BICA Response to the HFEA Code of Practice 9th ed Review

The British Infertility Counselling Association (BICA) is a registered charity and the only professional infertility counselling Association in the UK recognised by the Human Fertilisation and Embryology Authority and the British Fertility Society.

Our aims are:

- To support our members in their practice and professional development through the provision of information, training, opportunities for networking and through an accreditation process that ensures high quality standards and ethical practice are evaluated, maintained and adhered to.
- To safeguard the best interests of those who seek the services of our members, recognizing the sensitivity and expertise required when working with people affected by infertility, secondary infertility and involuntarily childlessness, many of whom face complex decisions related to alternative approaches to modern family creation such as donation, surrogacy and/or fertility preservation
- To ensure that those who seek the services of our members are making fully informed decisions in relation to their treatment and family building options.
- To inform and educate the wider public and our colleagues in the field of assisted conception about the psychological and social impact of infertility through the provision of training and information.

BICA welcomes the opportunity to respond to the review of the HFEA Code of Practice, particularly regarding the proposed amendments to the counselling sections. In addition, we welcome the greater emphasis on the emotional/psychosocial support of the patient, before during and after treatment, in section 3. We congratulate the HFEA for attempting to put these less quantifiable aspects of treatment on a par with the more measurable ones of clinical outcomes

We have the following comments:

Staff, Guidance Note 2

2.14 *Treatment centres should ensure that at least one individual is appointed to fulfil the role of counsellor. All counsellors should have specialist competence in infertility counselling and:*

1. *(a) hold a recognised counselling, clinical psychology, counselling psychology or psychotherapy qualification to the level of diploma of higher education or above, and*
2. *(b) be accredited under the scheme of the British Infertility Counselling Association (or an equivalent body), or show evidence of working towards such accreditation.*

- 2(b) BICA is concerned by the suggestion that a counsellor can be accredited by an equivalent body which can then be taken to mean that, for instance, accreditation by BACP, is sufficient to prove competence for infertility counselling. We strongly recommend that this be amended to:

  '(or an equivalent scheme)'

2.15 *It is recognised that it may be necessary to appoint a general counsellor to the role, who is not a fertility specialist. This member of staff should be able to provide evidence of being an accredited member of, or working towards accredited membership of, a recognised professional counselling body, in order to prove specialist competence in infertility counselling. The body should have with a complaints/disciplinary procedure, and the individual should have agreed to abide by this organisation's code of conduct or ethics. The appointed general counsellor should be compliant with the requirement to demonstrate specialist competence in infertility counselling within a period of two years.*

- L1: The term 'general' should be replaced by 'generic'. A generic counsellor is the term more commonly used to describe a non-specialist counsellor.
- L1: We are also concerned that some centres have little commitment to providing counselling and will make no effort to recruit a fertility specialist. We recommend this sentence is reworded to state:
  It is expected that centres seek to appoint a specialist fertility counsellor to the role as a matter of best practice. If this proves not possible in the short term it may be necessary to appoint a generic counsellor to the role. This counsellor should have experience of working with loss and grief so that they have the basic skills required for practice in this field.
- L1: We also strongly recommend that any generic counsellor appointed to the role, who is not a fertility specialist, is mentored and/or supervised by a counsellor who has already demonstrated specialist competence in infertility counselling as per guidance note 2.14. This is in accordance with the BICA Accreditation scheme requirements and ensures that a counsellor who is inexperienced in this setting is not practicing without appropriate specialist input. Additionally, we consider such mentorship and/or supervision critical where the generic counsellor is the centre's sole counsellor or is working only alongside another generic counsellor(s). BICA considers such practice, without this form of mentorship or supervision, to be unethical and to undermine the standard of the counselling provided and therefore the nature of fully informed consent. We therefore recommend the following additional wording:
  This counsellor should have experience of working with loss and grief so that they have the basic skills required for practice in this field and should be mentored / supervised by a qualified counsellor whose qualifications and experience satisfy the requirements of guidance note 2.14 to 2.16
- L4: 'in order to prove specialist competence in infertility counselling'. This phrase should be deleted. It does not relate to a generic counsellor who has not yet demonstrated specialist competence and appears to give the impression that obtaining accreditation of a recognized counselling body proves specialist competence as a fertility counsellor.
- L4: delete 'with'

2.16 Treatment centres carrying out pre-implantation genetic diagnosis or mitochondrial donation should ensure that patients have access to counsellors with appropriate knowledge and expertise in these specialisms, including a good understanding of the risks and implications for patients who have treatment involving mitochondrial donation techniques and any children that may be born following such treatment.

