Human Fertilisation & Embryology Authority

Guide to the anonymised Register

www.hfea.gov.uk

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About our Register

We hold the longest running register of fertility treatment data in the world. World class research has been carried out using our data, either alone or by linking to other datasets.

We collect data and statistics about over 70,000 fertility treatments performed each year in the UK from 1991 to 2016. We are committed to making as much of this information available as possible to inform patients, researchers and clinicians.

Data we collect includes:

- identifying information such as name, date and place of birth of patients, their partner and any children born as a result of treatment
- reasons for seeking treatment and obstetric history
- the type of treatment being used, the number of eggs collected, and the number of embryos transferred
- the number of babies born, their gestation and birthweight.

Using Register data for research

There are two main types of data which can be used:

- anonymised data, where no identifiers are present and some of the information is banded, or obscured, to protect patient privacy, and
- patient-identifying data, where the data may be very detailed, or contain actual identifiers (e.g., date and place of birth, names, address, place of treatment) allowing the records to be linked to another database.

Research can only take place within the strict confines of the law, which provides very strong protection of patient, donor and offspring confidentiality (stronger still than normal medical confidentiality).

Researchers who aim to use data in our Register only and not to link subjects to other datasets can use the anonymised version of the data in our Register. This anonymised dataset contains a large proportion of all the Register data going back to 1991, with the patient identifiers removed, and any secondary identifying fields aggregated or suppressed.

The anonymised Register allows professionals in the sector and the wider research community to make good use of the data we collect. The anonymised Register allows researchers to access a large and rich data set, but one that does not identify any patients, or children born as a result of treatment.

How useful is the anonymised Register?

Research using anonymised data can still answer important questions, like which factors influence treatment outcomes, or which factors indicate that a patient should have only one or two embryos transferred during treatment. In fact, due to legislative changes in 2009, researchers can have greater coverage of treatment cycles using the anonymised dataset than one including patient identifying information.

Additional data fields

We're not currently able to produce bespoke versions of the anonymised data with further information added (for instance a maternal identifier, or more granular data) as this increases the risk of patient identification.

If you would like further information on how to gain access to more detailed data for research, please email intelligenceteam@hfea.gov.uk.

Helping us get more value from the anonymised Register

Although we are unable to provide detailed feedback or guidance on anonymised Register queries, we would like to hear about any projects using anonymised register data.

We will use this to provide better information for patients, the public and other researchers. This also helps inform our policy and future research.

Please email intelligenceteam@hfea.gov.uk to let us know of your progress.

Data quality and collection

We invested in our Information for Quality programme to transform the way we collect, use and publish information to benefit patients and other stakeholders. A large part of this involved developing a new data submission system and Register to improve the quality of the data we hold. This will be live from Autumn 2018.

The types of forms, the information that we have collected, and the method of data collection have changed over the years so some of the data that we hold is not present across all the years of the Register or to the same degree of quality.

Using the anonymised Register

Opening the data

The anonymised register is supplied as an excel file and split into multiple files due to the size.

The file has been designed to be easily imported into a range of applications used for analysis, but we cannot guarantee this functionality. Unfortunately, we are not able to provide guidance on how you can import the anonymised Register into any applications. Please see the application help guides provided by whichever software/application you are using for details on how to import this type of file.

Using the data

The anonymised Register contains 87 fields of data on treatment cycles started between 1991 and 2016. We will aim to provide an updated every 15 months (i.e. by March 2018 for the 2016 year).

The content of each field is described in more detail in section 10.

Data types

The anonymised Register includes three types of data:

- Number: Numeric Value
- Characters: Greater, Equal >=
- Binary Integer: True/false (1,0)
- Text: Alphanumeric data

Data fields

The anonymised Register contains 95 fields as detailed below.

Field	Data type	Description
Patient Age at Treatment	Text	Patient's age at treatment, banded as follows: 18-34,35-37,38-39,40-42,43-44,45-50
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 treatment cycles of IVF and DI the patient has previously had

Total Number of Previous treatments, Both IVF and DI at clinic	Number	How many treatment cycles of IVF and DI the patient has previously had at the clinic associated with this treatment
Total Number of Previous IVF cycles	Number	How many treatment cycles cycles of IVF the patient has previously had
Total Number of Previous DI cycles	Number	How many treatment cycles of DI the patient has previously had
Total number of previous pregnancies, Both and DI	Number	How many time the patient has previously been pregnant, Both and DI
Total number of IVF pregnancies	Number	How many times the patient has been pregnant through IVF
Total number of DI pregnancies	Number	How many times the patient has been pregnant through DI
Total number of live births - conceived through IVF or DI	Number	How many live births the patient has had through IVF or DI
Total number of live births - conceived through IVF	Number	How many live births the patient has had through IVF
Total number of live births - conceived through DI	Number	How many live births the patient has had through DI
Type Infertility Female Primary	Bit	1 if the main cause of infertility is due to the patient, 0 otherwise
Type of Infertility – Female Secondary	Bit	1 if the secondary cause of infertility is due to the patient, 0 otherwise
Type of Infertility – Male Primary	Bit	1 if the main cause of infertility is due to the partner, 0 otherwise
Type Infertility – Male Secondary	Bit	1 if the secondary cause of infertility is due to the partner, 0 otherwise
Type of Infertility – Couple Primary	Bit	1 if the main cause of infertility is due to the patient/partner problem, 0 otherwise
Type of Infertility – Couple Secondary	Bit	1 if the secondary cause of infertility is due to the patient/partner problem, 0 otherwise
Cause of Infertility – Tubal disease	Bit	1 if the primary cause of infertility is as detailed, 0 otherwise

