

22 July 2005

Dear Colleague

### **EUROPEAN ASSISTED CONCEPTION CONSORTIUM (EACC)**

At the inaugural meeting of the European Assisted Conception Consortium in Copenhagen we debated some of the key challenges facing the ART sector across Europe over the coming months as we move to the new regulatory environment of the EU Tissue Directive.

In particular we recognised the challenges of setting up and maintaining new regulators and regulatory systems across the various member states and the need to engage people in this new regulatory system.

One of the major driving forces which led us to set up the EACC was a recognition that, through coming together across Europe, we would be able to share our knowledge and experiences of the issues and regulation of the sector, particularly in the face of the substantial challenges over the coming months.

In that spirit and as I promised at the meeting, I now have pleasure in enclosing a report of work carried out in the UK by the HFEA which gives preliminary findings of research into public attitudes to fertility treatment, embryo research and the regulation of this work.

Although we recognise that each member state will require a system which is grounded in the values and culture of that country, I believe that you will find it helpful to learn more about the current state of public opinion within the UK and how it interacts with the regulatory system.

This report provides preliminary findings from an analysis of public opinion. This is part of an ongoing programme of work which the HFEA is carrying out over the next few months and I hope to be able to share some more information with you later in the year.

[Human Fertilisation and Embryology Authority](#)

21 Bloomsbury Street, London WC1B 3HF

Telephone: 020 7291 8200

Fax: 020 7291 8201

[www.hfea.gov.uk](http://www.hfea.gov.uk)

I hope you find this report helpful and that you will be able to benefit from our experiences in the UK

Yours faithfully

A handwritten signature in black ink, appearing to read 'A. McNab'.

Angela McNab  
Chair, EACC

**PUBLIC ATTITUDES  
TO FERTILITY TREATMENT,  
EMBRYO RESEARCH  
AND THE REGULATION  
OF THIS WORK –  
Preliminary findings from the UK**

**HFEA Policy Briefing presented to members of  
the European Assisted Conception Consortium  
July 2005**

## EXECUTIVE SUMMARY

### Key Findings of UK Public Opinion

- 50% of people believe the benefits of fertility treatment outweigh the risks, compared to only 13% of people who believe that the risks outweigh the benefits.
- However, 48% of people believe treatment carries unknown consequences.
- 20% of people believe that treatment is tampering with nature and so is unethical. However, 59 % disagree with this
- Doctors are most trusted to provide information about fertility treatment and be involved in its regulation, followed by the HFEA.
- The UK regulator is trusted to be involved in decision making on fertility treatment by 39% of people. This rises in higher socio-economic groups with 58% of graduates trusting the HFEA to be involved.
- Openness and Honesty are most important to maintain trust in the regulatory system – followed by knowing that there is a system which will stop particular actions if there are concerns.
- Politicians, religious leaders and the media are trusted by relatively few people to be involved in the regulation of fertility treatment or embryo research
- 73% of people believe that human embryo research can improve the quality of life of future generations with inherited diseases
- 43% of people believe the benefits of embryo research outweigh the risks (but 20% believe the risks outweigh the benefits).
- Opinion is split on the ethics of research. 41% of people believe that embryo research is ethical, while 34% of people believe embryo research is unethical
- 42% of people believe the rules governing embryo research are strong enough as they stand at present.
- The UK regulator is most trusted to be involved in decision making on human embryo research and provide information to the public
- The public believe that the framework of rules and regulations should be developed by doctors and Parliament working together to develop a consensus. Very few people believe these decisions should be made by Parliament or doctors working alone.

### **Key Recommendations for the Future**

- A consensus between public, doctors and scientists is essential to maintain public confidence which allows treatment and research to continue and progress. Public opinion is finely balanced and fragile and requires continued openness, honesty and a consensual approach.
- The public want authoritative and trusted information and will trust an independent regulator to provide it.
- It is important for regulators to assess and evaluate public opinion on an ongoing basis to maintain confidence in the face of scientific developments.
- Patients can feel differently about these issues and are influential on others. Therefore, it is important to track the views of patients separately.

## **Introduction**

Fertility treatment and embryo research are controversial areas which give rise to strong feelings and concern. Many people take principled and opposing views as to what should be allowed to be carried out for treatment and research.

A number of countries, such as the UK, have regulators to govern the working of these sectors. The fundamental purpose of these regulators is to uphold the interests of wider society to ensure that the scientists and doctors operating in these areas do not carry out work that is unacceptable to the public.

