



Fertility • Genomics • Clarity

# Fertility, Genomics and Embryo Research: Public Attitudes and Understanding

June 2022

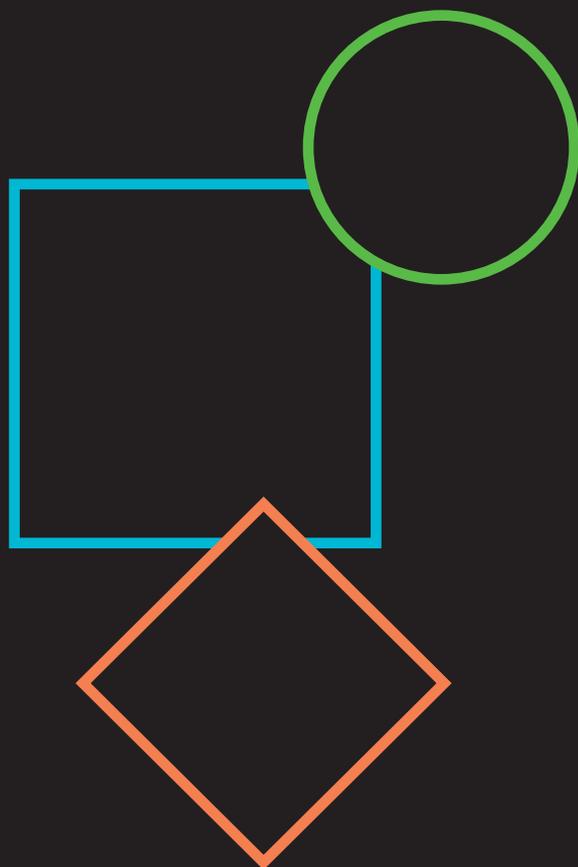


Commissioned by PET  
as part of its  
30th Birthday Programme

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# Thirty years of Progress



**1992:** PET Trustees hold their first meeting in the Houses of Parliament

**1996:** The first PET publication, *The Progress Guide to Genetics*, is published and distributed to every General Practice in England

**1999:** PET launches its flagship publication BioNews, an online news and comment digest that is still being published by PET today

**2003:** The UK Government's Genetics White Paper acknowledges '*the valuable work*' of PET and BioNews

**2006:** PET collaborates with the BBC on the series *A Child Against All Odds*, presented by Professor Lord Robert Winston

**2008:** PET is instrumental in changes to fertility and embryo research law, including improved access to fertility treatment for single women and people in same-sex relationships

**2014:** PET begins holding public events in partnership with Genomics England, discussing the 100,000 Genomes Project

**2015:** PET is instrumental in changing the law to permit the use of mitochondrial donation in treatment, and the Government's Chief Scientific Adviser is the keynote speaker at the PET Annual Conference

**2016:** PET begins holding public events in Scotland, in partnership with the Scottish Government

**2019:** PET publishes the 1,000th weekly edition of BioNews

**2020:** PET is cited in a Parliamentary debate about genome editing – including by a Government Minister, who says '*we have committed to engaging world-class academics and expert groups such as the Progress Educational Trust*' – and gives a presentation on genome editing to the World Health Organisation

**2021:** PET chairs a meeting of the All-Party Parliamentary Group on Surrogacy with contributions from a Government Minister, an MP and a Law Commissioner, as well as surrogates and intended parents

**2022:** As a result of the successful PET #ExtendTheLimit campaign, the law is changed to extend maximum storage periods for patients' eggs, sperm and embryos from 10 years to 55 years

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## A clear roadmap

**FERRING**

**PHARMACEUTICALS**

For any individual, 30 years is a defining milestone and, to be fair, it is no different for organisations. I take great pleasure today in extending my warmest congratulations to the Progress Educational Trust (PET) for their three decades of relentless campaigning and outstanding advocacy successes, which helped in profoundly reshaping the mindsets of British policymakers and society on the important issues of fertility, genomics and embryo research.

Since the 1970s and up to this day, the United Kingdom has led the way amongst the world's nations in building a political, legislative and regulatory environment supportive of major advances in life sciences, which in turn have offered individuals new chances to overcome infertility and build families, enabled breakthrough research into understanding and harnessing the power of the genome, and extended the confines of society's understanding and acceptance of embryo research to improve human health. This is an important legacy, albeit one that must be actively and ambitiously continued. The journey is not over, and complacency is not an option.

As a leader in reproductive medicine and maternal health with a history spanning well over 70 years, Ferring could not possibly be more delighted and proud to support this important initiative by PET. This report and the survey that underpinned it give us a fascinating snapshot of the thoughts of the British public – their acquired certainties, their lingering hesitations and, sometimes still, their remaining misconceptions.

The findings you will discover offer a telling indicator of the need for further education and information, but also for deeper societal debate. They also chart out a clear roadmap of what PET, together with all partners from the research community, academia and the private sector, needs to do next.

Assisted conception, and helping people build families of all shapes and sizes, is a central part of who we are and what we do at Ferring. In that respect, it is comforting to observe that a broad majority of respondents are supportive of fertility treatment being more comprehensively offered on the NHS to people



suffering from infertility and wishing to conceive, and are also increasingly in favour of extending that support to non-traditional families and single people.

This is an important wake-up call to all of us – and to British policymakers in particular – at a critical moment in time, when the NICE Clinical Guideline on the assessment and treatment of fertility problems is being reopened for review, and when HM Government is about to publish a long-awaited Women's Health Strategy for England which defines fertility, pregnancy, pregnancy loss and postnatal support as one of its priority areas. Both of those developments represent a unique opportunity to get things right.

I hope that this report and its important findings will inspire and mobilise us all to go even further in the next 30 years, to continue translating scientific research into greater medical, healthcare and societal benefits for all British people. PET will undoubtedly remain a central partner and guiding light in that journey.

To many more years!

A handwritten signature in blue ink that reads 'Julia Hoover'. The signature is fluid and cursive, with a large loop at the end of the first name.

Julia Hoover

**General Manager, UK and Ireland, Ferring**

# Thirty years and counting ...

PET turns 30 this year, but our story goes back further than that – at least as far back as the birth in 1978 of Louise Brown, the world’s first IVF baby. The impact of that event on science, medicine, law and policy is still being felt today, and we are delighted that Louise is among those who have contributed their voices to this report (see p9).

Our precursor organisation, the Progress Campaign for Research into Human Reproduction, was formed in 1985 to campaign against proposed legislation that would have banned IVF and embryo research in the UK.

Thankfully, the original Progress campaign was successful and the proposed legislation was defeated. Different legislation was passed instead – the Human Fertilisation and Embryology (HFE) Act, which permits fertility treatment and embryo research within a carefully regulated environment.

PET was founded as a charity – the Progress Educational Trust – in 1992. For the past 30 years, our charity’s work has informed public, patient, professional and policy debate about fertility, genomics and embryo research.

