	The year in which this cycle took place
Live birth occurrence	Bit	1 if there was 1 or more live births as a result of this cycle, 0 if not
Number of live births	Number	The number of live births as a result of this cycle, this number currently excludes neonatal deaths
Early outcome	Text	A comma separated list of the results of a patient scan which is approx 8 weeks after embryo transfer
Treatment cycle at clinic		
Number of foetal sacs with foetal pulsation	Number	If foetal sacs were present in the scan, the number of sacs that evidenced foetal pulsation

1st foetal heart - weeks gestation	Number	The number of weeks of gestation for this foetal heart, banded if less than 30 weeks or greater than 40 weeks
1st foetal heart - birth outcome	Text	Comma separated list of the outcome of this pregnancy
1st foetal heart - birth weight	Text	Banded birth weight of this child
1st foetal heart - sex	Text	The sex of this child - M if male, F if female
1st foetal heart - delivery date	Date	The year this child was delivered
1st foetal heart - birth congenital abnormalities	Bit	1 if a congenital abnormality was recorded, 0 if not - this data is supplied to the clinics by the parents after the birth of the child
2nd foetal heart - weeks gestation	Number	The number of weeks of gestation for this foetal heart, banded if less that 30 weeks or greater than 40 weeks
2nd foetal heart - birth outcome	Text	Comma separated list of the outcome of this pregnancy
2nd foetal heart - birth weight	Text	Banded birth weight of this child
2nd foetal heart - sex	Text	The sex of this child - M if male, F if female
2n foetal heart - delivery date	Date	The year this child was delivered
2nd foetal heart - birth congenital abnormalities	Bit	1 if a congenital abnormality was recorded, 0 if not
3rd foetal heart - weeks gestation	Number	The number of weeks of gestation for this foetal heart, banded if less than 30 weeks or greater than 40 weeks
3rd foetal heart - birth outcome	Text	Comma separated list of the outcome of this pregnancy

3rd foetal heart - birth weight	Text	Banded birth weight of this child
3rd foetal heart - sex	Text	The sex of this child - M if male, F if female
3rd foetal heart - delivery date	Date	The year this child was delivered
3rd foetal heart - birth congenital abnormalities	Bit	1 if a congenital abnormality was recorded, 0 if not
4th foetal heart - weeks gestation	Number	The number of weeks of gestation for this foetal heart, banded if less than 30 weeks or greater than 40 weeks
4th foetal heart - birth outcome	Text	Comma separated list of the outcome of this pregnancy
4th foetal heart - birth weight	Text	Banded birth weight of this child
4th foetal heart - sex	Text	The sex of this child - M if male, F if female
4th foetal heart - delivery date	Date	The year this child was delivered
4th foetal heart - birth congenital abnormalities	Bit	1 if a congenital abnormality was recorded, 0 if not

Modification history

Date	Modification	Author
26/04/2010	Version 1.0	David Moysen

Scope

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