Further information requested by LegCo Members
in the last BC meeting on HRT Bill

(A) Access to Information

UK

The Human Fertilisation & Embryology Act 1990 s. 31-35 puts strict limits on the disclosure of information about the gamete donor. When a child reaches the age of eighteen, or sixteen if they wish to marry, the Authority may inform them if they were born by donor insemination and if they are related to the person they wish to marry. The Authority cannot reveal any further information, but the treatment clinics may disclose non-identifying information provided by the donor.

2. The exceptions to this rule are outlined clearly in s.11.8 in the Code of Practice (extract of the relevant section of the Code of Practice is enclosed). In summary, information about an identifiable person can be disclosed:

(i) in connection with formal court proceedings for the purpose of establishing the genetic parentage of a child who is subject to an application for a parental order in a surrogacy case

(ii) to enable a centre or person covered by a licence to defend proceedings in England and Wales under the Congenital Disabilities Act 1976 and to enable them to bring connected proceedings for compensation against that donor (with reference to non-disclosure of any defects of which the donor was aware at the time of donation)

(iii) several other exceptions which related to the disclosure of donor information persons other than the child e.g. medical emergency.

US

3. Pending reply.

Australia

4. Information was provided in last Bills Committee Meeting.

5. Below please find a summary table comparing the practice of access to information in HK, UK and Australia.

	HK	UK	Victoria, Australia	Western Australia
Central Registry	v	v	v	v
Release of non-identifying information of donor to offspring upon request	v	v	v	v
Release of identifying information of donor upon request	v with donor's consent or under special circum-stances	v with donor's consent or under special circum-stances	v to commission-ing couples with donor's consent, to offspring as a matter of right	v with consent of all parties

(B) Surrogacy Legislation

UK

6. Surrogacy is regulated by the Surrogacy Arrangement Act 1985 which regulates all surrogacy arrangement, including those that involve RT.

7. Donated gametes can be used.

8. The Surrogacy Arrangement Act 1985 prohibits agencies or individual (other than the potential mother or intended parents) from acting on a commercial surrogacy arrangement. It does not prohibit payment to a surrogate mother.

9. The Human Fertilization & Embryology Act section 36 renders surrogacy contracts unenforceable.

10. Currently, the Surrogacy Arrangement Act 1985 is under review to consider:-

(i) whether payments, including expenses, should continue to be made to surrogate mother
(ii) whether a recognised body or bodies should regulate such arrangement.

11. It is also recommended a Code of Practice be drafted to set out the minimum standards for surrogacy arrangements to ensure the concern for the welfare of the child is paramount and that the interest of all parties are equally protected.

US

12. Pending reply.

(C) Papers on Sex Selection & Limitation on Cryopreservation

13. Please find the papers attached at Annex A and B.

explanation of unintelligible terms must be given. If the records were made within 40 days proceeding the application, access must be allowed within 21 days. No charge is payable except the cost of making a copy and postage. Where records were made more than 40 days before the application, the record holder must allow access within 40 days. In this case a fee not exceeding 10 may be charged and the cost of copying and postage.

Confidentiality

11.7 Centres must ensure that information provided in confidence is kept confidential and only disclosed in the circumstances permitted by law.[40] People should not have access to any other person's records (including those of their spouse or partner) without their consent.

11.8 The Act puts strict limits on the disclosure of certain information by centres.[41] Information about any identifiable person who receives treatment services, provides gametes or is born as a result of treatment services can generally only be disclosed to members and staff of the HFEA or to someone else who is covered by a licence for the purpose of licensed activities. This general rule is subject to the following exceptions:

a. information about an identifiable person who receives treatment services or provides gametes can be disclosed to that person;

b. information about an identifiable person who receives treatment services can also be disclosed:

i. with that person's consent to specified people, or to unspecified people who need to know in connection with medical treatment or carrying out a medical or financial audit. The procedure for obtaining consent is set out in paragraphs 3.5-3.8. The consent should be in writing and thoroughly discussed beforehand with the person to whom the information relates, In the case of consent to disclosure to unspecified people, centres should always satisfy themselves that the information is disclosed only to someone who really needs to know the client/patient' identity.