Now, in 2022, we stand on the threshold of key changes in all of these areas. The UK Government has signalled that the HFE Act is likely to be revised in the near future. A separate law that deals specifically with surrogacy is also being revised, with a draft surrogacy Bill due to be published later this year.

As for genetics and genomics, the UK now has an NHS Genomic Medicine Service. Next year, an NHS-embedded pilot will begin recruiting families, to explore whether whole genome sequencing might be offered routinely for all newborn babies.

Then there is the new frontier of genome editing, which opens up vast new possibilities while also bringing accompanying challenges.

For these reasons, and with the generous support of Ferring, we decided that now was the perfect time to commission a piece of wide-ranging,



nationally representative research – to take the measure of public opinion and understanding of these issues.

This report’s findings will guide our next 30 years of work, improving choices for people affected by infertility and genetic conditions.



Sarah Norcross

**Director, PET**



# Executive summary

**Ipsos carried out a nationally representative online survey of 2,233 UK adults on behalf of PET. The fieldwork was conducted over 24-27 March 2022. Full survey details can be found on p43.**

Two-thirds of respondents supported the provision of NHS-funded fertility treatment to people who are infertile and wish to conceive. This is a strong message to Government and commissioning bodies, when one considers that NHS-funded IVF provision has long been inconsistent in the UK.

A strikingly low proportion (just over a quarter) of respondents was aware that surrogacy is legal throughout the UK, despite the fact that surrogacy has been regulated and permitted by UK law for almost 40 years.

There are likely to be substantial changes to surrogacy law in the near future, with a new Bill currently being drafted by the Law Commissions of England, Wales and Scotland. There is an opportunity here to improve public awareness and understanding of this route to having children.

The posthumous use of a person's sperm or eggs to conceive a child can be contentious, but a majority of those whom we surveyed thought that this should be permissible in instances where the deceased was the husband/wife/partner of the person wishing to conceive, or where the deceased was a family member of the person wishing to conceive.

Recent years have seen a number of cases come before the High Court where a bereaved person has struggled to obtain the necessary permission for fertility treatment. If a way could be found to resolve such situations more easily, our findings suggest that this would find public support.

Fewer than 6 in 10 respondents were able to choose a scientifically correct definition of the term 'genome', and only around a tenth of respondents were able to choose a scientifically correct definition of the term 'embryo' (when shown varying timeframes and asked to select how long the term 'embryo' is applicable for).

This is concerning, at a time when genomic and reproductive technologies are playing an increasingly prominent role in people's lives, and when laws and policies governing these areas are under review.

That said, when asked about specific developments in medicine and research, survey participants were generally supportive. In particular, more than half supported the storage of individuals' genetic data in

a national database (separate to medical records), to be used in NHS care *or* to be used by medical researchers.

Furthermore, a majority of respondents supported the use of whole genome sequencing to screen newborn babies, for a larger number of rare conditions than is screened for using current methods. Genomics England is currently investigating this approach with its Newborn Genomes Programme research pilot, and our findings indicate that the public may be receptive to this work.

When it comes to embryo research, more respondents supported than opposed the use of human embryos in scientific and medical research to help understand, and develop treatments for, congenital disease. Additionally, more people supported than opposed the funding of such research by the UK Government.

However, around a quarter of respondents selected '*Neither support nor oppose*' when asked about these matters. This suggests that more public discussion and debate could be valuable.

Asked whether the 14-day limit on human embryo research is too long, too short or about right, more than half of those who supported (or neither opposed nor supported) the use of laboratory-created human embryos in research responded that the limit was about right. However, those survey participants who were not implacably opposed to embryo research were willing to countenance an extension to the '*14-day rule*', if reasons for the extension were presented to them.

This demonstrates the importance of scientists giving a clear explanation, of the benefits that such an extension to the 14-day rule may bring.

# PET future strategies

PET will use the results of this survey to inform its strategies in coming years.

- Through BioNews and other outlets, PET will help people to understand key scientific terms and concepts – such as '*genome*' and '*embryo*' – so as to facilitate greater engagement.
- PET will collaborate with other organisations to fill knowledge gaps and build greater understanding, so that people are better placed to form their own opinions and arrive at their own decisions.
- PET will share the findings of this survey with policymakers, so that policy takes account of patient opinion and broader public opinion, and keeps pace with change.
- The results of this survey indicate public openness to scientific advances in the challenging areas of genome editing and embryo research. PET will provide a forum for meaningful public debate.

Section 1

# Assisted Conception



## 1.1 Should the NHS offer fertility treatment for people who are infertile and wish to conceive?

Survey participants were introduced to fertility treatment as 'medical intervention to help people conceive'.

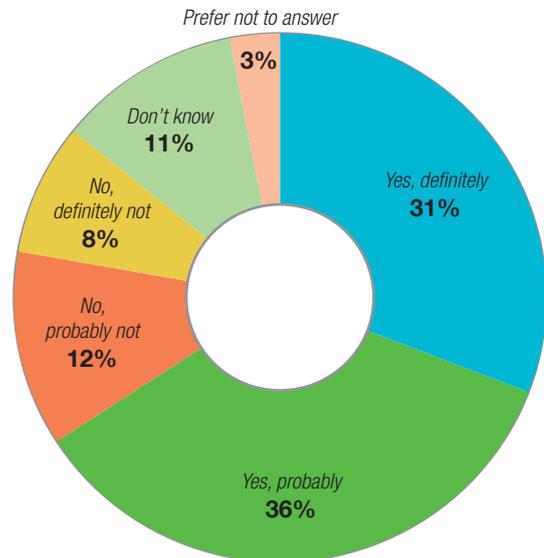
Respondents showed strong support for the NHS offering fertility treatment for people who are infertile and wish to conceive, with two-thirds (67%) saying that this treatment should be offered (31% saying 'Yes, definitely' and 36% saying 'Yes, probably').

Although both male and female respondents were supportive, there was a higher level of 'Yes, definitely' responses from female respondents compared with male respondents (35% female vs 28% male) and a bias towards female support (ie, those saying 'Yes, definitely' or 'Yes, probably') overall (70% female vs 65% male).

A higher proportion of respondents aged 44 and under said the NHS should offer treatment, compared with those aged 45 and over.

Respondents who supported the use of laboratory-created human embryos in research (see p34) were more likely to say 'Yes' (either 'definitely' or 'probably') to this question than those who opposed this.

Furthermore, those who supported Government funding of research that uses human embryos (see p35) were also more likely to say 'Yes' (either 'definitely' or 'probably') to this question.



Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

### PET says:

The UK is the country where IVF was pioneered, and we celebrate the fact that 67% of respondents in our UK survey support the availability of fertility treatment on the NHS.

But it is still a terrible indictment that in the birthplace of this life-changing treatment, IVF cannot be easily accessed by all who need it. Too many people still fall victim to the postcode lottery.

The NICE Guideline on fertility is clear. If you are a woman aged under 40, and you or your partner have infertility, then you should be offered three full cycles of IVF.

