HOUSE OF COMMONS

Women and Equalities Committee

Oral evidence: Egg donation and freezing, HC 1503

Wednesday 18 March 2026

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Watch the meeting

Members present: Sarah Owen (Chair); David Burton-Sampson; Dame Nia Griffith; Kim Leadbeater; Kevin McKenna; Rachel Taylor.

Questions 187 to 245

Witnesses

I: Rachel Cutting MBE, Director of Compliance & Information, Human Fertilisation and Embryology Authority; Clare Ettinghausen, Director of Strategy & Corporate Affairs, Human Fertilisation and Embryology Authority; Peter Thompson, Chief Executive, Human Fertilisation and Embryology Authority.

Written evidence from witnesses:

- Human Fertilisation and Embryology Authority [EDF0082]

Examination of witnesses

Witnesses: Rachel Cutting, Clare Ettinghausen and Peter Thompson.

Chair: Good afternoon and welcome to the Women and Equalities Committee. Today we are holding an oral evidence session on egg donation and egg freezing. We will hear from Rachel Cutting, director of compliance and information at the Human Fertilisation and Embryology Authority; Clare Ettinghausen, director of strategy and corporate affairs at HFEA; and Peter Thompson, chief executive of HFEA. Thank you for being with us today and welcome. I am going to hand straight over to Rachel.

Q187 **Rachel Taylor:** Thank you all for joining us today whether in person or online; we appreciate your time. Multiple witnesses to this inquiry have already told us that the long-term health risks of egg donation are under-researched. Is that something that the HFEA accepts?

Peter Thompson: You are right; it is under-researched. I have looked at the evidence and written submissions you have had over the last few weeks and a couple of things come from that. One is that the long-term health risks and outcomes of IVF in general are well researched and well understood; it is generally regarded as a safe treatment. Clearly much of the medical procedure associated with egg donation is part and parcel of that. On the face of it there is a reasonable starting place that says there is no reason why egg donation should be any riskier than IVF. That said, there are no really robust studies about the long-term health impacts of egg donation so there clearly is a gap there.

As with any medical procedure, egg donation involves some risks and clearly there are possible long-term psychological considerations to both freezing eggs and being a donor. We have an expert advisory committee at the HFEA—the Scientific and Clinical Advances Advisory Committee; it is a bit of a mouthful but it says what it is on the tin. It regularly looks at things such as health impacts of IVF and associated technologies. It last looked at this issue in the summer of last year and one of its conclusions was that there were no robust long-term health impact studies of egg donors. As a result of that we changed the information we present for patients on our website. The straightforward answer to your question is that we would very much welcome such studies.

I can say a little about how you might go about it. You may have picked up from the evidence that we hold a statutory register of IVF treatments that goes back to 1991. It is reputed to be the largest dataset of its kind in the world. It is very comprehensive but it is also quite limited. For example, we know about every licensed IVF treatment that has taken place since 1991 but we do not know that much about them. We know the people involved, including donors, the clinic where the treatment took place, the outcomes of the treatment and so on. Of course that in itself is not going to tell you much about long-term health impacts; effectively what we have is a subset of what the patient notes might be in the clinic.

If this work were to be done you would want to link the HFEA register with NHS national datasets. We know that can be done because our register is open for researchers and indeed in the past researchers have done similar sorts of work. There is a big study at UCL that took HFEA and National Cancer Registry data and asked the question: are women who undergo IVF more likely to get certain sorts of cancers than women who do not? The good answer is they are no more likely to. This is the sort of research that could be done.

Q188 **Rachel Taylor:** If it could be done, who do you think should commission the research into the long-term impacts of donation freezing in particular?

Peter Thompson: It is almost certainly going to be done by a university with funding from a big medical charity. These linkage studies are expensive, take a long time and require a lot of expertise—even just the technical aspect of getting the two datasets to talk to each other. It is certainly not something that we have either the expertise or resources to lead on although clearly—as we did in the case of the study I referenced—we would very much want to play a part in facilitating the linkage of that data and making any findings public on our website.

Q189 **Rachel Taylor:** Peter has already talked about there being quite a bit of data and information so I will come to Rachel on this. There is already a lot of information and research into IVF patients generally but would you accept that IVF patients and egg donors are different cohorts—at least in terms of age—and that this may have a bearing on long-term risks?

Rachel Cutting: IVF patients are obviously patients who are trying to achieve a family and a pregnancy so they have a real reason to go down the medical route of assisted conception. Donors do it for various reasons. I was an embryologist in a clinic for 25 years; I was the person responsible and I was involved in our donation programme. Many donors definitely had an altruistic motive because they genuinely wanted to help others create families. However, they are a different type of patient because they probably have not gone through years of trying to have a baby until they get there. A mix of patients undergo IVF treatments and of course there is the age restriction that a donor must be 35 years old or under.

Q190 **Rachel Taylor:** Is the information provided to patients sufficiently clear about the limitations of the data and the research that you have? Are you confident that donors and those freezing their eggs are in a position to give informed consent?

Peter Thompson: Yes. We have a series of rules that requires that patients are given appropriate information before treatment; that is absolutely crucial. We do not regard it as fully-informed consent if it is not taken before treatment. Fully-informed consent covers both short and long-term health impacts as well as other relevant information to donation which might include, for example, the fact that if you are a

donor then a donor-conceived individual may contact you when they become 18 and so on.

It is not just about the medical procedure and its risks in isolation; it is also about the longer-term relationship that goes with donors. We have licence conditions and a code of practice which make very clear the requirements about information provision and what we expect clinics to follow. We check compliance with those kinds of rules on inspection. In the round, the regulatory regime as it is and the standards I have just set out mean that patients have the opportunity to give properly-informed consent.

Q191 **Chair:** Do you think 18-year-olds are fully equipped to understand the long-term impacts that their egg donation could have?

Peter Thompson: It is difficult to see people in isolation; Rachel will perhaps say a bit more on this because she has actually done it. There are 18-year-olds who are more than capable of understanding these issues and giving properly informed consent and I suspect there are 18-year-olds who are not.

The important point about the process at the clinic is that those two things are winnowed out and the clinics reach a decision that in certain cases it would not be appropriate for an 18-year-old to give treatment. One problem is when you set national guidelines it is difficult to set guidelines that can cope with individuals. A way of seeing them is via the process of giving consent.

Q192 **Chair:** Do you collect data on the people who have been turned down or assessed as not being able to give informed consent?

Peter Thompson: No, we do not.

Q193 **Chair:** So we do not know that?

Peter Thompson: No. Rachel, do you know of any wider evidence that suggests what proportion of people who go through the process of counselling and the like do not in the end donate?

Rachel Cutting: It depends on individual clinics and the pathways that are done. If you look at our data, over 80% of donors were over the age of 25 and the average age was 30. In my experience in my clinic it was highly unusual to have a young patient at 18. This is where the pathway of donation is very important.

