

## Authority Paper

<b>Committee:</b>	Authority Meeting
<b>Meeting Date:</b>	18 February 2004
<b>Agenda Item:</b>	8
<b>Paper Number:</b>	Paper (18/02/04) 135
<b>Paper Title:</b>	<b>Minimum/Future Data Set</b>
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<b>For Information or Decision?</b>	Information/consultation
<b>Resource Implications:</b>	None
<b>Recommendation to the Committee:</b>	
<b>Paper:</b>	

This exercise began as a request from the Information Management Programme Board to review the HFEA Minimum Data Set. The MDS is the list of data items which are core to the HFEA (including both essential and statutory items). With guidance from the Information Management Programme Board, a list of data fields and records relating to treatments where a live birth definitely did or may have taken place (lost to follow up) have been produced and agreed. Additionally, a list of fields relating to all egg and sperm donors has also been created and agreed – please see Appendix 1

The Historic Audit Project will utilise the MDS list when comparing HFEA records with those of the clinics back to the start of the HFEA.

The Future HFEA Data Set is different to the MDS in that it attempts to identify the changing types of data that should be collected from Centres in the future to meet the reporting and data analysis requirements of the various stakeholders. This exercise has consumed a great deal of time and effort, and we are extremely grateful to all those people that have contributed so readily to the exercise already.

The consultation process began by reviewing the existing list of data items collected, the various reports that have been requested by stakeholders over the years (including those provided automatically), and any initiatives such as the EU Tissue Directive that we are aware of. This list was offered to various parties for comment and some fields that have been collected on forms in the past have been removed, with some new fields have been added. Using this list, the design of the existing forms has been taken as the basis for development,

allowing Centres an evolutionary rather than revolutionary step when transferring from the old to new forms. The changes/removal of data fields to date is less radical than might have been expected. The gamete and embryo tracking aspect seems to cause the greatest reason for discussion and surprisingly few fields have been suggested/requested for removal. The forms conform to NHS data standards wherever possible.

The latest draft version of the forms (v20042) has been sent to the Clinical Information Working Group, Department of Health, and Information Management Programme Board for comment. The Medical Research Council was involved in the consultation process but we are also seeking views from the BFS, ACE and the Fertility nurses groups.

We would welcome any comments that you or your colleagues may have on the documents. We hope that the new forms can be introduced alongside Electronic Data Interchange at the Centres. This would reduce the burden of additional data items where they can be imported directly from existing Electronic Patient Record Systems.

It is recognised that whilst debate of the new forms continues, written guidance for the existing forms is poor, so a new forms completion manual has been developed and issued to all Centres via a CDROM mail-out. Being in an electronic Portable Document Format, the Centres are able to search the document or print it out without the ability to make unauthorised changes. These manuals will also be published to the Centres Extranet in due course.

## Appendix 1 - Minimum Data Set

Data will be extracted from the Data Register and verified for ALL live births (where a Neonatal Death was not reported), ALL Lost To Follow Ups, and all Treatment forms where an Intrauterine Pulsation was seen BUT NO Outcome Form was received. Data will also be extracted and verified for all donors. Additionally, the babies name will be obtained for all babies where recorded at the Centres. Total approximate number of forms requiring verification: 200,000. Total number of fields for each outcome will vary according to circumstances, but the full list of fields which could be checked is:-

### Outcome Form Data

Live Birth Flag  
 Lost To Follow-Up Flag  
 Centre No.  
 Outcome Form No.  
 Patient ID  
 Patient Surname  
 Baby No. (1-5)  
 Sex of baby  
 Date of birth  
 Congenital abnormalities  
 Town of Birth  
 Country of birth  
 Related Outcome Form  
 Related Treatment Form No. (T or I)

### Treatment Form Data

Embryo Transfer date (IVF) OR First date or last treatment cycle (DI)  
 Patient is a surrogate (Y/N)  
 Partner/Donor Sperm used  
 Sperm Donor Centre No. (if applicable)  
 Sperm Donor No. (if applicable)  
 Donor Egg used in successful embryo creation (y/n)  
 Egg Donor Centre No. (if applicable)  
 Egg Donor Form No. (if applicable)

### Donor Information Form Data

Sperm Donor Current Surname  
 Sperm Donor Current Forename  
 Sperm Donor DOB  
 Sperm Donor DOB Approx (Y/N)  
 Sperm Donor Surname at birth (if different)  
 Sperm Donor Forenames at birth (if different)

Sperm donor Town of Birth  
Sperm donor Country of Birth  
Sperm donor Height  
Sperm donor weight  
Sperm donor Ethnic Group  
Sperm donor eye colour  
Sperm donor hair colour  
Sperm donor skin colour  
Sperm donor religion  
Sperm donor occupation  
Sperm donor Interests

### **Egg Donor Details (if not patients)**

Egg Donor Current Surname  
Egg Donor Current Forename  
Egg Donor DOB  
Egg Donor DOB Approx (Y/N)  
Egg Donor Surname at birth (if different)  
Egg Donor Forenames at birth (if different)  
Egg Donor Town of Birth  
Egg donor Country of Birth  
Egg donor Height  
Egg donor weight  
Egg donor Ethnic Group  
Egg donor eye colour  
Egg donor hair colour  
Egg donor skin colour  
Egg donor religion  
Egg donor occupation  
Egg donor Interests

### **Patient Registration Form data**

Patient Current Surname  
Patient Current Forename  
Patient DOB  
Patient DOB Approx (Y/N)  
Patient Surname at birth (if different)  
Patient Forenames at birth (if different)  
Patient Town of Birth  
Patient Country of Birth

**Partner Registration Data (if applicable)**

Partner Current Surname  
Partner Current Forename  
Partner DOB  
Partner DOB Approx (Y/N)  
Partner sex  
Partner Surname at birth (if different)  
Partner Forenames at birth (if different)  
Partner Town of Birth  
Partner Country of Birth

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