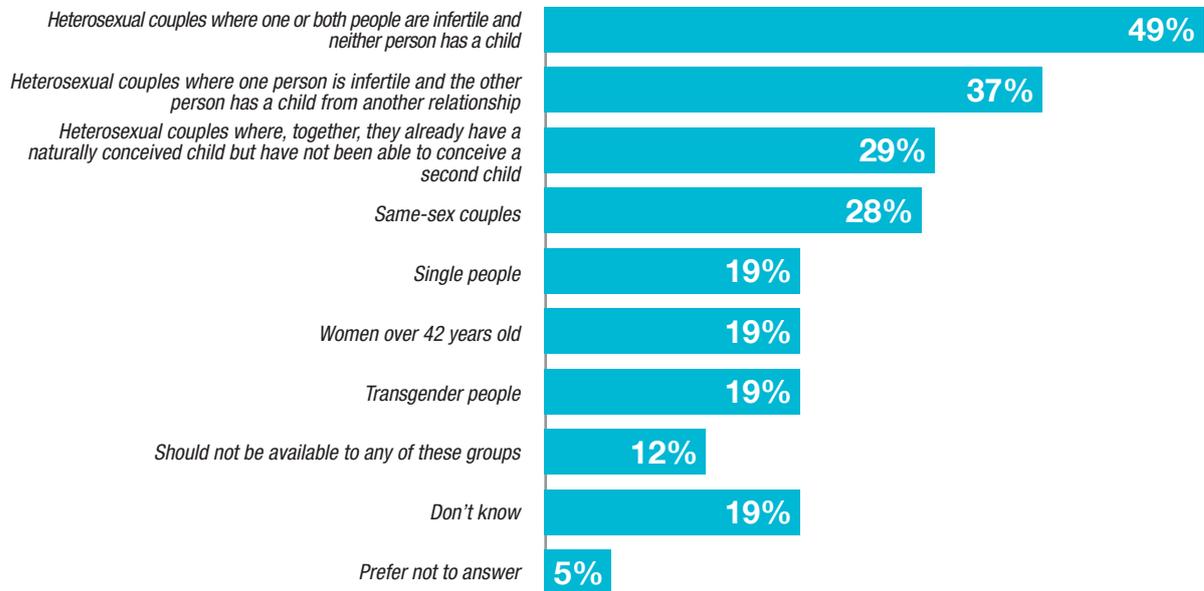
Too often in the UK, this is not what happens. Matters are made worse by a lack of clarity regarding what constitutes a full cycle.



'It is time to end the postcode lottery for fertility treatment. For people who don't have much money and desperately want a child, being told "We won't fund your IVF treatment" must be devastating.'

**Louise Brown**  
World's first IVF baby

## 1.2 Which, if any, of the following groups do you think IVF\* should be freely available to on the NHS? (Please select all that apply.)



Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

This question investigated attitudes towards different groups within our population.

The highest support (49%) was for childless heterosexual couples, with a female bias (54% female vs 44% male). In the survey, this group was also slightly better supported by respondents from the older age bands compared with the younger ones (16-34 years old).

The support for single people, women over 42 years old and transgender people receiving IVF on the NHS was lower, with greater support from female respondents, respondents from younger age bands and also single respondents.

\* The NHS describes IVF (in vitro fertilisation) as follows: ‘...one of several techniques available to help people with fertility problems have a baby. During IVF, an egg is removed from the woman’s ovaries and fertilised with sperm in a laboratory. The fertilised egg, called an embryo, is then returned to the woman’s womb to grow and develop.’

### PET says:

Although there was greatest support for childless heterosexual couples, it is also refreshing to see support for non-traditional families and single people.

PET is delighted to see some acceptance of diverse types of family, but recognises that there is a long way to go.



‘It’s disappointing that, despite gender discrimination being illegal in the UK, attitudes to family structures remain traditional. The better news, though, is that most people seem to

have no objection to IVF – a major change from 40 years ago. IVF is now a routine procedure, so why doesn’t the NHS give everyone a chance?’

**Professor Alison Murdoch**  
President of the British Fertility Society

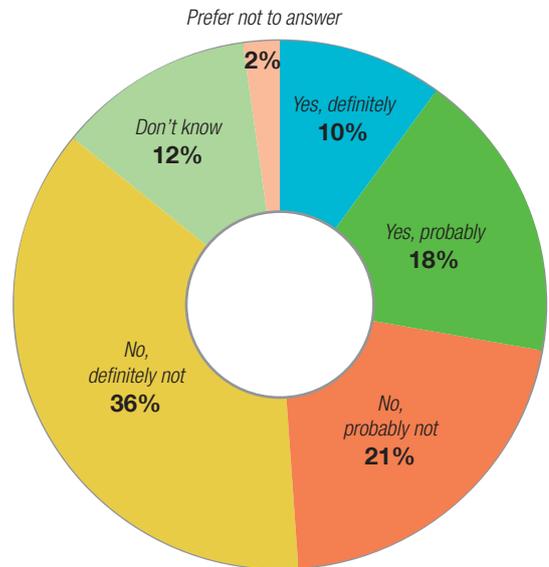
### 1.3 Should people undergoing private (ie, not paid for by the NHS) fertility treatment in the UK be able to choose the biological sex of their child based on their personal preference?

The majority of those surveyed said 'No' (either 'definitely not' – 36%, or 'probably not' – 21%) when asked this, with older respondents and female respondents more likely to do so. Overall, 57% gave a 'No' response, with 12% saying 'Don't know'.

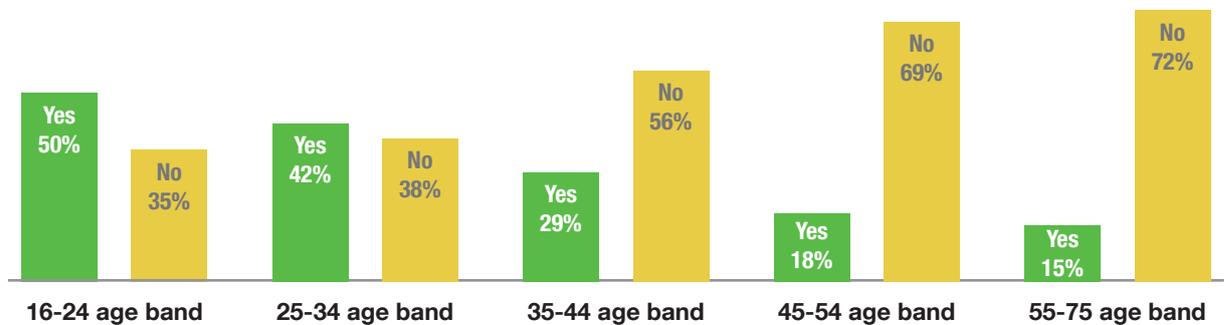
There was a statistically significant divide on this question, with 64% of female respondents saying 'No' (41% 'definitely not', 22% 'probably not') compared with 50% of male respondents (19% 'probably not', 32% 'definitely not').