One thing we recommended in our law reform proposals was mandatory implications counselling. In our clinic the pathway was that all prospective donors had two mandatory implications counselling sessions before they proceeded to donation. That gave chance to really understand the reasons for donation and the long-term implications. Although we do not have figures on the number of donors who are turned

down, it is something that we require to be documented in the code of practice guidance and that can be checked on inspection.

For example, we may look at the offer of counselling and whether people take that up. When we are looking through the notes we would notice if people were turned down as a donor but it is not something the HFEA collects as a data field.

Chair: I understand that you are answering from the point of view of your own clinic but we are asking you questions as the HFEA. We want to know what the general standards of practice and expectations are. As policy and lawmakers, we would perhaps have more trust in the system if we knew that the regulations were working and that some people were actually turned down and turned away from this. Currently we cannot say whether people are fully informed about the decisions they are making and whether they are genuinely suitable for egg donation.

Q194 **Rachel Taylor:** I have quite a few questions about collection of data. How does the HFEA currently collect data on post-donation health outcomes?

Peter Thompson: All clinics are required to report treatments and outcomes to us and we hold that information on the register. We then use that information for a whole variety of purposes including providing information to donors, parents and donor-conceived individuals.

During treatment, clinics have to meet quite strict requirements about incident reporting to us; our code of practice covers the rules on that. Were a woman to undergo treatment and she had OHSS, we require clinics to report severe and critical cases to us.

Q195 **Rachel Taylor:** Why are only severe and critical incidents reported and not moderate?

Peter Thompson: Rachel, can you provide a bit of insight on that from a clinical perspective?

Rachel Cutting: From a clinical perspective, severe and critical OHSS can be diagnosed because it often requires hospitalisation and is classed as a complication. Mild and moderate OHSS is quite common. It occurs in roughly 20% of all IVF cases and can be treated at home; very often it just gets better with time. It can often involve minor abdominal discomfort and bloating so it could actually be post-procedural pain rather than OHSS; it is difficult to determine exactly whether it is OHSS or not. That is why we collect the critical and severe cases because we would know that they were OHSS.

Peter Thompson: The incidents come in to us and depending on the pattern of incidents we might decide to take some regulatory action—if they were all coming from a particular clinic or gave rise to particular concerns, for example. We then compile that incidence and make it publicly available in two ways.

We have an annual report—a fertility sector report—that includes incidents. We also provide quarterly updates to all licensed clinics because we want to encourage learning. If we have good practice in one clinic, we want to spread that more widely. In that sense we have a very good understanding of post-donation outcomes but there are a couple of gaps, one of which is where a woman is treated, goes home, is in real pain and goes to A&E or a local hospital. What often happens then is that, due to the law on information in fertility treatment, confidentiality restrictions are very tight so the treatment record that resides in the fertility clinic does not automatically follow the woman when she goes to A&E and hospital without her explicit consent.

The majority of fertility treatment is private and in many cases women are travelling quite some distance for treatment. It may well be that home is not where the clinic is so they will end up going to a local hospital, which might be at some remove from where they were actually treated. There is a proper patient safety issue about changing the law so that the treatment record can easily flow across the system. That is something we have made clear in our recommendations to Government for reform.

The other gap is longer-term. Were a woman to have treatment and then feel ill several years later it is very unlikely that she would go back to the fertility clinic where she had the treatment. We regulate the fertility clinic, but if the clinic does not know that the woman has fallen ill then we would not know. Again, what it points to is linking treatment records within the fertility sector more generally to the wider NHS data systems. That is probably the way to tackle longer-term issues. We have a good handle on immediate and fairly-soon-after issues but there are gaps longer term.

Q196 **Rachel Taylor:** Do you know how many egg donors report to the NHS with complications following egg donation?

Peter Thompson: We are likely to know if the complications are relatively soon after treatment. The longer the passage of time, the less likely we are to know.

Q197 **Chair:** That is only if they are severe cases. Is it only linked to OHSS that the clinics have a duty to respond? Are there other things such as bleeding and infections?

Peter Thompson: There are other things and Rachel might be able to give you a wider sense of that.

Rachel Cutting: Anything that may cause harm to a patient or even a near miss is mandatory reporting. We would expect any complication to be reported to us; that is a legal requirement.

Q198 **Chair:** Would the HFEA be open to expanding what is reported to it via the clinics to moderate and mild complications to get a better outcome? I imagine there are a large number of women who do not necessarily come

forward unless it is utterly severe and debilitating because as women we are always told that our pain does not really matter.

Clare Ettinghausen: There is no issue with us having more information. It is whether the woman has gone back to the clinic and the clinic is able to pass that information on. We do not think there is widespread under-reporting of severe and critical OHSS but the symptoms you have just described where someone may not go to their GP or if they do it might not get back to the clinic is where the lack of data sharing is becoming a real problem.

Rachel Cutting: This is something we check on clinic inspection. When the egg donor has the egg collection they are given detailed information, including any symptoms of OHSS, to look out for. Each clinic will have an emergency phone number as well.

If anybody starts with symptoms—even mild or moderate—they are encouraged through that information to contact the clinic so that they can be monitored. Clinics will be aware of mild or moderate cases; it would be whether we could facilitate it and we would have to decide how we could collect that data. At the moment we have a pro forma for severe and critical OHSS which clinics use to report directly to our clinical governance team.

Q199 **Chair:** Do you collect data on the levels of stimulant drugs used for collection?

Rachel Cutting: We would not know individual doses for that. On inspection we would look at the regimes that are used. Certainly if a clinic had a severe or critical OHSS case we would expect a detailed analysis of why that case occurred, which includes the drug dose. We would hold management meetings with clinicians at that clinic and if we felt the drug dose was inappropriately high we would question it and we can take regulatory action if needed.

Q200 **Chair:** Have you seen any clinics using, for example, higher dosage for those who are donating or using freeze-and-share as opposed to collection for themselves or loved ones?

Rachel Cutting: I do not have that information to hand; it is something we could do analysis on. Last year we had just over 60 OHSS cases reported to us. I cannot recall offhand if any of those were down to a high drug dose on their own but certainly they are cases that we review as a clinical governance team.

Chair: If you have that information and you can share it with us at a later stage it would be really helpful because it is about identifying whether there are any patterns or whether there is different treatment between those who are donating for different reasons.

Q201 **David Burton-Sampson:** Rachel, what actions has the HFEA taken in relation to the recent ruling by the Advertising Standards Authority

regarding egg donation adverts?

Rachel Cutting: Clare has led on the ASA work.

Clare Ettinghausen: It is a very good thing that the ASA has taken action against an advert; it shows that the system works. The ASA is obviously the advertising regulator; we are not. It is a positive thing and we welcome it.

We have worked with the ASA for several years. Back in 2020 or 2021 we issued a joint enforcement notice about fertility services to the fertility sector. The Advertising Standards Authority has been periodically monitoring compliance across the fertility sector. It should be said that is for adverts widely, not specifically for egg donation; it might be for a particular clinic or location. The ASA reviewed something like 2,300 or 2,500 adverts from 60 clinics and found that 96% of adverts were compliant. That is a pleasing statistic.

