Fertility • Genomics • Clarity

Women's Health Strategy for England

Consultation response by PET
11 June 2021

Introduction

The **Progress Educational Trust** (**PET**) is a registered charity which advances public and professional understanding of science, law, ethics and policy in the fields of assisted conception, embryology and genomics.

PET's vision is to improve the choices for people affected by infertility and genetic conditions. **PET**'s mission is to educate and debate the responsible application of reproductive and genetic science.

PET's experience in the field of women's health is substantial. The charity was founded in 1992, while its precursor organisation – the **Progress Campaign for Research into Human Reproduction** – was founded in 1985 to campaign on legal and ethical issues that had come before the UK Parliament.

PET welcomes the UK Government's consultation on the **Women's Health Strategy for England**, and believes that a number of issues related to **fertility treatment** deserve substantial attention in the Strategy.

Summary of key issues

A number of issues related to fertility treatment are currently having far-reaching consequences for the health of women in the UK.

In particular, **PET** would like to draw attention to five areas that should be addressed in the **Women's Health Strategy for England**. A brief overview of key issues in each area is provided below and overleaf, and a more detailed account of each area is provided thereafter.

1. Law reform around fertility treatment

UK fertility treatment is governed principally by the **Human Fertilisation and Embryology Act**, which is in need of full-scale review to take account of the many changes in science and society that have occurred since its last thoroughgoing review in 2008. Two priorities should be an extension to the current **10-year storage limit** for eggs frozen for non-medical reasons, and the removal of the exceptional status of **medical secrecy** that currently applies to fertility treatment.

The 10-year storage limit should be extended because it has no scientific basis, is discriminatory against women, limits women's reproductive choices, and harms women's chances of becoming biological mothers. The exceptional status of medical secrecy should be removed because it only exists for historical reasons that no longer apply, it is not a status that applies to other areas of medicine that are equally sensitive (such as termination of pregnancy), and it creates problems for both patients and health professionals.

2. Access to fertility treatment

The **National Institute for Health and Care Excellence** (**NICE**) has long since recommended that three full cycles of NHS-funded IVF be offered to women under 40, but compliance with this recommendation continues to be wildly inconsistent across England. In February 2020, **Matt Hancock** – Secretary of State for Health and Social Care – described this situation as *'absurd'* and *'unacceptable in a national service'*. PET agrees with this assessment.

In Essex alone, there are seven clinical commissioning groups with differing policies on IVF provision – two offer no NHS-funded IVF whatsoever, one offers a NICE-compliant service, and the other four offer something in between. This situation is appalling, when one considers that infertility is – according to the World Health Organisation – not just a misfortune, but also a disease. It is morally unacceptable for women with the same medical need not to be treated equally.

3. Add-ons to fertility treatment

The lack of access to NHS-funded fertility treatment has fuelled the growth of and dominance of the private fertility sector. This has been accompanied by growth in the promotion of '**add-ons**' – optional procedures and treatments offered alongside IVF, often at considerable expense – to women undergoing fertility treatment. Evidence for the effectiveness (and even the safety) of add-ons is often poor. Nonetheless, add-ons are marketed to patients by fertility clinics and by the companies who originally devise the add-ons.

The situation needs to be addressed by making more reliable information about add-ons available to patients, via official channels including the main NHS website and app, thereby equipping patients to better understand and evaluate scientific and medical evidence as it relates to fertility treatment. The **NICE Fertility Guideline**, should also be updated, to address add-ons and (where their benefits are poorly evidenced) disincentivise their use.

4. Women's health following fertility treatment

Pregnancy, whether achieved via natural or assisted conception, can involve **risks** to women's health and even their life. There are simple and effective ways to reduce these risks, particularly in the context of **fertility treatment**. Assisted conception offers unique opportunities to identify, anticipate and minimise risks to pregnant women at an early stage. Unfortunately – as we know from data on women who die during or after pregnancy – these opportunities are not always taken.

There are variety of measures, mostly simple and inexpensive, which could be taken by fertility professionals to minimise risks to patients. In particular, there are measures recommended by the project **Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK** (**MBRRACE-UK**) – and also by **Professor Catherine Nelson-Piercy**, editor of the

Handbook of Obstetric Medicine – which should be promoted by relevant bodies as part of the treatment pathway.

5. Research related to fertility treatment

There are a number of areas of **scientific research** that could bring dramatic improvements to women who wish to have children. Counterintuitively, these include research into causes of and treatments for **male infertility**. By far the most common treatment offered as a solution to male infertility involves the infertile man's female partner undergoing all of the invasive and onerous procedures involved in IVF. If male infertility were better understood and could be treated, this could obviate the need to treat women.