Although both male respondents and female respondents were more likely to say 'No' to this question than 'Yes', the male group was more likely to say 'Yes' (33% male vs 23% female).

There was also a statistically significant generational divide, with younger age bands more likely to support people being able to choose the biological sex of their child.



Base: n=2233 UK Adults aged 16-75 of whom: 16-24 = 344, 25-34 = 392, 35-44 = 399, 45-54 = 432, 55-75 = 666, online fieldwork conducted: 24-27 March 2022.



#### PET says:

At present, in the UK, it is not permitted to choose the sex of a child for non-medical reasons. Our research indicates that the public does not want to change this arrangement.

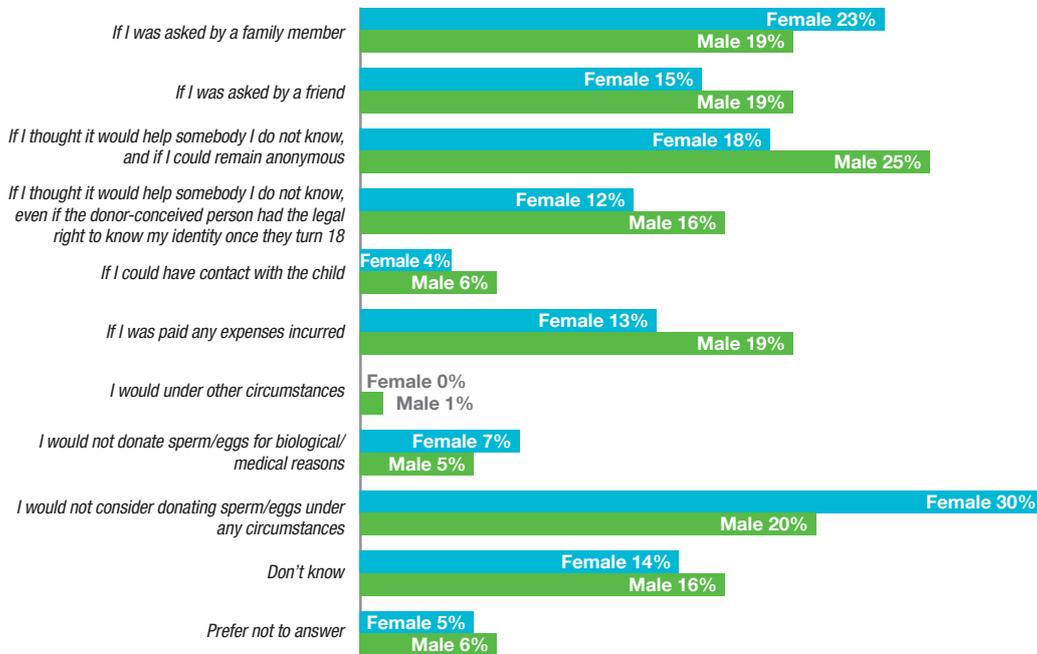
However, given such a marked generational divide, the situation may change in future. It is important that we consider the implications.



'Procreative autonomy is important. Parents should be free to make their own decisions about their family (within limits). There are no good ethical reasons to oppose sex selection for "family balancing" – having a mixture of sexes in the family. This would allow sex selection for the second or third child.'

**Professor Julian Savulescu**  
Director of the Oxford Uehiro Centre for Practical Ethics

## 1.4 Under which, if any, of the following circumstances would you personally consider donating sperm or eggs to help others have children? (Please select all that apply.)



Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

Male respondents were more likely to consider donating their gametes than female respondents, with 53% of male respondents (compared with 45% of female respondents) saying they would donate in one or more circumstances.

There was no significant difference between male and female respondents when considering donating to a family member, but male respondents were more likely than female respondents to say they would donate anonymously to someone whom they

did not know, or to a friend. The responses from male and female respondents alike showed a drop in willingness to donate if they were identifiable.

Male respondents were more likely to be influenced by the payment of expenses. This was also seen in the younger age groups, with respondents in the 16-24 and the 25-34 age bands more likely to choose 'If I was paid any expenses incurred' (compared with older respondents) as a circumstance under which they would consider donating.

### PET says:

Only 25% of the respondents would *not* consider donating sperm or eggs under any circumstances. Some people would be more willing to donate if anonymity was an option.

It is heartening to see that so many would be open to the idea of becoming a sperm or egg donor, if this could help family or friends who were facing fertility issues.

However, we must ask why it is the case – if so many people in the UK are willing to consider donating – that a large proportion of UK fertility treatments use sperm imported from overseas.



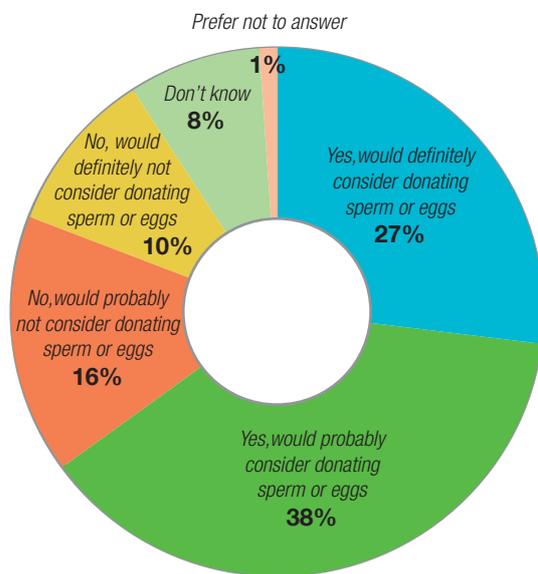
'This seems to show that there is a significant proportion of people for whom the sense of helping – whether family, friend or stranger – would motivate them to donate. Financial incentive, even just covering expenses, doesn't seem to be the factor that makes a difference.'

**Nina Barnsley**  
Director of the Donor Conception Network

## 1.5 In the UK, donor-conceived children are legally entitled to find out the identity of their donor(s) upon reaching the age of 18.

You said that you would personally consider donating sperm or eggs to help others have children.

Knowing that, in the UK, donor-conceived children are legally entitled to find out the identity of their donor(s) upon reaching the age of 18, would you still consider donating sperm or eggs to help others have children?



Base: n=1083 UK Adults aged 16-75, who would consider donating their sperm or eggs under one or more circumstances, online fieldwork conducted: 24-27 March 2022.

This question was asked only to those who were prepared to consider donating their sperm or eggs in one or more circumstances (see p12). This was 49% of the original sample of respondents.

The loss of anonymity resulted in 26% of those who had previously considered donating sperm or eggs saying they would not (either 'definitely not' – 10%, or 'probably not' – 16%) consider donating sperm or eggs. The gender differences reported on p12 were not observed here.