We have also worked with the Competition and Markets Authority over the last few years because it has different powers to us. You will have seen in our written evidence that we have talked about our lack of modern powers and the CMA can act on issues in relation to consumer law. We have worked quite closely with it on various issues, not adverts particularly. We ensured that clinics were aware of the ruling and more broadly we have done quite a lot of work with them in recent years reminding them that any adverts and publicity material should be designed and written with regard to the sensitive issues involved in recruiting donors. If it is helpful, I can outline our guidance in this area in more detail.

David Burton-Sampson: That would be helpful.

Clare Ettinghausen: We understand—you have heard this from other witnesses—there is a balance between advertising for donors and making people aware that there is such a thing as egg donation. We know clinics often advertise through local Facebook pages and sometimes on local radio or social media. It is important that anyone looking at those adverts who is interested in becoming an egg donor understands the seriousness of it. As you have heard, it is a serious medical procedure; there are lifelong consequences to it.

In our code of practice, we specify that advertising and publicity materials should be designed and written with regard to the sensitive issues involved in recruiting donors. Although we share concerns where there are misleading adverts, it is really important to note that adverts are really the starting point.

For many people who see adverts—whether it is for egg donation or for a clinic—this is the start of a long process for someone interested in donating to actually becoming a donor. In our regulatory role—as Rachel set out—we can review the information provided to any patient before

treatment, the counselling that is taking place, the follow-up and so on. Advertising is only the start of that process. We remind clinics about the sensitivity of that and we welcome our continued working with the ASA on this very sensitive issue.

Q202 **David Burton-Sampson:** That is helpful. Crossing over a little to advertising and compensation, what guidance do you give in relation to how the compensation should be advertised and how are decisions made about the appropriate level of compensation for egg donation?

Clare Ettinghausen: In our code of practice, we are very clear that adverts should not refer to financial gains; for example to become an egg or sperm donor and earn a certain amount of money. Adverts can refer to the fact that there is financial compensation but any material that the prospective donor would then get from the clinic or the egg bank should have full information about the medical risks, lifelong consequences, the expectation that you will be contacted by a donor-conceived child in future and so on. The advert should certainly not focus on any payment involved.

Q203 **David Burton-Sampson:** Lots of adverts include the compensation figure and it can often be quite bold. Is that a breach of the guidance and how would that sort of advert be treated?

Clare Ettinghausen: This is probably for the ASA to answer. Where we have concerns we have worked closely with it and we, like anyone, can refer if we see an advert of concern. We work with clinics to make sure they are aware that it is a sensitive issue and area.

As far as I can remember, this is the first time the ASA has issued a ruling in this area. I am sure clinics will have seen this ruling because they read the material that comes from us and elsewhere; hopefully they will have acted accordingly but we will continue to be vigilant and work with the ASA as much as we can.

Q204 **David Burton-Sampson:** Can you comment on setting the level of compensation?

Peter Thompson: Looking back at the evidence you have received, you will be aware that HFEA policy on donor compensation has evolved over time. The short summary would be that up until 2011 compensation was limited to actual expenses. In 2011 the decision was taken to introduce a much simpler fixed sum per cycle. In 2024 that same principle was merely uprated to account for the changes in inflation over time.

The big change in decision then is the 2011 decision. That followed a large-scale policy review including a public consultation. As part of that work the HFEA set out a set of principles which it thought should guide work in this area. In thinking about compensation, the sorts of principles it was trying to balance were altruism, fairness, welfare of the child and the safety of the donors, patients and donor-conceived. At the consultation exercise those principles were widely supported by people

who responded to it. The decision in 2011, which I think you are aware of, was that egg donors should be offered a fixed sum of £750 per cycle. The feeling at the time was that this struck a balance between fairly compensating donors for their time, inconvenience, expenses and the like and reducing the barriers to donation while maintaining standards and not setting it at a level which acted as an inducement.

At the time, that figure was arrived at because it was based broadly on comparators within certain EU countries, a sense of what time and lifestyle alterations donors were required to make including time off work, and acknowledgement that this was a communal and generous act. That balance has remained at the heart of HFEA policy since.

Q205 **David Burton-Sampson:** It is interesting you mention ensuring that it does not act as an inducement. Do you have any concerns that certain demographics, perhaps—maybe the more deprived demographics who, from the data I have seen, tend to be more likely to partake in egg donation—are more likely to be induced by adverts?

Peter Thompson: I do not think the data supports that they are more likely to donate. This is a bit of an incomplete, but we take postcode-level data. If you map social economic categories to the postcodes of donors you see a pattern of donors that broadly matches those categories. It is undoubtedly true that there are donors in lower socioeconomic groups but they do not appear to be disproportionately skewed to those groups.

I would refer you to the sorts of things that Rachel and Clare were talking about: the advert, or what have you, might be the starting point but the point of the counselling and conversations in the clinic is to actually try to work out whether somebody is being induced into donation or not. If clinics do their job properly there should also be checks and balances at the clinic.

I do not think we have seen evidence that suggests women in lower socioeconomic groups are induced into donation. That is not to say that there may be particular instances in particular places but in the round that is not what the data tells us.

Q206 **David Burton-Sampson:** If we take the inducement out of it, would the compensation perhaps be more attractive to lower-income groups as a reason for making a donation than to other higher-income groups?

Peter Thompson: That is true in theory. Today's sum of £985 would mean more to someone on a lower income than to someone on a higher income; that must be the case. Donation is an extraordinary gift. It has enabled many thousands of families to have much wanted for children. Egg donation in particular is really quite a commitment; it is an invasive medical procedure and involves time and all the rest of it. There is a dilemma here. In the UK we could clearly move to a system where there is no financial compensation but would that be fair? There are no easy answers here.

Q207 **Kim Leadbeater:** Thank you all for coming this afternoon. Do you or the clinics ask people if or where they have seen an advertisement? Do clinics do that and do they feed that information to you?

Clare Ettinghausen: Clinics do not feed it in centrally. If it is posting on its Facebook page, I imagine at a clinic level it will want to know if that is where it is getting people from. Given the number of cycles of fertility treatment is something like 100,000 cycles per year, there are about 1,500 egg donors a year across the UK. Most clinics will have a very individual relationship with those donors; they will know where they came from and whether they came by word of mouth.

In the last oral evidence session someone said they only talk locally to people and they get donors by word of mouth. We do not collect that information. We publish a national patient survey every three years across the UK—a representative sample of fertility patients—which includes those who have frozen or donated their eggs asking them for example where they found information, how they found the consent process, the quality of counselling and that sort of thing but it would not go into the level of detail that you have asked about.

Q208 **Kim Leadbeater:** That is really interesting. Is there is a role that you could or should have in that? You are right: individual clinics would want to know if their marketing—for want of a better word—was working. Do you think you should have a role in monitoring and regulating that?

Peter Thompson: The difficulty in part is because we do not regulate advertising. Where that sort of data might be most useful is if it showed a particular skew to a clinic. We might be able to tell that a clinic was perhaps marketing in a particularly aggressive way or something. There is a real risk that we could end up collecting data that actually turns out to not be very useful and slightly outside our remit. It is difficult to say much more beyond that really.

