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IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 15/03/2024

Before :

MRS JUSTICE THEIS DBE

- -

Between :

	Wessex Fertility Limited	**Claimant**
	- and -	
	University Southampton Hospital NHS Foundation Trust	
	- and -	
	Human Fertilisation and Embryology Authority	
	-and-	
	Donor Conception Network	**Interested Parties**

- -

Mr Peter Mant (instructed by **Lawford Davies & Co**) for the **Claimant**
Mr Michael Mylonas K.C. (instructed by **DAC Beachcroft**) for the **University Southampton Hospital NHS Foundation Trust**
Mr Ravi Mehta and Mr Tom Lowenthal (instructed by **Blake Morgan LLP)** for the **Human Fertilisation and Embryology Authority**
The Donor Conception Network were not represented

Hearing date: 12 December 2023
Judgment: 15 March 2024

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Approved Judgment

This judgment was handed down remotely at 10.30am on 15th March 2024 by circulation to the parties or their representatives by e-mail and by release to the National Archives.

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MRS JUSTICE THEIS

This judgment was delivered in public and may be published

Mrs Justice Theis DBE :

Introduction

1. The claimant, Wessex Fertility Limited ('the Clinic') seeks declarations that

   (1) It is lawful for it to request that an egg donor, Donor A, provide a DNA sample for the purposes of genetic analysis; and

   (2) The processing of Donor A's personal data involved in making this request is lawful by reason of articles 6(1)(f) and 9(2)(h) of the General Data Protection Regulation ('GDPR') as being necessary for the purpose of medical diagnosis and/or in the provision of health treatment and proportionate to any interference with the rights of Donor A not to be told information about her health.

2. The application is supported by the University Southampton Hospital NHS Foundation Trust ('the Trust'), albeit they get their position by a different route than the Clinic. The Human Fertilisation and Embryology Authority ('HFEA') are neutral, although seek to emphasise the importance of the integrity of any consent given. The Donor Conception Network ('DCN') are also neutral but seek to provide information to the court through their knowledge and experience.

3. The court heard oral submissions on 12 December 2023 and reserved judgment. The court is extremely grateful to the comprehensive written submissions from Mr Mant, Mr Mylonas K.C., Mr Mehta and Mr Lowenthal. They each set out their submissions with admirable clarity. The court is also grateful to the DCN for providing the information they did in the statement from their director, Ms Barnsley.

Relevant background

4. This can be taken from the Details of Claim filed by the claimant in support of the application.

5. The Clinic has been licensed by the HFEA to offer fertility treatment and services since 1992.

6. The Clinic treated a couple, Mr and Mrs H, using donor eggs and Mr H's sperm. The treatment was successful and a baby girl, AH, was born. AH was born with a number of health problems including polydactyly, a cardiac abnormality and gross motor delay.

7. The eggs donated for the treatment received by Mr and Mrs H were from Donor A. She has twice donated eggs to the Clinic, the eggs for Mrs H's treatment were from the first egg collection, which were inseminated through in vitro fertilisation and created three embryos. Two were transferred to Mrs H resulting in the birth of AH. The eggs from the second collection were all given to one recipient and their use resulted in the birth of one child, a boy, who has no health problems. The Clinic does not currently hold any eggs donated by Donor A.

8. The statement from the Clinic's Medical Director, Dr Sue Ingamells, outlines the standard process for selection and treatment of egg donors. This involves a detailed review of the donor's medical history and blood screening for blood born viruses and cystic fibrosis. These are standard tests undertaken as required by every HFEA clinic

licence. In addition, although not a requirement of their HFEA licence, the Clinic carries out karyotyping for chromosomal abnormalities for all donors.

9. Once this initial screening process has been undertaken and the donor has been accepted, they are invited to the Clinic to discuss the process of egg donation. At this meeting they are informed of the fact that children conceived as a result of gamete donation are legally entitled to seek identifying information about their donors when they turn 18 years.

10. At the time of the first egg donation all donors were asked to complete a number of forms prior to donation, including the following:

    (1) HFEA pro forma 'CD' form *'Your consent to the disclosure of identifying information'*.

    (2) HFEA pro forma 'WD' form *'Your consent to the use and storage of your donated eggs'*.

    (3) The Clinic's internal consent form *'Consent form – Altruistic/Known Donor – Egg Recovery'* ('the Clinic consent form').

11. The HFEA CD form requires the donor to indicate whether she consents to identifying information being disclosed to various groups of professionals or for the purposes of medical or other research. The opening part of the form provides as follows:

    'Under the Human Fertilisation and Embryology Act 1990 (as amended) you need to give your consent if you want identifying information about you, in relation to your or your partner's treatment, your storage or donation to be shared with any other non-HFEA licensed people…Your clinic cannot disclose any identifying information without this consent (other than in a medical emergency)'.

12. When Donor A completed this form she confirmed her consent to disclosure of identifying information to her GP, other healthcare professionals outside the Clinic, auditors or administrative staff who give essential support to the Clinic and for the purpose of non-contact research. She did not give her consent for the purposes of research that would involve her direct participation.

13. Part of the internal Clinic consent form provides as follows:

    'I/we wish to be notified if Wessex Fertility learns (e.g., through the birth of an affected child) that I have a previously unsuspected genetic disease, or that I am a carrier of a harmful inherited condition'. Beside this part of the form there is a box to tick 'yes' or 'no'. In this case Donor A, who completed this form in advance of her first egg collection for use by Mr and Mrs H, ticked the box to state that she did not wish to be notified in the event of such a discovery. Consistent with this, Donor A also completed the form in the same way when at the time of her first egg collection for use with a different recipient couple and another when she returned for her second egg collection the following year.

14. Professor Anneke Lucassen, the clinical geneticist responsible for AH's care at the Trust has asked that the Clinic contact Donor A to request that she provides a DNA

sample. This could be provided either by a mouth swab or a blood sample. The sample would be used to carry out genetic analysis with the aim of establishing a genetic diagnosis of AH's condition.

15. In her written evidence, Professor Lucassen sets out why 'trio testing' (genetic analysis using the genetic codes of both parents) greatly increases the chance of a diagnosis. Such testing is of assistance not only in the scenario where AH is found to suffer from an autosomal recessive condition inherited from her father and Donor A, it is also of benefit in excluding a genetic condition as the cause of AH's health difficulties or confirming that AH has a new dominant condition, not inherited from her father or Donor A.

