

Information for Quality programme: update

Strategic delivery: Setting standards Increasing and informing choice Demonstrating efficiency economy and value

Details:

Meeting	Authority
Agenda item	7
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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 progress made on the programme.
Resource implications	Nil
Implementation date	During 2015–16 and 2016–17 business years
Communication(s)	Regular, range of mechanisms
Organisational risk	<input type="checkbox"/> Low <input type="checkbox"/> Medium <input checked="" type="checkbox"/> High
Annexes	Annex 1 Data Dictionary background Annex 2 Data Dictionary

1. Background

1.1. The Information for Quality (IfQ) programme encompasses:

- The redesign of our website and Choose a Fertility Clinic (CaFC) function
- The redesign of the 'Clinic portal' (used for interacting with clinics) and combining it with data submission functionality that is currently provided in our separate EDI (Electronic Data Interchange) system (used by clinics to submit treatment data to the HFEA)
- A revised dataset and data dictionary which will be submitted for approval by the Standardisation Committee for Care Information (SCCI)
- A revised Register of treatments, which will include the migration of historical data contained within the existing Register
- The redesign of our main internal systems that comprise the Authority's Register and supporting IT processes.

1.2. Given the importance of the programme to the achievement of the Authority's strategy, updates on progress are provided to each meeting of the Authority and approval for direction and actions sought.

1.3. This brief paper updates Members on:

- Update on approvals process to proceed to 'beta' phase
- The HFEA annual conference
- Data migration
- progress regarding the data dictionary, see annexes 1 and 2
- Programme timelines and budget implications

2. Update on approval to proceed to 'beta' phase

2.1. As members have been previously advised, the externally facing part of the programme could not formally proceed beyond 'alpha' (proof-of-concept) stage until approvals in line with Government Digital Service Standards had been granted by the Department of Health (DH).

2.2. The first, Alpha, stage assessment – undertaken by the Department of Health Digital Projects team was passed to a high standard. The second stage assessment – to be undertaken by the Government Digital Service (essentially a check on the first stage Departmental process) has now also been passed.

2.3. In early May 2016, both the website and Clinic portal will be again require assessment, and subject to the associated approvals from DH and GDS, both products will be released to 'public beta'.

3. Beta progress

- 3.1. The Programme is currently half way through the beta phase of *Release 1* development, and is producing tangible components of the new website, Choose a fertility clinic and Clinic portal. Despite some delays reported to the previous meeting of the Authority related to progressing design work, and balancing external resources, the programme remains on track to meet reported deadlines and for the beta DH assessment deadline.
- 3.2. For CaFC, significant work has been completed on the search tool and profile pages, with both nearing completion for beta. The CaFC search design and CaFC profile prototype were shared with a recent stakeholder group meeting and feedback will be incorporated in the next iteration of the pages.
- 3.3. The new website is now well progressed, with the team having completed templates for key landing and content pages. Revised content is now being migrated to the beta version of the new website, following consultation with internal HFEA teams, Authority members and external stakeholders.
- 3.4. For Clinic portal, design work is also making good progress. Designs for the new Clinic portal are also well progressed, with the team are nearing completion on the dashboard and a searchable knowledge base page.
- 3.5. The Internal Systems team have now completed a majority of the work required to support the updated functionality of the website, CaFC and Clinic portal beta phase builds. Shortly, the team will be commencing foundational work on the key functionality required in Release 2, notably, the new Register and EDI.

4. The HFEA annual conference

- 4.1. As previously advised, a centre-piece of the HFEA annual conference will be showcasing the progress made and generating a sense of anticipation for the roll-out of the beta version of the updated website, CaFC and clinic portal. This demonstration is anticipated to include aspects of the search tool and the clinic portal knowledge base and dashboard.

5. Data migration

- 5.1. As previously advised, we have now finalised the extent to which data in the current Register needs to be cleansed (that is with input necessary from clinic staff) such that we can effect a smooth transfer to the new Register (with a different data structure), in line with the HFEA data dictionary.
- 5.2. The Information and IT teams are carrying out substantial cleansing activity and the burden placed on clinics to undertake this work has been minimalised. However, the quantum of effort required by some clinics will be material. We are focusing on the work which must be done to enable the migration to take

place, and expect this work to start soon after the HFEA conference, which provides a useful opportunity to ‘warm up’ clinics to the task.

- 5.3.** In order to form a clearer idea of the amount of time clinics will need to conduct cleansing, a selected number of clinics have been identified to undertake a pilot of cleansing activity this month.
- 5.4.** More broadly, we have been communicating with clinics preparing them for the coming requirement to cleanse data, and we are hopeful that the prospective benefits offered by the new system will act as an incentive. Equally we are realistic about the potential for this not being a popular move.

6. Data dictionary

- 6.1.** A significant part of the Information for Quality programme (IfQ) is about restructuring the HFEA Register. Both what and how we collect information and how we hold it in the future is changing. A background paper is attached at annex 1, detailing the progress that has been made.
- 6.2.** In addition, the full details of the new proposed data dictionary are attached at Annex B. Whilst this is relatively dense it will be useful and interesting for clinic staff to see – so by publishing this paper the data dictionary goes in to the public domain. The changes are all about details as the fundamentals of what is required for the HFEA Register has not varied. As such, it is expected that not all Members will wish to engage with the document but there is an audience who will wish to engage in some detail.
- 6.3.** In any event, we will continue to collect information on each IVF treatment (including ICSI) and donor insemination treatment; registration information to uniquely identify each patient, partner, intended parents or donors involved in treatments; the outcome of treatments and movement of eggs, embryos or donor sperm.

7. Programme timelines and budget implications

- 7.1.** A revised IfQ programme plan was finalised and signed off by the IfQ Programme Board in January 2016, in line with the overall £1.134m agreed by Authority.
- 7.2.** As previously advised, the changes to the timeline meant that the public beta for the website and Clinic portal were pushed back approximately three months and two months respectively – with both now expected to be launched (for beta testing) in July 2016.
- 7.3.** Whilst the overall budget for IfQ remains unchanged at £1.134m, this revised timeline does extend work that was expected to be completed this financial year, in to the next. This will result in circa £450,000 being carried from this financial year to next financial year within the IfQ budget. Despite invoices for

beta work not expected from our primary supplier until July 2016, the Finance team will work closely with DH and the NAO to capitalise work completed during beta as accrued costs incurred in this financial year to minimise the impact of this underspend.

- 7.4.** As part of reviewing HFEA's overall budget position at the end of this financial year, the Finance team is also considering the establishment costs of IfQ on the HFEA. These are primarily comprised of the non-IfQ dedicated staff costs of managing the programme, and the associated impacts to de-prioritised business-as-usual work.

8. Recommendation

- 8.1.** The Authority is asked to
- Note the progress made on the IfQ programme.
 - Note and comment on annex 1, background to the data dictionary
 - Note and comment on annex 2, the data dictionary and endorse the work carried out so far and approve of continuation

Information for Quality programme: update

Annex 1 - Background to the data dictionary

1. Background

- 1.1.** Licensed fertility clinics submit information about each cycle of treatment they carry out, such as patient and donor details, the treatment provided and its outcome. This information is held on a database called the Register. The requirement to keep a Register of Treatments stems from the Human Fertilisation and Embryology Act 1990 (as amended) (the Act).
- 1.2.** The Register is an extremely valuable asset to both us and our stakeholders. We use it to:
- securely hold information about donors and their donations
 - ensure traceability of gametes and embryos
 - provide patient information on success rates
 - monitor clinic performance, and
 - facilitate research into the safety of treatments.

2. Re-statement of purpose

- 2.1.** In January 2015 the Authority received a report from the Authority's IfQ Advisory Group which made a range of recommendations based on our public consultation in late 2014. The Advisory Group noted that the HFEA has not in the past been explicit about why information is required for the Register and how it is then used. Furthermore, that without an agreed structure to justify the submission of data, we could:
- collect more information than necessary without a clear purpose for its use and thus increase the burden on clinics, or
 - collect less information than necessary with the effect that we would not have the required information to allow us to use the Register effectively for our stakeholders.
- 2.2.** The Authority agreed that data should only be collected if it meets at least one of the following criteria:
- because it is required by law, in particular to enable us to provide donors, donor-conceived people and their parents with the information they are entitled to
 - to provide prospective and current patients and donors with sufficient, accessible and up-to-date information in order to allow them to make informed decisions
 - to provide information that enables the HFEA to assess compliance of individual clinics against agreed standards
 - to provide information that enables the HFEA to alert clinics of performance changes

- to obtain information about current practice that is considered by the professional groups and other relevant stakeholders to be useful and beneficial
- to provide identifying information that enables linkage studies about children conceived as a result of licensed treatment
- to enable ethically and scientifically approved research.

2.3. It was also agreed the HFEA

- Should establish a dedicated standing group to assess any future requests for additions (or deletions) to the dataset, using agreed criteria
- Information required for the Register should only be submitted if it meets at least one of the justifications (in 2.2 above)
- Only data that is clearly defined and that can be validated or verified should be submitted to ensure only accurate and meaningful information is held on the Register
- NHS number should be a mandatory data requirement. Where unavailable, the passport number or unique ID number relevant to the patient's citizenship should be the preferred unique identifier.

2.4. The team have been working since then on finalising the data items, further to the consultation taking into account the need to ensure the criteria at 2.2 are met. The principal changes to the current dataset are set out below.

3. Data elements removed from data collected

3.1. A number of data elements have been removed because they could be inferred from other data and didn't need to be collected as specific items. These are:

- Date donor gametes first supplied will now be inferred from donor usage
- Whether donor sperm or eggs is imported will now be derived from donor registration
- Whether patient has partner will be inferred from presence of partner record.

3.2. Some data elements have been removed because they were very rarely used or provided detail which wasn't considered useful:

- Whether assisted hatching technique used
- Multiple dates for donor insemination – only first date.
- Type of insemination
- Thawed for research and found not viable
- Reason for removing eggs/ embryos or donor sperm from storage and allowing to perish.