- *L2. BICA feels that the term 'have access to' is insufficient and should be replaced by 'be offered counselling with a counsellor who has …'*
- L3: BICA would expect counsellors working with patients considering PGD or mitochondrial donation to have an '**in depth'** rather than simply a **'**good**'** understanding of the risks and implications involved. This is essential for the exploration of such risks and implications in counselling and to ensure that patients fully understand these prior to giving consent.

Counselling and Patient Support, Guidance Note 3

3.1 *The centre should provide a suitable opportunity for counselling after the individual or couple has received oral and written information about the services to be provided and before they consent to treatment, donation, or to the storage or use of gametes or embryos. Counselling should be accessible in terms of location. The timing and frequency of counselling sessions should be agreed between counsellor and the person or couple concerned, in order to meet their needs.*

- *L4:* we are aware that some centres provide limited counselling hours and people are faced with long waiting lists for a first appointment. We believe that counselling should be accessible in terms of location and availability and therefore recommend that this be added to L4. Furthermore, BICA is aware that some centres provide no free counselling sessions and charge very high rates. This inevitably means that counselling is not realistically accessible to people on low or modest incomes. If NHS funding is not available, many people struggle to raise the funds and resort to loans, debts to relatives and foregoing any holidays or social spending. To keep costs to a minimum they will also forego counselling and this is not in their best interests. Where third party is concerned, BICA believes it is also not in the best interests of the children who may be born. We therefore suggest the following wording: *"Counselling should be accessible to all in terms of location and any associated costs that may be involved"*
- L5: We welcome this emphasis on meeting the patient(s)' needs in terms of counselling session arrangements. However, we suggest the insertion of 'best', as in "…in order to **best** meet their needs.", more appropriately reflects the importance of prioritizing the needs of the person or couple concerned and is commensurate with best practice.

3.6 *The centre should offer people the opportunity to have counselling either with their partner or alone, depending on what each person prefers. In the case of counselling on the implications of treatment or donation, if two people are being treated together, then we would recommend they both attend the counselling session. In the case of an intended surrogacy arrangement, please see 3.7*

- We are pleased to see, and fully support, the requirement for counselling to be provided in relation to surrogacy but it is an anomaly that people involved in third party donation are only 'offered the opportunity' (3.7 – 9). BICA considers that all parties involved in either surrogacy or third party donation should be provided with counselling. The implications for both surrogacy and third party donation involvement are significant, far-reaching and life-long. The welfare of all parties concerned as well as any children who may be conceived and any existing children should be paramount. Consent in both surrogacy arrangements and in third party donation cannot be considered to be fully informed unless all parties have fully understood, at an emotional as well as factual

level, all the implications of their proposed involvement. It is essential that such implications are explored at a personal level on an individual, couple and relationship basis [the latter being of particular significance not only in a surrogacy arrangement but also where the donor is known to the recipient(s)].

- L1. BICA believes that it is essential for both partners to have attended counselling if third party donation is being considered but the HFEA seems to be supporting an either or option. The partner of a donor will be especially affected if the couple have children given that his/her children will have genetic half-siblings, with potential for consanguinlity in future relationsships. The partner of a recipient is undoubtedly affected if his/her partner has a child that is created through donation. We find it entirely unacceptable for the Code of Practice to support an option.

- L4. This suggests that only one counselling session is required and provided which does not reflect BICA's Guidelines for Best Practice nor the reality that some people will need to see the counsellor a number of times before they feel ready to make an informed decision. We therefore recommend that it is amended to "session(s)". (There are other instances in this draft Code where reference is made "a counselling session" or "an appointment". We have tried to identify them all but recommend that the draft is proof- read to ensure all are changed to recognize multiple sessions)

Implications counselling for surrogacy arrangements

3.7 *The centre should ensure that any person intending to begin treatment as a surrogate has implications counselling (depending on their wishes, alone, or with a partner, if the surrogate has one). The implications counselling should be provided by a qualified counsellor. The intended parents should not attend this appointment and where practicable this appointment should take place on a date separate to any appointment to be attended by or with the intended parent(s). This appointment should address potential risks and implications of surrogacy (including, but not limited to, risks to the surrogate's physical and mental health, legal implications, practical and financial matters and emotional impact on the surrogate and the surrogate's partner and/or family. This appointment should allow full opportunity for the intended surrogate to ask questions and discuss any concerns.*

- The wording here suggests that where the surrogate has a partner, she may choose to be seen with him/her or without. It is of course essential that implications counselling also be provided to the surrogate's partner/husband/wife if she has one. The emotional, legal and practical implications for him/her are significant and highly complex. BICA considers it essential that his/her need for implications counselling, alone or with his/her partner depending on their wishes, is clearly stated in this guidance note. The centre should also take account of any objections the surrogate's partner may have to proceeding with the arrangement and provide further counselling as appropriate.
- Again it is being suggested that counselling involves one appointment and we feel it is essential that 3.7 is amended to state "appointment(s)"

3.8 *The centre should ensure that any person intending to enter a surrogacy arrangement as an intended parent has implications counselling provided by a qualified counsellor. The surrogate should not attend this appointment and where practicable this appointment should take place on*

a date separate to any appointment to be attended by or with the surrogate This appointment should address potential risks and implications of surrogacy, including, relevant risks outlined in 3.7 and the risk of the surrogate not wishing to agree to the parental order being made once a child is born. This appointment should allow full opportunity for the intended surrogate to ask questions and discuss any concerns.