16. A clinical diagnosis would greatly assist the diagnosis and treatment of AH's condition. In the event of a diagnosis, it would allow for use of particular educational interventions, targeted treatments or allow certain medications to be excluded or indicated. In her evidence, Professor Lucassen states that there is a *'small but definite chance*' that treatment will be indicated as part of a diagnosis that would not otherwise be available. She gave brief oral evidence when she confirmed trio testing was first used between 2013 – 2015 although mainly as a research exercise at that time and was not launched in the NHS until 2018. She was clear that if Donor A stated she did not want to be informed about any genetic disease there would be *'no chance'* she would be. As she stated, the purpose of the DNA sample is to rule out matters for AH, stating *'we need to weed out rare variants, the sample is acting as a control rather than diagnostic test'*.

17. In her written evidence, Dr Ingamells expresses her concern about the impact on Donor A of such contact. In her view, Donor A has consistently expressed the view that she did not wish to be informed if the Clinic learns through the birth of an affected child that she has a previously unsuspected genetic disease, or is the carrier of a harmful inherited condition. Contacting Donor A in the circumstances suggested is likely to disclose the existence, if not the details, of AH's condition. It is also recognised that even if contacted, Donor A may not agree to provide the DNA sample. This has to be balanced with the possibility that if the DNA sample were provided by Donor A, it may result in diagnosis and treatment for AH, and may be relevant to those who have conceived or may conceive in the future using Donor A's eggs. Having balanced these considerations, Dr Ingamells concludes that Donor A should be contacted and there is justification for acting contrary to her stated wishes.

18. The Clinic instructed Professor Peter Turnpenny, Consultant Clinical Geneticist, to provide an expert report on the issues and balancing exercise to be undertaken. In his report, he concludes that obtaining a DNA sample from Donor A would increase the possibility of achieving a genetic diagnosis for AH. He recognises that there is a small chance that information of medical significance for Donor A would be uncovered. He recommends that if Donor A is contacted she should be offered genetic counselling.

19. The court also has the benefit of a statement from Nina Barnsley, the Director of the DCN, which all parties agree should be considered by the court.

20. Ms Barnsley has been the director of the DCN for 8 years. The DCN is a charity established in 1993 to support donor conception families and prospective families. As Ms Barnsley sets out, the aim of the DCN is to '*deliver high quality, non-judgmental*

and inclusive support and information to would-be and current parents and their children to enable them to navigate the often complex and individual journey of donor conception. We include donors in our wider support as they are of significance in the family story. Additionally, some of our members are both recipients and donors themselves.'

21. Ms Barnsley confirms that the DCN was notified about this case on behalf of the Clinic as they were conscious that the person at the centre of this case, Donor A, had no one representing her possible thoughts and feelings and the DCN may be able to provide some helpful context from that perspective. Ms Barnsley makes it clear the DCN is neutral as to the claim itself and can only provide information as to generic issues that face donors in general. Although a payment of £750 is made to donors, Ms Barnsley considers that most, if not all, donors are altruistic with a range of motivations to donate. Equally there is a range of feelings that donors have around donating, from simply donating a cell they do not need to having a stronger feeling about their gametes and any genetic connection with a child. As Ms Barnsley sets out, it is difficult to say definitively what a donor would want or expect from donation, in terms of privacy or otherwise, as donors vary enormously.

22. It is her view that the consent wording in this case was *'not clear',* as a result it is difficult to know whether this particular donor understood that the circumstances the court is considering in these proceedings would be included. As she sets out, if the declaration is granted, careful thought needs to be given as to how Donor A is approached if the courts' decision is to grant the application.

23. After the hearing the court has been provided with a detailed revised draft contact plan dated 6 March 2024 which sets out a staged approach as to how Donor A would be contacted, summarised at the start of the plan as follows:

'A three-staged approach will be taken to contacting Donor A, as set out in more detail below. Initial contact will be made by telephone, and with Donor A's consent this will be followed by letter with a request for a DNA sample and some brief context about why this is sought. The next steps will then depend on Donor A's response but may include a meeting if requested by Donor A, to answer any questions that she may have.'

Legal and Regulatory Framework

24. There is no significant issue between the parties as to the applicable legal framework, the focus has been on how it is applied in the circumstances of this case. As a consequence, much of what is set out below is taken from the helpful summary provided by Mr Mant.

25. The Human Fertilisation and Embryology Act 1990 ('HFEA 1990'), as amended by secondary legislation and the Human Fertilisation and Embryology Act 2008 ('HFEA 2008'), regulates the donation, storage and use of gametes and embryos. The legislation is supplemented by a Code of Practice issued by the HFEA pursuant to s 25 HFEA 1990.

26. The 8th Edition (v.6) of the HFEA Code of Practice (issued on October 2013) was in force at the material time when the eggs were donated. All references to the Code of Practice are to that version, unless otherwise specified.

27. As regards consent to storage and use of gametes for treatment of others s 4 HFEA 1990 provides that no person shall store or, in the course of providing treatment services for any woman, use a gamete except in pursuance of a licence.

28. Section 12(1)(c) HFEA 1990, as amended, states:

"*The following shall be conditions of every licence granted under this Act:-*

(c) except in relation to the use of gametes in the course of providing basic partner treatment services or non-medical fertility services, that the provisions of Schedule 3 to this Act shall be complied with."

29. Paragraph 5 of Schedule 3 HFEA 1990 provides:

"(1) A person's gametes must not be used for the purposes of treatment services or non-medical fertility services unless there is an effective consent by that person to their being so used and they are used in accordance with the terms of the consent.

(2) A person's gametes must not be received for use for those purposes unless there is an effective consent by that person to their being so used."

30. Paragraph 3 of Schedule 3 provides:

"(1) Before a person gives consent under this Schedule - (a) he must be given a suitable opportunity to receive proper counselling about the implications of taking the proposed steps, and (b) he must be provided with such relevant information as is proper."

31. Paragraph 4 of Schedule 3 sets out that the terms of any consent can be varied or withdrawn with notice being given, but the terms of any consent to use the embryo cannot be varied or withdrawn once the embryo has been used.