Cause of Infertility - Ovulatory Disorder	Bit	1 if the primary cause of infertility is as detailed, 0 otherwise
Cause of Infertility – Male Factor	Bit	1 if the primary cause of infertility is as detailed, 0 otherwise
Cause of Infertility – Patient Unexplained	Bit	1 if the primary cause of infertility is as detailed, 0 otherwise
Cause of Infertility - Endometriosis	Bit	1 if the primary cause of infertility is as detailed, 0 otherwise
Cause of Infertility – Cervical factors	Bit	1 if the primary cause of infertility is as detailed, 0 otherwise
Cause of Infertility – Female Factors	Bit	1 if the primary cause of infertility is as detailed, 0 otherwise
Cause of Infertility – Partner Sperm Concentration	Bit	1 if the primary cause of infertility is as detailed, 0 otherwise
Cause of Infertility – Partner Sperm Concentration	Bit	1 if the primary cause of infertility is as detailed, 0 otherwise
Cause of Infertility – Partner Sperm Morphology	Bit	1 if the primary cause of infertility is as detailed, 0 otherwise
Cause of Infertility – Partner Sperm Motility	Bit	1 if the primary cause of infertility is as detailed, 0 otherwise
Cause of Infertility - Partner Sperm Immunity	Bit	1 if the primary cause of infertility is as detailed, 0 otherwise
Main Reason for Producing Embryos Storing Eggs	Text	A comma separated list of the main reason for this cycle which can include: Treatment Now, For Donation, For Storing Eggs, For Research
Stimulation used	Bit	1 if this was a stimulated cycle, 0 otherwise
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
Type of treatment - IVF or DI	Text	IVF or DI
Specific Treatment Type	Text	A comma separated list of specific treatment types used in this cycle
PGD	Bit	1 if this cycle involved the use of preimplantation genetic diagnosis, 0 otherwise
PGD treatment	Bit	1 if this cycle would be contained in the 'PGD' CaFC category on the HFEA website, 0 otherwise
PGS	Bit	1 if this cycle involved the use of preimplantation genetic screening, 0 otherwise
PGS treatment	Bit	1 if this cycle would be contained in the 'PGS' CaFC category on the HFEA website, 0 otherwise
Elective Single Embryo Transfer	Bit	1 if this cycle involved the deliberate use of only one embryo, 0 otherwise
Egg Source	Text	Indicates whether the eggs used in this cycle came from the Patient (P) or a Donor (D)
Sperm From	Text	Indicates whether the sperm used in this cycle came from the Patient (P) or a Donor (D)
Fresh Cycle	Bit	1 if this cycle used fresh embryos, 0 otherwise
Frozen Cycle	Bit	1 if this cycle used frozen embryos, 0 otherwise
Eggs Thawed	Number	If this cycle used frozen eggs, the number of eggs thawed
Fresh Eggs Collected	Number	The number of eggs collected in this cycle
Fresh Eggs Stored	Number	The number of eggs collected in this cycle and subsequently frozen
Total Eggs Mixed	Number	The number of eggs mixed with sperm
Eggs Mixed with Partner Sperm	Number	The number of eggs mixed with sperm from the partner
Eggs Mixed with Donor sperm	Number	The number of eggs mixed with sperm from a donor
Total Embryos Created	Number	The total number of embryos created in this cycle

Eggs Micro-injected	Number	The number of eggs that were injected with sperm e.g. By ICSI
Embryos from Eggs Micro-injected	Number	The number of embryos that were created in this cycle using ICSI
Total Embryos Thawed	Number	If this was a frozen cycle, the total number of embryos that were thawed
Embryos Transferred	Number	The number of embryos transferred into the patient in this cycle
Embryos Transferred from Eggs Micro-injected	Number	The number of embryos transferred into the patient in this cycle that were created using ICSI
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.
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.
Date of Egg Collection	Number	The number of days between egg collection and the first date provided in the series: egg collection date; egg thaw date; egg mix date; embryo thaw date; embryo transfer date
Date of Egg Thawing	Number	The number of days between egg thawing and the first date provided in the series: egg collection date; egg thaw date; egg mix date; embryo thaw date; embryo transfer date
Date of Egg Mixing	Number	The number of days between egg mixing and the first date provided in the series: egg collection date; egg thaw date; egg mix date; embryo thaw date; embryo transfer date
Date of Embryo Thawing	Number	The number of days between embryo thawing and the first date provided in the series: egg collection date; egg thaw date; egg mix date; embryo thaw date; embryo transfer date
Date of Embryo Transfer	Number	The number of days between embryo transfer and the first date provided in the series: egg collection date; egg thaw date; egg mix date; embryo thaw date; embryo transfer date
Year of Treatment	Number	The year in which this cycle took place