Q209 **Kim Leadbeater:** That is fine; thank you very much. Witnesses have told us that counselling and aftercare provision can be inconsistent across clinics. Does the HFEA currently assess and monitor services during inspections? Do you check what counselling looks like across individual clinics and then across the broader piece?

Peter Thompson: Rachel leads the inspection team and can probably answer best.

Rachel Cutting: It might be useful to set out what clinics are required to do and then explain how the inspectors monitor that. The law at the moment requires counselling to be offered when anybody is seeking to donate eggs, sperm or embryos, and for treatment. There must be what is classed as a suitable opportunity for counselling and a separate offer for implications counselling.

The code of practice says that proper counselling should be provided throughout donation and afterwards if requested. Counselling should

comply with current professional guidance from fertility counsellors and only qualified counsellors should deliver that counselling. You heard from the chair of the British Infertility Counselling Association. We look for the qualifications in that. Clinics should also have a patient support policy in place to ensure that donors are supported before, during and after donation.

During inspection, the inspectors use an audit assessment tool to interrogate the specific requirements I just outlined. We review patient and donor records to ensure that the information has been provided properly, that the offer of counselling is recorded and when that offer took place. If a donor or a patient turned it down we would expect a clinic to note that as well. If it took place we would expect to see when the counselling took place and ensure that that was done before any consent was given. We then obviously assess the non-compliances and how compliant a clinic is against those requirements and we can take regulatory action if we have concerns.

For example, we had a clinic with an unacceptably long counselling wait. To us that was not a suitable opportunity because there was a several-month wait. In those circumstances we held management review meetings with the chief inspector and myself. We wanted to see improvement plans and we had closer scrutiny. Although we have limited powers at the HFEA, we have the ability to reduce a licence. We gave that clinic a slightly shorter licence so that we could have enhanced monitoring over it and work with it. The inspectors have good relationships with the person responsible at clinics and we expected to see those improvements put in place, which we did.

Q210 **Kim Leadbeater:** Did you say earlier that you would be in favour of implications counselling being mandatory before egg donation?

Rachel Cutting: Yes, certainly that was something we put in our law reform proposals. For us, donation is a serious decision and it obviously has lifelong consequences. The current statutory requirement of an offer of counselling is insufficient to the seriousness and considerations of that decision. When we did our law reform work in 2023 we put forward that there should be mandatory implications counselling for those involved in donation because of the complexity, the wider relationships and the longer-term implications. We did not include therapeutic counselling—that should be separate—but the recommendation was certainly for the implication counselling to be mandatory.

Q211 **Kim Leadbeater:** Peter and Clare, I assume you agree with that?

Peter Thompson: Yes. It is part of HFEA policy position these days.

Q212 **Kim Leadbeater:** Should clinics offer counselling ahead of egg freezing?

Clare Ettinghausen: This is not something that we necessarily made an actual recommendation for in our law reform proposals in 2023 but I do not think it is something that we would not support in any way. I do not

know if we are going to have a chance to talk about information in advance of egg freezing; I can perhaps touch upon it there.

Kim Leadbetter: We are coming on to that.

Clare Ettinghausen: Implications counselling should happen before any treatment. Certainly we made the recommendation that it should be mandatory through the donation but there is no reason why it could not be required for people thinking of freezing their eggs as well.

Q213 **Kim Leadbeater:** What additional steps do you think could be taken to ensure that there are consistently high standards across all clinics?

Rachel Cutting: Evidence suggests that in the UK there are generally high standards in clinics. We produce an annual report: "State of the Fertility Sector," which shows very good compliance with our legal requirements. Obviously the legal requirements are set out in the Human Fertilisation and Embryology Act 2008 and we have a very detailed code of practice which is backed up by our inspection regime where we physically go into premises at least every two years.

We think our current framework for counselling provision, information provision and informed consent is detailed. We work very closely with clinics to make sure that they are using those best practice models. We also have a good relationship with professional bodies to ensure that any clinical best practice guidance is followed. We publish learnings from inspection reports and incidents in our annual reports. We also do a clinical governance quarterly update, which shares non-compliances so clinics can learn from what has happened on previous inspections and put improvements in place. That said, standards can always improve further.

Our inspectors work closely with clinics to ensure that any improvements are undertaken. We have obviously touched upon the implications counselling being mandatory; that would improve standards without a doubt. There is also the wider work we did in 2023 recommending how we could improve standards such as having more effective powers so that we can drive compliance forward and covering patient protection in any law reform work in the future.

Q214 **Kim Leadbeater:** Peter and Clare, do you want to add anything?

Peter Thompson: The only gloss I would add is simply that we are interested in regulation both as a tool to ensure compliance and to improve standards generally. The sorts of things that Rachel outlined are not just designed to make sure that clinics are following the rules but by playing back what we find to the sector we are interested in making sure that what is going on in good clinics is understood in not so good clinics.

Q215 **Chair:** I just want to pick up on a couple of points. Rachel, you said at the beginning of this session that your clinic has two mandatory counselling sessions on implications. Is that right?

Rachel Cutting: I left my clinic in 2019 to join HFEA but at the time we decided that it was good practice to have mandatory implications counselling.

Q216 **Chair:** Would that be deliverable for all clinics?

Rachel Cutting: It depends on the individual people involved in the donation pathway and how you want to do it. Obviously, there are cost implications in providing counselling sessions and it depends on the individual. That was an individual decision in our clinic on the way we wanted to work. It would depend on what could be covered by one counsellor in one session. We could ask for advice on that from the British Infertility Counselling Association, for example.

Q217 **Chair:** What difference did that make?

Rachel Cutting: Any implications counselling is there to help people understand not just the treatment but the implications for the family and donors; for example, for the identifiability of the donation when any children turn the age of 18.

For me it was really important that they were not just thinking about donating their eggs; they were really thinking and making that informed consent based on anything that could happen in the future: how their children in the future may feel about finding out that there is a donor sibling or if they were not married and had since married how future partners may feel about that. For me it was all about exploring that which made the consent process much more informed.

Q218 **Chair:** Rachel and Peter, you both mentioned extra powers and powers to look at cases. What would those powers look like? What are the extra powers that you need to strengthen this work in counselling and aftercare?

Peter Thompson: Rachel has already touched on them. Perhaps I can talk later on about the sort of powers we are seeking in the round. We think the offer of counselling is simply not strong enough and there ought to be a move to a mandatory implications counselling.

Q219 **Chair:** What powers do you have at the moment if you find that a clinic is not operating in the way that it should?

Peter Thompson: We run a licensing scheme. Effectively under the Act you need a licence from us in order to provide IVF services. We can issue a licence up to five years in length. We must inspect the physical premises at least every two years. We tend to issue four-year licences because two is a divisor of four and it reduces the burden all round.

The powers we have range from influencing-type powers to some very draconian powers whereby we can effectively take a clinic's licence away, suspend it or put conditions on that licence. For example, they could do certain sorts of treatments and not others. There is a very large gap and we lack any powers between the two extremes.