32. Pursuant to s 25 HFEA 1990 the HFEA shall issue a Code of Practice. That Code sets out information which a clinic should provide to prospective donors prior to obtaining consent. The following sections are relevant:

"*11.34 Before any consents or samples are obtained from a prospective donor, the recruiting centre should provide information about:*

(a) the screening that will be done, and why it is necessary

(b) the possibility that the screening may reveal unsuspected conditions (eg, low

sperm count, genetic anomalies or HIV infection) and the practical implications

(c) the scope and limitations of the genetic testing that will be done and the implications for the donor and their family

(d) the importance of informing the recruiting centre of any medical information that may come to light after donation that may have health implications for any woman who receives treatment with those gametes or for any child born as a result of such treatment

[…]

(i) the fact that the centre or the HFEA (or both) may disclose non-identifying information about the donor, for example to prospective recipients or to the parents of donor-conceived children

(j) the HFEA's obligation to disclose non-identifying information (and identifying information if donation took place after 31 March 2005), to someone who applies for such information if: (i) the applicant is aged over 16 (to access non-identifying information) or 18 (to access identifying information), and (ii) the applicant appears to have been conceived using the donor's gametes, or embryos created using the donor's gametes

(k) the importance of supplying up-to-date contact information so that they can be informed if and when disclosure of identifiable information will be made

(l) the importance of the information provided at 11.29 and 11.30 to people born as a result of their donation

(m) the possibility that a donor-conceived person who is disabled as a result of an inherited condition that the donor knew about, or ought reasonably to have known about, but failed to disclose, may be able to sue the donor for damages

[…]"

33. The Code of Practice also states that at registration a donor should be asked to

indicate whether they would wish to be informed if the centre learns they have a previously unsuspected genetic disease or they are a carrier of a harmful inherited condition:

"11.28 At registration, donors should indicate whether or not they wish to be notified if the centre learns (e.g., through the birth of an affected child) that they have a previously unsuspected genetic disease or they are a carrier of a harmful inherited condition. They should also be asked whether or not they would like their primary care physician to be informed. Their wishes should be recorded in the donors' medical records."

34. Turning to selection and screening of donors, it is a condition of every HFEA clinic licence that donors are selected, assessed and screened in accordance with HFEA requirements. Licence condition T52 prescribes the selection criteria for donors (age, health and medical history) and requires laboratory tests for blood born viruses, genetic screening and an assessment of the risk of transmission of inherited conditions.

35. Section 13(9) HFEA 1990 provides:

"(9) Persons or embryos that are known to have a gene, chromosome or mitochondrion abnormality involving a significant risk that a person with the abnormality will have or develop—

(a) a serious physical or mental disability,

(b) a serious illness, or

(c) any other serious medical condition,

must not be preferred to those that are not known to have such an abnormality."

36. The Code of Practice provides:

"11.12 The use of gametes from a donor known to have an abnormality as described above [s.13(9) of the 1990 Act] should be subject to consideration of the welfare of any resulting child and should normally have approval from a clinical ethics committee.

11.13 If a centre determines that it is appropriate to provide treatment services for a woman using a donor known to have an abnormality as described above, it should document the reason for the use of that donor."

37. As regards retention and disclosure of information about donors s 31 HFEA 1990 specifies that the HFEA must keep a register containing any information relating to:

"(a) the provision for any identifiable individual of treatment services other than basic partner treatment services,

(b) the procurement or distribution of any sperm, other than sperm which is partner-donated sperm and has not been stored, in the course of providing non-medical fertility services for any identifiable individual,

(c) the keeping of the gametes of any identifiable individual or of an embryo taken from any identifiable woman,

(d) the use of the gametes of any identifiable individual other than their use for the purpose of basic partner treatment services, or

(e) the use of an embryo taken from any identifiable woman, or if it shows that any identifiable individual is a relevant individual."

38. Section 33A HFEA 1990 prevents any person from disclosing the information stored pursuant to section 31, subject to certain limited exceptions. Pursuant to s 41(5) HFEA 1990, disclosure of information in contravention of section 33A is a criminal offence, triable either way.

39 The exceptions to the non-disclosure rule in s 33A are narrow with the effect that there are limited circumstances in which it is permissible to disclose identifying information to a third party. For example, section 33A(2)(t), which permits disclosure necessarily made *"for any purpose preliminary to proceedings, or for the purpose of, or in connection with, any proceedings"* is subject to the caveat in section 33A(4) that such disclosure does not apply to disclosure of identifying donor information.

40. Section 31ZA HFEA 1990 provides that a person may request the HFEA give notice as to whether information in the register shows that a donor is their genetic parent and, if it does show that, to be provided such information as is required by regulations. Regulation 2 of the Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004 specifies the information that the HFEA is required to provide to an applicant by virtue of s.31ZA(2)(a). Where a request is made by an applicant who is above the age of 16 but under 18, the HFEA must provide the non-identifying information listed at subparagraph (2), namely:

"(a) the sex, height, weight, ethnic group, eye colour, hair colour, skin colour, year of birth, country of birth and marital status of the donor;

(b) whether the donor was adopted;

(c) the ethnic group or groups of the donor's parents;

(d) the screening tests carried out on the donor and information on his personal and family medical history;

(e) where the donor has a child, the sex of that child and where the donor has children, the number of those children and the sex of each of them;

(f) the donor's religion, occupation, interests and skills and why the donor provided sperm, eggs or embryos;

(g) matters contained in any description of himself as a person which the donor has provided;

(h) any additional matter which the donor has provided with the intention that it be made available to an applicant;"

41. Once an applicant has reached 18, he or she is entitled to the identifying information listed at subparagraph (3), namely:

"(b) the surname and each forename of the donor and, if different, the surname and each forename of the donor used for the registration of his birth;

(c) the date of birth of the donor and the town or district in which he was born;

(d) the appearance of the donor;

(e) the last known postal address of the donor."

42. Section 31ZD HFEA 1990 provides that a donor may request that the person responsible at the treating clinic or the HFEA informs them of the number of genetic children born by virtue of use of the donor's gametes, the sex of each of those persons and the year of birth of each of those persons.

43. Turning to contact with a donor following donation the 1990 Act does not place any restrictions on the circumstances in which a clinic may contact a donor.

44. The HFEA Code of Practice provides guidance on how a donor who has expressed a desire to be given information about unsuspected heritable conditions should be contacted and informed.

"11.29 If a centre learns that a donor has a previously unsuspected genetic disease or is a carrier of a harmful inherited condition, the centre should:

(a) notify the primary centre (where there is one) and the HFEA immediately

(the primary centre should immediately notify other centres who have received gametes obtained from that donor)

(b) inform patients who have had a live birth as a result of treatment with gametes from that donor, and offer these patients appropriate counselling

(c) carefully consider when and how a woman who is pregnant, as a result of treatment with gametes from that donor, is given this information,

(d) refer to the donor's medical records to establish whether, and in what way, they would like to be given the information. If the donor has indicated that they would like to be given such information, the centre should notify their primary care physician, so that the donor can be referred for the appropriate medical care and counselling. If the donor has indicated that they would not like their primary care physician to be informed, the centre should contact the donor directly.

11.30 The centre should tell gamete donors that they should inform the centre if, after the donation:

(a) they discover they are affected by an unsuspected genetic disease, or

(b) they find they are a carrier of a harmful recessively inherited condition (eg, through the birth of an affected child).

The centre should then proceed as indicated above."

45. The Code does not address what clinics should do where the donor has indicated that she does not wish to be notified in the event that the Clinic learns that she has a previously unsuspected genetic disease or is the carrier of a harmful inherited condition.