Live Birth Occurrence	Bit	1 if there were 1 or more live births as a result of this cycle, 0 otherwise
Number of Live Births	Number	The number of live births as a result of this cycle
Early Outcome	Text	A comma separated list of the results of a patient scan
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 for less that 30 weeks or greater than 40 weeks
1st Foetal Heart – Birth Outcome	Text	Comma separated list of the outcome of this pregnancy: Embryo reduction; live birth; miscarriage; still birth; termination
1st Foetal Heart - Birth Weight	Text	Banded birthweight of this child: Less than 1kg; Between 1.5kg and 1.99Kg; Between 1kg and 1.49Kg; Between 2.0kg and 2.49Kg; Between 2.5kg and 2.99Kg; Between 3.0kg and 3.49Kg; Between 3.5kg and 3.99Kg; Between 4.0kg and 4.49Kg; Between 4.5kg and 4.99Kg; Between 5.0kg and 5.49Kg; Between 5.5kg and 5.99Kg; 6kg or greater
1st Foetal Heart – Sex	Text	The sex of the child: Male (M), Female (F)
1st Foetal Heart – Delivery Date	Number	Year the child was delivered
1st Foetal Heart – Birth Congenital Abnormalities	Bit	1 if a congenital abnormality was recorded, 0 otherwise
2nd Foetal Heart – Weeks Gestation	Number	The number of weeks of gestation for this foetal heart: banded for less than 30 weeks or greater than 40 weeks
2nd Foetal Heart – Birth Outcome	Text	Comma separated list of the outcome of this pregnancy: Embryo reduction; live birth; miscarriage; still birth; termination
2nd Foetal Heart - Birth Weight	Text	Banded birthweight of this child: Less than 1kg; Between 1.5kg and 1.99Kg; Between 1kg and 1.49Kg; Between 2.0kg and 2.49Kg; Between 2.5kg and 2.99Kg; Between 3.0kg and 3.49Kg; Between 3.5kg and 3.99Kg; Between 4.0kg and 4.49Kg; Between 4.5kg and 4.99Kg; Between 5.0kg and 5.49Kg; Between 5.5kg and 5.99Kg; 6kg or greater
2nd Foetal Heart – Sex	Text	The sex of the child: Male (M), Female (F)

2nd Foetal Heart – Delivery Date	Number	Year the child was delivered
2nd Foetal Heart – Birth Congenital Abnormalities	Bit	1 if a congenital abnormality was recorded, 0 otherwise
3rd Foetal Heart – Weeks Gestation	Number	The number of weeks of gestation for this foetal heart: banded for less than 30 weeks or greater than 40 weeks
3rd Foetal Heart – Birth Outcome	Text	Comma separated list of the outcome of this pregnancy: Embryo reduction; live birth; miscarriage; still birth; termination
3rd Foetal Heart - Birth Weight	Text	Banded birthweight of this child: Less than 1kg; Between 1.5kg and 1.99Kg; Between 1kg and 1.49Kg; Between 2.0kg and 2.49Kg; Between 2.5kg and 2.99Kg; Between 3.0kg and 3.49Kg; Between 3.5kg and 3.99Kg; Between 4.0kg and 4.49Kg; Between 4.5kg and 4.99Kg; Between 5.0kg and 5.49Kg; Between 5.5kg and 5.99Kg; 6kg or greater
3rd Foetal Heart – Sex	Text	The sex of the child: Male (M), Female (F)
3rd Foetal Heart – Delivery Date	Number	Year the child was delivered
3rd Foetal Heart – Birth Congenital Abnormalities	Bit	1 if a congenital abnormality was recorded, 0 otherwise
4th Foetal Heart – Weeks gestation	Number	The number of weeks of gestation for this foetal heart: banded for less that 30 weeks or greater than 40 weeks
4th Foetal Heart – Birth Outcome	Text	Comma separated list of the outcome of this pregnancy: Embryo reduction; live birth; miscarriage; still birth; termination
4th Foetal Heart - Birth Weight	Text	Banded birthweight of this child: Less than 1kg; Between 1.5kg and 1.99Kg; Between 1kg and 1.49Kg; Between 2.0kg and 2.49Kg; Between 2.5kg and 2.99Kg; Between 3.0kg and 3.49Kg; Between 3.5kg and 3.99Kg; Between 4.0kg and 4.49Kg; Between 4.5kg and 4.99Kg; Between 5.0kg and 5.49Kg; Between 5.5kg and 5.99Kg; 6kg or greater
4th Foetal Heart – Sex	Text	The sex of the child: Male (M), Female (F)
4th Foetal Heart – Delivery Date	Number	Year the child was delivered

4th Foetal Heart – Birth Congenital Abnormalities	Bit	1 if a congenital abnormality was recorded, 0 otherwise

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