3.3. 'Causes of infertility' has been removed because of concerns about accuracy and completeness of the data given the often complicated nature of fertility problems and particularly the possibility that since data is collected at

registration it is not updated as further patient or partner investigations adds information.

- 3.4.** Reason for termination of pregnancy, reason for embryo reduction, reason for lost to follow-up and abandoned cycle reason have all been removed. The information has not been used in analysis and so not required in the revised Register.
- 3.5.** Collecting both the number of eggs fertilised normally and number of embryos developed was felt to be duplication. Initially we were only going to collect the number of eggs fertilised normally but after further consideration this has changed to only collecting the number of embryos developed to ensure clearer embryo accounting.
- 3.6.** 'Sperm procurement' fields are not required as recording at use or times of movement would meet requirements.
- 3.7.** Congenital abnormalities observed in the baby (currently collected as - Yes/No/Maybe) will not be recorded since the information is known to be incomplete because of the large number of anomalies which would not be identified at birth or immediate perinatal period potentially giving false outcome information.

4. Data elements added or amended in the data collected

- 4.1.** When the HFEA issued new guidance around surrogacy treatments in clinic it was recognised that those involved should not always be recorded as donors but the changes required for The following elements have been added:
 - New role of 'intended parent'
 - Is donor known to patient on treatment
 - IVM as treatment option
 - Details of treatment carried out at a primary clinic's satellite or transport centre.
 - Number of embryos re-frozen
 - Embryo & egg storage now recording if slow freeze or vitrification used
 - BMI at time of treatment
 - Number of embryos remaining in storage
 - NHS status indicator and identification type
 - Items required for collection of mitochondrial donation treatments, including mitochondrial donor, PNT only sperm donor and additional treatment fields when MRT treatments occur. They have been included in the data dictionary but kept separate as possible so that clinics which aren't doing MRT, nor plan to, do not need to consider them when reviewing the data dictionary.

- Confirmation flags for some fields to replace confirmation that currently takes place at verification.
- Extra fields on for Single European Code (SEC) – the new European Directive requirements being introduced in 2017
- The current ‘screening type’ list is replaced with shorter list under ‘embryo biopsy’

5. Standardisation Committee for Care Information (SCCI)

- 5.1.** SCCI was setup by the National Information Board (NIB) to ensure common standards in data collection. It does so by reviewing the details of collections and issuing Information Standards Notices (ISNs). The Health and Social Care Information Centre (HSCIC) supports applicants to prepare papers so that applications are consistent with HSCIC standards and provide sufficient detail for SCCI to make a decision.
- 5.2.** HFEA staff have been working with HSCIC staff to enable the HFEA Register Data submission to become an official ISN. It will be called UK ART Data Set. There are number of stages to the process and we have passed the ‘need’ stage and working towards moving from ‘need’ to ‘requirement’. This is currently planned for May 2016 SCCI board. There is a subsequent stage from ‘requirement’ to ‘full’ which we would hope to accomplish in July 2016.
- 5.3.** Some of the changes described above have been driven by wanting to ensure compatibility of data standards with those set at national level. This applies to both the data and submission mechanism.

6. The data submission system

- 6.1.** The changes to the data collected should be seen alongside the planned improvements in the data *collection* method. The IfQ aim to reduce the burden for centres has always been firmly based on changing the collection method.
- 6.2.** The changes in method of data entry are being developed, and will include:
- Improve accuracy of inputting information by using more on screen prompts and guidance on what needs recording and access to data descriptions while inputting
 - More incentives to improve the quality of information by the use of flagging and more real-time error information so that issues can be readily understood and problems fixed on the spot.
 - Saving time and improving quality by having no opportunity for clinics to enter duplicate information and consequent issues with identifying and deleting previous or copy records.

- Minimising the burden of clinics undertaking periodic verification work by confirming information as it is the data is entered when notes are readily available for checking.

Annex 2 (Proposed Data Dictionary)

Information for Quality programme: update Annex 2 (Proposed Data Dictionary)

The details below are of the proposed data dictionary for HFEA Register data submission. This presentation is a limited version of the data dictionary which will be submitted to SCCI board as UK ART Data set. There will be version available soon with additional fields available, showing links to existing NHS data dictionary elements where they exist, whether fields are mandatory and data validation rules.

Note: the data below has been grouped into tables to clearly define what centres are expected to collect for inclusion on the HFEA Register the re-development of the data collection system may use differently structured tables for the collection process. In particular the information that needs to be collected for patients, partners and intended parents has considerable overlap around personal details but is included in each table here.

Summary of tables

Table name	Overview
Patient Details table	This table should include a record for each patient being treated. The patient is the woman who is undergoing egg collection and/or will receive embryos. The patient number is assigned by the centre and must be unique within the centre.
Partner Details table	This table should include a record for each partner. A partner (male or female) of the woman who is undergoing treatment to become pregnant and where that partner intends to be the legal parent of any child born as a result of treatment. Partner information does not need to be supplied if the woman is a gestational surrogate. The partner record is linked to the patient by inclusion on the partner record of the patient number.
Intended Parent Details table	This table should include a record for each intended parent. An intended parent is person (usually as part of a couple) who is providing gametes for the use in treatment and is intending to be the parent of any children born from the treatment but is not undergoing the treatment.
Donor Registrations	This table should include a record for each egg or sperm donor registered.
Donor re-registrations	This table should include a record for each donor re-registration. Those who donated before 1/4/2005 and are currently anonymous to the recipients of their donation can re-register to be identifiable with via the centre where they donated or HFEA.
Mitochondrial Donor Registration details	This table should include a record for each mitochondrial donor. Since the information for a mitochondrial donor differs to that collected for egg donors a person who is both should have a donor record and a mitochondrial.
PNT only sperm donor details	This table should include a record for each PNT only sperm donor. This is a man who provides sperm solely for the fertilisation of mitochondrial donated eggs as part of the PNT (pro-nuclear transfer) mitochondrial treatment of a patient.
Treatment type for the patient	This table should include a record for each patient treatment,
Donor Inseminations	This table should include a record for each donor insemination
Start of stimulation to collect eggs	This table should include a record for each stimulation with the intention of collecting eggs.
Egg Collection	This table should include a record for each egg collection
Mixing of eggs and sperm	This table should include a record for each mixing of eggs from an identifiable person with the sperm from an identifiable person. Separate records need to be created where the eggs from one person are mixed with sperm from 2 different men. This includes the record of transfer or storage of embryos created from the mixing.
Frozen embryo transfers	This table should include a record for each time frozen embryos are thawed for transfer. It also records where embryos are

	thawed and then re-frozen.
Early Outcome	This table should include a record for each embryo transfer event
Outcome of pregnancy	This table should include a record for the outcome of each embryo transfer event that resulted in a pregnancy and holds information that would be common to several fetal outcomes. The detailed outcome from each fetal heart should be included on fetal outcomes table.
Individual fetal outcomes of pregnancy	This table should have a record for every fetal heartbeat indicated on early outcome form for the treatment. Information common to the fetal outcomes, e.g. country of birth is included on outcome.
Transfer out	This table should have a record for each transfer out of eggs or embryos or donor sperm.
Transfer in	This table should have a record for each transfer in of eggs or embryos or donor sperm.
Consent variation	This table should have a record when a patient wished to vary their consent from the originally submitted. The consent covered in this table is the consent to use of their identifying information in contact or non-contact research.

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Patient details table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre.	an4		0001 - 9999
Local Patient Identifier	PATIENTNO	This is the number given to the patient by the centre. This is allocated by the centre, unique within the centre and used by the centre.	an13		
Patient Forenames	Forename	The forenames of the female patient who will receive embryo transfer or insemination with intention of giving birth to a child. This will be as written on their NHS number/ID.	an50		Free text
Patient Surname	Surname	The surname of the female patient who gave birth to the child. This will be as written on their NHS number/ID.	an50		Free text
Patient Date of birth	DoB	Date of birth of the patient	Date		
Unusual DoB confirmation	UnusualDOB	This is for centres to provide confirmation on dates of birth which show the patient is under 18 or over 49 at the time of registration or treatment. Centre will be prompted to confirm the DoB is correct when a patient's calculated age at registration or treatment is under 18 or over 50.	a1	Y	Should be set to Y when asked and DoB is correct.
Patient Surname at birth	surnameAtBirth	Surname of patient at birth (if different from current)	an50		Free text
Patient Town or district of birth	BirthTownDistrict	Town or district of birth of the patient	an50		Free text
Patient Country of birth	birthCountry	Country of birth of the patient	a3		ISO codes
				ZZZ	Not stated
				EEE	England
				WWW	Wales
				SSS	Scotland
IDENTIFIER TYPE	IDType	Indicates what sort of identifier the patient has supplied. It is expected that patients will provide NHS / CHI / HCN numbers but where if not this shows reason and what number was provided instead. Only NHS numbers can be traced by HSCIC.	an1	1	NHS number has been provided
				2	CHI - Community Health Index (Scotland) provided.
				3	HCN - Health Care Number (Northern Ireland) provided
				4	Travelled from abroad for treatment - passport number provided
				5	UK resident unable to provide NHS/CHI/HCN number - passport provided instead

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
				6	UK resident where neither NHS/CHI/HCN or passport number supplied but another identifier, e.g. driving licence
NHS / CHI / HCN NUMBER	NHSCHIHCONO	This is the NHS / CHI / HCN number of the patient.	n10		
NHS NUMBER STATUS INDICATOR CODE	NHSNOStatus	Where NHS number has been given this Indicates the status of the NHS Code	an2	01 02 03 04 05 06 07 08	Number present and verified Number present but not traced Trace required Trace attempted - No match or multiple match found Trace needs to be resolved - (NHS Number or PATIENT detail conflict) Trace in progress Number not present and trace not required Trace postponed (baby under six weeks old)
PassportNo	PassportNo	Passport number of patient provided for identification purposes	an20		
Passport country of issue	PassportCountry	Country of issue of passport whose number has been entered in passport number field	a3		ISO 3 character country codes
Patient Ethnic Category Code	ETHNIC	The ethnicity of a PATIENT, as specified by the PATIENT. The first character of the value must be from the list below.	an2		<p>White</p> <p>A British</p> <p>B Irish</p> <p>C Any other White background</p> <p>Mixed</p> <p>D White and Black Caribbean</p> <p>E White and Black African</p> <p>F White and Asian</p> <p>G Any other mixed background</p> <p>Asian or Asian British</p> <p>H Indian</p> <p>J Pakistani</p> <p>K Bangladeshi</p> <p>L Any other Asian background</p> <p>Black or Black British</p> <p>M Caribbean</p> <p>N African</p> <p>P Any other Black background</p>