46. Licensed clinics are required by s 23(2) HFEA 1990 to comply with directions issued by the HFEA under the Act. General Direction 007 on Consent – in force since 1 October 2009 (V.7 dated 18 January 2017) – requires licensed centres to record consent for donating gametes in an HFEA pro forma WD form. It also requires that anyone receiving treatment at a licensed centre must complete an HFEA pro forma CD form 'Consent to the disclosure of identifying information form' ("CD form").

47. The Human Tissue Act ("HTA 2004") regulates the collection, removal, storage and use of human tissue (defined as material that has come from a human body and consists of, or includes, human cells). The Human Tissue Authority

("HTA") was established under the HTA 2004 to regulate activities concerning the removal, storage, use and disposal of human tissue.

48. Section 1 HTA 2004, read together with schedule 1 of paragraph 4, provides that consent is required for material to be removed, stored or used for *"obtaining scientific or medical information about a living or deceased person which may be relevant to any other person (including a future person)"*.

49. Section 3 HTA 2004 provides that where the person from whom the human tissue or blood is to be removed is alive, *"appropriate consent"* means his (or her) consent. Consent does not have to be provided in writing.

50. Section 5 HTA 2004 provides that in the absence of requisite consent, the removal, testing, or storing of human tissue is a criminal offence.

51. Section 45 HTA 2004 provides that a person commits an offence if he has any bodily material intending that DNA in the material should be analysed without qualifying consent and that the results of the analysis should be used otherwise than for an excepted purpose.

52. Excepted purposes are defined in Schedule 4, paragraph 5, to include such things as the functions of a coroner, the prevention or detection of crime or the purposes of national security. The only excepted purpose of potential relevance to the present case is that contained in paragraph 9, which relates to material subject to a direction under section 7.

53. Section 7 HTA 2004 allows the HTA to dispense with the need for consent in certain circumstances. Where relevant, material from a living person could be used to obtain scientific or medical information which may be relevant to another person, the HTA has the power to deem consent to be in place where it is not reasonably possible to trace the person from whom the material came, or they have not responded to requests for consent to use of their material. It is a condition for the use of this power that *"there is no reason to believe… that a decision of the donor to refuse consent to the use of material for that purpose is in force"*.

54. There is no statutory power to direct that a capacitous adult provide a DNA sample for the purpose of genetic analysis. It follows that unless genetic analysis is for an excepted purpose under the HTA 2004, it cannot be carried out without the appropriate consent.

55. The Article 8 rights of Donor A and AH are engaged in this case. Article 8 provides

"1. Everyone has the right to respect for his private and family life, his home and his correspondence. 2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic wellbeing of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others."

56. The steps that are proposed in this case involve the processing of Donor A's personal data. The applicable legal framework and the Clinic's detailed analysis in relation to the General Data Protection Regulation ('GDPR') and the Data Protection Act 2018

('DPA 2018') were set out in some detail by Mr Mant. His summary is not in issue namely, information concerning Donor A obtained by the Clinic at the time of her treatment constitutes personal data of which she is the data subject ("the existing personal data") for the purposes of the GDPR and the DPA 2018. In addition, the information the Clinic has been given as to AH's state of health is previously unknown personal data in respect of Donor A, in so far as it indicates that she may have a previously unsuspected genetic disease or be a carrier of a harmful inherited condition ("the new personal data") and is also personal data for the purposes of the GDPR and DPA 2018.

57. Consequently, it follows that under Article 6(1) of the GDPR, processing of that data shall only be lawful if and to the extent that one of the lawful bases for processing set out in that Article applies. The relevant parts are under Article 6 (d) and (f) namely

'(d) processing is necessary in order to protect the vital interests of the data subject or of another natural person; […]

(f) processing is necessary for the purposes of the legitimate interests pursued by the controller or by a third party, except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject which require protection of personal data, in particular where the data subject is a child'

58. In addition, the existing personal data and the new personal data are *'data concerning health'* within the meaning of Article 9 of the GDPR. To be lawful, processing must also be justified on one of the grounds listed in Article 9(2).

Submissions

59. In his comprehensive submissions on behalf of the Clinic, Mr Mant submits the following issues require determination:

(1) Is there anything in the legislation regulating the donation, storage and use of gametes and embryos which prevents the Clinic from contacting Donor A in these circumstances?

(2) Does Donor A's expressed wish not to be provided with information about her health give rise to any duty on the part of the Clinic not to provide such information? If so, are there any circumstances which would justify informing Donor A of information about her health contrary to her express wishes?

(3) Is Donor A's wish not to be informed of information about her health protected by Article 8 of the European Convention on Human Rights ('EHCR'), such that any interference with that right must be justified under Article 8(2) as being necessary in pursuit of a legitimate aim? Do the circumstances of this case justify informing Donor A of information about her health contrary to her express wishes having regard to any duty owed by the Clinic and Donor A's rights under Article 8 ECHR?

(4) Is the processing of Donor A's personal data involved in contacting Donor A in accordance with the requirement of GDPR and the (DPA 2018.

60. Mr Mant agrees with the Trust that the facts in this case are not covered directly by the wording of the consent form, as it is common ground that AH does not have a diagnosed genetic condition, the Clinic has not learned that Donor A has a previously unsuspected genetic disease or that she is a carrier of a harmful inherited condition and there is only a small chance that the proposed genetic testing will reveal something of medical significance to Donor A.

61. Taking each issue in turn, first Mr Mant submits there is nothing in the HFEA 1990 which prevents the Clinic from contacting Donor A to request that she provides a DNA sample.

62. Section 33A HFEA 1990 imposes a strict obligation on the Clinic not to disclose information relating to the keeping and use of gametes of any identifiable individual. Mr Mant submits that as the request in this case is for Donor A to provide a DNA sample for the purpose of genetic analysis this would not be caught by disclosing any information covered by s33A HFEA 1990. This analysis is agreed by the Trust. The HFEA agree to a point, but draw the courts' attention to what is set out in HFEA 1990 regarding the need to heed the terms of any consent given (see Schedule 3 paragraph 5(1)) and to consider the relevant matters set out in the Code of Practice.

63. Turning to the second issue relating to any duty of care the Clinic may owe Donor A as their patient not to provide her with information about her health contrary to her expressed wishes. If such a duty exists, Mr Mant submits it is not absolute and must be weighed against the interests of AH. The decision whether such a step can be justified is a matter of clinical judgement.