Another key area is **human embryo research**, which has considerable potential to improve IVF success rates and/or help avoid miscarriage (following either natural or assisted conception). However, such research is dependent upon fertility patients donating embryos to research following treatment, and is also dependent upon fertility clinics being able to accept such donated embryos. Both of these prerequisites are currently being frustrated, and there are steps that should be taken to resolve this.

Law reform around fertility treatment

UK fertility treatment is governed principally by the **Human Fertilisation and Embryology Act**, which was passed in 1990 and last had a thoroughgoing review in 2008. The Act is now in need of another full-scale review, to take account of the many changes in science and society that have occurred in the intervening years.

Two of the most pressing changes needed to the Act, in relation to women's health, are:

- An extension to the current **10-year storage limit** for eggs frozen for non-medical reasons.
- The removal of the exceptional status of **medical secrecy** that currently applies to fertility treatment.

We shall discuss these in turn.

The 10-year storage limit

The 10-year storage limit should be extended because it has no scientific basis (eggs remain viable if frozen for longer than 10 years), is discriminatory against women (female fertility declines far more steeply with age than does male fertility), limits women's reproductive choices, and harms women's chances of becoming biological mothers.

To quote UK patient **Sharon Jones**, who has campaigned with **PET** for the limit to be extended: *'I first considered freezing my eggs when I was 28, when my eggs were at their best, but I was put off because of the 10-year storage limit. I froze my eggs at 33 in an attempt to escape the stress of a ticking biological clock, but the arbitrary 10-year storage limit has only added a new pressure. What if I don't have the opportunity to use my eggs before they are destroyed? It is outrageous that*

the government will destroy my eggs. My eggs are my genetic material; surely this is my reproductive choice.'

If a woman wishes to try to preserve her fertility, the best time for her to freeze her eggs is in her 20s. But under current UK law – the **Human Fertilisation and Embryology Acts** of 1990 and 2008, and the **Human Fertilisation and Embryology (Statutory Storage Period for Gametes and Embryos) Regulations** of 2009 – women who freeze their eggs for non-medical reasons can only store them for a maximum of 10 years.

This means that if a woman freezes her eggs when she is 28, she has to be ready to use them before she is 38. If she is *not* ready to use her eggs by the time she is 38, she has a limited number of options which are potentially debilitating, both emotionally and financially.

- She can see her eggs destroyed, and with them perhaps her best or only chance of becoming a biological mother.
- She can become a parent before she is ready to do so, either with a partner or as a single mother using sperm donation.
- She can try to fund the transfer of her eggs to a fertility clinic overseas, and then try to have fertility treatment abroad at a later date.

The 10-year limit acts as a perverse incentive for women to wait until their mid-to-late 30s before freezing their eggs, when their egg quality is declining and their chance of becoming a biological mother is reduced. A woman's age at the time of egg collection plays a vital role in the likelihood of a successful outcome from fertility treatment, as discussed in the following research.

- **Association between the number of eggs and live birth in IVF treatment: an analysis of 400 135 treatment cycles**
  Sunkara, Rittenberg, Raine-Fenning *et al*, *Human Reproduction*, 2011

  https://doi.org/10.1093/humrep/der106

- **Predicting the likelihood of live birth for elective oocyte cryopreservation: a counselling tool for physicians and patients**
  Goldman, Racowsky, Farland *et al*, *Human Reproduction*, 2017

  https://doi.org/10.1093/humrep/dex008

It is dispiriting, therefore, to see that in 2019 – the most recent year for which data is available – more than **two-thirds** of egg freeze cycles in the UK (1,589 out of 2,377) were performed for women *older* than 35. See:

- **Fertility treatment 2019: trends and figures**
  Human Fertilisation and Embryology Authority, 2021

  https://www.hfea.gov.uk/about-us/publications/research-and-data/fertility-treatment-2019-trends-and-figures/

This is situation is only encouraged by the current legislation, which is in urgent need of reform.

Medical secrecy

Information concerning a woman's fertility treatment is subject to special legal considerations in the UK, over and above the sensitivity with which all medical information must be handled. This means that such information does not automatically form part of the medical records that can be accessed by health professionals.

The only professionals who are entitled to access patient-specific fertility treatment information are staff at the relevant fertility clinic and staff at the fertility regulator (plus, in certain circumstances, the Registrar General or a court). Except in a medical emergency, this information cannot be disclosed to anyone else – not even the patient's GP – unless the patient has given specific consent for disclosure.