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
				Other Ethnic Groups	
				R	Chinese
				S	Any other ethnic group
				Z	Not Stated
Is the patient disabled	Disabled	Records whether the patient is disabled. This is self-declared by the patient and does not have to be registered disability.	an1	Y	Patient has indicated that they have a disability
				N	Patient has indicated that they have NO disability
Number of previous natural or DI pregnancies	previousNaturalDIPregnancies	A pregnancy is said to have occurred if a test on a sample of urine or blood to detect pregnancy hormone (β hCG) is positive or an ultrasound scan confirms a gestation at any site. This will include a pregnancy reported by the patient even if it was not confirmed in a clinic/GP. It includes pregnancies to any partner.	n2		
Number of natural or DI live births	NaturalDILiveBirths	The number of live birth events that result from a conception that did not involve IVF(including ICSI). This will be as reported by the patient. It includes pregnancies to any partner. It includes conception involving donor insemination.	n2		
Number of previous IVF	PreviousIVFPregnancies	The number of IVF treatments previously started in which stimulation medication was taken or treatment was intended in a natural ovarian cycle. This information is reported as given by the patient at the start of treatment. It includes pregnancies to any partner.	n2		
Number of IVF live births	IVFLiveBirths	The number of live birth events from a conception that involved IVF(including ICSI) and frozen/thawed embryos. This information is reported as given by the patient at the start of the treatment. It includes pregnancies to any partner.	n2		
Date that intercourse without contraception started.	DateInfertilityStart	From this date, the duration of Infertility can be calculated. This will be approximate date in most cases. Where month is known 15 should be used as day, where only year is known use 1 July, e.g. 01/07/2013. It indicates the date at which the couple stopped using contraception with the assumption that it would then be possible to conceive. If there has been no chance of pregnancy i.e. the partner has had a vasectomy or same sex couple this should be left blank. If the patient has had a previous live birth, this date relates to the period after that pregnancy.	an10		
Height in metres	HeightM	The height in metres of the patient at the time of registration.	n1. max n2		
Weight in kilograms	WeightKGS	The weight in kilograms of the patient at the time of registration	n3.max n3		
Body Mass Index (BMI)	BMI	Body mass index of patient at time of registration. This will be calculated for the centre if height and weight are provided.	n2.n1		

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
Consent to non-contact research	ConsentNonContactResearch	This is taken from the CD form completed by the patient in 'Disclosing your identifying information ..' section. This records whether they agreed or not to non-contact research.	an1	Y	Yes
				N	No
Consent to contact research	ConsentContactResearch	This is taken from the CD form completed by the patient in 'Disclosing your identifying information ..' section. This records whether they agreed or not to contact research.	an1	Y	Yes
				N	No
Comments on any part of the patients details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		
Date comment added	CommentDate	This is the date the comment was added.	Date		

Partner details table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre.	an4		
Local Patient Identifier	PARTNERNO	This is the number given to the partner by the centre. This is unique within the centre, allocated and used by the centre.	an13		
Link to patient	PATIENTNO	This is unique number of the patient who is linked to this partner. This provides link between partner and patient records.	an13		
Forenames	Forename	The forenames of the partner. This will be as written on their NHS number/ID.	an50		Free text
Surname	Surname	The surname of the partner. This will be as written on their NHS number/ID.	an50		Free text
Date of birth	DoB	Date of birth of this individual	Date		
Surname at birth	surnameAtBirth	Surname of partner at birth (if different to current surname)	an50		
Gender of the partner	PartnerGender	This is the sex of the partner, if they are a gamete provider within a treatment cycle this should define their role of either egg or sperm source. Thus a transsexual male to female whose sperm was being used in treatment should be recorded as male.	an1	1	Male
				2	Female
Town or district of birth	BirthTownDistrict	Town or district of birth of the partner	an50		
Partner Country of birth	BirthCountry	Country of birth of the partner	a3		ISO country codes
				ZZZ	Not stated
				EEE	England
				WWW	Wales
				SSS	Scotland

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
				NNN	Northern Ireland
IDENTIFIER TYPE	IDType	Indicates what sort of identifier the partner has supplied. It is expected that partners will provide NHS / CHI / HCN numbers but where this is not possible this shows reason and what number was provided instead. Only NHS numbers can be traced by HSCIC.	an1	1	NHS number has been provided
				2	CHI - Community Health Index (Scotland) provided.
				3	HCN - Health Care Number (Northern Ireland) provided
				4	Travelled from abroad for treatment - passport number provided
				5	UK resident unable to provide NHS/CHI/HCN number - passport provided instead
				6	UK resident where neither NHS/CHI/HCN or passport number supplied but another identifier, e.g., driving licence
NHS / CHI / HCN NUMBER	NHSCHIHCN NO	This is the NHS / CHI / HCN number of the partner	n10		
NHS NUMBER STATUS INDICATOR CODE	NHSNOSatus	Indicates the status of the NHS Code	an2	01	Number present and verified
				02	Number present but not traced
				03	Trace required
				04	Trace attempted - No match or multiple match found
				05	Trace needs to be resolved - (NHS Number or PATIENT detail conflict)
				06	Trace in progress
				07	Number not present and trace not required
				08	Trace postponed (baby under six weeks old)
PassportNo	PassportNo	Passport number of partner provided for identification purposes	an20		
Passport country of issue	PassportCountry	Country of issue of passport whose number has been entered in passport number field	a3		
Ethnic Category	ETHNIC	The ethnicity of a PARTNER as specified by the PARTNER. The first character of the value must be from the list below.	an2	White	
				A	British
				B	Irish
				C	Any other White background

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
				Mixed	
				D	White and Black Caribbean
				E	White and Black African
				F	White and Asian
				G	Any other mixed background
				Asian or Asian British	
				H	Indian
				J	Pakistani
				K	Bangladeshi
				L	Any other Asian background
				Black or Black British	
				M	Caribbean
				N	African
				P	Any other Black background
				Other Ethnic Groups	
				R	Chinese
				S	Any other ethnic group
				Z	Not Stated
Consent to non-contact research	consentNonContactResearch	This is taken from the CD form completed by the person in 'Disclosing your identifying information ..' section. This records whether they agreed or not to non-contact research.	an1	Y	Yes
				N	No
Consent to contact research	consentContactResearch	This is taken from the CD form completed by the person in 'Disclosing your identifying information ..' section. This records whether they agreed or not to contact research.	an1	Y	Yes
				N	No
Comments on any part of the partner details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		
Date comment added	CommentDate	This is the date that the comment was added.	Date		

Intended Parent details table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre.	an4		
Local Patient Identifier	IntendParentNo	This is the number given to the intended parent by the centre. This is unique within the centre and used by the centre.	an13		
Forenames	forename	The forenames of the intended parent. This will be as written on their NHS number/ID.	an50		
Surname	surname	The surname of the intended parent who gave birth to the child. This will be as written on their NHS number/ID.	an50		

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
Date of birth	DoB	Date of birth of this of the intended parent	Date		
Surname at birth	surnameAtBirth	Surname of intended parent at birth	an50		
Gender of the intended parent	gender	This is the biological sex of the partner, if they are a gamete provider within a treatment cycle this should define their role of either egg or sperm source. Thus a transsexual male to female whose sperm was being used in treatment should be recorded as male.	an1	1	Male
				2	Female
Town or district of birth	birthTown/district	Town or district of birth of the intended parent	an30		
Intended parent Country of birth	birthCountry	Country of birth of the intended parent	a3		ISO codes
				ZZZ	Not stated
				EEE	England
				WWW	Wales
				SSS	Scotland
	NNN	Northern Ireland			
IDENTIFIER TYPE	IDType	Indicates what sort of identifier the intended parent has supplied. It is expected that intended parents will provide NHS / CHI / HCN numbers but where if not this shows reason and what number was provided instead. Only NHS numbers can be traced by HSCIC.	an1	1	NHS number has been provided
				2	CHI - Community Health Index (Scotland) provided.
				3	HCN - Health Care Number (Northern Ireland) provided
				4	Travelled from abroad for treatment - passport number provided
				5	UK resident unable to provide NHS/CHI/HCN number - passport provided instead
				6	UK resident where neither NHS/CHI/HCN or passport number supplied but another identifier, e.g., driving licence
NHS / CHI / HCN NUMBER	NHSCHIHCONO	This is the NHS/CHI/HCN number of the intended parent.	n10		
NHS NUMBER STATUS INDICATOR CODE	NHSNOSStatus	Indicates the status of the NHS Code	an2	01	Number present and verified
				02	Number present but not traced
				03	Trace required
				04	Trace attempted - No match or multiple match found