64. Mr Mant submits the relationship between the Clinic staff and Donor A is one of healthcare professional and patient (see *ARB v IVF Hammersmith Ltd* [2017] EWHC 2438 (QB)) which involves a duty to take reasonable care in the provision of medical treatment and services. As a consequence, do they owe a duty to Donor A not to inform her of information about her health against her express wishes and, if so, he asks whether contacting her to ask her to give a DNA sample for the purpose of genetic analysis would breach that duty? Mr Mant submits there is no established case law that addresses this particular issue but in considering this the court would need to consider the foreseeability of damage, the proximity of the relationship between the Clinic, its staff and Donor A and whether it is fair, just and reasonable to impose an extended duty of care on the Clinic and its staff.

65. Mr Mant submits that any risk of physical or psychiatric injury to Donor A by requesting a DNA sample would be extremely low however the Clinic accept that providing information to a patient against their wishes could, in principle, cause shock or psychiatric harm and therefore requires the exercise of reasonable care.

66. In *Montgomery v Lanarkshire Health Board* [2015] A.C 1430 at [88] the Supreme Court identified limited exceptions to the duty to advise: a doctor is entitled to withhold from the patient information if the doctor reasonably considers that its disclosure would be seriously detrimental to the patient's health or the patient requires treatment urgently but is unconscious or otherwise unable to make a decision ([88]), or a patient has expressed a capacitous wish not be informed of such matters ([85]).

67. In *ABC v St George's Healthcare NHS Trust* [2017] EWCA Civ 336 the Court of Appeal concluded that the duty of confidentiality owed by a doctor to his patient was not absolute and might, in some circumstances, give way to a duty of care owed by the doctor to a third party to disclose information about the patient relevant to the third party's health. The Court of Appeal stated at [35] that the duty of care owed by a doctor in such circumstances would be measured (in accordance with *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582) by reference to relevant professional standards, with particular weight being given to relevant professional practice and guidance. At [37]-[38] the court stated that in such circumstances the clinician would engage in a balancing act, weighing the potential harm to the patient against the potential benefit to the third party from communicating such information.

68. For present purposes, Mr Mant submits, the court does not need to make a definitive ruling on whether the Clinic owes a duty of care not to contact Donor A as any duty would not be absolute, it would require the court to undertake a balancing exercise as between risk of harm to Donor A against the interests of AH assessed against the standard of a responsible body of medical opinion. He places reliance on the evidence of Dr Ingamells, Professor Turnpenny and Professor Lucassen who all support the declaration sought.

69. Mr Mant articulates the considerations that are likely to apply when considering the scope of any duty owed to a patient not to provide medical information contrary to the patient's wishes as follows:

(1) There may be circumstances in which the public interest in informing the patient of information contrary to his or her expressed wishes outweighs the patient's interest in respecting that wish not to know.

(2) In such circumstances, the clinician would need to balance the potential harm to the patient against the potential benefit to the third party from communicating such information.

(3) That balancing act is an exercise of clinical judgement and would be measured in accordance with *Bolam* by reference to the standard of a responsible body of medical opinion.

70. Mr Mant submits there is no relevant professional guidance on how such a balancing exercise would be undertaken. The GMC guidance on confidentiality referred to in *ABC* is, Mr Mant submits, of assistance. A section of that guidance is entitled *'Using and disclosing information for secondary purposes'* and at paragraph 106 states as follows:

'In exceptional circumstances, there may be an overriding public interest in disclosing personal information without consent for important health and social care purposes if there is no reasonably practicable alternative to using personal information and it is not practicable to seek consent. The benefits to society arising from the disclosure must outweigh the patient's and public interest in keeping the information confidential'

71. The guidance goes on to say that when making such a decision a range of factors must be considered by the doctor, including:

(1) The potential harm or distress to the patient arising from the disclosure e.g their future engagement with treatment.

(2) The potential harm to trust in doctors generally.

(3) The potential harm to others if the information is not disclosed.

(4) The potential benefit to others if the information is disclosed.

(5) The nature of the information to be disclosed and any views expressed by the patient.

(6) Whether the harms can be avoided or benefits gained without breaching the patient's privacy or, if not, what is the minimum intrusion.

72. This section of the guidance concludes with the following at paragraph 111:

'If you know that a patient has objected to information being disclosed for purposes other than their own care, you should not disclose the information in the public interest unless failure to do so would leave others at risk of death or serious harm'.

73. Mr Mant outlines that in the particular circumstances of this case the Clinic has concluded that requesting Donor A to provide a DNA sample for the purposes of genetic analysis carries a real risk that Donor A will learn that a child conceived through use of one of Donor A's donated eggs has a congenital disability and that Donor A herself may have an unsuspected genetic disease, or is the carrier of a harmful inherited condition, which is contrary to her wish not to be provided with such information. The request for a DNA sample in itself would not communicate that Donor A has an unsuspected genetic disease or is the carrier of a harmful inherited condition. This is because it is not known whether AH's difficulties are genetic and, if they are, whether they are attributable to either of her biological parents. Dr Ingamells makes the point that there is a real possibility that the request for a DNA sample will lead to Donor A being informed that a child conceived using her donated egg has a congenital disorder and that it is likely Donor A will infer from this that she has a genetic disease, or is the carrier of a harmful genetic condition.

74. Donor A's stated wish not to be informed that the Clinic has learned, through the birth of an affected child, that she has an unsuspected genetic disease or is the carrier of a harmful inherited condition, encompasses the wish not to be informed of a risk that she is the carrier of a genetic disease. Mr Mant submits that the Clinic and its staff may owe a duty to Donor A not to contact her to request a DNA sample as that may inform her indirectly that there is a risk that she has a previously unsuspected genetic disease or is a carrier of a harmful inherited condition, contrary to her wish not to be so informed. If that analysis is correct, Mr Mant submits that duty is not absolute and the Clinic staff may form the view that there is justification for providing information to Donor A contrary to her express wishes. For example, where avoidance of harm to another would outweigh Donor A's wishes and any risk of harm to Donor A can reasonably be addressed through sensitive communication and the offer of counselling.

75. Turning to the third issue identified by Mr Mant, Donor A's wish not to be informed of information about her health engages Article 8 EHCR as an aspect of her right to private

life. Such a right is not absolute and any interference may be justified, if shown to be necessary and proportionate to the pursuit of a legitimate aim.

76. He sets out this right has been interpreted to include the right to exercise one's personal autonomy (*UK v Pretty* (2002) 35 EHRR 1) and that can include the right to decline to consent to treatment which might have the effect of prolonging life (*Jehovah's Witnesses of Moscow v Russia* [2011] EHRR 4). Mr Mant submits that consistent with this, a person's decision not to be provided with information must also be within Article 8.

77. If Article 8 is engaged it is a qualified right and interference with it may be justified if it is shown to be necessary and proportionate to the pursuit of a legitimate aim, including the protection of the rights and freedom of others (see *Evans v United Kingdom* (2008) 43 EHRR 21).