The historic reason for this is that when the **Human Fertilisation and Embryology Act** was originally passed, an enduring taboo still surrounded infertility and associated treatment. Exceptional restrictions were therefore placed on the disclosure of fertility treatment information, and the issue was considered so sensitive that there was a criminal sanction against breach of the provision.

The extent to which fertility treatment is (still) a medical secret is almost unique in UK law. There are few comparable restrictions, except those which concern **sexually transmitted diseases** and **gender reassignment**. By contrast, information concerning the termination of a woman's pregnancy – an area which involves as much sensitivity and need for confidentiality as assisted conception, if not more so – is not subject to such restrictions.

Fertility patients should, of course, be entitled to the same confidentiality as patients undergoing any other treatment. But partitioning fertility treatment records from a patient's other medical records leads to problems. Separate sets of notes need to be kept, even within the same medical facility (for example if a fertility clinic is embedded in an NHS Trust).

This is not good medical practice, in terms of either safety or efficiency. It can also lead to confusion – on the part of patients and health professionals alike – as to what information has been disclosed, or can be disclosed, and to whom.

Fertility professionals aspire to offer – and are increasingly expected to offer – a seamless service, from GP referral through investigation to appropriate treatment. The mandatory secrecy of fertility treatment makes such a service difficult, if not impossible, to achieve. Furthermore, health services are increasingly expected to be paperless, and the partitioning of fertility patient notes involves contorted and onerous uses of IT.

None of this is to diminish the importance of recording, handling and storing patient information in secure and diligent ways, which is (quite correctly) a high priority in public discussion. Rather, it is to say that fertility treatment information should be subject to the same standards as – and, where appropriate, should be integrable with – other forms of patient information.

There are many challenges that need to be addressed in the use of IT in healthcare, but partitioning fertility treatment information from other patient information should not be among those challenges. Resources consumed by that requirement would be better used elsewhere.

In 2019, **PET** held a public event in Edinburgh entitled '**Does Fertility Treatment Still Need to Be a Medical Secret?**'. The audience, which was made up of both fertility patients and fertility professionals, responded to the question posed in the event title with an overwhelming 'no'.

Access to fertility treatment

In February 2020, **Matt Hancock** – Secretary of State for Health and Social Care – said the following in his address to the Nuffield Trust Annual Summit: *'Why should three cycles of IVF be allowed in some parts of the country while some parts offer none? A local part of the NHS deciding it's okay not to offer IVF, with no accountability – it's absurd and it's unacceptable in a national service.'*

See:

- **Putting the national, the health and service into NHS**
  Matt Hancock, Department of Health and Social Care, 2020

  https://www.gov.uk/government/speeches/putting-the-national-the-health-and-service-into-nhs

PET agrees entirely with this statement by Matt Hancock. For more than a decade, **PET** has campaigned to end the postcode lottery for access to NHS-funded fertility treatment.

The **National Institute for Health and Care Excellence** (**NICE**) has long since recommended that three full cycles of NHS-funded IVF be offered to women under 40, but compliance with this recommendation continues to be wildly inconsistent across England. Worse, it is difficult to piece together an accurate picture of the situation, because the relevant clinical commissioning group (CCG) policies are not centrally monitored or disseminated by Government

This means that over the years, it has been left to small charities such as **PET** to try to collate nationwide information (if and when funding for such work is available) via painstaking freedom of information requests. The picture that emerges is one of prevailing inequality.

Consider the example of **Essex**. In this area alone, there are seven clinical commissioning groups (CCGs) with differing policies on IVF provision – two of these CCGs currently offer no NHS-funded IVF whatsoever, one offers a NICE-compliant service, and the other four offer something in between.

The policies break down as follows.

- **Basildon and Brentwood** – offers 0 cycles (completely decommissioned services in 2016)
- **Mid-Essex** – offers 0 cycles (completely decommissioned services in 2014)
- **North-East Essex** – reinstated NHS-funded IVF in 2020 (after completely decommissioning services in 2015), now offers 2 partial cycles to women under 40 and 1 cycle to women aged 40-42
- **Castlepoint and Rochford** – offers 2 partial cycles to women under 40 and 1 cycle to women aged 40-42
- **Thurrock** – offers a NICE-compliant service, 3 full cycles to women under 40 and 1 cycle to women aged 40-42
- **Southend** – offers 1 full cycle to women under 40 and 0 cycles to women older than 40