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
				05	Trace needs to be resolved - (NHS Number or PATIENT detail conflict)
				06	Trace in progress
				07	Number not present and trace not required
				08	Trace postponed (baby under six weeks old)
PassportNo	PassportNo	Passport number of intended parent provided for identification purposes	an20		
Passport country of issue	PassportCountry	Country of issue of passport whose number has been entered in passport number field	a3	ISO Codes	
Ethnic Category	ETHNIC	The ethnicity of an intended parent as specified by the intended parent. The first character of the value must be from the list below.	an2		
				White	
				A	British
				B	Irish
				C	Any other White background
				Mixed	
				D	White and Black Caribbean
				E	White and Black African
				F	White and Asian
				G	Any other mixed background
				Asian or Asian British	
				H	Indian
				J	Pakistani
				K	Bangladeshi
				L	Any other Asian background
				Black or Black British	
				M	Caribbean
				N	African
				P	Any other Black background
				Other Ethnic Groups	
				R	Chinese
				S	Any other ethnic group
				Z	Not Stated
Last UK centre if treatment elsewhere	lastUKTreatmentClinic	If intended parent has been treated elsewhere this is centre code of last UK treatment.	an4		
Consent to non-contact research	consentNonContactResearch	This is taken from the CD form completed by the intended parent in 'Disclosing your identifying information ..' section. This records whether they agreed or not to non-contact research.	an1	Y	Yes
				N	No
Consent to contact research	consentContactResearch	This is taken from the CD form completed by the intended parent in 'Disclosing your identifying information ..' section. This	an1	Y	Yes
				N	No

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
		records whether they agreed or not to contact research.			
Comments on any part of the intended parent details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		
Date comment added	CommentDate	This is the date that the comment was added.	Date		

Donor details table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre.	an4		0001 - 9999
NUMBER OF DONOR	DONORNO	This is the unique number given to the donor in the clinic when gametes are collected and stored. If the donor has been imported from outside the UK the centre will register the donor and the first 2 characters should represent the country where the donor lived at time of donation.	an13		
Donor current surname	Surname	The current surname of the donor as written on their NHS number/ID.	an50		
Donor forenames	ForeName	The current forenames of the donor as written on their NHS number or ID.	an50		
Donor surname at birth (if different)	SurnameAtBirth	The surname of the donor at birth	an50		
Donor forenames at birth (if different)	ForeNameAtBirth	Any previously used forenames	an50		
Date of birth of donor	DoB	Date of birth of the donor	an10		
Town or district of birth	birthTown/district	Town of District of birth of the donor	an30		
Donor Country of birth	BirthCountry	The country of birth of the donor	a3		ISO 3 character country codes
				ZZZ	Not stated
				EEE	England
				WWW	Wales
				SSS	Scotland
IDENTIFIER TYPE	IDType	Indicates what sort of identifier the donor has supplied. It is expected that donor will provide NHS / CHI / HCN numbers but where if not this shows reason and what number was provided instead. Only NHS numbers can be traced by HSCIC.	an1	1	NHS number has been provided
				2	CHI - Community Health Index (Scotland) provided.
				3	HCN - Health Care Number

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
					(Northern Ireland) provided
				4	Travelled from abroad for treatment - passport number provided
				5	UK resident unable to provide NHS/CHI/HCN number - passport provided instead
				6	UK resident where neither NHS/CHI/HCN or passport number supplied but another identifier, e.g., driving licence
NHS / CHI / HCN NUMBER	NHSCHIHCONO	This is the NHS/CHI/HCN number of the donor.	n10		
NHS NUMBER STATUS INDICATOR CODE	NHSNOSatus	Indicates the status of the NHS Code	an2	01	Number present and verified
				02	Number present but not traced
				03	Trace required
				04	Trace attempted - No match or multiple match found
				05	Trace needs to be resolved - (NHS Number or PATIENT detail conflict)
				06	Trace in progress
				07	Number not present and trace not required
				08	Trace postponed (baby under six weeks old)
PassportNo	PassportNo	Passport number of patient provided for identification purposes	an15		
Passport country of issue	PassportCountry	Country of issue of passport whose number has been entered in passport number field	a3		ISO 3 character country codes
Current address	BS7666Address	The address of the donor at the time of donation			
Donor phone	DonorPhone	This is the contact phone number provided by the donor.	an20		
Donor email	DonorEmail	This is the email provided by the donor.	an100		
Person marital status	MaritalStatus	An indicator to identify the legal marital status of a DONOR.	an1	S	Single
				M	Married / In Civil Partnership
				D	Divorced/Person whose Civil Partnership has been dissolved

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
				W	Widowed/Surviving Civil Partner
				P	Separated
				N	Not Disclosed
Does donor have own biological children?	OwnBiologicalChildren	This asks if the donor has their own biological children and should be answered Y/N. If yes the number of boys and girls needs to be completed	an1	Y	Yes
				N	No
Number of own boys	OwnChildrenBoys	This is the number of male children born to this donor at the time of donation..	n2		
Number of own girls	OwnChildrenGirls	This is the number of female children born to this donor at the time of donation.	n2		
Height in metres	HeightM	The height in metres of the donor at the time of donation.	n1. max n2		
Weight in Kilograms	WeightKGS	The weight in kilograms of the donor at the time of donation	n3.max n3		
Eye colour of donor	EyeColourLookUpID	The eye colour of the donor.	an2	01	Blue
				02	Brown
				03	Green
				04	Grey
				05	Hazel
				06	Green/brown
				07	Blue/Grey
				08	Blue/Green
				09	Green/Grey
				10	Green/Hazel
				11	Black
				12	Blue/Green/Grey
				13	Dark Brown
Natural Hair colour of donor	HairColourID	The natural hair colour of the donor.	an2	01	Black
				02	Blonde dark
				03	Blonde light
				04	Brown dark
				05	Brown light
				06	Red
Skin colour of donor	SkinColourID	The skin colour of the donor.	an2	01	Light/Fair
				02	Medium
				03	Dark
				04	Freckles
				05	Olive
Last UK centre if donated previously	lastUKTreatmentClinic	If donor has donated elsewhere this is centre code of last UK donation treatment. If the donor is known to have also donated	an4		

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
		outside the centres should enter 9005			
Was the donor adopted?	adopted	If the donor knows that they were adopted, this is recorded as 'yes'.	an1	Y	Yes
				N	No
Was the donor conceived by donation?	conceivedByDonation	If the donor knows that they were donor-conceived, this is recorded as 'yes'.	an1	Y	Yes
				N	No
Ethnic category of donor	ETHNIC	The ethnicity of a DONOR, as specified by the DONOR. The first character of the value must be from the list below.	an1	White	
				A	British
				B	Irish
				C	Any other White background
				Mixed	
				D	White and Black Caribbean
				E	White and Black African
				F	White and Asian
				G	Any other mixed background
				Asian or Asian British	
				H	Indian
				J	Pakistani
				K	Bangladeshi
				L	Any other Asian background
				Black or Black British	
				M	Caribbean
				N	African
P	Any other Black background				
Other Ethnic Groups					
R	Chinese				
S	Any other ethnic group				
Z	Not Stated				
Ethnic group of donor's mother	mothersEthnicity	The ethnicity of the mother of the DONOR, as specified by the DONOR. The first character of the value must be from the list below.	an1	White	
				A	British
				B	Irish
				C	Any other White background
				Mixed	
				D	White and Black Caribbean
				E	White and Black African
				F	White and Asian
				G	Any other mixed background
				Asian or Asian British	
				H	Indian
				J	Pakistani
				K	Bangladeshi

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
				L	Any other Asian background
				Black or Black British	
				M	Caribbean
				N	African
				P	Any other Black background
				Other Ethnic Groups	
				R	Chinese
				S	Any other ethnic group
				Z	Not Stated
Ethnic group of donor's father	FathersEthnicity	The ethnicity of the father of the DONOR, as specified by the DONOR. The first character of the value must be from the list below.	an1	White	
				A	British
				B	Irish
				C	Any other White background
				Mixed	
				D	White and Black Caribbean
				E	White and Black African
				F	White and Asian
				G	Any other mixed background
				Asian or Asian British	
				H	Indian
				J	Pakistani
				K	Bangladeshi
				L	Any other Asian background
				Black or Black British	
				M	Caribbean
				N	African
				P	Any other Black background
				Other Ethnic Groups	
				R	Chinese
				S	Any other ethnic group
				Z	Not Stated
How many families has the donor consented to?	LimitFamilyNo	This is the information that is recorded in the clinical records about the decision made by the donor in relation to the maximum number of family units that they wish to result from their donation. This value can't be more than 10.	n2		
Consent to non-contact research	consentNonContactResearch	This is taken from the CD form completed by the donor in 'Disclosing your identifying information ..' section. This records whether they agreed or not to non-contact research.	an1	Y	Yes
				N	No
Consent to contact research	consentContactResearch	This is taken from the CD form completed by the donor in 'Disclosing your identifying information ..' section. This records whether they agreed or not to contact research.	an1	Y	Yes
				N	No

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
Comments on any part of the intended parent details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		
Date comment added	CommentDate	This is the date that the comment was added.	Date		

Donor Re-registration table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre. This is the centre where donor was registered.	an4		
Local Donor Identifier	DONORNO	This is the donor number given to the donor by the centre, This will be a unique reference number within the centre and will be the number by which the centre have recorded details of the donor. Centres need to register donors which they have recruited or imported from outside the UK.	an13		
Donor current surname	surname	The current surname of the donor as written on their NHS number/ID.	an50		
Donor forenames	foreName	The current forename of the donor as written on their NHS number/ID.	an50		
Donor surname at birth (if different)	surnameAtBirth	The surname of the donor at birth	an50		
Donor forenames at birth (if different)	foreNameAtBirth	Any previously used forenames	an50		
Date of birth of donor	DoB	Date of birth of the donor	Date		
Town or district of birth	birthTown/district	Town of District of birth of the donor	an50		
Donor Country of birth	birthCountry	The country of birth of the donor	a3		ISO codes ZZZ Not stated EEE England WWW Wales SSS Scotland NNN Northern Ireland
IDENTIFIER TYPE	IDType	Indicates what sort of identifier the donor has supplied. It is expected that donor will provide NHS / CHI / HCN numbers but where if not this shows reason and what number was provided instead. Only NHS numbers can be traced by HSCIC.	an1		1 NHS number has been provided 2 CHI - Community Health Index (Scotland) provided. 3 HCN - Health Care Number (Northern Ireland) provided