78. It is established that obtaining information about aspects of a person's personal identity, such as the identity of one's parents, is an Article 8 right. In *Mifsud v Malta no 62257/15 29 January 2019* the Strasbourg court held that ordering a person to undergo a DNA test for the purposes of determining paternity constituted an interference with the man's Article 8 rights, but that right was overridden by the Article 8 right of an individual to know their genetic origin (see [77]-[78]).

79. By analogy, Mr Mant submits, if providing a patient with information about his or her health contrary to an expressed wish not to be so informed constitutes an interference with the patient's Article 8 rights, it may be justified if it pursued a legitimate aim, such as protecting the right of another to establish details of their identity or to protect the health of others.

80. On the facts of this case the Clinic have undertaken the balancing exercise and have reached the conclusion that Donor A should be contacted.

81. Mr Mant relies upon the written evidence Dr Ingamells where she has identified the following points as relevant to the balancing exercise undertaken by the Clinic:

(1) The views expressed by Donor A at the time of donating eggs;

(2) The potential harm and distress to Donor A arising from this request;

(3) The fact that there is no guarantee that, having been asked, Donor A will agree to provide a DNA sample for the purpose of genetic analysis;

(4) The potential harm to trust in fertility clinics if it is widely perceived that healthcare staff will inform donors of information indicating that they are carriers of a harmful genetic condition contrary to an expressed wish not to be told.

(5) The potential benefit to others if the request is made. This includes the potential benefits to AH and to others who may have been conceived, or may be conceived in the future, using Donor A's eggs.

82. In addition to the matters listed above, a request on behalf of AH to be provided with information about her genetic origin may engage AH's Article 8 rights to know information about her genetic origin. Whilst the evidence does not suggest that AH will

suffer serious harm if a genetic analysis is not possible, there is the possibility that such testing will yield health benefits leading to the possibility of a diagnosis and/or provision of better treatment and care. Additionally, Donor A's wish not to be informed in the event that a child born using her donated eggs has a congenital disability is not guaranteed. When a child turns 18 they are legally entitled to identifying information about the donor. In those circumstances AH would be entitled, assuming she is aware she is donor conceived and able to make such a request, to be informed of Donor A's identity, to contact her and make the request directly. Consequently, the statutory regime, in certain limited circumstances, overrides a gamete donor's expressed wish not to be provided with information about a child conceived using a donated egg.

83. Finally, turning to the fourth issue identified by Mr Mant, he submits the processing of Donor A's personal data involved in contacting Donor A is lawful by reason of articles 6(1)(f) and 9(2)(h) GDPR as being necessary for the purpose of medical diagnosis and/or providing health treatments and are proportionate to any interference with the rights of Donor A not to be told information about her health.

84. The '*legitimate interest'* in accordance with article 6(1)(f) GDPR is the ability to carry out trio testing which will increase the chances of a diagnosis and/or provision of health treatment for AH. Processing is necessary for the purpose of those interests, as unless Donor A consents to provide a DNA sample such testing is not possible. Alternative steps to obtain a diagnosis have been attempted without success (including karyotype testing as recommended by Professor Turnpenny) and the clinicians have not identified any further steps that could be taken short of contacting Donor A.

85. The processing of Donor A's personal data is lawful by reason of article 9 (2)(h), as it is necessary for the purposes of medical diagnosis of AH and/or for the provision of health or social care or treatment. Reliance is placed on the evidence of Professor Lucassen regarding the benefits of trio testing as increasing the chance of a diagnosis in AH and/or provision of particular health treatment. The safeguards required by article 9(3), for processing to be carried out by a professional under obligation of secrecy, is met as the processing would be under the obligation of a health professional. By definition, contacting Donor A will involve processing of her contact details, and Mr Mant submits that is not incompatible with the purpose for which those details were collected (Article 5(1)(b)) as those details were provided so the Clinic could contact her as and when required, which could include in accordance with any declaration made by this Court.

86. Mr Mylonas K.C. on behalf of the Trust supports the application, albeit the Trust gets to the same conclusion by a different route than the Clinic. They submit if the application is granted, by whichever route, very serious consideration should be given as to how Donor A is approached, a detailed plan agreed as to how that is done, the steps to be taken at each stage and agreement reached about what can be disclosed and what can't. Such detailed planning, submits Mr Mylonas, will mitigate any risks to Donor A.

87. The Clinic's analysis is based on the document signed by Donor A at the time of her egg collection, the Clinic consent form that included the following option *'I/we wish to be notified if Wessex Fertility learns (eg through the birth of an affected child) that **I have** a previously unsuspected genetic disease, or that I am a carrier of a harmful inherited condition' [emphasis added]*. Donor A ticked the box 'no'. Mr Mylonas

emphasises the wording 'I have', it only refers to Donor A's health and does not prohibit any approach to Donor A for the assistance or support in diagnosis and treatment of the child.

88. The Trust submit it is important to set out the information that would need to have been raised to cover the current situation. Mr Mylonas suggests, in the Trusts' written response to the claim, it would now be put as follows (admittedly with the benefit of hindsight):

'Sometimes a child created with your eggs will need to be investigated for health problems they are having. Just occasionally clinicians looking after the child may find it helpful to compare the child's genetic code (DNA) with yours and the other biological parent. This can be very helpful in excluding certain conditions and thus identifying the right support for the child. Health professionals may contact you to explain how your sample could help, but you are under no obligation to provide a sampler. If such a situation arose, are you content for the clinicians to contact you and seek a sample?'

Put this way, submits Mr Mylonas, the focus is on the child rather than the donor.

89. The Trust submit the Clinic's focus on the wording in the existing consent form advances their case on two bases; either the wording used is directly applicable to the current situation, or the current situation is so close to the wording in the form that it is covered, so by implication.

90. As regards the direct application of the wording Mr Mylonas refers to Dr Ingamells' statement at paragraph 41 when she states *'Donor A similarly and consistently requested that she not be notified* ***if a child was born with genetic problems'*** (emphasis added). This, Mr Mylonas submits, is not an accurate summary of the relevant documentation. The question Donor A was responding to was whether she had *'…a previously unsuspected genetic disease, or that I am a carrier of a harmful inherited condition'.*

91. Mr Mylonas submits that Dr Ingamells' analysis also assumes that AH definitely has *'genetic problems'* which is not supported by the evidence. Although Professor Lucassen thinks that AH's *'combination of problems was likely to have a genetic explanation…genetic investigations that were routine at the time had not found an explanation'.* The proposed DNA testing would be useful, whether it confirmed or excluded a genetic cause for AH's difficulties. Mr Mylonas submits that Dr Ingamells overstates the current level of knowledge and what can be inferred about Donor A from AH's condition. The Trust does not support the analysis by Dr Ingamells that the wording of the consent form is directly applicable to the current situation.