Overall, 64% of those who were asked this question would consider donating, knowing that donor-conceived children are legally entitled to find out the identity of their donor(s) upon reaching the age of 18 (27% said 'definitely', 39% said 'probably').

### PET says:

The question of whether, when and how donors should become identifiable can be complex and contentious. The option of using donors from overseas (where the rules might be different), and the advent of direct-to-consumer genetic testing (which can be used to identify donors), have only made the matter more complex.

It is good to allow for a diversity of donor conception arrangements, rather than imposing one model upon everyone.



'It's interesting to see the extent to which not allowing donors to retain their anonymity reduces willingness to donate. This isn't a problem if there's a plentiful supply

of donors but, in situations of shortage, there could be circumstances in which we face an ethically difficult choice between allowing anonymous donation and restricting the number of people born through donor conception.'

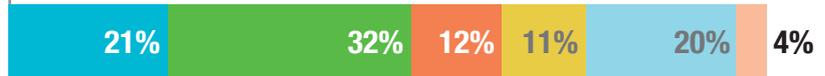
**Professor Stephen Wilkinson**  
Professor of Bioethics at Lancaster University

## 1.6 If a person has passed away, should it be permissible for their stored sperm or eggs to be used for conceiving in each of the following circumstances?

If the deceased was not known to the person wishing to conceive (eg, in a sperm or egg bank, etc), but the deceased gave explicit consent for their stored sperm or eggs to be used in this way



If the deceased was a family member of the person wishing to conceive, and there is evidence that the deceased intended for their stored sperm or eggs to be used in this way



If the deceased was the husband/wife/partner of the person wishing to conceive, and there is evidence that the deceased intended for their stored sperm or eggs to be used in this way



■ Yes, should definitely still be used for conceiving

■ No, should definitely not still be used for conceiving

■ Yes, should probably still be used for conceiving

■ Don't know

■ No, should probably not still be used for conceiving

■ Prefer not to answer

Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

60% of respondents said 'Yes' to the use of sperm or eggs donated by a deceased person for conception by a partner. This was significantly higher than for use to conceive by a family member, or by someone unknown to the deceased.

However, there was a degree of uncertainty with all scenarios. The proportion of 'Don't know' ranged

from 17% if the deceased was the partner of the person wishing to conceive, to 21% for use by a person unknown to the donor.

Broadly, the responses did not vary significantly with respect to gender, age or region.

### PET says:

Perhaps unsurprisingly, support for posthumous conception was strongest when the person wishing to conceive was the husband, wife or partner of the deceased.

However, it is interesting to note that respondents were not implacably opposed to the idea of posthumous sperm or egg donation, where the intended parent(s) had no connection to the deceased donor.



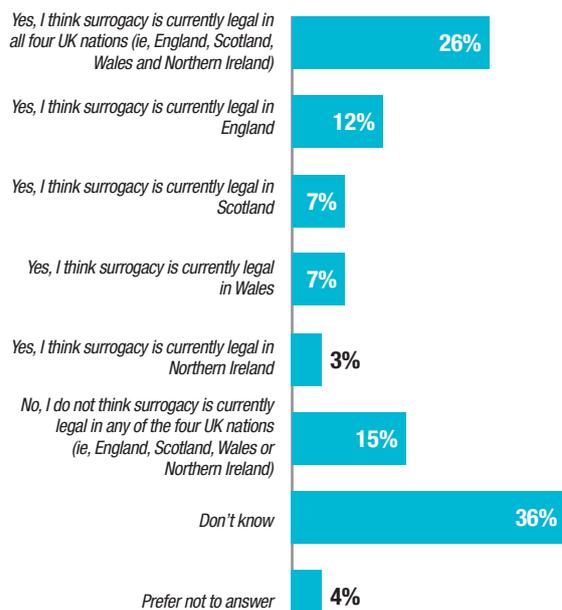
'There have been a series of cases where significant distress has been caused to the surviving partner of a deceased patient, as a result of an overly bureaucratic

approach to the posthumous use of gametes and embryos. In all of these cases, it has been clear what the patient wanted, and these wishes should not be overlooked merely because of a missing tick in a box.'

**James Lawford Davies**  
Solicitor and Partner at Hill Dickinson

## 1.7 Surrogacy is when a woman carries a baby for those who are unable to conceive or carry a child themselves for medical or physical reasons.\*

Do you think that surrogacy is currently legal? That is, where the surrogate is a UK national and living in the UK?  
(Please select all that apply.)



Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

26% of respondents correctly identified that surrogacy is legal throughout the UK.

15% of respondents thought that surrogacy is not legal in any part of the UK. This was higher for female respondents compared with male respondents (17% vs 13%).

The proportion of respondents who said they did not know the legal status of surrogacy was high, at 36%.

\* The intended parent(s) is a person or persons who become the parent(s) of a child born through surrogacy. The surrogate is a woman who helps the intended parent(s) by carrying children for them. A surrogate may or may not have a genetic relationship to the child that she carries (ie, the egg which is fertilised for the pregnancy either comes from the surrogate, an intended parent, or an egg donor who is not the surrogate or intended parent).

### PET says:

It is surprising that so many people were uncertain of the answer to this question, given that surrogacy has been regulated and permitted by UK law since 1985, and has recently been a theme in popular soap operas.

It is also the case that the number of parental orders made following surrogacy has increased significantly in the UK in recent years, and this may not fully reflect the actual number of people using surrogacy arrangements (which may be greater still).

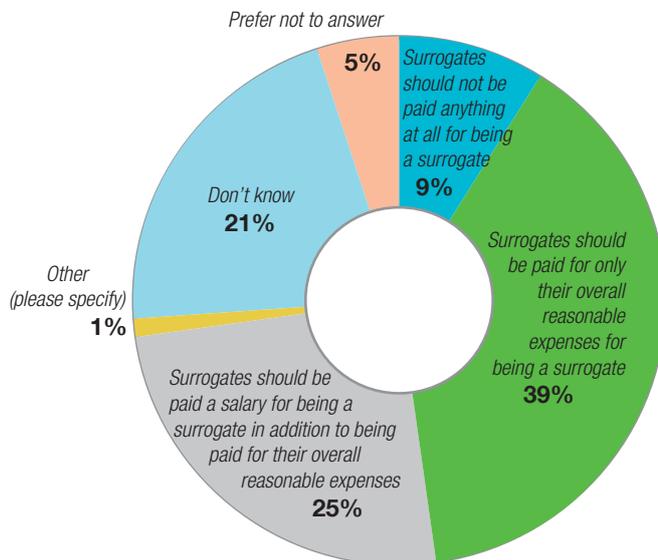
There is a need for greater awareness of, and clarity in, the law concerning surrogacy.



'We are grateful for PET's support for our work reforming the law of surrogacy, and welcome this addition to the knowledge base around surrogacy.'

**Professor Nick Hopkins**  
Law Commissioner responsible for Surrogacy  
at the Law Commission of England and Wales

## 1.8 Thinking about surrogacy, which one of the following statements do you agree with?



Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

The most commonly held view was that reasonable expenses should be paid to surrogates, with significantly more female than male respondents choosing this answer (43% vs 36%).