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
				4	Travelled from abroad for treatment - passport number provided
				5	UK resident unable to provide NHS/CHI/HCN number - passport provided instead
				6	UK resident where neither NHS/CHI/HCN or passport number supplied but another identifier, e.g., driving licence
NHS / CHI / HCN NUMBER	NHSCHIHCNN O	This is the NHS/CHI/HCN number of the donor.	n10		
NHS NUMBER STATUS INDICATOR CODE	NHSNOSatus	Indicates the status of the NHS Code	an2	01	Number present and verified
				02	Number present but not traced
				03	Trace required
				04	Trace attempted - No match or multiple match found
				05	Trace needs to be resolved - (NHS Number or PATIENT detail conflict)
				06	Trace in progress
				07	Number not present and trace not required
				08	Trace postponed (baby under six weeks old)
PassportNo	PassportNo	Passport number of patient provided for identification purposes	an15		
Passport country of issue	PassportCountry	Country of issue of passport whose number has been entered in passport number field	a3		ISO country codes
Current address	BS7666Address	The address of the donor at the time of donation			
Gender of the donor	gender	This is the gender as provided on the donor re-registration application of the individual.	an1	1	Male
				2	Female
Donor phone	DonorPhone	This is the contact phone number provided by the re-registering donor.	an20		
Donor email	DonorEmail	This is the email provided by the re-registering donor.	an100		
Comments on any part of the donor re-registration details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		
Date comment added	CommentDate	This is the date that the comment was added.	Date		

Mitochondrial Donor table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre.	an4		
Local Patient Identifier	DONORNO	This is the number given to the mitochondrial donor by the centre. This is unique within the centre and used by the centre	an13		
Forenames	forename	The forenames of the mitochondrial donor. This will be as written on their NHS number/ID.	an50		
Surname	surname	The surname of the mitochondrial donor who gave birth to the child. This will be as written on their NHS number/ID.	an50		
Date of birth	DoB	Date of birth of Donor	an10		
Surname at birth	surnameAtBirth	Surname of mitochondrial donor at birth	an50		
Town or district of birth	birthTown/district	Town or district of birth of the mitochondrial donor	an30		
Donor Country of birth	birthCountry	Country of birth of the mitochondrial donor	a3		ISO country codes
				ZZZ	Not stated
				EEE	England
				WWW	Wales
				SSS	Scotland
				NNN	Northern Ireland
IDENTIFIER TYPE	IDtype	Indicates what sort of identifier the donor has supplied. It is expected that donor will provide NHS / CHI / HCN numbers but where if not this shows reason and what number was provided instead. Only NHS numbers can be traced by HSCIC.	an1		
				1	NHS number has been provided
				2	CHI - Community Health Index (Scotland) provided.
				3	HCN - Health Care Number (Northern Ireland) provided
				4	Travelled from abroad for treatment - passport number provided
				5	UK resident unable to provide NHS/CHI/HCN number - passport provided instead
				6	UK resident where neither NHS/CHI/HCN or passport number supplied but another identifier, e.g., driving licence
NHS / CHI / HCN NUMBER	NHSCHIHCONO	This is the NHS/CHI/HCN number of the donor.	n10		
NHS NUMBER STATUS INDICATOR CODE	NHSNOSStatus	Indicates the status of the NHS Code	an2		
				01	Number present and verified
				02	Number present but not traced

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
				03	Trace required
				04	Trace attempted - No match or multiple match found
				05	Trace needs to be resolved - (NHS Number or PATIENT detail conflict)
				06	Trace in progress
				07	Number not present and trace not required
				08	Trace postponed (baby under six weeks old)
PassportNo	PassportNo	Passport number of mitochondrial donor provided for identification purposes	an20		
Passport country of issue	PassportCountry	Country of issue of passport whose number has been entered in passport number field	a3		ISO codes
<u>Ethnic Category</u>	ETHNIC	The ethnicity of a mitochondrial donor as specified by the mitochondrial donor. The first character of the value must be from the list below.	an2		
				White	
				A	British
				B	Irish
				C	Any other White background
				Mixed	
				D	White and Black Caribbean
				E	White and Black African
				F	White and Asian
				G	Any other mixed background
				Asian or Asian British	
				H	Indian
				J	Pakistani
				K	Bangladeshi
				L	Any other Asian background
				Black or Black British	
				M	Caribbean
				N	African
				P	Any other Black background
				Other Ethnic Groups	
				R	Chinese
				S	Any other ethnic group
				Z	Not Stated
Last UK centre if treatment elsewhere	lastUKTreatmentClinic	If mitochondrial donor has been treated elsewhere this is centre code of last UK donation.	an4		
Consent to non-contact research	consentNonContactResearch	This is taken from the CD form completed by the mitochondrial donor in 'Disclosing your identifying information ..' section. This	an1	Y	Yes
				N	No

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
		records whether they agreed or not to non-contact research.			
Consent to contact research	consentContactResearch	This is taken from the CD form completed by the mitochondrial donor in 'Disclosing your identifying information ..' section. This records whether they agreed or not to contact research.	an1	Y	Yes
				N	No
Comments on any part of the mitochondrial donor details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		
Date comment added	CommentDate	This is the date that the comment was added.	Date		

PNT only sperm donor details table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre.	an4		
NUMBER OF DONOR	DONORNO	This is the unique number given to the donor in the clinic when gametes are collected and stored.	an13		
Donor current surname	surname	The current surname of the donor as written on their NHS number/ID.	an50		
Donor forenames	foreName	The current forenames of the donor as written on their NHS number or ID.	an50		
Donor surname at birth (if different)	surnameAtBirth	The surname of the donor at birth	an50		
Donor forenames at birth (if different)	foreNameAtBirth	Any previously used forenames	an50		
Date of birth of donor	DoB	Date of birth of the donor	an10		
Town or district of birth	birthTown/district	Town of District of birth of the donor	an50		
Donor Country of birth	birthCountry	The country of birth of the donor	a3		ISO country codes
				ZZZ	Not stated
				EEE	England
				WWW	Wales
				SSS	Scotland
IDENTIFIER TYPE	IDtype	Indicates what sort of identifier the donor has supplied. It is expected that donor will provide NHS / CHI / HCN numbers but where if not this shows reason and what number was provided instead. Only NHS numbers can be traced by HSCIC.	an1	1	NHS number has been provided
				2	CHI - Community Health Index (Scotland) provided.

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
				3	HCN - Health Care Number (Northern Ireland) provided
				4	Travelled from abroad for treatment - passport number provided
				5	UK resident unable to provide NHS/CHI/HCN number - passport provided instead
				6	UK resident where neither NHS/CHI/HCN or passport number supplied but another identifier, e.g., driving licence
NHS / CHI / HCN NUMBER	NHSCHIHENNO	This is the NHS/CHI/HCN number of the donor.	n10		
NHS NUMBER STATUS INDICATOR CODE	NHSNOSTatus	Indicates the status of the NHS Code	an2	01	Number present and verified
				02	Number present but not traced
				03	Trace required
				04	Trace attempted - No match or multiple match found
				05	Trace needs to be resolved - (NHS Number or PATIENT detail conflict)
				06	Trace in progress
				07	Number not present and trace not required
				08	Trace postponed (baby under six weeks old)
PassportNo	PassportNo	Passport number of patient provided for identification purposes	an15		
Passport country of issue	PassportCountry	Country of issue of passport whose number has been entered in passport number field	a3		ISO codes
Ethnic Category	ETHNIC	The ethnicity of a PNT only sperm donor as specified by the PNT only sperm donor. The first character of the value must be from the list below.	an2		White
				A	British
				B	Irish
				C	Any other White background
					Mixed
				D	White and Black Caribbean
				E	White and Black African
				F	White and Asian
				G	Any other mixed background

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
					Asian or Asian British
				H	Indian
				J	Pakistani
				K	Bangladeshi
				L	Any other Asian background
					Black or Black British
				M	Caribbean
				N	African
				P	Any other Black background
					Other Ethnic Groups
				R	Chinese
				S	Any other ethnic group
				Z	Not Stated
Consent to non-contact research	consentNonContactResearch	This is taken from the CD form completed by the PNT only sperm donor in 'Disclosing your identifying information ..' section. This records whether they agreed or not to non-contact research.	an1	Y	Yes
				N	No
Consent to contact research	consentContactResearch	This is taken from the CD form completed by the PNT only sperm donor in 'Disclosing your identifying information ..' section. This records whether they agreed or not to contact research.	an1	Y	Yes
				N	No
Comments on any part of the PNT only sperm donor details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		
Date comment added	CommentDate	This is the date the comment was added.	Date		

Treatment type table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre.	an4		
Local Patient Identifier	PATIENTNO	This is the number given to the patient or egg donor by the centre. This is unique within the centre and used by the centre. If this patient or donor number doesn't exist the centre will be prompted to enter basic registration details.	an13		
Main treatment type	MainTreatmentType	This is the intended primary treatment that is required to be reported under the HFE Act i.e. the creation of a human embryo in vitro or the use of donated gametes for fertility treatment. Multi-	an9	87600016	SNOMED Code - In vitro fertilization - the removal of oocyte(s) from a woman's body which are then placed in culture with a defined population of motile spermatozoa to

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
		options are possible,			assist fertilisation and the formation of a diploid zygote. The zygote then undergoes pre-implantation development 'in vitro' and, if appropriate, is returned to a synchronous uterus.
				338482017	SNOMED Code - ICSI - Intracytoplasmic sperm injection - the removal of oocyte(s) from a woman's body which are then each injected with a single spermatozoa to assist fertilisation and the formation of a diploid zygote. The zygote then undergoes pre-implantation development 'in vitro' and, if appropriate, is returned to a synchronous uterus.
				236896006	SNOMED code - Artificial insemination by donor - The placing of spermatozoa from a man who is not her partner and does not intend to be the father of the child, directly into a woman's uterus with the purpose of fertilising oocytes 'in vivo'.
				441369004	SNOMED code - Thawing of cryopreserved embryo (procedure) -Planned replacement of thawed embryos created in a previous treatment
				440645004	SNOMED code - cryopreservation of oocyte. This is recorded where intention at the start of the stimulation procedure is to store eggs and not to create embryos within that treatment procedure e.g. eggs are to be frozen prior to an oncology treatment.
				236912008	SNOMED Code - Gamete Intrafallopian Transfer - GIFT - This is a rarely performed procedure that should be recorded via data submission.
				MRT	SNOMED code yet to be available - Mitochondrial Replacement Therapy
Secondary treatment type	SecondTreatType	These are additional procedures that are required to be submitted under Directions. Multiple options may be included. Further fields may be required and, it appropriate, these may be separated into clinical, embryology or socio-demographic subtitles.	an2	01	Freeze all / storage of embryos - recorded if there is no intention at the start of the stimulation procedure to transfer embryos to the uterus within that treatment procedure e.g. embryos are to be frozen prior for later transfer or long term storage