92. The Trust also disagrees with the Clinic's argument that there is sufficient proximity between the current situation and the wording on the form that it can be implied that Donor A would not wish to be informed of AH's condition.

93. Mr Mylonas relies on the plain wording of the consent form. He submits that by ticking 'no' Donor A specifically and only expressed a desire not to be informed if <u>she</u> had *'a previously unsuspected genetic disease, or that (she was) a carrier of a harmful inherited condition'.*

94. Mr Mylonas submits that is not what is proposed for the following reasons:

(1) Neither the Clinic nor the Trust know whether AH has a genetic disease or inherited condition.

(2) It is not intended to carry out testing on Donor A to identify whether she has such a disease/condition.

(3) The type of testing proposed (trio testing) uses Donor A's genetic code as a healthy control sample. If a particular variation in AH's genetic code is shared with a healthy genetic parent, that means that this variation is not the cause of the child's abnormalities.

(4) Since trio testing involves using Donor A's genetic code as a filter through which to consider AH's genetic code, rather than an analysis of Donor A's genetic code in its own right, the testing would not inadvertently reveal that Donor A has a genetic disease or harmful inherited condition.

(5) Even if testing confirmed that AH did have such a disease/condition it would not mean that Donor A was similarly affected.

(6) As a consequence, the testing would be set up so that there was no prospect of a discovery that Donor A had such a disease/condition arising out of the trio testing that is proposed.

(7) There is the possibility that Donor A may have changed her mind and would not wish to be informed if anything was discovered that may be relevant to her or her children.

95. Mr Mylonas outlines that the consent form is not *'cast in stone'* due to the passage of time, the advance in science and the difference between the scenario envisaged in the consent form and that which is now before the court. Capacitous adults may change their views for a whole myriad of reasons such as passage of time or changed circumstances. Whatever the potential reason for change, the consent forms explicitly acknowledged that a donor may change their decision. The HFEA's CD form, setting out the circumstances in which Donor A consented to the sharing of information, states: *'you can change or withdraw your consent at any time by asking your clinic for new forms'*, above the place for the signature it states *'It is your right to change the consent you give here at any time'* and a little further down, before the signature, it states '*I understand that I can make changes to or withdraw my consent at any time…'.*

96. The HFEA WD form contains similar provision stating *'You can make changes to or withdraw your consent at any point until the time of the egg or embryo transfer or their use in research or training'*, and later in the form *'I understand that I can make changes to or withdraw my consent at any point until the eggs or embryos have been transferred…'*.

97. Mr Mylonas recognises the limitations, including on consent until the eggs/embryos have been transferred for obvious reasons, however, the point he makes is that they do not prevent the donor from reviewing their decision making in relation to the issue of receiving information or requests from the Clinic, which remains without limit of time.

98. Finally, Mr Mylonas submits that Donor A's right to change her mind, as is emphasised in the consent forms, is only meaningful if she is given the opportunity to re-consider it with new information that is relevant to that decision. He submits that if there had been no change in circumstances reliance could be placed on the previously expressed consent or if the decision that had been taken was the same decision that was being considered now. For example, the Supreme Court decision in *Montgomery* addressed and greatly extended the information to be provided to patients so that they can reach a fully informed decision. He refers to the significant scientific advances since the form was signed. The trio testing now being considered was simply not available when the consent form was signed.

99. In summary, Mr Mylonas submits on either analysis Donor A's response to the questions posed to her in the consent form does not cover the situation now being considered and does not prevent a carefully structured approach to Donor A. He submits his analysis is supported by the statement of Nina Barnsley who, whilst supporting the importance for donors of believing that the current legal framework is robust and their wishes respected, considers the wording of the current form was not clear. Mr Mylonas considers whilst Ms Barnsley acknowledges she does not know any details of Donor A, the views expressed on behalf of the DCN are *'powerful, informed and independent'*. He goes as far to suggest that to view the consents signed in this case as covering the current circumstances would amount to medical paternalism, effectively depriving Donor A of the ability to make an informed decision herself.

100. If his analysis is correct he accepts the court will still need to consider issues regarding Donor A's Article 8 rights and the use of her data under the GDPR and supports the submissions of the Clinic in relation to those matters.

101. If the court does consider there does need to be a balancing exercise Mr Mylonas submits an important consideration is the fact that AH can make contact with Donor A when she is 18 years old. Weighed in the balance the court should consider matters such as the impact on AH of any further delay in that context, the possible impact on Donor A when she learns about that delay and any possible impact that could have if Donor A had any children. Mr Mylonas recognises that the court needs to keep in proportion the matters it takes into account and be careful about conjecture.

102. In his detailed submissions on behalf of the HFEA, Mr Mehta makes it clear their role is to assist the court, not to advocate any particular result although he states *'the HFEA's primary position before the Court is that cogent and weighty reasons should be required for Donor A's stated wishes to be overridden, in accordance with the applicable legislation'.* The HFEA consider Donor A has made her wishes very clear, to be *'circumspect about any suggestion that her views were equivocal'* and urges the court to construe the consent widely which would include not being informed of the risk of any such genetic disease. In addition, the HFEA would caution against an approach to Donor A that would not be upfront about the reason why she is being contacted, with careful planning and counselling and support being offered. Finally, the HFEA cautions about any speculation about Donor A's views. They submit Donor A was an adult at the time she signed the forms, is entitled to change her views and the fact is she has not done so. The HFEA remind the court that it does not have before it any representative of or representations from Donor A.

103. Mr Mehta expresses caution regarding Mr Mant's submissions about any duty of care. He considers the circumstances in this case are very fact specific and the Court would need to take care to consider them in accordance with principle. They take issue with the Clinic's assessment of any risk of physical or psychiatric injury to Donor A by requesting a DNA sample as being *'extremely low'*, stating that cannot simply be assumed to be correct. Whilst the HFEA accept that Donor A's indication that she would not wish to be contacted in this situation may be overridden, the court should weigh in the balance the high value the law places on consent and private autonomy.

104. The HFEA accept that Article 8 is engaged and rely on their position of the need for weighty and cogent justification in order for it to be proportionate to contact Donor A, assuming such interference is lawful, necessary and in pursuit of a legitimate aim.

105. In relation to data protection the HFEA submits there are two acts of processing (i) to retrieve and use Donor A's contact details for the purpose of contacting her, and (ii) to transmit to Donor A information about her health (and genetics) which is classed as special category data. They agree the proposed processing must fall within one of the lawful bases for processing personal data set out in Article 9 GDPR which, in summary, requires the court to consider whether it is 'necessary' to do so and submit that in the *'final analysis [is] broadly similar to that under domestic common law: weighty and cogent reasons, supported by evidence, would be required to justify processing Donor A's data to contact her when she has explicitly said that she does not consent to that'.*

Discussion and decision

106. As was emphasised in *Jennings v Human Fertilisation and Embryology Authority* [2022] EWHC 1619 (Fam) the principle of consent is at the heart of the regime under the HFEA 1990, its role and purpose *'is to ensure that gametes and embryos are used in accordance with the relevant person's wishes'* [101].