- **West Essex** – offers 1 partial cycle to women aged 23-42

This situation is appalling, when one considers that infertility is not just a misfortune, but also a disease. In 2009, the **World Health Organisation** adopted a *'clinical definition'* of infertility as *'a disease of the reproductive system'* – see:

- **ICMART and WHO revised glossary of ART terminology**
  Zegers-Hochschild, Adamson, de Mouzon *et al*, Fertility and Sterility, 2009
  https://doi.org/10.1016/j.fertnstert.2009.09.009

It is morally unacceptable for women with the same medical need not to be treated equally. The current situation means that those who cannot afford private sector IVF are – unless they happen to be winners in a cruel postcode lottery – liable to be left childless.

Add-ons to fertility treatment

The lack of access to NHS-funded fertility treatment has fuelled the growth of and dominance of the private fertility sector. This has been accompanied by growth in the promotion of '**add-ons**' to women undergoing fertility treatment.

The situation needs to be addressed by:

- Making more reliable **information** about add-ons available to patients, equipping them to better understand and evaluate scientific and medical evidence as it relates to fertility treatment.

- Updating the **NICE Fertility Guideline**, so as to address add-ons and (where their benefits are poorly evidenced) disincentivise their use.

What are add-ons?

Fertility treatment add-ons are optional procedures and treatments offered alongside IVF, often at considerable expense to the patient. They can involve tests, drugs, equipment, holistic or alternative therapies, and laboratory or surgical interventions. Because of the nature of fertility treatment, it is most often women who undergo the relevant procedures.

Add-ons are marketed to patients not just by fertility clinics, but by the companies who originally devise and supply the add-ons. This is done in order to create a situation where patients attending clinics request a particular add-on (even if it has not been offered to them), thereby placing pressure on the clinic to begin offering the add-on (for fear that if they do not then they will cede advantage to a competing clinic).

Companies and clinics that promote add-ons claim that add-ons can improve chances of achieving a pregnancy or a live birth, or else claim that add-ons can shorten the time taken to achieve a pregnancy. Evidence for the effectiveness (and even the safety) of add-ons is often poor, almost by definition (because if this was *not* the case then the add-on in question would arguably have become incorporated into more standardised treatments).

Recent research suggests that *'add-ons are commonly offered in the context of self-funded treatment'*, *'they are frequently marketed using claims that are not clearly supported by robust evidence'*, and *'the promotion and provision of add-on treatments with a limited evidence base is common'*. See:

- **The prevalence, promotion and pricing of three IVF add-ons on fertility clinic websites**
  Van de Wiel, Wilkinson, Athanasiou *et al*, *Reproductive BioMedicine Online*, 2020

  https://doi.org/10.1016/j.rbmo.2020.07.021

A defence of add-ons that has been advanced is that these are pioneering new approaches, and benefits will be established in due course. This is not persuasive, partly because it is unreasonable to expect patients to pay handsomely in order to participate in what is effectively ongoing research, and partly because there has already been ample time for some of the promised benefits to emerge.

Consider this newspaper headline from 2013:

- **New IVF technique could give 78% chance of success**
  Devlin, *The Times*, 2013

  https://www.thetimes.co.uk/article/new-ivf-technique-could-give-78-per-cent-chance-of-success-5kl0skmvrj8

The *'new IVF technique'* referred to in this article involved the time-lapse monitoring of embryos, marketed directly to patients. Several years later, benefits on such a scale have not yet emerged. For an assessment of the relevant evidence, see:

- **Time-lapse systems for embryo incubation and assessment in assisted reproduction**
  Armstrong, Bhide, Jordan *et al*, *Cochrane Database of Systematic Reviews*, 2019

  https://doi.org/10.1002/14651858.CD011320.pub4

The UK fertility regulator – the **Human Fertilisation and Embryology Authority** (**HFEA**) – has sought to inform the public about the evidence (or lack of it) for add-ons, via a 'traffic light' system. See:

- **Treatment add-ons with limited evidence**
  Human Fertilisation and Embryology Authority

  https://www.hfea.gov.uk/treatments/treatment-add-ons/

However, not all fertility patients are aware of this information, or even of the HFEA's existence.

For many years, **PET** has run an exhibition stand (alongside commercial exhibitors from the UK and overseas) at **Fertility Show** events in London and Manchester, which are attended by thousands of members of the public who face difficulty in conceiving a child. Many of the people to whom **PET** has spoken at these events have not been aware of the existence or the activities of the HFEA.