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
					due to an oncology treatment
				02	Screening - Whether any screening will be done on one or all embryos. Screening covers pre-implantation genetic diagnosis (PGD) is the removal of polar bodies, or cell (s) during pre-implantation development 'in vitro' for genetic profiling of the pre-implantation embryo for any other reason.
				03	Use of surgically retrieved sperm – The use of spermatozoa obtained by surgical means directly from the testis or the epididymis for the purpose ICSI in males for whom sperm cannot be obtained by ejaculation.
				04	Thawed eggs used. The thawing of oocytes that have been previously cryopreserved which are then injected with a single spermatozoa to assist fertilisation and the formation of a diploid zygote. The zygote then undergoes pre-implantation development 'in vitro' and is returned to a synchronous uterus.
				05	Surrogate - The woman patient who intends to become pregnant does not intend to be the woman who will care for the child as a parent.
				06	Eggs are collected that are not at metaphase 2 and need development for more than 24 hours before insemination.
				07	Unstimulated / natural cycle - No drugs are given to stimulate the ovaries before treatment is provided e.g. clomifene, gonadotrophins, hCG.

Donor Insemination table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre.	an4		
Local Patient Identifier	PATIENTNO	This is the number given to the patient by the centre. This is unique within the centre and used by the centre.	an13		
Donor Insemination ID	DonorInsemID	Unique number at centre identifying this DI treatment. This is generated for those submitting directly or supplied by EPRS submitter.	an12		
Sperm donor centre	donorSpermCentre	This is the centre number where the sperm donor is registered. This will be the centre which recruited and procured the donor sperm or imported the sperm from abroad.	an4		
Sperm donor code	spermDonorNumber	This is donor number allocated by the donor sperm centre and unique within the donor centre. If the donor has been imported this code will start with 2 digit country code indicating donor's country of residence at time of donation.	an13		
Stimulated or not	Stimulated	Whether the patient has been stimulated or not before the donor insemination treatment	an1	Y N	Yes No
Date of insemination	DITreatmentDate	This is the first date of insemination. Only the first date of insemination needs to be recorded where the patient is inseminated with donor sperm on several consecutive days	an10		Date as YYYYMMDD
NHS funded treatment?	NHSFunded	States whether NHS funded treatment or not.	an1	Y N	Yes No
Organisation funding treatment	commissioningOrg	The commissioning body where the cycle has been NHS funded - this could be CCG in England, health board in Scotland, Wales or Northern Ireland	an50		
Comments on any part of the donor insemination details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		
Date comment added	CommentDate	This is the date that the comment was added.	Date		

Egg stimulation details table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre.	an4		
Local Patient Identifier	PATIENTNO	This is the number given to the patient by the centre. This is unique within the centre and used by the centre.	an13		

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
Stimulation date	Stimdate	This is the date stimulation was started for the egg collection process	an10		Date as YYYYMMDD
Stimulation organiser	StimOrganiser	If the stimulation will not or was not done at the centre reporting the subsequent egg collection and mixing or storage then this field records the type of organisation who did organise stimulation for the patient.	an1	1	All stages of treatment completed at this centre.
				2	Stimulation and pre-stimulation patient care completed at satellite or transport centre.
Stimulation location	StimLocation	This will be the centre code or satellite or transport code where stimulation took place.	an8		
Comments on any part of the stimulation details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		
Date comment added	CommentDate	This is the date that the comment was added.	Date		

Egg collection details table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre.	an4		
Local Patient Identifier	PATIENTNO	This is the number given to the patient or egg donor by the centre. This is unique within the centre and used by the centre. If this patient or donor number doesn't exist the centre will be prompted to enter basic registration details.	an13		
Egg collection number	EggCollectionRecord	This is unique number identifying the egg collection	an12		
Egg collection organiser	EggCollOrganiser	If the egg collection was not done at the centre reporting the egg collection and mixing or storage then this field records the type of organisation who did egg collection for the patient.	an1	1	All stages of treatment completed at this centre.
				2	Egg collection, stimulation and pre-stimulation patient care completed at transport centre.
Egg collection location	EggCollLocation	This will be the centre code or satellite or transport centre code where stimulation took place.	an8		

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
Egg collection/ abandonment/ thaw of eggs date/Freeze date	EggDate	This is date that the eggs are collected or the date that the decision is made to abandon a planned IVF or ICSI treatment after the stimulation of the ovaries has started but the egg collection has not taken place. If thawed eggs are used, this is the date of the thawing of the eggs. If any eggs collected are frozen this is the date of freezing.	an10		
EggDate indicator	EggDateFlag	This flags whether the eggdate refers to a collection date or a cycle abandoned date or an egg thaw date.	an1	1 2 3	Fresh egg collection date Egg collection abandoned date - when no egg collection was attempted Egg thaw date
Total number of eggs collected from patient	TotalEggsCollected	Total number of eggs collected from patient	n3		
Unusual egg number confirmation	Unusualeggnumbers	This is for centres to provide confirmation egg numbers if they are unusual in the context of the egg collection. This will apply if egg collection is unstimulated but not IVM and more than 2 eggs are collected or if more than 40 eggs are collected.	a1	Y	Should be set to Y when asked and data is correct.
Number of eggs mixed IVF		This is the number of eggs to which sperm were added by conventional insemination	n2		
Number of eggs injected with sperm ICSI		This is the number of eggs injected using the technique of ICSI	n2		
Number of eggs donated fresh	EggsDonatedFresh	Number of eggs donated for use by egg recipient fresh	n2		
Number of eggs donated for mitochondria donation treatment only	EggMitoDonated	Number of eggs donated for use in mitochondrial donation treatment	n2		
Number donated for research	EggsResearch	Number of eggs donated for research	n2		
Number of eggs stored for patient	EggsFrozen	Number of eggs stored for future use by patient	n2		
Number of eggs donated frozen	EggsDonatedFrozen	Number of eggs donated which have been stored for future recipient	n2		
Method of egg freezing	EggFreezeMethod	Method of egg freezing. Where eggs have been stored for future use of patient or donated for future use is defined the method of freezing.	an1	1 2	Frozen via vitrification method Frozen using slow freeze method

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
Number of eggs discarded	EggsDiscarded	Number of eggs discarded, those which are not suitable for fresh mixing, donation or frozen	n2		
Comments on any part of the donor insemination details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		
Date comment added	CommentDate	This is the date that the comment was added.	Date		

Mixing details of an individual woman's eggs with an individual man's sperm

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre.	an4		
Local Patient Identifier	PATIENTNO	This is the number given to the patient by the centre. This is unique within the centre and used by the centre. This is the female who	an13		
MixingID	MixingID	This is unique number identifying generated by the centre for this mixing event	an12		
Gamete source	Gamete source	Gamete source. Each mixing can only have one egg provider (either patient's own eggs or donated eggs) and one sperm provided (either from the patients' partner or from a donor)	an1	1	Patient eggs and partner sperm
				2	Patient eggs and donor sperm
				3	Donor eggs and patient's partners sperm
				4	Donor eggs and donor sperm
Egg collection number	EggCollectionRecord	This is the record number of the egg collection which is the source of the eggs being mixed. When the mixing event is using donated eggs this is the egg collection number which records the donated eggs collection or transfer file number import for imported donor eggs	an12		
Partner number	PartnerNo	The number of the patient's partner whose sperm is being used in the creation of embryos	an13		
Sperm donor centre	SpermDonorCentre	This is the centre number where the sperm donor is registered. This will be the centre which recruited and procured the donor sperm or imported the sperm from abroad.	an4		

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
Sperm donor code	SpermDonorNumber	This is donor number allocated to the sperm donor by the sperm donor centre and unique within the centre who have registered the donor.	an13		
Egg donor centre	EggDonorCentre	This is the centre number where the egg donor is registered. This will be the centre which recruited and procured the donor eggs or imported the eggs from outside UK.	an4		
Egg donor code	EggDonorNumber	This is donor number allocated by the egg donor centre and unique within the egg donor centre.	an13		
Egg and sperm mixing date	MixingDate	This is the date of egg and sperm mixing where different to the egg collection date	an10		
Number of embryos developed after IVF.	IVFembryos	This is the number of inseminated eggs that developed into embryos.	n2		
Number of embryos developed after ICSI.	ICSIembryos	This is the number of injected eggs that developed into embryos	n2		
Embryo biopsy	EmbryoBiopsy	This records if embryo biopsy has occurred and which types.	an1	0	NONE
				1	PGD
				2	PGS
				3	HLA
				4	OTHER
Date of embryo transfer	EmbryoTransferDate	This is the date the embryo transfer occurred.	an10		
No. of embryo's transferred	EmbryoTransferNumber	This is the number of embryos transferred.	n1		
Elective single embryo transfer	eSET	Elective single embryo transfers are those where a single embryo, rather than 2 or more embryos, is transferred by choice, when more than one suitable embryo is available	an1	Y	
Date of embryo storage	EmbryoStorageDate	This is the date the embryo storage occurred if not on same date as transfer.	an10		
No. of embryos stored for patient	EmbryosStoredPatient	This is the number of embryos that were cryopreserved for the woman's own use.	n2		
No. of embryos stored for donation using slow freeze	Number of embryos stored slow freeze	This is the number of embryos that were cryopreserved by the slow freeze method for the donation only.	n2		
No. of embryos stored for donation	NumberEmbryosStoredDonated	This is the number of embryos that were cryopreserved for donation only.	n2		
Method of embryo freezing	EmbryoFreezeMethod	Method of embryo freezing. Where embryos have been stored for future use of patient or donated for future use this defines the method of freezing.	an1	1	Frozen via vitrification method
				2	Frozen using slow freeze method