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[40] This is an obligation under the general law

[41] HF&E Act 1990 s.33(5)-(7)

ii. in an emergency, i.e. where it is necessary to avert imminent danger to the health of the person to whom the information relates, and where it is not reasonably practicable to obtain that person's consent If it is practicable to obtain consent in an emergency, and that consent is refused or not requested, then the information must not be disclosed.

c. information about an identifiable person may be disclosed if it is necessary for any purpose preliminary to, or in connection with, legal proceedings or formal complaints procedures. However, no information may be disclosed in these cases which links a donor's identity to an individual who was, or may have been, born as a result of treatment with that donor's gametes;

d. identifying information may be disclosed in connection with formal court proceedings for the purpose of establishing the genetic parentage of a child who is subject to an application for a parental order in a surrogacy case;

e. information potentially identifying a donor can be disclosed to enable a centre or person covered by a licence to defend proceedings in England and Wales under the Congenital Disabilities (Civil Liability) Act 1976, and to enable them to bring connected proceedings for compensation against that donor;

f. under the Access to Health Records Act. 1990 information held on health records about a patient may be disclosed subject to certain safeguards to that patient, or to certain persons authorised to act on their behalf (applies only in Great Britain).

11.9 Information can also be disclosed if it cannot lead to the identification of anyone to whom the information relates.

11.10 Centres should ensure that people to whom they disclose identifying information are aware that the information remains protected by the existing common law on confidentiality. Those receiving information should also be advised that if it is not kept confidential, a child might learn in an inappropriate way that they were born as a result of treatment services (see paragraphs 3.8-3.10).

11.11 Centres should have clear security procedures which will prevent unauthorised access to records, and particular care should be taken where records are kept outside the licensed premises, e.g. when counselling takes place outside the centre. If confidentiality is breached, the centre should investigate and deal with the breach and submit a full explanation to the HFEA. If it appears that a criminal offence has been committed the centre should inform the police but where the centre is in any doubt it should consult the HFEA.

ANNEX A

Sex Selection

Background

Sex selection by means of reproductive technology (RT) is a new technique which had not been covered in the two consultation exercises conducted by the former Committee on Scientifically Assisted Human Reproduction in 1989 and 1993. Both the Provisional Council on Reproductive Technology and the Government considered it necessary to gauge the views of the public in drawing up regulatory proposals on the new and sensitive area of sex selection. A public consultation on the Draft Reproductive Technology Bill including the regulation of sex selection was conducted in July 1996[1] and to collect views on the following -

(a) whether sex selection for medical reasons should be allowed;

(b) whether sex selection for non-medical reasons should be allowed;

(c) if allowed, should it be regulated under legislation and the Code of Practice as for other RT procedures; and

(d) if not allowed, should it be prohibited under the legislation or the Code of Practices?

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[1] A copy of the Consultation Paper has been provided to the Bills Committee subsequent to the first Bills Committee meeting.

Summary of Responses on the Consultation Exercise

2. The consultation exercise attracted 41 written responses, including those from medical professionals and professional bodies, social service groups, religious bodies, academic institutions and organisations involved in the practice of RT as well as members of the general public. A total of 15 public views were also collected from a call-in radio programme and articles/editorials published in newspapers.

For Medical Reasons

3. The majority view was that sex selection for medical reasons should be allowed since it could avoid the birth of a child suffering from a serious sex-linked hereditary disease, which in turn might help to reduce the burden on the parents and family. Almost all respondents opined that strict control should be placed over sex selection achieved by means of RT procedures. It should be regulated under legislation and the Code of Practice as for other RT procedures. In order to prevent the possibility of abuse, some respondents suggested that the public should be consulted on the list of serious genetic diseases for which sex selection would be allowed and specific approval had to be sought for each application. The provision of counselling for parents concerned to facilitate an informed decision was also suggested in some submissions.

For Non-medical Reasons

4. While a few respondents opined that it was against human right to

prohibit sex selection for social reasons, most respondents expressed great concern on its consequences and requested prohibition of the practice by legislation. They commented that allowing sex selection for non-medical reasons was an act against natural law and it would upset the sex ratio between the two sexes. Moreover, it might create other severe social problems, such as perpetuating sexual discrimination, increasing incidents of abortion due to unsuccessful cases, causing adverse effects on the children born and being manipulated to encourage eugenics.

Recommendations of the Provisional Council on Reproductive Technology

5. The Provisional Council has deliberated on the appropriate regulatory mechanism by taking public views into account. The Council憩 views coincided with those of the majority of respondents that sex selection is only acceptable for medical reasons. Clause 13(3) of the Human Reproductive Technology Bill had taken into account views expressed in the public consultation exercise and reflected the majority public view that sex selection should not be allowed for social reasons and should only be allowed for avoiding the birth of a child with a severe sex-linked genetic diseases. To provide better control, clause 13(3) will require not less than 2 registered medical practitioners to each state in writing that the selection is for that purpose.