What should be done?

Reliable information about fertility treatment add-ons should continue to be maintained and updated on the HFEA website, and in other HFEA materials. Additionally, such information should be incorporated into other official channels including the main NHS website and app (formerly known as '**NHS Choices**').

This will need to be handled carefully, so as not to inadvertently further promote the add-ons in question. But it is worth doing, because it will increase opportunities for patients to find accurate information about add-ons, amid a bombardment of well-funded and often misleading marketing.

The growing prominence of add-ons also adds to the case for a thorough update of the **NICE Fertility Guideline**. See:

- **Fertility problems: assessment and treatment**
  National Institute for Health and Care Excellence, 2013 (updated 2017)

  https://www.nice.org.uk/guidance/cg156

The original version of this guideline was published in 2004. There was a thoroughgoing update in 2013, and the most recent minor update was in 2017.

There are many reasons to update the guideline. For example, the requirement that female same-sex couples need to have six rounds of self-funded artificial insemination or intrauterine insemination, before they become eligible for NHS-funded fertility treatment, needs to be revisited. But setting this aside, a compelling reason to update the guideline is to disincentivise clinics from offering, and women from seeking, poorly evidenced add-ons.

As new add-ons are devised and marketed, opportunities arise for promoters of add-ons to claim that the reason a particular add-on is not addressed in the **NICE Fertility Guideline** is because the guideline has become outdated. Updating the guideline will help to close off these opportunities.

Women's health following fertility treatment

Pregnancy, whether achieved via natural or assisted conception, can involve **risks** to women's health and even their life. There are simple and effective ways to reduce these risks, particularly in the context of **fertility treatment**.

Assisted conception can involve many challenges, but there is one respect in which it offers a unique advantage in the context of health – it often involves detailed engagement between women and health professionals *before* these women become pregnant. Consequently, it offers many opportunities to identify, anticipate and minimise risks to pregnant women at an early stage.

Unfortunately, these opportunities are not always taken. We know this from data on women who die during or after pregnancy, collected and studied by the **University of Oxford**'s **National Perinatal Epidemiology Unit** as part of its ongoing project **Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK** (**MBRRACE-UK**).

MBRRACE-UK reports that in 2015-2017, 82 women died from heart disease associated with or aggravated by pregnancy. Of these 82 women, six had become pregnant following IVF treatment,

and *'there was no evidence that any of them had any assessment of their cardiovascular health prior to their assisted reproduction treatment'*.

The same MBRRACE-UK report argues that *'guidance is needed on maternal medical assessment and screening prior to assisted reproduction, particularly for older women who are at higher risk of comorbidities such as cardiac disease and cancer'*. See:

- **Saving Lives, Improving Mothers' Care: Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2015-2017**
  Knight, Bunch, Tuffnell *et al (eds)*, MBRRACE-UK, 2019

  https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/MBRRACE-UK%20Maternal%20Report%202019%20-%20WEB%20VERSION.pdf

In March 2021, **PET** held a public event entitled '**IVF and Women's Health: What Do We Know? What Do We Need to Find Out?**'. At this event, **Professor Catherine Nelson-Piercy** – a Consultant Obstetric Physician, and editor of the ***Handbook of Obstetric Medicine*** – outlined a variety of measures, mostly simple and inexpensive, which could be taken by fertility professionals to minimise risks to patients.

These measures included:

- Taking a thorough history, including a family history.
- Checking blood pressure.
- Checking urine, and – if it contains excess proteins – then checking renal function (via an inexpensive blood test).
- Checking fasting blood glucose and lipid profile.
- If concerned, performing electrocardiography (and asking an appropriate colleague to interpret the results if this is outside one's competence).
- If the patient is assessed to be at risk, referring them for pre-pregnancy counselling (certainly prior to embryo transfer, and perhaps prior to egg collection).

These measures, and measures recommended by MBRRACE-UK, should be promoted by relevant bodies as part of the treatment pathway and should be incorporated into the **NICE Fertility Guideline** when it is next updated.

Research related to fertility treatment

There are a number of areas of **scientific research** that could bring dramatic improvements to women who wish to have children, in relation to both natural and assisted conception.

PET would like to draw attention to two such areas, which do not currently receive sufficient attention or support:

- Causes of and treatments for **male infertility**.

- Research using **human embryos**.

We shall discuss these in turn.

Male fertility

It may seem counterintuitive to discuss *male* infertility in response to a consultation that concerns women's health, but there is a direct connection. If male infertility were better understood and could be treated, this could obviate the need to treat women.