## **Fertility Regulation in the UK**

The UK has the world's longest-established system of regulation for fertility treatment and research. The Human Fertilisation and Embryology Authority (HFEA) was set up by the UK parliament and came into operation on 1 August 1991.

However, the principles on which the UK's fertility law is based date back to the major public debate in the early 1980s. This subsequently led to the Committee of Inquiry into Human Fertilisation and Embryology chaired by philosopher Mary Warnock, which reported in 1984. The Warnock inquiry took evidence from interested groups across society including patients and doctors, scientists and church leaders, lawyers and ethicists and formed the basis of a broad public consensus over fertility treatment.

This broad public consensus has allowed the UK to build on its pioneering work in fertility treatment and research, effectively ensuring public consent for fertility treatment and research to progress and develop, with the confidence that there are proper controls in place to prevent unacceptable actions from taking place.

Fertility regulation has a high public profile in the UK. 59% of the public say they have heard of the HFEA, with 31% of people saying they know at least a little about the work that we do<sup>1</sup>. This compares with only 49% of the public who have heard of the Healthcare Commission – the main regulator for both NHS and private health services (23% said they knew at least a little about the Healthcare Commission's work).

Another important context for fertility treatment in the UK is that between 75-80% of treatment is carried out in the private sector with individuals funding their own treatment (so not being paid for by the state, or private medical insurance.)

---

<sup>1</sup> MORI Perception Audit for HFEA. Face to face interviews of 1840 British adults in March 2005

## Public Attitudes: the Wider Context

The UK public have shown that there is a delicate balance between public opinion and scientific developments, and that this balance can rapidly change if the public are not confident that there is adequate scrutiny of what scientists are doing and management of the longer-term implications.

A major study of UK attitudes has found that, in general, the UK public are mistrusting of genetic science as a whole<sup>2</sup>.

- Only a quarter of people trust those 'in charge of new developments' to act in society's interests – while a third do not.
- While just under a quarter of people think that government legislation will protect the public from risk, nearly twice as many people disagree.
- Six in ten people believe that genetic scientists only tell the public what their employers want the public to hear.

The case of GM food is a very good example of how public attitudes have shaped the progress of science<sup>3</sup>. In the UK the public concerns and fears about GM food were not adequately addressed in the early stages. This led to public opinion becoming more strongly against the use, or even testing of, GM food.

This example shows the importance of a good knowledge of public perceptions of both the issues and the steps taken to control them in ensuring a continued consensus around scientific developments.

It has been the previous experience of the HFEA that public opinion on issues around fertility treatment and embryo research falls into distinct groupings<sup>4</sup>. We have found in previous consultations that these groups of opinions include:

- that treatment or research is fundamentally wrong, because it interferes with divine will or the course of Nature;
- concerns about the long-term consequences of intervening in a self-regulating natural process;
- acceptance of a particular course of action when it has been rationally argued and there is a clear benefit to others;

---

<sup>2</sup> Park A et al (2004), British Social Attitudes – the 21<sup>st</sup> Report, London: Sage Chapter 6 'Genomic Science: Emerging public opinion'

<sup>3</sup> A good summary of the problems encountered in the handling of the GM debate in the UK can be found in the Economic and Social Research Council's briefing 'The Politics of GM Food' produced by the ESRC's Global Environmental Change Programme. This can be found on the internet at <http://www.sussex.ac.uk/Units/gec/gecko/gec-gm-f.pdf>

<sup>4</sup> HFEA Report 'Sex Selection: Options for Regulation', Oct 2003; Public Attitudes to Embryo Selection for Tissue Donation, Opinion Leader Research study for HFEA, May-June 2004

- the belief that an individual's choice and medical possibility should dictate what is permissible.

### **Research and Methodology**

Although the HFEA has carried out a number of public opinion studies related to specific issues it had not previously carried out an overall assessment into public opinion on fertility treatment, embryo research and the regulation of these activities.

The HFEA commissioned polling experts MORI to carry out a research study, interviewing a representative sample of 1,929 adults across the UK in March 2005 to find out their opinions. This report gives some of the preliminary findings of this research.

The HFEA felt it was important not to attempt to lead public opinion in the research questions, but to look at the underlying factors and opinions of people. So in a number of questions – particularly when asking people to suggest who they felt should be involved and who should be making the final decisions about issues – the options of 'independent regulator' or 'the HFEA' were not included. However, in those areas where the public would be expected to have some knowledge of the HFEA, then it was included as part of the questions.