Q220 **Chair:** We will explore those in a bit. When it comes to counselling, do you have any powers over that at the moment?

Clare Ettinghausen: I think Rachel outlined that we took action against a clinic where on inspection there was a concern with counselling.

Q221 **Chair:** Do you need more powers on counselling to enforce better practice?

Clare Ettinghausen: On counselling in particular it is not specifically the powers relating to counselling; we have no agility to do any short, effective regulatory action. Whether it was counselling, information provision or medicines management the similar argument for us would be the agility. Closing a clinic is often the worst scenario for the patients involved and for those who have embryos and gametes in storage; we do not really have anything in between. I am not sure there is anything more to add on counselling specifically.

Q222 **Dame Nia Griffith:** I want to focus on egg freezing and the global sale of eggs. To start with the freezing process, what steps does the HFEA take to ensure that clinics provide accurate information about the success rate of egg freezing and its limitations?

Clare Ettinghausen: This is something the media are very interested in because there has been a big rise in egg freezing in recent years. As an advocate for women I would always say it is great to have this reproductive choice available, but no one should consider it a guarantee of having a baby. A number of women are freezing their eggs for what is called social or elective egg freezing, not for medical treatment. There is no NHS funding for this and it costs a lot of money. Although the number of women choosing to freeze their eggs is growing, the numbers who decide to use those frozen eggs remains small.

Another interesting fact is that the majority of people who are choosing to freeze their eggs are single patients and that number is increasing; but very few patients who return to use those frozen eggs are in that single patient category. There is something going on between the time people are choosing to freeze their eggs and the time when they go back to use them; most do not return at all.

But it is important to say that before any treatment takes place, we set out very strict requirements in our code of practice, which as Rachel said, is part of an inspection. It includes information about all aspects of treatment, including success rates; we would expect those figures to cover generalised success rates for people in the patient's age group or with a similar medical background, as well as specific information on success rates based, for example, on an individual's medical history or their particular circumstances. We provide some information on the HFEA website; the information on egg freezing is one of the areas of our website that is most used and it emphasises that this is not a guarantee of having a baby in the future. But I should say there are limitations to this.

First, as you heard in one of the previous sessions, a patient—whatever treatment they are seeking at the clinic—can hear that a success rate is likely to be very low and still want to have that treatment. It may have been Dr Sarris or one of the other witnesses who said that, even when people are told that this is not always a binary choice and that their success is likely to be very low, it is not necessarily the case that they will say, "Okay, I won't have the treatment."

From our perspective, the role that social media plays in this is more worrying. We have seen the rise of women, particularly influencers, sometimes celebrities, who are promoting their own egg freezing journey. Sometimes this is helpful—it is good public information—but it is not always clear whether it is an advert or whether they were given a discount for treatment. In our view, it glamourises the process as well as raising awareness.

The HFEA plays an important role in publishing success rates and clinics play an important role in providing that information. It is really important for patients to be clear that egg freezing is not necessarily just about the treatment at the outset. If I choose to freeze my eggs in 2026, there will be ongoing costs relating to storage, again with no NHS funding. If I then want to go back and use those eggs in fertility treatment it will cost me thousands of pounds. It is not a one-time purchase and we want to make sure that anyone thinking of freezing their eggs understands that, as well as the likely success rates.

Q223 **Dame Nia Griffith:** In terms of reporting the actual success rate, do you have a standardised system across the sector that you require everybody to use? Is that a realistic proposal?

Clare Ettinghausen: We do. The HFEA reports on the success rates of every clinic in the UK and we require clinics to link to our data. Although we have very weak powers which we can come back to in relation to what clinics present to patients in terms of partial rates or selective data. The work we have done and the work of the Competition and Markets Authority has generally improved this over the last few years we think. Last summer, we worked with both patients and clinic staff to look at what statistics they would find most useful and as a result we have improved the way we present our data.

It is really important for me to say that this is a very unusual area of UK healthcare and particularly of women's health. The vast majority of people are paying for their own treatment; that is something we are not used to in the UK. In their work, the CMA described fertility patients as vulnerable consumers because patients are not making hard binary choices based only on cost or success rates. There are other factors involved as well and success rates are only part of the picture.

There is a standardised way of reporting, but patients are not making decisions only, for example, on cost or success rates. We know from our research that location remains the most important factor for a patient

choosing a particular clinic but as the work of the CMA shows this is not a binary purchasing decision—you are not making the same assessment you might when purchasing other items.

Q224 **Dame Nia Griffith:** That is very helpful. Moving on to the global sale of eggs, clearly people move about the place and the world is becoming ever smaller. How do we tackle this? Should there be a global limit on the number of families created by a single donor? If so, how would we go about achieving that and have you had discussions with other regulators about what we might be able to do?

Peter Thompson: Let me take that in three parts. First—and this part is easy—global shared standards are desirable; at least they should be wider than the UK. However, achieving that is difficult.

One of the reasons is that laws on fertility treatment vary enormously from country to country; it is a classic example of national laws matching the culture of different countries, and cultures have very different views about what is allowable, for instance whether single women can get treatment and so on. Many countries that you might think we would want to reach agreements with do not even have regulatory bodies; in a practical sense, it is not clear who we would talk to in trying to build that coalition. But having set out the difficulties we clearly recognise the significance of cross-border gamete trade.

Secondly, I think you know or have heard elsewhere that we currently have a rule in this country whereby donated gametes cannot be used to create more than 10 families. Inevitably that is only a UK-wide rule. We have no jurisdiction anywhere else and it is quite possible that donated gametes that have come from outside the UK might also have been used outside the UK; so even if we set a 10-family limit in the UK, there might be a wider number of families elsewhere. That is an issue.

What can we do about this? In one sense it is about a series of trade-offs. We could simply ban the import of gametes from outside the UK but that would impact a number of UK couples and single people desperate to have a family who would not have access to donated gametes. Another impact might well be that those people would go abroad for treatment; such treatment may be of very good quality, or it may not. It might also mean—particularly if donated gametes are involved—that they have treatment somewhere where, if they are successful, their children will never be able to find out their genetic parentage in the way that is possible in the UK. Clearly it is an issue, but there are definitely no easy answers.

Thirdly, on the last part of your question, we are involved in discussions with other bodies on this issue, particularly in Europe. If agreement is to be reached it is most likely to be either Europe-wide or with a subset of Europe. A wider international agreement would almost certainly require an international treaty, and in truth the sheer political effort of trying to

achieve that would probably outweigh any benefit. There is a real issue here and resolving it is genuinely one of the trickiest problems we face.

Q225 **Dame Nia Griffith:** Did I understand you to say that there is no way you can tell if someone whose eggs come into the country to be used has actually donated elsewhere and has many other families?

Rachel Cutting: There is no mechanism for us to find that out because there is no central registry that we can tap into. Individual patients or clinics may be able to ask that question but the data is not something we can collect or would know.

Q226 **Dame Nia Griffith:** So there is no actual system?

Rachel Cutting: No.