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
No. of embryo's donated fresh	NumberEmbryoDonatedFresh	This is the number of fresh embryos that were donated to a recipient(s)	n2		
No. of embryos donated fresh to research	NumberEmbryoDonatedResearch	This is the number of embryos that were donated to a licensed research project	n2		
No. of embryo's discarded	NumberEmbryoDiscarded	This is the number of embryos discarded from those created in this treatment	n2		
Number of embryos remaining in storage.	NumberEmbryosRemainStored.	See calculation from linked date under heading 'Linked forced entry with another field'.	n2		
Reason if embryo's created but none transferred	ReasonNoneTransferred	Reason if embryo's created but none transferred	an1	1	OHSS Risk
				2	No suitable embryos after biopsy
				3	Social reasons
				4	Other
Comments on any part of the patient details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		
Date comment added	CommentDate	This is the date that the comment was added.	Date		

Mitochondrial Donation Treatments

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre.	an4		
Local Patient Identifier	PATIENTNO	This is the number given to the patient by the centre. This is unique within the centre and used by the centre. This is the patient number of the person receiving the mitochondrial donation.	an13		
Treatment number	TreatmentID	Unique treatment identifier	an12		
Mitochondrial application reference		This is reference number of the MDT application which has been approved by HFEA licence committee	an15		
Mitochondrial donor centre	MitoDonorCentre	The centre number where the mitochondrial donor is registered for mitochondrial donation.	an4		
Mitochondrial donor code	MitoDonorNumber	The unique number within the donor centre given to the mitochondrial donor.	an13		
Patients Egg collection number	PatientEggCollectionRec	This is the record number of the egg collection which is the source of the patient's eggs which will be part of mitochondrial treatment..	an12		

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
Mitochondrial donors Egg collection number	MitoEggCollectionRecord	This is the record number of the egg collection which is the source of the mitochondrial donor's eggs which will be part of mitochondrial treatment..	an12		
Sperm donor centre	donorSpermCentre	If donor sperm is used this is the centre number where the sperm donor is registered. This will be the centre which recruited and procured the donor sperm or imported the sperm from abroad.	an4		
Sperm donor code	spermDonorNumber	If donor sperm is used this is donor number allocated by the donor sperm centre and unique within the donor centre. If the donor has been imported this code will start with 2 digit country code indicating donor's country of residence at time of donation.	an13		
PNT only sperm donor centre	PNTonlyDonorCentre	The centre number where the PNT only donor is registered for PNT only sperm donation.	an4		
PNT only sperm donor code	PNTonlyDonorNumber	The unique number within the donor centre given to the PNT sperm donor.	an13		
PNT - number of patient's eggs mixed	PNTpatienteggsmixed	The number of patient's eggs mixed with partner or donor sperm to create embryos for PST treatment	n2		
PNT - number of embryos developed from patient's eggs	PNTpatientembryosDevelop	The number of embryos developed from patient's eggs mixed with partner or donor sperm for PNT treatment	n2		
PNT - number of mitochondrial donor's eggs mixed	PSTmitoDonoreggs mixed	The number of mitochondrial donor's eggs mixed with sperm to create embryos for PNT treatment	n2		
PNT - number of embryos developed from mitochondrial donor's eggs	PNTmitodonorembryosDevelop	The number of embryos developed from mitochondrial donor's eggs mixed with sperm for PNT treatment	n2		
PNT - number of embryos developed from mitochondrial donor's eggs	PNTmitodonorembryosDevelop	The number of embryos developed from mitochondrial donor's eggs mixed with sperm for PNT treatment	n2		
Number of PNT embryos created	PNTembryonumber	Number of PNT embryos created which contain the patient's nuclear DNA and donor mitochondria	n2		
MST Number of patients eggs used	MSTpatientsEggs	Number of patient eggs used in MST	n2		
MST Number of mitochondrial donors eggs used	MSTmitodonorEggs	Number of mitochondrial donors eggs used in MST	n2		
Number of MST eggs created	MSTeggscreated	Number of MST eggs created which contain the patient's nuclear DNA and donor mitochondria	n2		
Number of MST	MSTembryonumber	Number of MST embryos created which contain the patient's	n2		

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
embryos created		nuclear DNA and donor mitochondria			
Number of PNT embryos transferred	PNTtransfernumber	Number of embryos created via PNT transferred to the patient	n2		
Number of MST embryos transferred	MSTtransfernumber	Number of embryos created via MST transferred to the patient	n2		
Date of embryo transfer	EmbryoTransferDate	This is the date the embryo transfer occurred.	an10		
Date of embryo storage	EmbryoStorageDate	This is the date the embryo storage occurred, .if not on same date as transfer.	an10		
Number of PNT embryos stored for patient use	PNTembryosStored	Number of PNT embryos stored for future use of patient	n2		
Number of PNT embryos stored for patient use	PNTembryosStored	Number of PNT embryos stored for future use of patient	n2		
Number of MST embryos stored for patient use	MSTembryosStored	Number of MST embryos stored for future use of patient	n2		
Number of PNT embryos donated to research	PNTembryosStored	Number of PNT embryos donated to research	n2		
Number of MST embryos donated to research	MSTembryosStored	Number of MST embryos donated to research	n2		
Number of PNT embryos discarded	PNTembryosStored	Number of PNT embryos discarded	n2		
Number of MST embryos discarded	MSTembryosStored	Number of MST embryos discarded	n2		
Comments on any part of the mitochondrial replacement treatment details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		
Date comment added	CommentDate	This is the date that the comment was added.	Date		

Frozen embryo treatments table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre.	an4		
Local Patient Identifier	PATIENTNO	This is the number given to the patient by the centre. This is unique within the centre and used by the centre.	an13		
Embryo creation treatment identifier	MixingID	This is the number of mixing event (mixingID) where the embryos being thawed were created.	an12		
Embryo thaw date	EmbryoThawDate	This is the date that the embryos are thawed/warmed.	an10		
Number of embryo's thawed	NumberEmbryosThawed	The number of embryos thawed/warmed this should be the number removed from cryostorage for the purpose of thawing	an2		
Number of viable embryo's following thawing	NumberViableEmbryos	Number of viable embryo's following thawing. The definition of viability is it with >50% cells apparently surviving immediately post thaw or re-expanding within 1.5h of the thaw (for blastocysts) / cleaving overnight (for cleavage stage embryos)?	an2		
Embryo Biopsy on thawed embryos	EmbryoBiopsyThawed	This records if embryo biopsy has occurred and which types. If the embryos had a biopsy before freezing it will show here. If the embryos undergo biopsy after thawing it should be recorded here.	an1	0	NONE
				1	PGD
				2	PGS
				3	HLA
				4	OTHER
Date of embryo transfer	EmbryoTransferDate	This is the date the embryo transfer occurred.	an10		
Number of thawed embryos transferred	NumberThawedEmbryosTransferred	This is the number of thawed/warmed embryos that are transferred.	an2		
Elective single embryo transfer	eSET	Elective single embryo transfers are those where a single embryo, rather than 2 or more embryos, is transferred by choice, when more than one suitable embryo is available	an1	Y	
Number of embryos refrozen	NumberEmbryosRefrozen	This is the number of embryos that are refrozen after thawing and returned to storage after thaw/warm.	an2		
Date of refreezing	DateEmbryoRefreezing	Date of refreezing of embryos if any have been refrozen	an10		
Number of thawed viable embryos discarded	NumberThawedEmbryosDiscarded	This is the number of embryos that are thawed/warmed and then discarded. This only includes those viable after thawing	an2		
Comments on any part of the outcome details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		
Date comment added	CommentDate	This is the date that the comment was added.	Date		

Early outcome table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre.	an4		
Local Patient Identifier	PATIENTNO	This is the number given to the patient by the centre. This is unique within the centre and used by the centre.	an13		
Treatment to early outcome refers	TreatmentID	Number of treatment that records transfer event that EO refers to. This links EO to embryo transfer activity	an12		
Number of fetal pulsations	Pregnant	A clinical pregnancy is an intrauterine gestation sac that contains a fetal pulsation. The number of fetal pulsations is given here. This information indicates that there is a viable fetus present and follow up data is required. If there is no intrauterine fetal pulse seen this is entered as zero e.g. there was a negative pregnancy test or a biochemical pregnancy or an ectopic pregnancy or a molar pregnancy.	n1		
Number of gestational sacs	numberOfGestationalSacs	This is the number of gestational sacs identified. It is used with number of fetal pulsations to identify a monozygotic twin pregnancy	n1		
Has centre been unable to obtain treatment outcome information?	NoOutcomeObtainable	This is when all attempts to trace the outcome of the treatment have failed either at pregnancy or birth - formerly recorded as 'lost to follow-up'	an1	Y	Yes
				N	No
Comments on any part of the early outcome details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		
Date comment added	CommentDate	This is the date that the comment was added.	Date		

Outcome table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre.	an4		
Local Patient Identifier	PATIENTNO	This is the number given to the patient by the centre. This is unique within the centre and used by the centre.	an13		
Outcome identifier	OutcomeID	Unique reference number for this outcome record	an12		
Treatment that outcome refers too	TreatmentID	Number of treatment that records DI or embryo transfer event that outcome refers to. This links outcome to embryo transfer or DI treatment	an12		
Pregnancy terminated	PregnancyTerm	This indicates that the pregnancy has been terminated by the patient. Note that selective embryo reduction should be recorded	an1	Y	

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
		on fetal outcome			
Number of fetal outcomes	Total fetal outcomes	Number of fetal outcomes for this pregnancy. Should match number of fetal hearts on early outcome and same number of fetal outcomes records linked.	an1		1-9
Baby's town or district of birth	BabyBirthTownDist	This is the town or district in which the baby or babies were born.	an50		Free Text
Baby's country of birth	BabyBirthCountry	This is the country in which the baby or babies were born.	a3		ISO Country Codes
				ZZZ	Not stated
				EEE	England
				WWW	Wales
				SSS	Scotland
	NNN	Northern Ireland			
Comments on any part of the outcome details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		Free Text
Date comment added	CommentDate	This is the date that the comment was added.	Date		

Fetal outcome table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre.	an4		
Local Patient Identifier	PATIENTNO	This is the number given to the patient by the centre. This is unique within the centre and used by the centre.	an13		
outcome ID		The outcome record number which this fetal is providing detail for.	an12		
Fetal number	Fetal number	The fetal number within this pregnancy outcome	n1		
Fetal outcome	Fetal outcome	The outcome of this fetus,		10	Live Birth. This is when a baby has been delivered after 24 weeks gestation and shows signs of life.
				20	Stillbirth. The baby is born dead after 24 weeks gestation
				30	Miscarriage. A miscarriage is the expulsion of the fetus from the uterus before 24 weeks gestation.
				70	Embryo reduction at less than 24 weeks.