## **FINDINGS ON ATTITUDES TO FERTILITY TREATMENT**

There is widespread agreement that fertility treatment represents a major advance in science.

Nearly half of adults regard fertility treatment as something with unknown consequences, and a large majority calls for regulation of the prices charged by clinics for fertility treatment.

### **Knowledge about Treatment**

Spontaneous association with the phrase 'fertility treatment' is high, with over eight in ten adults citing something related to the field.

- Over half (58%) associate fertility treatment with couples who need help with fertility or conception, with help getting pregnant or with fertilisation.
- Nine in ten (91%) correctly identify at least one type of fertility treatment when prompted - women aged 35 to 44 being most likely to do so (98%).
- Nine in ten adults (90%) also agree that fertility treatment allows couples who may not have been able to, to have children, with half the public agreeing strongly.
- In-vitro fertilisation (IVF) is the best known type of fertility treatment, mentioned by almost three-quarters after prompting (72%). Women in general are more likely than men to name specific treatments such as IVF or drug therapy.
- Over two in three adults (69%) have had, or know someone who has had, fertility treatment.

### **Attitudes towards Fertility Treatment**

#### *Are the benefits worth the risks?*

Overall attitudes towards fertility treatment are largely positive. Far more say the benefits of fertility treatment outweigh the risks, than the risks outweigh the benefits (50% compared with 13%).

Those who know of someone who has had fertility treatment are even more likely to view the benefits as exceeding the risks, with almost two-thirds (64%) doing so, compared to 44% among those not knowing such a person.

However, young people are more concerned: those in the 15-24 age group are more likely than all other age groups to believe the risks of fertility treatment to outweigh the benefits (22%).

Despite most people feeling the benefits outweigh the risks of fertility treatment, just under half (48%) say fertility treatment has unknown consequences, with far

fewer - one in five - disagreeing. Women aged 45-54 are much more likely to agree than others, with 63% doing so. Those who believe regulations to be too relaxed are also more likely to agree (65%) that the consequences of fertility treatment are unknown.

However, three in five (59%) disagree with the proposition that fertility treatment is tampering with nature and therefore unethical. Women aged 25-44 are most likely to disagree with the statement. Conversely, those with no formal qualifications are more likely to view fertility treatment negatively in this regard.

### *A good thing and part of modern medicine?*

There is widespread agreement that fertility treatment represents a major scientific advance. 85% believe this (and 31% agree strongly), with just 3% disagreeing. The only group with agreement significantly below average (at 69%) is those with no formal qualifications, but even among this group a mere 6% disagree, and the remainder are neutral or express no opinion.

There is less consensus on fertility treatment being a routine medical treatment. While over half agree that it is (55%), around a quarter (23%) disagree. Women (27%) are more likely to disagree than men (18%), with women aged 25 to 34 and 45 to 54 being particularly sceptical (34% disagree in each case).

## **Attitudes towards Regulation of Fertility Treatment**

### *Is regulation keeping up?*

There is a marked split in opinion on whether regulation *is* keeping up with developments. Approaching half of adults (45%) have a fair amount of confidence that rules and regulations are keeping pace with science. However a significant minority of people (35%) say they have not very much or no confidence at all. One in five don't know how they feel.

When asked about **trust** in the system, approaching two in three (63%) trust the regulatory system for fertility treatment specifically to keep pace with scientific advances, while 10% do not trust the system to do so.

When asked specifically about whether they trust the regulatory system for fertility treatment more people are neutral or express no opinion (42%) than give any other response. While over one in three (37%) disagree that they have a lack of trust in the system for regulating fertility treatment, over one in five agree (20%).

### *Are the rules tough enough?*

Half (51%) agree that Britain probably has tough rules compared with other countries (8% disagree), and over half (59%) expect that the rules governing fertility treatment are well enforced (11% disagree). Inspectors are trusted to

highlight any misconduct occurring in fertility treatment facilities by 59%, with 14% disagreeing. A similar proportion trusts the regulatory system to fully consider patients' interests (61%), with one in ten disagreeing.

When asked specifically about the severity of regulations governing fertility treatment half (49%) believe regulation to be about right, with 12% saying they are too strict and 15% saying regulations are too relaxed.

#### *The costs of treatment?*

Support for regulating prices which clinics charge for fertility treatment is high, with over three-quarters (76%) agreeing prices should be controlled. Those who strongly agree make up over a third of the public (37%). Disagreement with the regulation of such prices is registered by only 3%.