Clare Ettinghausen: I would just add that the vast majority of treatment with donor eggs in the UK is with UK donors; only about 3% of donor eggs are imported from overseas. The issues that you and Peter have touched upon relate more to donor sperm where there is a real international market: about 50% of treatments with donor sperm in the UK, primarily those involving female same-sex couples and single patients, are with imported donor sperm from overseas.

As Peter says, the 10-family limit only applies to those families created in the UK. With egg donation, only a small number of eggs are imported from overseas, and often that is in cases where people are hoping to have an ethnic match but cannot find a donor with that ethnic background in the UK. It is not something that is quite at the same level as donor sperm where there is real concern for the families involved.

Q227 **Dame Nia Griffith:** So the three scenarios that Peter described are not so applicable in the UK then?

Clare Ettinghausen: They are more applicable with sperm donation than egg donation.

Peter Thompson: I should just add that the 10-family limit is rarely reached, even in the UK context. The vast majority of donated gametes are used in one or two families.

Q228 **Dame Nia Griffith:** How are the overseas clinics which import to or export from the UK vetted or monitored by the HFEA to ensure that they exhibit similar ethical standards to ours?

Peter Thompson: Rachel can describe the process we go through.

Rachel Cutting: As we know, the HFEA has no jurisdiction outside the UK. However, we stipulate the rules that HFEA-licensed centres must consider when importing or exporting eggs, sperm or embryos. An HFEA clinic must apply to the HFEA for what is called an importing tissue establishment certificate for each overseas clinic it wishes to import from;

that is a very detailed document that the clinic must fill out and submit to the HFEA for approval.

We set out directions with the requirements that clinics must meet. For instance, they must provide information as to whether they are accredited or licensed and what quality and safety measures are in place. We ask if the gametes and embryos have been procured in appropriate facilities and what procedures are in place to minimise contamination. We ask whether the clinics have quality management systems and traceability. If clinics are seeking to import donated gametes we must be satisfied that compensation levels are in line with HFEA directions in the UK. As we heard earlier this means that one compensation rate is applied for all donations.

If the ITE certificate is not fulfilled and we are not happy with it there is still an option of applying for importation but that has to be considered by our statutory approvals committee and is granted through a special direction; applications will only be approved for exceptional reasons. We also require a clinic to complete a transfer notification so that the HFEA know when any eggs have been imported into the country. The general directions stipulate that the HFEA clinic has to have a written agreement with any clinic it is importing from and that goes into a lot of detail.

We would expect the importing clinic to provide information on donor selection, evaluation, procurement, information provided to donors before donation, consent recorded, staff involved, and premises. We would want the importing clinic to be satisfied that there is a mechanism to report any serious adverse events or reactions.

All those requirements that I have just described through the ITE certificate and the third-party agreement with clinics are then picked up on inspection. We use an audit tool, as I described earlier for counselling, and we go through the notes of patients receiving donor gametes to make sure there is evidence to show that those requirements are met. For example, we would check that there is a record of all the payments to overseas donors and that those compensation details are placed within the notes. We will also look at evidence of proper confirmation and information and how consent was given. We go into quite a lot of detail to check what agreement the clinic has with the importing clinic and we will take regulatory action; I gave an example earlier.

Another example is where a clinic imports eggs but fails to get an approved ITE certificate from the HFEA; in that case, we would stop it importing through a special direction against their licence. We take importation and ensuring UK standards are achieved very seriously.

Q229 **Dame Nia Griffith:** Let us look at it the other way round: if a donor's eggs are going to be sent abroad, are they asked for additional consent or are they just not told about it?

Rachel Cutting: The HFEA has a mandatory export direction, which specifically states that the donor has to consent to the specific country or countries where any eggs are going to be exported, so that would absolutely be picked up on inspection.

Q230 **Chair:** Is data collected by the HFEA—or any other agency—as to the number of people who are motivated by financial reasons to donate eggs abroad? In America, egg donors can obtain up to £20,000 in compensation.

Peter Thompson: The short answer is no. We have no powers or knowledge about why people might travel to a country in order to donate.

Q231 **Chair:** Is there any international work between similar agencies anywhere else?

Clare Ettinghausen: The problem is that there is no similar agency, certainly in the US or even in Europe; I cannot even think of any other equivalent. There is what is called a competent authority in Denmark, which is mostly related to sperm donation.

Q232 **Kevin McKenna:** You have already told us that the vast majority of people using services at these clinics are paying for them themselves, which is quite different to much of the health system in this country. I would like to explore what is driving the cost. We have heard that increasingly many clinics are being taken over by private equity firms; obviously, that is a market effect. As the regulator, has that raised any concerns for you?

Peter Thompson: You are right that private equity investment is increasing. Just to step back for a moment, the HFEA Act does not differentiate between NHS and private clinics. Effectively, they all have to meet the same standards.

It is also worth pointing out that there is a blurring here because the vast majority of NHS clinics treat private patients and vice versa, although there is a distinction between ownership structures and whether patients pay for treatment. We have no regulatory powers over ownership or financial arrangements, including private equity. What I am about to say now therefore is driven more by our sense of what is going on in the market than hard regulatory data.

It is undoubtedly true that private equity firms are increasingly investing in UK fertility clinics. Typically, they make a big upfront investment and look to recoup that investment by making efficiencies over a five to seven year period; they then sell it on, typically to other private equity investors. Our concern would be whether those further efficiencies or changes to the resource model of clinics impacts on the quality of care that is being offered. Looking at our data there does not seem to be any evidence of a correlation between poor care and private equity involvement. Indeed, given NHS cuts, we are just as likely to see the

impact of resources on quality of care in the NHS as we are in private clinics with private equity investors.

Where we may see this resource question bear down most directly is with regard to staff numbers: whether there are too few staff in the lab, too few nurses and so on. We have had examples in the past where we have reached a view that staffing levels mean the clinic's throughput is unsafe. We have then put a special direction on that clinic saying, "Given that you've only got so many staff in the laboratory, or so many nurses, we think a safe number of treatments for you to do until you increase that resource is X," and we put a special condition on this. But in the round, we are not seeing any evidence suggesting that private equity investment is a driver of poor quality care.

Q233 **Kevin McKenna:** It is not just a matter of quality but the cost to the people using the services. Do you think private equity has an impact on that?

Peter Thompson: We are not a cost regulator so it is difficult to say. Although we have no control over costs one of our requirements is that clinics have what we call a costed treatment plan, which sets out the costs of treatment for each individual patient. As part of the work that Clare referred to, the Competition and Markets Authority tried to do some work on standardised costs but it could not reach an agreement with the clinics.

Q234 **Kevin McKenna:** How transparent are these costs ahead of people enlisting for these services? Do people see that full rate set out and is it completely transparent?

Clare Ettinghausen: Things have improved since the work carried out by the Competition and Markets Authority. Most clinics have their costs available on their websites. The issue is that it is quite personalised; it is unlike going for a hip operation, for example, where costs will be pretty much standard wherever you go.