- 'surrogate' should read 'intended parent(s)'

3.9 *In addition to the separate implications counselling referred to at 3.7 and 3.8, the surrogate and intended parent(s) should attend a joint implications counselling session with a qualified counsellor. This should cover any relevant risks/considerations mentioned in 3.7 and 3.8. Both the intended surrogate and the intended parent(s) should have full opportunity to ask questions and discuss any concerns.*

- As 3.7 – the surrogate's partner if she has one, is part of this arrangement / group dynamic and BICA considers it essential that s/he also attends joint implications counselling so that the centre can assure itself of the agreement of all parties to the proposed arrangement and how they expect to manage the various different and complex stages of the treatment, pregnancy, postnatal period and beyond.
- By deleting session in the above, it has removed the suggestions that only one counselling session is required.
- L2. BICA supports the practice of having a joint session in addition to individual sessions but some of our members have expressed concern about making this a requirement and state that this should be a matter of professional judgement by the counsellor. In some cases, the intended parent and surrogate have already gone through an extensive period of contact and exploration with an agency (e.g Surrogacy UK) and an additional session may not be so necessary.

3.11 *The counselling service should comply with current professional guidance on good practice in infertility counselling. Only qualified counsellors should provide counselling.*

- To ensure consistency (see 3.12) and adherence to the guidance that counsellors must be appropriately qualified, BICA suggests a reference to Guidance Note 2.14 – 16 should be inserted here

3.12 *Counselling should be available from a counsellor attached to the centre whose qualifications and experience satisfy the requirements of guidance note 2.14 to 2.16. If this is not possible or if the patient prefers to seek counselling elsewhere, the centre should provide:*

(a) information on local counsellors who have specialist competence in infertility counselling and who meet the requirements of guidance note 2.14 to 2.16

(b) information on organisations that can provide specialist support.

- BICA can see no reason why any centre should be unable to comply with 2.14. to 2.16 but 3.12 is offering a way out of doing this which we do not believe will be in the best interests of people involved with treatment. We strongly recommend that "*If this is not possible"* is deleted

- BICA suggests that an 'AND' be included between (a) and (b) to ensure that centres follow **both** guidance points.
- It is possible that centres following the above guidance will make assumptions about people's attendance for counselling elsewhere. It is vital that centres satisfy themselves of the counsellor's specialist competence; this is particularly important where surrogacy and third party donation are concerned. Centres should also be able to evidence that parties to surrogacy and third party donation have attended for counselling and therefore fully understand the implications for themselves and any other individuals who may be affected by the process. BICA therefore strongly advises that an additional point (c) be added as follows:

  '(c) *The centre also has a responsibility to satisfy itself of an external counsellor's specialist competence and, in cases of surrogacy and third party donation, the completed attendance of the patient(s) / surrogate / gamete provider for implications counselling*.'

3.14 The centre should ensure that counselling facilities provide quiet and comfortable surroundings for private, confidential and uninterrupted sessions. The centre should also consider the use of other media for counselling sessions, such as video or audio calls in order to make counselling as accessible as possible for patients and donors.

- BICA agrees that people should have access to other media for counselling sessions but are concerned that some centres are already using this to the exclusion of face to face counselling. We recommend that it be worded as:

'*The centre should also consider the use of other media for counselling sessions, such as video or audio calls, as an addition to face to face counselling, in order to make counselling as accessible as possible for patients and donors*.'

Embryo Testing and Sex Selection, Guidance Note 10

Genetic consultation and counselling

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.*

- Counselling should be offered before, **during** and after treatment in accordance with the guidance at **3.5** of the Code "*The centre should provide proper counselling throughout the treatment, donation or storage processes, and afterwards if requested*."