Only 9% of respondents believed a surrogate should not be paid at all. This view was more common in male compared with female respondents (11% vs 7%).

A quarter of respondents believed that a surrogate should receive a salary in addition to reasonable expenses.

A significant number of respondents had not formed an opinion, with 21% responding 'Don't know'.

### PET says:

The payment of reasonable expenses was the most popular option. Such payment is currently permitted by UK law.

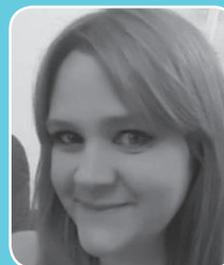
Given that a quarter of respondents thought a surrogate should be paid a salary, and around a fifth answered 'Don't know', it will be interesting to see what the Law Commissions of England, Wales and Scotland propose in relation to paying surrogates.

The Law Commissions' draft Bill updating surrogacy law is due to be published later this year.



'These new findings are consistent with previous research that supports an "expenses" model of surrogacy in the UK. However, the support for additional payment on top, and the fact that so many people "Don't know", shows that there is some ambivalence. This was also reflected in responses to the consultation carried out in 2019 by the Law Commissions of England, Wales and Scotland.'

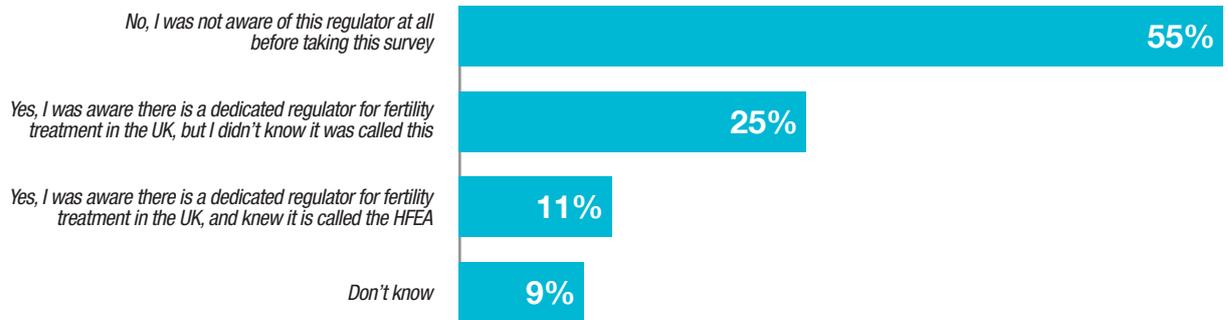
**Dr Kirsty Horsey - Adviser to PET**  
Senior Research Associate at the  
London Women's Clinic



'Surrogacy UK's surrogates overwhelmingly do not wish to be paid a salary for helping someone to have a baby. They wish only to not be out of pocket for their altruistic act. Surrogacy is a relationship between intended parents and surrogates, not a transaction.'

**Sarah Jones**  
Head of Surrogacy at Surrogacy UK

## 1.9 Before taking this survey, were you aware that there is a dedicated regulator for fertility treatment in the UK, called the HFEA (Human Fertilisation and Embryology Authority)?



Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

Over a third (36%) of those surveyed were aware that there is a dedicated regulator for fertility treatment in the UK. This proportion is 47% among the 16-24 year-old respondents.

However, only 11% of all respondents knew specifically that the regulator is called the HFEA.

The majority of respondents (55%) said they were not aware of the HFEA prior to participating in this research, with a further 9% selecting 'Don't know' when asked this question.

### PET says:

The law which defines the HFEA's powers and functions may be reviewed in the near future. While this is being considered by the UK Government, our research provides a useful insight into public awareness of the regulator's work.

There is an opportunity here for the HFEA to do more to explain how it helps those involved in fertility treatment – patients and professionals alike.