With fertility treatment—whether it is egg donation, egg freezing, IVF, or whatever—it can be hard to understand the price information unless you have already had a cycle of treatment because it involves a lot of medical and drug terminology. However, in advance of treatment—certainly in advance of signing consent forms—individuals should be talked through all those items and the expected cost of treatment.

Our code of practice also requires clinics to abide by consumer law and ensure that someone has the full information before making a purchasing decision and understands the full or partial refund arrangements if they change their mind. There has been general improvement in this area since the CMA did that work a few years ago.

Kevin McKenna: I am picturing this as being like booking a budget airline ticket, where there are lots of extra costs that come in afterward; it is not always clear at the start.

Clare Ettinghausen: I do not want to steal Peter's thunder by talking about our wider powers but it is a frustration. To stay with the analogy of the budget airline it is your choice if you want to take a carry-on bag or check a suitcase in and those choices are understandable. However with fertility treatment you might not know why one thing is being offered instead of another. You are vulnerable; you want to ensure—especially if you are paying a lot of money—that the chances of success are as high as possible. Unfortunately, we are restricted in what we are able to enforce about what clinics can and cannot offer in that price list.

Peter Thompson: To build on what Clare said: from a patient's perspective cost comparison is really difficult; that is something we also feel. Clinic A may have bundled up everything into one cost. Clinic B may have a core cost that looks very attractive but it turns out that everything flowing from that is charged additionally. The patient is left wondering which is the better offer. It is not helpful.

Q235 **Kevin McKenna:** What are the risks of people being persuaded to freeze their eggs or take up IVF largely so that companies can profit from their eggs? How do you reassure yourselves that this is not happening?

Peter Thompson: It would be foolish of me to comment on an area of medicine where, unusually for this country, 70% is paid for privately; it is no surprise that clinics take such considerations into account. In a sense, everything the three of us have set out here in terms of the general rules, inspection and so on tries to get under exactly those kinds of issues, but we do not have direct, finance-type powers. There is no getting away from it: this is a commercialised area of healthcare.

Q236 **Kevin McKenna:** That leads on to a discussion about your powers. Given that the sector is changing and there are issues such as you have just raised, it is really hard for people to fully grasp all the costs and treatment implications. Do we need to make changes to the Human Fertilisation and Embryology Act in order to meet these challenges and this fundamentally changing marketplace?

Peter Thompson: The short answer is yes. The Act was passed in 1990; it was the first of its kind in the world and it has been updated once since then in 2008. In one sense, it has stood the test of time remarkably well. There is an awful lot of it that is absolutely fit for purpose but it is no surprise that after 30-odd years parts of it are showing their age.

There are four key areas. First, the point to which you refer—the size and structure of the fertility sector—has changed significantly since 1990. It was always a mix of private and NHS but in recent years we have seen the growth and consolidation of big private sector groups often as groups of clinics rather than individual clinics regardless of how they are financed. We have also seen the emergence of services online; clearly certain medical aspects of treatment can only be done in the clinic but other things are being done online.

Secondly, there has been a marked change in popular attitudes. If you go back 20 or 30 years, for many people IVF was a subject of considerable secrecy, if not shame; it is now the subject of very widespread public discussion in all sorts of fora. Thirdly, in donor treatment, we are now seeing the profound impact of the growth of social media and cheap DNA testing through 23andMe and the like. We exist in a world where we hold a statutory register and look after this data; once people reach 18 they can come to us and we can tell them stuff. I do not blame the Act, but they can now find this information in all sorts of informal ways that were simply not possible at the time.

Fourthly, there are now some really significant advances, both clinically and scientifically, that are pushing at the barriers of what is lawful in this country. The 1990 Act was absolutely cutting edge and the UK has had a longstanding reputation as one of the leading countries in this area and in biosciences generally; that is now coming under threat.

As Rachel said earlier, we did a big piece of work in 2023 involving a public consultation. We came up with 15 proposed reforms to the HFEA Act, which we published late in 2023; you will be pleased to know that I will not take you through all 15 but there are a couple of things that are worth saying.

Fundamentally—and this goes to the heart of your inquiry—we want to put the patient at the centre of the regulatory regime. If you take the HFEA Act, it has an awful lot to say about embryos and about the welfare of the child, but it has very little to say about the women actually undergoing treatment. Maybe that was okay in 1990, but it certainly does not look okay in 2026.

We also want a much more flexible and, as Clare put it, agile range of regulatory powers. I will not repeat myself but we have influencing-type powers and we have very draconian powers but we lack the powers you would associate with any modern regulator, such as the power to levy a fine. Given the commercialised nature of the market, the ability to levy a fine might be one of the most useful powers we could have; it would certainly influence behaviours.

The other problem is that our present powers are analogue rather than digital. We can only regulate licensed physical premises, but part of what normally takes place in a physical clinic is increasingly done online, for example, taking consent through a concierge arrangement.

You will see such clinics online now that look to the world like a clinic and they do all the consents and advice and stuff online but they have an arrangement with an actual clinic to do the medical transfer. People will think, “That’s a clinic.” It looks like a clinic but we cannot regulate it. We would like a neutral regulatory system; if the services need regulating, it does not matter whether they are online or in person so we should have equivalent powers. No one would have thought about this in 1990 but not being able to regulate online is a real problem now.

Kevin McKenna: That is helpful. I was going to ask about the direct-to-consumer genetic testing and that sandwich of powers between the absolute sanction and—

Peter Thompson: I have described the register where we hold all this donor information; if you were born of donated treatment since 2005 when anonymity was lifted you can write to us when you become 18 and say, for instance, "Who is my genetic father?" and we can give you that information. Social media, 23andMe and the like have blown a hole through that. Having an official record of truth is useful but people should be able to get access to that information from the birth of the child, rather than waiting for 18 years because at least there would be a level playing field.

Q237 **Kevin McKenna:** One final thing: you have talked a lot about the competition, markets and costing side of things and made clear that this is outside your scope. Is there an argument for bringing all that in-house into one body?

Peter Thompson: There could be but there is a dilemma here. It is a bit like the advertising sector; clearly the ASA are the specialist advertising regulator and the CMA are the specialist competition regulator. So the question would be, what are the benefits and disbenefits from taking elements of those powers and giving them to a fertility regulator? Would it perhaps be better to keep the expertise where it is and create a regulatory regime which better links to those other regimes? We are agnostic about that.

Clare Ettinghausen: It is worth adding that when we did very in-depth work with the Competition and Markets Authority over several years, it was quite shocked—if that is not too strong a word—about our lack of powers. In fact when we did our public consultation lots of public bodies responded and the Competition and Markets Authority provided a very robust response endorsing us to have stronger powers; it felt that fertility patients are a group of vulnerable consumers who are under-protected at the moment.

Q238 **Kevin McKenna:** How siloed is your working between these organisations? You came together to look at this in depth a few years ago. Do you have regular catch-ups? Do you talk about single organisations together where you all come into one room and discuss a particular clinic or a particular area?

Clare Ettinghausen: We do not talk about a particular clinic or a particular area. We came together over several years, both before and after the pandemic, with these pieces of work. That question is probably more for the CMA; it has many areas of interest and I am not sure if this is an ongoing piece of work for it. But the requirement to comply, for example, with consumer law or with advertising codes does not go away, even if there is no ongoing monitoring.