6. As regards the suggestion to draw up a list of severe sex-linked genetic diseases, the Provisional Council has consulted the relevant medical bodies including the Hong Kong College of Paediatricians, the UK Human Fertilisation and Embryology Authority and the Fertility Society of Australia,

and found that it would be difficult and impractical to draw up such a list. The reason is that different people would have different perception and acceptance level of the severity of a sex-linked genetic disease, and it would depend more on the counselling process The decision on whether to perform sex selection also depended on factors such as the parents' acceptance of the procedure, their willingness to raise a handicapped child and their ability to cope with such situations. Therefore counselling played a very important part in helping the parents to make an informed decision. Taken into account the above views, the Council recommended that a non-exhaustive list of sex-linked genetic diseases without defining the severity of diseases would be provided in the code of practice for reference purpose.

7. The Provisional Council has also suggested in the draft code of practice to require the RT centres to report to the future Council on cases of sex selection achieved through RT.

ANNEX B

Limitations of Cryopreservation

Introduction

1. Cryopreservation means the freezing and storing of gametes or embryos, usually in liquid nitrogen at-196^{00}}}C, for subsequent use. Currently, the technique of cryopreservation only allows sperm and embryos to be frozen and stored for subsequent use. The technique of cryopreservation has presented some ethical problems in relation to the storage and disposal of human embryos.

Reasons for Storing Embryos

2. In vitro fertilisation (IVF) is a method of treatment for infertility. It involves the administration of drugs to stimulate the ovaries of a woman. The eggs are retrieved from the body of a woman and then mixed with sperm to create embryos in vitro. On average six eggs may be produced during each IVF cycle. Usually, a maximum of three embryos are transferred to a woman's womb to reduce the risk of multiple pregnancy. The "surplus" embryos can be frozen and stored for use in later cycles so that the woman does not need to go through the procedure of drug stimulation and egg retrieval again.

3. If the couple decides to donate the "surplus" embryos for other infertile patients, storage of embryos allows time for the donating couple to be appropriately screened to prevent transmission of diseases.

4. It is proposed in the Human Reproductive Technology Bill that no embryos should be created deliberately for research. Hence, the donation of "surplus" embryos created in the course of IVF treatment is probably the only source of embryos for research.

5. For some patients (e.g. cancer patients) who may be rendered infertile as a result of chemotherapy, radiotherapy or surgery, they may wish to preserve their chance of having children by storing their embryos (or sperm) for future use.

Effect of Cryopreservation on the Embryo

6. The Working Group on Embryo Freezing set up by the Human Fertilisation and Embryology Authority (HFEA) of UK reported in 1994 that there was no reason to believe that viable embryos stored in proper conditions would suffer harm from longer periods (the then statutory maximum was five years), even indefinite storage. It found no evidence of lack of safety for patients or their potential children.

Controversies over Gamete or Embryo Storage and Disposal

7. The technique of cryopreservation of gametes or embryos has presented important ethical dilemmas. There will be disposal problems to the reproductive technology (RT) service providers since without the agreement of the patients or couples, they may not dispose of the stored gametes or embryos even if the patients or couples do not turn up for subsequent treatment.

Besides, there are possible disputes over the right of use or disposal of the sperm or embryos if the couple separate or divorce. In the case of death of the patient or one party, further complication arises when requests are made for the use of the stored gametes or embryos to bring about a posthumous child.

Recommendations of the Provisional Council on Reproductive Technology

8. According to the recommendations of the Provisional Council on Reproductive Technology (the Provisional Council), embryos could be stored for the following purposes -

(a) for own subsequent treatment;
(b) for donation for treatment of other infertile couples; and
(c) for donation for research.

9. Although there was no reason to believe that viable embryos stored in proper conditions would suffer harm from long, or even indefinite storage, in view of the potential legal and ethical complications that might arise, the Provisional Council suggested that the maximum storage period of both gametes and embryos would be set at 10 years. For cancer patients or other types of patients, the maximum storage period of gametes would be until the patient reaches the age of 55, and that for embryos would be 10 years. The setting of maximum storage periods was not based purely on biological grounds but had also taken into account the administrative constraints faced by RT service providers. When the maximum storage period is reached, the stored gametes or embryos would be allowed to perish or donated to other couples or for research, depending on the prior written consent obtained from the patient.

The above requirements will be stipulated in the drafted code of practice.

10. In view of the paramount consideration of the welfare of the child, the Provisional Council recommended that no posthumous use of gametes or embryos by the surviving spouse should be allowed. The stored gametes or embryos of the patients who had died could be donated for research or for infertility treatment of other couples, subject to their written consent given.