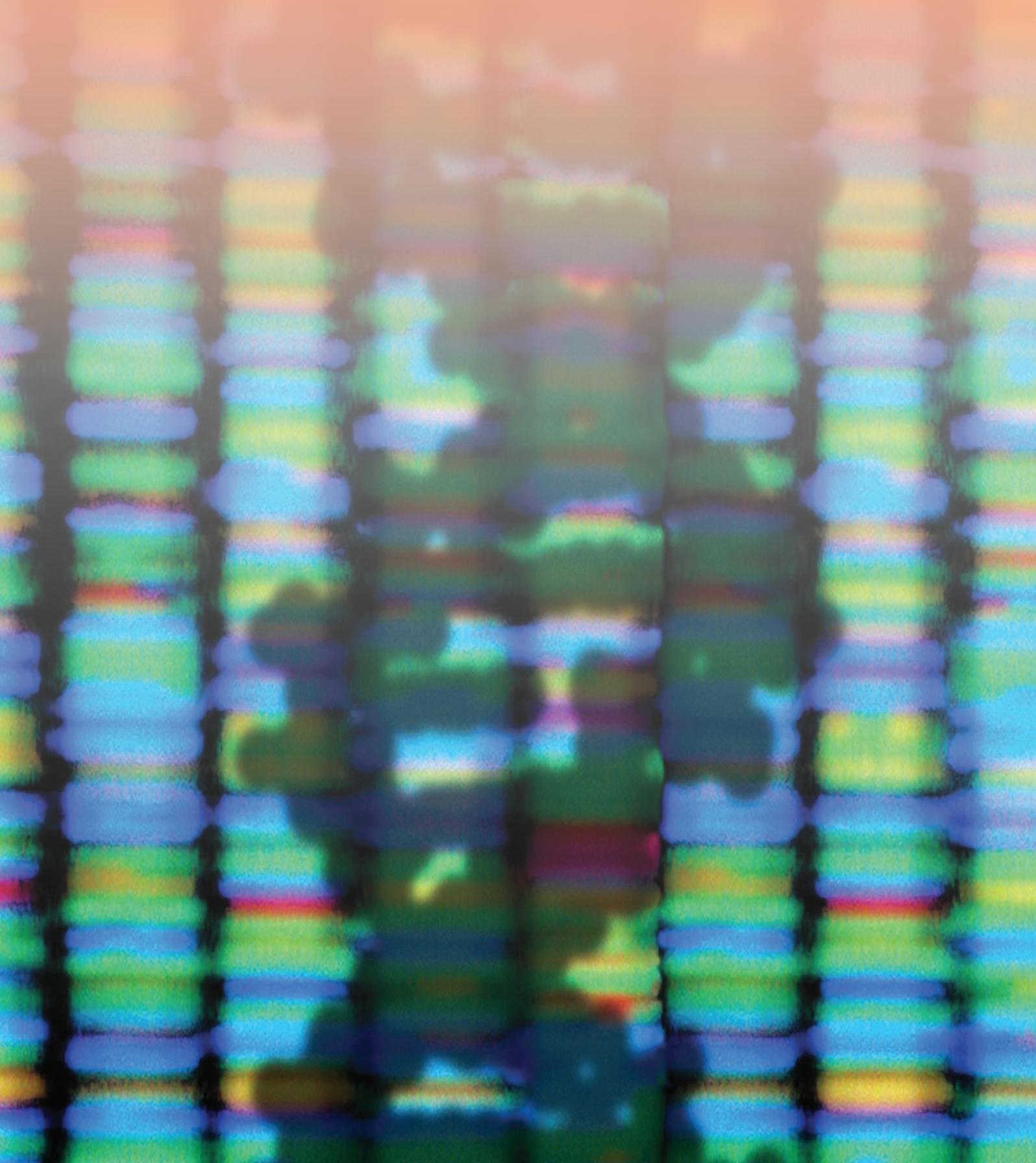


'Most of the public will not be in need of fertility treatment, but we provide assurance to those who do, ensuring fertility clinics across the UK have high standards of treatment and patient care. For those who use fertility treatment to help create their families, the HFEA has a well-deserved reputation for providing evidence-based impartial information to the public, and ensures everyone can be sure that all fertility treatment and embryo research is safe.'

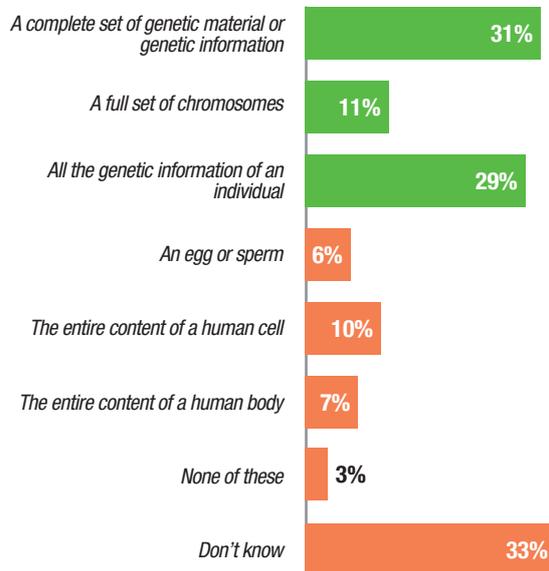
**Julia Chain**  
Chair of the HFEA

Section 2

# Genetics and Genomics



## 2.1 Which, if any, of the following do you think describe the term 'human genome'? (Please select all that apply.)



### Result overview



Correct or partially correct

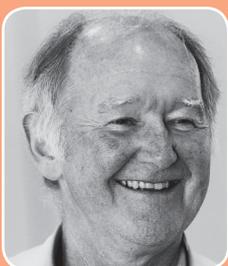
Wrong or 'Don't know'

Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

## PET says:

Genomics is becoming increasingly important in medicine, and the NHS Long Term Plan includes a commitment to *'be the first national health care system to offer whole genome sequencing as part of routine care'*.

We are therefore concerned to see such low levels of understanding of the term *'human genome'*. However, it is encouraging to see that younger respondents are more likely to be informed.



**'What a disappointingly low level of understanding of our own genome. The youngest respondents had slightly more knowledge. In terms of correcting the situation, I think this young group is the one to target, in the hope of some "trickle up" of information to their older family and friends.'**

**Professor Marcus Pembrey - Patron of PET**  
Emeritus Professor of Paediatric Genetics at the UCL/GOSH Institute of Child Health

Levels of understanding were explored by asking respondents to identify the correct definition(s) of the term *'human genome'*. 45% of respondents selected only (one or more) scientifically correct answers, whereas 43% either selected only (one or more) incorrect answers, or selected *'Don't know'*.

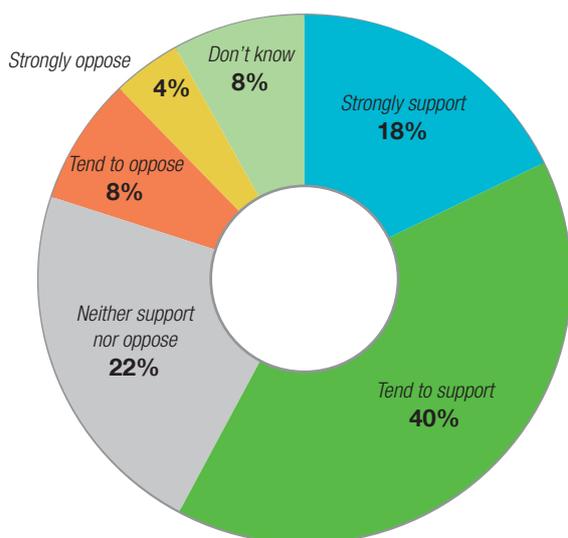
More female than male respondents answered *'Don't know'* (35% of female respondents selected *'Don't know'*, compared with 31% of male respondents). This may indicate levels of comfort with giving a *'Don't know'* response among female respondents, rather than indicating their levels of actual knowledge.

16-24-year-old respondents were more likely to select only correct answers than some of the older age groups. 62% of this age group chose only correct responses from the answer list, compared with 53% of 45-54s and 51% of 55-75s.

Respondents who supported the use of laboratory-created human embryos in research (see p34) were more likely to select only correct answers in response to this question, compared with those who opposed this (67% vs 51%).

Furthermore, those who supported Government funding of research that uses human embryos (see p35) were also more likely to choose only correct options from the list of definitions in response to this question, when compared with those who opposed this (64% vs 54%).

## 2.2 To what extent do you support or oppose an individual's genetic data\* being stored in a national database (separate to medical records) used by the NHS, for access by the individual and healthcare professionals for the individual's direct care?



Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

The use of an individual's genetic data for their direct care is broadly supported, with 57% either strongly supporting or tending to support, and only 12% either strongly opposing or tending to oppose.

Male respondents were significantly more likely to be supportive than female respondents (60% vs 55%). People who were married, or living as married, were more likely to strongly support compared with those who were single (60% vs 50%).

**\* GDPR (General Data Protection Regulation) guidelines describe genetic data as follows: "Genetic data" means personal data relating to the inherited or acquired genetic characteristics of a natural person which give unique information about the physiology or the health of that natural person and which result, in particular, from an analysis of a biological sample from the natural person in question.'**

### PET says:

We are glad to see that people are receptive to the idea of their genetic data being stored, particularly if the data is to be used for their own direct care.