107. In this case the competing positions taken by the parties, the Clinic and the HFEA on one side and the Trust on the other, is whether the court should construe the relevant consent in this case on a narrow or broad basis. In his attractive submissions Mr Mylonas sets out the basis upon which he says the situation the court is now faced with is not covered by the consent given by Donor A. What Donor A was saying in the consents she signed is she did not want to be contacted in circumstances where it was discovered she had a previously unsuspected genetic disease or that she is the carrier of a harmful inherited condition. That is not the situation here, as it is unknown whether Donor A has a genetic condition in the same way that it is not known whether AH has. What is sought is to request Donor A to provide a DNA sample which may assist in the diagnosis and/or treatment of AH.

108. Whilst I recognise the force of the submissions made by Mr Mylonas, I equally recognise the points made by the Clinic and the HFEA of the need to err on the side of caution when considering the terms of any consent given in these circumstances. If looked at through a broader lens it is arguable that there is a duty of care owed between the Clinic staff and Donor A as one of healthcare professional and patient which involves a duty to take reasonable care in the provision of medical treatment and services. Also, more generally, Donor A's wish not to be informed about her health engages Article 8 EHCR as an aspect of her right to private life.

109. I agree with Mr Mant that in the circumstances of this case it is not necessary to determine whether such a duty of care exists as if it does it would not be absolute and would require a balancing exercise to be undertaken as between the risk of harm to Donor A against the interests of AH assessed against the standard of a responsible body of medical opinion.

110. In any event Donor A's rights to privacy are engaged under Article 8, as are the rights of AH to know her genetic origins, however they are also not absolute and any interference may be justified, if shown to be necessary and proportionate to the pursuit of a legitimate aim.

111. Focussing on Article 8, as it is accepted that is engaged in any event, the considerations include:

(1) The views expressed by Donor A at the time of donating eggs. Donor A stated that she did not want to be contacted in certain circumstances which, on a narrow view, do not include the circumstances being considered now.

(2) The potential harm and distress to Donor A arising from this request. It is simply not known how she will view what is proposed, but the evidence does establish that such initial contact will make clear the purpose for which she is being contacted, which is for DNA testing and is not because it is known she may have a genetic condition. I agree with Mr Mylonas that Dr Ingamells' analysis assumes that AH definitely has *'genetic problems'* which is not supported by the evidence. Professor Lucassen thinks that AH's *'combination of problems was likely to have a genetic explanation…genetic investigations that were routine at the time had not found an explanation'.* The use of the proposed DNA testing is whether it confirmed or excluded a genetic cause for AH's difficulties. Dr Ingamells overstates the current level of knowledge and what can be inferred about Donor A from AH's condition. The analysis by Dr Ingamells that the wording of the consent form is directly applicable to the current situation is not on a very secure foundation.

(3) In addition, the evidence from Professor Lucassen was clear, if Donor A did not want to know the results of any DNA or trio-testing that would be respected.

(4) The court needs to weigh in the balance that even once contacted Donor A may refuse to provide DNA testing. That is a reality which must be weighed in the balance.

(5) The wider consideration regarding trust in fertility clinics if it is widely perceived that healthcare staff will inform donors of information contrary to an expressed wish is a factor but needs to be considered in the context of the particular facts of this case. The ambiguity about the consents signed by Donor A in relation to the situation the court is faced with here is relevant. The equivocal wording of the particular consents being considered in this particular situation and changes in scientific testing since the consent was signed also need to be taken into account.

(6) The potential benefit to others, such as AH and any other children who may have been conceived, or may be conceived using Donor A's eggs. This to some extent is not known, as until the testing has been undertaken the significance for AH remains unknown, although on any view it would remove one further uncertainty.

(7) AH is, at the age of 18 years, legally entitled to identifying information about Donor A and would be entitled (assuming she knows she is donor conceived and is able to make such a request) to be informed of Donor A's identity, could make contact with her and make the request directly.

112. Having carefully weighed each of these matters I have reached the conclusion that any interference with Donor A's Article 8 rights are justified and proportionate if this court made the declaration requested. This is for the following reasons:

(1) There is an ambiguity as to whether the wording of the consent actually covers the particular situation in this case. Whilst the court has erred on the side of the broader interpretation it is a relevant consideration as the court is not being asked to interfere with consent that has been clearly expressed and articulated and is being sought to be overridden.

(2) The declaration sought is to make a request for a DNA sample, Donor A will retain the right to her own decision as to whether she provides it or not.

(3) The medical evidence makes clear that Donor A could decide that she does not wish to know the results of any DNA testing and that request would be respected.

(4) Whilst it is unknown what the impact would be on Donor A of making such a request, the proposed plan ensures there is informed and effective support available to Donor A should she seek it and a robust system in place if she did not want to know the results of any testing.

(5) The wider issue regarding trust in fertility clinics is unlikely to be impacted due to the ambiguity regarding the terms of this consent and the issue that the court is now presented with. I agree with Ms Barnsley's view that the consent wording in this case was *'not clear'*.

(6) There is an obvious benefit to AH as it may provide clarity about her diagnosis and/or treatment options in the widest sense. There may also be a wider benefit to others who may have been conceived, or may be conceived in the future, using Donor A's eggs.

(7) At the age of 18 years AH would have the right, if she so wished and was able to, to seek from the Clinic identifying information regarding Donor A and in turn could make the request herself directly or indirectly.

(8) The court has carefully weighed in the balance that this decision is being made without the benefit of any representations being made on behalf of Donor A but it does have the benefit of the evidence from Ms Barnsley and the independent opinion expressed by Professor Turnpenny.

113. The court separately needs to consider whether the processing of Donor A's personal data is lawful under the GDPR. It is clear the *'legitimate interest'* under article 6(1)(f) is to enable trio testing to increase the chances of a diagnosis for AH and/or the provision of the correct treatment. Whilst it is recognised Donor A may not consent to providing DNA there is still a need to request it and all other steps short of making the request have been undertaken.

114. The processing under article 9(2)(h) is lawful as it is necessary for the purposes of AH's diagnosis and/or provision of treatment. Professor Lucassen's evidence is clear about the benefits of trio testing, such a request will be made by a health professional under obligation of secrecy. The request will not be incompatible with the purposes for which the details were collected, namely to enable the Clinic to contact Donor A as and when required, which would include in accordance with any declarations made by this Court.

115. The declarations sought will be granted.