The ASA has committed to annual monitoring of the fertility sector, which has been really helpful. As I said at the outset, it did a report at the end of last year and found high levels of compliance and it will continue to monitor that.

Peter Thompson: The CMA effectively tends to do it sector by sector. It is interested in better compliance with consumer law and will focus on sectors where it thinks there are compliance issues. You may have seen its recent report about vets; it previously did one about higher education. It is clearly looking at this market by market and reviewing the extent to which a particular market is properly understanding and following through on consumer law.

Q239 **Chair:** Do you feel that you are resourced enough in terms of staff and finances to do what you currently do? Do you have scope to expand your powers?

Peter Thompson: There is no chief executive in the land who would sit before you and not say that more resources would be nice; clearly, public finances are tight. Were we to get new powers and new responsibilities, we would definitely need significant extra resources to go with them.

Q240 **Rachel Taylor:** We are moving to a slightly different topic but still one within your realm. Sperm donation outside regulated fertility clinics seems to be on the increase; I have certainly heard that from my constituents. What concerns, if any, do you have about this?

Clare Ettinghausen: I am really pleased to have the opportunity to cover this. When I first saw the terms of reference for the Committee, I noticed that it mentioned vulnerable women. If there is something that gives me and many of us at the HFEA sleepless nights it is the rise in the prolific use of unregulated donation.

First, I will say a few words about what unregulated donation is not. Known donation from a friend or a distant family member is not of concern; such donors may only donate once or perhaps twice to help someone in need. There are many women who go down this route primarily because of a lack of NHS funding and they are not to blame. For some of them, it has been very successful: they have a much longed-for family. They may even have a relationship with the donor, who could be a distant relative or sending birthday cards and so on. These are not the people we are concerned with, they might have donated once or twice to help people they know.

The people we are concerned about are advertising through apps, websites, Facebook, and Instagram. They have hundreds of offspring. They often advertise that natural insemination is more successful; to be frank they are coercing women into having sex yet they claim to only be doing this for the good of such women. As I said, the women are not to blame. Going down the clinic route costs thousands of pounds; we hear stories of people mortgaging their house, not going on holiday, or selling

their car, and for many people those are not possibilities and so this may be the only route they feel is possible. In the short term, we can understand why that would be but in the long term—I cannot say this strongly enough—it poses a huge risk to these women, their personal safety and to any children born.

First, there is a serious medical risk. We do not know what sexually transmitted diseases the donor may have, let alone what genetic diseases they may be passing on to the children. Secondly, there is no certainty about parenthood. There have been some terrible judgments that are in the public domain where someone years on from the time of donation has been trying to claim parental responsibility for the child. Potentially there are hundreds, if not more, donor-conceived siblings within England, let alone more widely. So although this may seem like a cheaper and easier option than having treatment at a licensed clinic, it is certainly outweighed by the long-term consequences.

The question is what can be done? First, we should say very clearly that these men are committing offences under the Human Fertilisation and Embryology Act for distributing sperm without an HFEA licence. Secondly, we would like the police to take stronger action. Thirdly, we think Meta that owns Facebook and Instagram should recognise that their platforms are being used in a way that at best enables—if not encourages—dangerous behaviour, including encouraging people to be coerced into having sex, which is what is happening.

We want anyone thinking about going down this route to really consider whether the risks are worth it. With the lack of NHS funding, those going down this route are mainly single women and same-sex female couples; they are the people in the UK who are least likely to have NHS funding. As I have said several times, we are not in any way trying to blame the women involved but I do not think we would be doing our duty as a public body if we did not raise our concerns at every possible opportunity so I am grateful to be able to raise them here today.

Q241 **Rachel Taylor:** Do you think there is anything more that the HFEA can do to mitigate those risks and inform the public of what you have told us today?

Clare Ettinghausen: That is a good challenge. We try to raise awareness wherever possible but by their very nature these are unregulated donations. We have no data to collect and we cannot take regulatory action because it is happening outside licensed clinics. But we are using opportunities to raise awareness and will continue to work with the police where possible. We will continue to press those who have social media channels to take action but we would welcome any firm recommendations from your Committee as well.

Q242 **Rachel Taylor:** What seems to be happening is that Facebook algorithms are targeting women within those groups, whether they are in same-sex couples or single women who are looking online for fertility advice and

information. Surely adverts from the HFEA could also be sent out to those algorithms. Is that something you would think of doing?

Clare Ettinghausen: Potentially, yes. It should be said that when we have spoken to Meta about whether it could have a health warning on these groups, the answer was no.

In my view there is more work that Facebook and Instagram could do. It should be said that if the donors are not on those Facebook groups or Instagram channels, they are going to be elsewhere; there are lots of apps and websites, so it is not just a social media problem. But in our view, more could be done as a public health issue by those social media channels to inform prospective women that this could be an unwise route to go down.

Q243 **Rachel Taylor:** Turning the issue on its head, what do you think the barriers are to people accessing regulated fertility services for sperm donation?

Clare Ettinghausen: The plain and simple answer is money. As we have outlined, more than three quarters of patients across the UK are paying for their own treatment but there are differences within that. The family groups who are least likely to have access to fertility treatment funded on the NHS are single patients and female same-sex couples who by their very nature will need treatment with donor sperm when there is almost no funding available wherever they live in the UK.

If there was 100% NHS funding there would still be people who want to have treatment with a known donor for various reasons: they do not want a clinical environment, or they would like to have a relationship. At the moment donations are anonymous until someone turns 18; perhaps they want to have that slightly distant familial relationship. But these are not the situations that we are talking about with prolific unregulated donors.

Peter Thompson: More widely, even if the NICE guidelines were fully met, a large number of people would fall outside those guidelines. And if you look at the demographic trend of people delaying starting a family—for a whole series of reasons which I do not need to repeat here—those are precisely the kinds of women who are going to find themselves outside the guidelines. So there will be a significant number of people who will need to pay for treatment just by virtue of those demographic trends.

Q244 **Chair:** We are coming to the end of our session and I am being told that we will have votes shortly, but I wanted to pick up on something Clare said about the police taking this very seriously. How many men have been prosecuted under the HFE Act for unlicensed sperm donation?

Clare Ettinghausen: As far as we are aware two men were prosecuted several years ago for having a business where they sold sperm. This is a difficult issue for the police: if women do not come forward, it is seeking

to prosecute what is arguably a victimless crime. But it is important to say that it is not the women who are to blame here. Most of them would not see themselves as victims even if they felt coerced into having sex.

Q245 **Chair:** On that front, are Meta and other social media platforms breaking any laws by advertising these services?

Clare Ettinghausen: I do not think they are advertising services. They are facilitating people to run these groups and advertise themselves. For them, that is a grey area. For us, it is black and white.

Peter Thompson: There is a distinction between platforms and publishers.

Chair: Yes, but they are publishing information. Thank you very much; this has been really informative. This brings the session to a close.