At present, by far the most common treatment offered as a solution to male infertility is IVF with **intracytoplasmic sperm injection** (**ICSI**), whereby a single sperm cell is injected directly into an egg cell in order to achieve fertilisation. However, this approach necessarily involves the infertile man's female partner undergoing all of the invasive and onerous procedures involved in IVF, even if she is completely fertile.

This is a key concern of **Dr Sarah Martins Da Silva**, who works as an Obstetrician and Gynaecologist while at the same time researching male infertility (work that led to her being named one of the **BBC**'s 100 most inspiring and influential women of 2019).

In a recent interview with **PET**, Dr Martins Da Silva said of ICSI: *'It's a great treatment for a couple that are affected by male infertility, but it doesn't address the problem, it doesn't correct the problem. And it's clearly a very involved treatment, focused more around the woman and delivering treatment that she has to go through – in terms of hormone injections, egg collection and so – for the male partner's health problem. And that's an injustice in its own right.'*

See:

- **Sarah Norcross and Dr Sarah Martins Da Silva discuss the future of male fertility**
  Progress Educational Trust, 2021

  https://www.progress.org.uk/film-sarah-norcross-and-dr-sarah-martins-da-silva-discuss-the-future-of-male-fertility/

Furthermore, if a heterosexual couple conceive a child via IVF with ICSI because of the male partner's infertility, and that couple wishes to have further children, then this usually means that the female partner will have to go through the same process repeatedly.

There should be greater commitment to funding research into male infertility, and development of new treatments for male infertility, in order to reduce the number of fertile women undergoing IVF.

Embryo research

Human embryo research has considerable potential to improve IVF success rates and/or help avoid miscarriage (following either natural or assisted conception), among its other benefits.

However, such research is dependent upon fertility patients donating embryos to research following treatment, and is also dependent upon fertility clinics being able to accept such donated

embryos and convey them to an appropriate research centre. Both of these prerequisites are currently being frustrated, and there are steps that should be taken to resolve this.

Women who undergo fertility treatment may have unused IVF embryos left in storage at the end of their treatment. If women consider themselves to have completed their family (meaning that are unlikely ever to wish to use the remaining embryos to have further children), then this leaves them with five options.

- Donate the embryos for use in research.
- Donate the embryos for use in training.
- Donate the embryos to others who face difficulty in conceiving a child.
- Consent to the embryos being allowed to perish.
- Delay or avoid the decision.

Many women find this choice difficult to make. Consequently, they 'choose' the final option – or, more accurately, the final option occurs by default.

Under UK law, embryos may be stored for up to 10 years. If the patient received fertility treatment for medical reasons, then this storage period may be extended every 10 years, up to an overall maximum of 55 years. If the end of a 10-year storage period is reached, and the woman does not (or is not eligible to) extend storage, then the embryos are allowed to perish.

Women with unused embryos in storage receive little or no information or support to help them make a decision, either immediately after their fertility treatment or when the end of a 10-year storage period is imminent. This is one reason why few embryos are donated to research in the UK.

Another reason why few embryos are donated to research in the UK is that few fertility clinics are able to accept embryos donations of embryos for research, even if this is what the patient wishes and requests. **PET** has been told of patients with a profound wish to donate unused embryos for research, who are unable to find a way to make this happen before the embryos must be allowed to perish.

This situation is not necessarily due to shortcomings on the part of fertility clinics, but rather is a consequence of regulatory arrangements. Consider the example of Bourn Hall Clinic, which was actually founded by the inventors of IVF – inventors who were only able to pioneer and refine this revolutionary method of fertility treatment because they were able to conduct human embryo research.

In keeping with its origins, Bourn Hall Clinic has a strong commitment to enabling the donation of embryos for research, and its facility near Cambridge has an intricate system in place which allows patients to do this. This system is only made possible by the fact that Bourn Hall has forged strong links with research centres – patients at a clinic that does *not* have such links are unlikely to be able to donate their embryos for research.

Furthermore, even Bourn Hall is unable to accept the donation of embryos from patients at its own satellite clinics in Norwich, Peterborough, Wickford, King's Lynn and Colchester – even though

Bourn Hall would very much like to accept such donations – because the regulatory requirements involved in moving embryos from one location to another are prohibitively bureaucratic and expensive.

In short, opportunities to ask for and receive donated embryos for research are being squandered. This situation must be resolved by addressing the impediments to donation in current regulations, and by providing adequate information, support and (if needed) counselling to women who have embryos in storage.