#### *Who should be involved in making decisions?*

The groups the public trust most to be involved in discussions about fertility treatment are doctors working in NHS hospitals (51%) and GPs (50%).

The UK regulator is trusted to be involved in discussions on fertility treatment by more than a third (39%). This rises to 49% in the higher socio-economic groups [the ABC1s], and even further to 58% among graduates.

Politicians are much less trusted by the public – with only 5% trusting MPs to be involved in decisions. Scientists working for Government are trusted by 15%.

Those who know someone who has had fertility treatment are almost twice as likely as those who have not to place their trust in the HFEA (57%, compared with 31%).

#### *Who should be involved in regulation?*

Doctors working in NHS Hospitals (52%) and GPs (48%) are most often selected (in this survey) to be involved in discussions about how to regulate fertility treatment. The UK Regulator again performs relatively well, being chosen by 42% to be involved. The higher socio-economic groups are considerably more likely to name the HFEA than the lower ones (though this is often the case when the UK public are asked of their knowledge of institutions). MPs are mentioned by 12%.

Reflecting the results of the earlier question (about who should be involved in discussions about how to regulate fertility treatment), doctors working in NHS hospitals (31%) are most often chosen to have the greatest involvement in discussions about how to regulate fertility treatment. The HFEA comes a close second with 28%, followed by GPs at 25%.

It is notable that the UK regulator's relative position increases on the third question in this sequence, when people are asked about who should have most involvement on regulation.

*Who should provide information?*

In terms of provision of honest and balanced information about fertility treatment and its regulation, doctors working in NHS hospitals (43%), GPs (42%), BPAS (35%) and HFEA (33%) are the most trusted institutions. The media are least trusted to provide honest and balanced information, 42% saying they would not trust them. Religious leaders are not trusted by 38%.

*Who should make the rules?*

Joint responsibility between doctors and Parliament for formulating regulations regarding fertility treatment is the public's preferred option. Almost two-thirds (63%) of the public state this.

A quarter (26%) believe doctors should have sole responsibility for formulating regulations, but only 5% feel this responsibility should lie solely with Parliament. This reinforces the findings that the public places far less trust in MPs and Government than doctors to be involved in discussions about how to regulate fertility treatment.

*What makes people trust the system?*

Honesty and openness are the keys to instilling trust in the regulatory system for fertility treatment, with 13% saying spontaneously that these factors would give them trust in the system. This rises to 47% when respondents are prompted. It is followed (at the prompted question) by a system that monitors developments after they have become available to the public, and is prepared to withdraw them if there are concerns (41%).

## **FINDINGS ABOUT HUMAN EMBRYO RESEARCH**

There is considerable agreement that human embryo research can improve the quality of life of future generations with inherited diseases, and that it enables scientists to increase their understanding of how the body works.

More than twice as many people think that the benefits of human embryo research outweigh the risks. However, a similarly high proportion feel human embryo research has unknown consequences. There are also concerns about the social consequences of allowing the research with half the public believe it will lead to human cloning, despite the fact that this is clearly and explicitly prohibited by UK law.

The UK regulator is the organisation most often nominated to be trusted to be involved in decisions about human embryo research, and to be involved in discussions about how to regulate it. It is also among the most trusted sources to provide honest and balanced information about human embryo research and its regulation. Doctors are also trusted - with the media, government, pro-life organisations, religious leaders and MPs being significantly less trusted to provide honest and balanced information. This is the same five groups as for fertility research.

### **Knowledge about Embryo Research**

Spontaneous association with the phrase 'human embryo research', at 78%, is high (and almost as high as spontaneous associations for 'fertility treatment').

'Medical Research' is most often mentioned (at 17%), followed by cloning at 15%. A wide variety of other answers is given (28%). Over one in three (39%) associate the term with finding cures for diseases, medical research or stem cell research. Higher socio-economic groups [ABC1s] (48%) are almost twice as likely as lower socioeconomic groups [C2DEs] (28%) to mention one of these three activities.

On being presented with a list of options, stem cell research (57%) becomes the technique most strongly associated with human embryo research. Cloning also occupies a prominent position in the public's mind, with half (49%) making the association. Gene therapy is mentioned by 46%. ABC1s are most likely to give an example.