Egg Sharing Arrangements, Guidance Note 12

12.10 *Centres should ensure that where a gamete provider elects not to have counselling, the implications of donation are discussed with the gamete provider. Centres should record that the implications of donation have been discussed and why the gamete provider has elected not to have counselling. The gamete provider should be given enough time to consider the implications of donating, before giving consent.*

- BICA strongly objects to this new guidance. The consequence will be to undermine the principle and policy of implications counselling being an area of work that requires specialist expertise and we are dismayed that the HFEA in 2018 should take any course of action that undermines this. It is particularly troubling given that the HFEA set out in 1992 to work with BICA and BFS to ensure that 'proper counselling' would involve recognized training and accreditation. 12.10 suggests that it is sufficient for any member of staff to talk to gamete providers in an egg sharing arrangement about the implications of their decision. It will be open for clinics to argue that, if it is sufficient for Egg Sharing, then it must be acceptable for all other forms of third party donation. It is essential that the HFEA understands that the implications of donating gametes are highly complex for all individuals and couples and therefore can only be fully explored with the professional support of a qualified counsellor who meets the requirements of Guidance Note 2.14 - 16. The implications of donation, whether provided within a benefits in kind arrangement or otherwise, are not a tick list simply to be "discussed". A prospective gamete provider must be able to fully understand the emotional and social implications for their own personal set of circumstances and this process should be facilitated by a qualified counsellor. BICA considers it unethical to proceed to donation without proper counselling and therefore valid consent.
- As noted previously, this is also a matter of safeguarding the interests of the children who might be born and any existing children.
  It should be noted that the inclusion of the guidance is yet another anomaly, wholly inconsistent with the surrogacy guidance at 3.7 – 9.

Interpretation of mandatory requirements

12A *The centre must offer anyone intending to participate in a benefits in kind arrangement the opportunity for counselling.*

- To ensure consistency, BICA advises that the above interpretation should be amended to read:

  "The centre must **provide** anyone intending to participate in a benefits in kind arrangement a **suitable** opportunity for counselling"

12.19 *The agreement should include a statement from the egg or sperm provider confirming that they have:*

(a) had an opportunity to talk with a member of staff qualified to explain the procedures involved in providing gametes as part of a benefits in kind arrangement

(b) received verbal and written information about the treatment

(c) received all the appropriate information listed in the relevant parts of this Code of Practice

(d) been offered counselling

(e) received information about the implications of the treatment and donation, and

(f) been made aware of the screening that will be done before treatment begins

AND

12.27 *The agreement should include a statement from the recipient confirming that she has:*

(a) had an opportunity to discuss with an experienced member of the centre's staff the procedures involved in receiving eggs or sperm as part of a benefits in kind arrangement

(b) received verbal and written information about her treatment

(c) received all the appropriate information listed in the relevant parts of this Code of Practice (written information should be attached to the agreement)

(d) been offered counselling

(e) received information about the implications of the treatment and using donated gametes, and

(f) been informed about the screening that the egg or sperm provider has undergone and the limitations of that screening in avoiding transmissible conditions.

- BICA considers the points at 12.19 (c) and (e), 12.27 (c) and (e) to be anomalous with the guidance on surrogacy and the mandating of counselling to ensure all parties fully understand the implications. Counselling should be provided. It is unethical to only provide information about the implications of the treatment and using donated gametes without a full exploration facilitated by a qualified counsellor who meets the requirements at 2.14 – 16. A full understanding cannot be assumed where implications counselling has not taken place.

Storage of Gametes and Embryos, Guidance Note 17

End of Storage Period

17.24 *The centre should establish and use documented procedures to contact patients who have gametes or embryos in storage for their own treatment when the end of the permitted storage period is approaching but long enough in advance to allow the centre and patient to take any steps necessary to comply with the 2009 Regulations where extension of storage is an option for the patients. The centre should use all contact details available to them, including at least one written form of contact. Patients should be provided with information about the options available to them as the end of their permitted storage period approaches. They should be given enough notice to enable them to consider those options and to access appropriate advice. Options could include the donation of the gametes or embryos for research, training or for the treatment of others. If contact with the patient is not possible, the centre should record the steps it has taken in the patient's medical records.*

- BICA considers that L 8 should include the offer of counselling to ensure that patients are appropriately supported in their decision making process prior to the end of the storage period. Offering access to advice only may limit patients' ability to make / reach a fully informed decision. We would also consider the omission of an offer of counselling at this crucial stage to be incompatible with the emotional support pathway.

Confidentiality, Guidance Note 30

30.5 *In relation to the treatment of patients and donors entering into surrogacy arrangements, centres must ensure that appropriate arrangements are in place to maintain confidentiality. The centre must keep separate up-to-date records for the surrogate and the intended parents. The centre should provide separate implications counselling sessions for the surrogate and the intended parents, on different dates. Throughout treatment the clinic should allow opportunity for separate consultations with the surrogate and with the intended parents. During any appointment or occasion where both the surrogate and intended parent(s) are present, the centre should ensure that consideration is given to their confidentiality and ensure that parties are offered an opportunity to speak to members of staff in private should they wish to.*

- BICA considers that the same confidentiality guidance should apply to all parties in third party donation.