Scientific and Clinical Advances Advisory Committee (SCAAC) – matters arising

Monday 8 June 2020

Date and item	Action	Responsibility	Due date	Progress to date
03/02/2020 4.13	HFEA to revise the workplan and prioritisation list as agreed in this discussion and circulate to committee members.	Victoria Askew, Policy Manager	Completed	Revised work plan circulated with the committee papers for the June 2020 SCAAC meeting (Annex A)
03/02/2020 5.16	HFEA to send the Committee the exact wording in the Code of Practice for genetic counselling and incidental findings	Victoria Askew, Policy Manager	Completed	Appropriate sections of the Code of Practice circulated with the committee papers for the June 2020 SCAAC meeting (Annex B)

Annex A (revised work plan)

The Executive considers the following topics to be high priority for consideration in 2020/21. No new topics have been added to the high priority list based on horizon scanning findings, however the committee have re-prioritised the order of the list as of February 2020:

a) Treatment add-ons
b) Health outcomes in children conceived by ART
c) Embryo culture media
d) New technologies in embryo testing (including embryo biopsy and non-invasive methods for PGD)
e) Genome editing
f) Artificial Intelligence (AI)
g) Mitochondrial donation
h) Synthetic human entities with embryo like features, “SHEEFs”
i) Alternative methods to derive embryonic and embryonic-like stem cells

Annex B (Code of Practice – genetic counselling)

the exact wording in the Code of Practice for genetic counselling and incidental findings

Guidance note 3 - Counselling and patient support

3.5 The centre should provide proper counselling throughout the treatment, donation or storage processes, and afterwards if requested. Counselling should routinely be offered following adverse events and/or unsuccessful outcomes. If a person who has previously donated gametes or embryos (including mitochondrial donation), or received treatment, requests further counselling at any point, the centre should take all practicable steps to help them obtain it. Group sessions may be offered in addition to individual and couple sessions.

3.10 The centre should ensure that arrangements are in place to provide, or refer people for, specialist counselling if appropriate, taking account of their duty of confidentiality under the HFE Act. This might include genetic counselling, counselling for patients undergoing treatment involving mitochondrial donation and counselling for oncology patients or others requiring the long-term storage of gametes or embryos.

Guidance note 9 – Pre-implantation genetic screening (PGS)

9.6 Where patients seek PGS, but do not wish to be given any additional genetic information that may be found via sophisticated genetic testing methodologies (e.g., segmental aneuploidies), the centre should follow, where possible, guidelines around PGD for non-disclosure (paragraphs 10.10-10.12).

9.7 Where PGS is carried out using technologies that give rise to additional genetic information, the centre should ensure that people seeking treatment are offered access to genetic counselling and, where appropriate, infertility counselling before and after treatment has occurred.

Guidance note 10 - Embryo testing and sex selection

10.1 A senior clinical geneticist should be involved in deciding whether a particular patient should receive treatment involving embryo testing.

10.3 Treatment should include patient support following embryo testing.

10.6 The use of PGD should be considered only where there is a significant risk of a serious genetic condition being present in the embryo. When deciding if it is appropriate to provide PGD in particular cases, the seriousness of the condition in that case should be discussed between the people seeking

treatment and the clinical team. The perception of the level of risk for those seeking treatment will also be an important factor for the centre to consider.

10.7 In instances where a patient is undergoing PGD for a heritable condition, a centre may offer PGD for additional condition(s) that do not meet the particular risk requirements but have been deemed, by the Authority, to be of significant risk (as set out in box 10A). Patients should give consent for this which should be recorded in the patient notes.

10.13 The centre should ensure that people seeking treatment have access to clinical geneticists, genetic counsellors and, where appropriate, infertility counsellors before and after treatment.

10.15 The centre should ensure that people seeking PGD are given the appropriate information about the treatment. This should include:

a) the process, procedures and possible risks involved in IVF and biopsy procedures when providing a sophisticated genetic test.
b) the experience of the centre in carrying out the procedure.
c) that sophisticated genetic tests can reveal additional genetic information about an embryo(s) and that the clinical effect of these findings on a child born may not be known.