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
					This is when a procedure or intervention has been carried out to remove an embryo from a multiple gestation.
				80	Embryo reduction at equal to or greater than 24 weeks. This is when a procedure or intervention has been carried out to remove an embryo from a multiple gestation.
				XX	Other including vanishing/papyraceous twin, or ectopic
Baby weight	Babyweight	This is the birth weight of the baby in grams.	n4		
Baby's Gender	Babygender	This is the gender of the baby as assigned at birth.	n1	1	Male
				2	Female
				9	Indeterminate, i.e. unable to be classified as either male or female
Delivery date	DeliveryDate	Date that the baby was delivered for live birth or still births.	an10		
Indicator of Neonatal death	NeonatalDeath Flag	Neonatal death. This is an indicator that the baby born live died before 28 completed days after birth. http://www.perinatal.nhs.uk/pnm/definitions.htm	an1	Y	
Baby's NHS Number	NHSNO	This is the NHS/CHI/HCN number of the baby	n10		
Baby's NHS number Status Indicator Code	NHSNOSatus	Indicates the status of the NHS Code	an2	01	Number present and verified
				02	Number present but not traced
				03	Trace required
				04	Trace attempted - No match or multiple match found
				05	Trace needs to be resolved - (NHS Number or PATIENT detail conflict)
				06	Trace in progress
				07	Number not present and trace not required
				08	Trace postponed (baby under six weeks old)
Baby's forenames	BabyForename	The forenames of the baby. This will be as written on their NHS/CHI/HCN record.	an50		Free text
Baby's surname	BabySurname	The surname of the baby. This will be as written on their NHS/CHI/HCN record.	an50		Free text
Comments on any part	Comments	This is to allow the clinic to add any relevant comments	an250		Free text

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
of the fetal outcome details		that they wish as free text.			
Date comment added	CommentDate	This is the date that the comment was added.	Date		

Transfer In of eggs, embryos and donor sperm table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre. This is the centre receiving the eggs or embryos or donor sperm	an4		
Local Patient Identifier	PERSONID	This is a number given to the egg, donor sperm or embryo provider by the centre. This is unique within the centre and used by the centre. For eggs or embryos this will be the patient they belong too. For a donor sperm being imported from outside the UK this will be donor code used for registration. For donor sperm transferred from another UK centre this will be the number allocated by the centre sending the donor sperm. For eggs or embryos this will be the patient they belong too.	an13		
Transfer type	TransferType	This defines whether the transfer record refers to eggs, embryos or donor sperm.	an1	1	Eggs
				2	Embryos
				3	Donor Sperm
Where imported from	ImportedFrom	Indicates if the transfer is from a UK centre or whether from outside the UK	an1	1	Transferred into the centre from another UK Licensed centre
				2	Transferred into the centre from outside the UK
Transferred from centre code	TransferFromCentre	If from inside the UK the number of the UK centre which the eggs/embryos or donor sperm have been imported from.	an4		
Country imported from	ImportCountryCode	If from outside the UK country where eggs/sperm/embryos have been imported from	an3		ISO codes
Special directions	SpecialDirections	If the import has been done under special directions this is the special directions number supplied by Licence committee.	an20		
Egg collection or Embryo creation treatment identifier	TreatmentID	Where eggs or embryos are being imported this contains either the egg collection or embryo creation treatment identifier so that eggs can be linked to egg collection or embryos linked to gamete source information form number to link embryos being thawed to their creation	an12		Could be multiple treatment reference numbers
Number of eggs	NumEggs	Number of eggs being transferred	n2		
Number of embryos	NumEmbryos	Number of embryos being transferred	n2		
Quantity of donor	QuantityDonor	Quantity of donor sperm samples being transferred.	n2		

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
sperm	Sperm				
Measurement of donor sperm	MeasureSperm	Where a quantity of donor sperm has been submitted please complete the method of storage.	an1	1 2 3	Ampoules Straws Vials
Single European Code	SEC	The SEC will be attached to the movement of any donor eggs or sperm or embryos created using donor eggs or sperm. If this transfer has SEC attached it should be entered here.	an40		
Comments on any part of the fetal outcome details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		
Date comment added	CommentDate	This is the date that the comment was added.	Date		

Transfer out of eggs, embryos and donor sperm table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre. This is the centre sending the eggs, embryos or donor sperm.	an4		
Local Patient Identifier	PERSONID	This is the number given to the egg or sperm or embryo provider by the centre. This is unique within the centre and used by the centre to refer to the patient or donor. For a donor sperm being exported this will be donor code used for registration. For patients eggs this will refer to the patient number as used on egg collection record. For donor eggs this will refer to the egg donor code. For embryos either the patients whose eggs were used to create the embryos or in case of surrogacy one of the intended parents who contributed gametes.	an13		
Transfer type	TransferType	This defines whether the transfer record refers to eggs, embryos or donor sperm.	an1	1 2 3	Eggs Embryos Donor Sperm
Transfer Reason	TransferReason	This is the type of transfer that is occurring. Whether for use in another centre or abroad or to be destroyed, because of end of consent or storage period.	an1	1 2 3 4	Transferred out of the centre to another UK licenced centre Transferred out of the centre to outside of the UK. Donated to Research Destroyed because reached end of storage period or withdrawal of consent.
Transferred to UK	TransferToCe	If transferring within the UK the number of the UK centre which	an4		

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
centre code	ntre	the eggs/embryos or donor sperm have been transferred too.			
Country exported too	ExportCountry Code	If transferring to outside the UK this records the country where eggs/sperm/embryos have been exported too.	a3		ISO country codes
Special directions	SpecialDirections	If the export has been done under special directions this is the special directions number supplied by the Licence committee.	an12		
Transfer date	TransferDate	This is the date that the eggs/embryos or donor sperm left the centre which is sending them elsewhere	an10		
Egg collection or Embryo creation treatment identifier	TreatmentID	Where eggs or embryos are being imported this contains either the egg collection or embryo creation treatment identifier so that eggs can be linked to egg collection or embryos linked to gamete source information form number to link embryos being thawed to their creation	an12		Could be multiple treatment reference numbers
Number of eggs	NumEggs	Number of eggs being transferred	n2		
Number of embryos	NumEmbryos	Number of embryos being transferred	n2		
Quantity of donor sperm	QuantityDonor Sperm	Quantity of donor sperm samples being transferred.	n2		
Measurement of donor sperm	MeasureSperm	Where a quantity of donor sperm has been submitted please complete the method of storage.	an1	1 2 3	Ampoules Straws Vials
Donor consent expiry date	DonorConsent Expiry	Where donor gametes are being exported the donor consent expiry date needs to be included in transfer document since it is part of SEC.	an10		date in YYYYMMDD format
Single European Code	SEC	The SEC needs to be attached to the movement of any donor eggs or sperm or embryos created using donor eggs or sperm. This number will be generated from the information supplied above as UK country code + centre code + donor code (or patient for embryos) + transfer type + iteration number + expiry date.	an40		
Comments on any part of the fetal outcome details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		
Date comment added	CommentDate	This is the date that the comment was added.	Date		

Consent variation table

Data Item Name	Access Name	Definition	Format	Codes	Value Descriptions
UK ART Centre Number	CentreCode	This is HFEA assigned centre number for licenced UK centre. This is the centre where the patient, partner or donor was registered or where patient had treatment resulting in child whose consent is to be varied.	an4		0001 to 9999
Type of person whose consent is being varied.	CVType	This indicates the type of person to which the consent variation will apply. Whether it is for a patient or partner or donor or child. consent variation enables changes to the consent currently applied for that person with regard to identifying information for research purposes.	an1	1	Patient
				2	Partner
				3	Donor
				4	Child
Local patient/partner/donor identifier	CVID	This the patient/partner/donor number given to the patient, partner or donor by the centre, This will be a unique reference number within the centre and will be the number by which the centre have recorded details of the patient / partner / donor. Where the consent variation is for a child this will be the birth mothers patient number	an13		
Patient/partner/donor surname	Surname	This is the surname of the patient, partner or donor who want to change their consent. Where changing consent for a child this should be patient's surname	an50		
Child's DOB	ChildDOB	Where the CV form is for a child the child's DOB needs to be included here so the child can be identified	an10		
Consent to non-contact research	ConsentNonContactResearch	This is the new consent taken from the CD form completed by the patient/partner/donor in 'Disclosing your identifying information ..' section. This records whether they agreed or not to non-contact research.	an1	Y	Yes
				N	No
Consent to contact research	ConsentContactResearch	This is taken from the CD form completed by the patient in 'Disclosing your identifying information ..' section. This records whether they agreed or not to contact research.	an1	Y	Yes
				N	No
Comments on any part of the consent variation details	Comments	This is to allow the clinic to add any relevant comments that they wish as free text.	an250		
Date comment added	CommentDate	This is the date that the comment was added.	Date		