### **Attitudes towards Human Embryo Research**

*Are the benefits worth the risks?*

The benefits of human embryo research are seen as outweighing the risks by 43%, with one in five (20%) thinking the opposite. Higher socio-economic groups [ABC1s] more often believe than lower socio-economic groups [C2DEs] that the benefits outweigh the risks (51%, compared with 33%); while lower socio-economic

groups [C2DEs] are more often undecided than higher socio-economic groups [ABC1s]. One in three people in lower socio-economic groups [C2DEs] are undecided. Over one in five people in lower socio-economic groups [C2DEs] say they do not know.

The public broadly agrees that the consequences of human embryo research are unknown. While seven in ten (70%) agree with that proposition, one in ten (9%) disagree. The public believes that human embryo research poses risks to future generations, 46% agreeing with the statement. C2DEs are less likely than ABC1s to disagree, but once again are less inclined to express an opinion.

### *Is embryo research ethical and worthwhile?*

There is high agreement with the proposition that human embryo research can improve the quality of life of future generations with inherited diseases (73%). This is consistent with the public's strong association of human embryo research with stem cell research.

The public is divided over the ethics of human embryo research. While one in three (34%) agree that it is tampering with nature and therefore unethical, a further two in five (41%) disagree. Again, there is a difference between the upper socio-economic groups and the lower; while 50% of the higher socio-economic groups [ABC1s] disagree that the activity is unethical, 30% agree. Lower socio-economic groups [C2DEs] are more equivocal, 38% agreeing, 32% disagreeing.

Human embryo research is seen as contributing to scientists' knowledge of the body by three in four adults (75%). Only 8% disagree. Socio economic grouping once more is a prime determinant of attitudes; 83% of ABC1s agree that to be the case, compared with 65% of C2DEs.

Half the population believe that human embryo research will lead to human cloning, more than twice the number who feel it will not (22%).

## **Attitudes towards Regulation of Human Embryo Research**

### *Is regulation keeping up?*

While 42% have confidence that rules and regulations are keeping pace with biological developments and scientific research, almost as many (39%) say they do not have confidence. This is broadly similar to the findings for fertility treatment.

However, the public has more trust in the regulatory system for human embryo research specifically; over half (57%) agree that it will keep pace with scientific advances, with 16% disagreeing.

### *Are the rules tough enough?*

Over two in five (42%) think that rules and regulations governing human embryo research are about right. Regulation is perceived as being too strict by 11% and too relaxed by 22%. There are similar levels of trust and distrust in the regulatory system for human embryo research: 30% agree that they have a lack of trust in the system, while 32% disagree.

Despite the equivocal nature of trust in the regulatory system, most people (52%) feel Britain has tough rules governing human embryo research compared with other countries. Over half (52%) agree with the statement, while one in ten do not. One in five are neutral, and a further 18% are undecided.

There is also confidence in the enforcement of the regulations, over half (53%) agreeing that they expect that the rules in Britain on human embryo research are well enforced, while 14% disagree. Inspectors are trusted by similar proportions to bring to light any misconduct.

### *Who should be involved in regulation?*

The UK regulator is the institution most trusted (by 46%) to be involved in decisions about human embryo research, followed by scientists working for medical research charities (39%) and doctors working in NHS hospitals. Government is trusted by 14%, MPs by 5%. As with fertility treatment, there is a rank order of citations for scientists, with those working for medical research charities and universities coming ahead of those for government and industry. However for human embryo research, all four types of scientists get better ratings than for fertility treatment, and particularly scientists working for universities and for government.

The UK regulator is also the institution which most people (47%) feel should be involved in discussions about how to regulate human embryo research, and also takes lead vote as the institution, professional or group which should have most involvement in those discussions (36%).

Doctors working in NHS hospitals come second to the HFEA on both measures.

### *Who should provide the information?*

The UK regulator is also most trusted to provide honest and balanced information about human embryo research and its regulation (37%). The HFEA is again ahead of doctors working in NHS hospitals or GPs in this regard.

The media (40%) and Government (39%), followed by pro-life organisations, are least trusted to give honest and balanced information about human embryo research and its regulation. The HFEA is not trusted to do so by very few: 6%.

*What makes people trust the system?*

As with regulation of fertility treatment, honesty and openness (43%) are the qualities that are most likely to give the public trust in the regulatory system for human embryo research. A transparent system allowing the public to have access to information on the outcomes of decisions and the reasons behind those outcomes instils trust in 42% of the public.

As with fertility treatment, a joint approach between doctors and parliament to formulating regulations about human embryo research is the public's preferred option. Two in three (67%) state their preference for it. One in five (19%) believes doctors should have sole responsibility, while one in twenty (6%) think the role should be solely for Parliament. This confirms once again the low levels of support for politicians being involved in regulation.

## **CONCLUSIONS**

### ***Attitudes to Treatment***

Views on fertility treatment are largely positive – particularly in relation to it representing a major advance in science. Although a majority of people believe it is a routine medical treatment, around half of the public still feel that fertility treatment has unknown consequences.

We believe that these public views show the importance of building and maintaining a consensus between wider society and the doctors and scientists involved in delivering treatment. Although people accept that fertility treatment is something that doctors routinely offer, the public acceptance of this activity is not unconditional and the public are not unreflective about the consequences and risks.

Many people still have concerns about the long-term consequences of providing fertility treatment and views suggest that a sufficiently trusted and balanced system of regulation is important in underpinning public confidence to permit ongoing use of these techniques. This shows that consensus should not be taken for granted and continued trusted regulation is needed to maintain consensus and confidence in these activities.

### ***Attitudes to Research***

Human embryo research receives a more mixed reception than fertility treatment. While a large majority feels research enables scientists to increase their understanding of how the body works and believes it will improve the quality of life of future generations with inherited diseases, a substantial majority of people (seven in ten) feels that embryo research has unknown consequences (this is far more than for fertility treatment alone).

Many more people feel that human embryo research poses risks to future generations than say it does not, and one in three (compared to one in five for fertility treatment) believe human embryo research is tampering with nature and therefore unethical.

### ***Lessons for Regulators and Regulation***

The fact that approximately half of people believe IVF is a mainstream medical treatment, yet half of people believe that IVF treatment carried unforeseen consequences demonstrates the potential fragility of the public acceptance of these activities.

Earlier studies into genomic science and GM foods show that public opinion can be fluid and volatile – so the balance can be rapidly shifted, and may not easily be recovered. This was the experience of the Italian fertility sector where the public

became very concerned following claims of controversial practices made by a certain Italian fertility doctor. The church was particularly unhappy with this situation and this helped influence further public opposition. This public concern prompted politicians to introduce restrictive new fertility laws, which could not be overturned by the recent referendum. So a breakdown in the consensus between society (influenced by the church), doctors and scientists has led to significant and permanent change.

The research also shows that the public has greater trust in publicly-funded doctors and scientists than government, or other scientists or doctors. If this is replicated in other EU countries this may have implications for the pattern and nature of regulation across Europe as the northern European states, such as Denmark and Finland, tend to have a majority of treatment funded by the state, while in southern European countries, such as Italy and Spain the majority of treatment is funded privately.

Care was taken in the design of the survey to avoid slanting peoples' opinions in favour of independent regulation or the HFEA. This is why, in particular, the questions were phrased to look at which professions, specialities and interest groups should be included within the regulatory framework. The HFEA is generally very positively regarded. However, of course it is quite possible that some of this public regard was a response to the words in the name: 'Human', 'Fertilisation' and 'Embryology' 'Authority', rather than displaying any detailed awareness of the HFEA. Nevertheless, the UK regulator is trusted - in both the areas of fertility treatment and human embryo research - to be involved in decisions and in discussions about regulation, and in the provision of honest and balanced information.

## Recommendations for the Future

- A consensus between public, doctors and scientists is essential to maintain public confidence in fertility treatment and embryo research which allows treatment and research to continue and progress. This research shows that the public view of the sector is finely balanced and potentially fragile, even in the UK where the regulatory system is well established. **Openness, honesty and a consensual approach** to bring together doctors and public representatives are the key elements to maintaining confidence in a regulatory system.
- There is a public demand for authoritative and trustworthy information in these controversial sectors. The public will accept information from an independent regulator to be more trustworthy than other sources.
- Public opinion on fertility treatment and embryo research – as with other genomic science – is fluid and volatile. It is important for regulators to assess and evaluate public opinion on an ongoing basis if they are to keep

track of changes in relation to ongoing scientific development and maintain confidence in the operation of the sector.

- The high level of concern about the long term consequences of treatment and how treatment is carried out will be particularly strongly felt by patients who are currently undergoing treatment. It is important that regulators engage with patients and their particular view as these people are likely to have a different perception to the population as a whole. As two-thirds of people know someone who is, or has, undergone fertility treatment then patients may be particularly important in shaping wider public opinion.