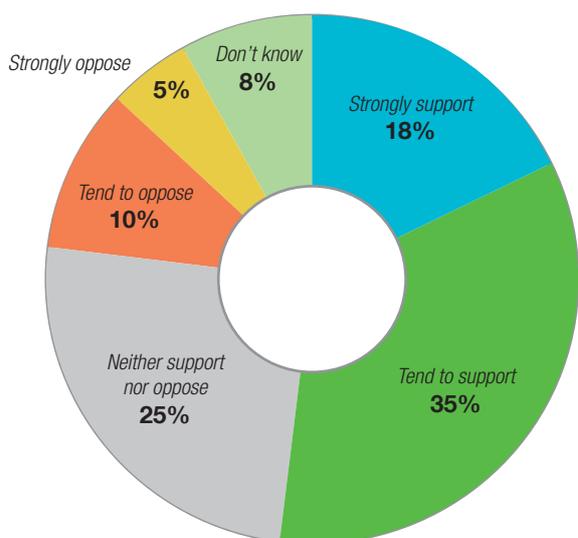
With the advent of the NHS Genomic Medicine Service and related initiatives, stored genetic data is likely to become increasingly important to people's medical treatment.



'Progress in this field is likely to be dependent on the availability of large-scale data. Protections for individuals are important, as is the need to improve healthcare and to prevent and manage illnesses at an early stage.'

**Professor Pali Hungin**  
Head of the Changing Face of Medicine project

## 2.3 To what extent do you support or oppose an individual's genetic data\* being stored in a national database (separate to medical records) used by the NHS, for access by the individual's immediate family (ie, parents, siblings and children) and healthcare professionals tasked with their direct care, where the individual allows their genetic data to be shared?



Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

The storage of an individual's genetic data for access by immediate family is broadly supported, with 52% of respondents either strongly supporting or tending to support, compared with 14% either strongly opposing or tending to oppose.

Male respondents were more likely than female respondents to select 'Strongly support' (22% vs 13%), whereas female respondents were more likely than their male counterparts to select 'Tend to support' (37% vs 32%). Those in the 55-75 age band were more likely to be supportive than those in the 35-44 age band (57% vs 46%).

A quarter of respondents answered 'Neither support nor oppose', with a further 9% answering that they 'Don't know'.

Respondents who supported the use of embryos in research (see p34) were more likely to support the storage of an individual's genetic data for access by immediate family, with 71% either strongly supporting or tending to support, compared with 39% of respondents who opposed the use of embryos in research.

\* GDPR (General Data Protection Regulation) guidelines describe genetic data as follows: "Genetic data" means personal data relating to the inherited or acquired genetic characteristics of a natural person which give unique information about the physiology or the health of that natural person and which result, in particular, from an analysis of a biological sample from the natural person in question.'

### PET says:

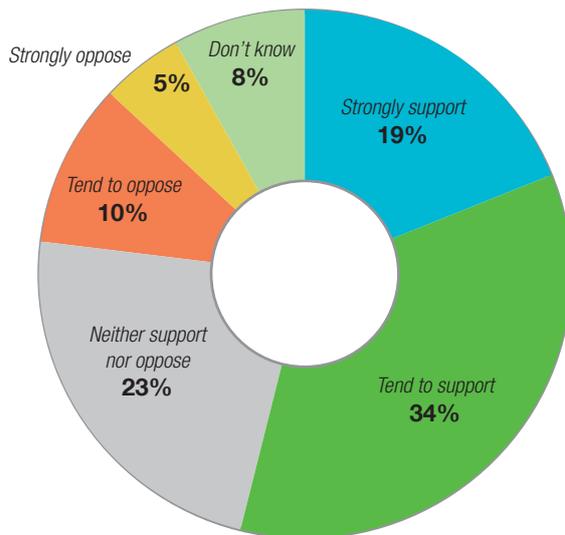
There can be a tension between an individual patient benefiting from the storage of their genetic data, and these scenarios which involve the care of the patient's wider family. It is understandable that some people will have reservations, and there are ethical considerations that need to be handled carefully. Nonetheless, levels of support are still strikingly high.



'I would strongly support a secure, central repository of heritable disease predispositions that could be used to benefit family members, without breaching any clinical confidences.'

**Professor Anneke Lucassen**  
Director of the University of Oxford's  
Centre for Personalised Medicine

## 2.4 To what extent do you support or oppose an individual's genetic data\* being stored in a national database, accessed by medical researchers for research purposes only, where no other identifying data is stored with the genetic data (eg, names, addresses, etc)?



Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

53% of respondents supported the storage of their genetic data for research purposes.

Male and female respondents were equally likely to support (53% vs 54%), with only 15% of respondents choosing 'Strongly oppose' or 'Tend to oppose'.

\* GDPR (General Data Protection Regulation) guidelines describe genetic data as follows: "Genetic data" means personal data relating to the inherited or acquired genetic characteristics of a natural person which give unique information about the physiology or the health of that natural person and which result, in particular, from an analysis of a biological sample from the natural person in question.'

### PET says:

For a number of years, Genomics England and UK BioBank have been doing pioneering work making the deidentified genomic data of large numbers of people available to researchers. This sort of research is already yielding significant benefits.

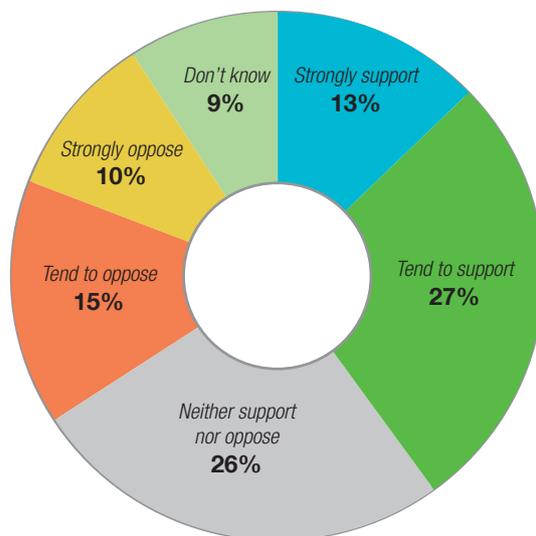
Our survey results suggest that a majority of the public would support this. We hope to see levels of support increase in future.



'Linking healthcare to research enables us to improve care. It's positive to see public support, but we want to engage with communities more, to ensure that those benefits reach everyone.'

**Dr Richard Scott**  
Chief Medical Officer at Genomics England

## 2.5 To what extent do you support or oppose an individual's genetic data\* being stored in a national database for access by Government authorities including the police, where the individual can be identified?



Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

This is the least supported scenario for the storage of genetic data, out of the four that were presented to the respondents in our survey.

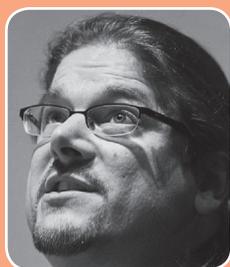
40% of respondents supported the storage of genetic data for access by Government authorities, but 25% of those surveyed opposed this, with a further 26% neither supporting nor opposing and 9% responding that they 'Don't know'.

Male respondents were more likely than their female counterparts to say 'Strongly support' in response to this question (15% vs 10%).

Some regional differences in the degree of support or opposition were seen in the survey results. Those surveyed in the North-West were more likely to support this (47%) than those in the South-West (34%) or Greater London (37%).

Those in Yorkshire and Humberside were more likely to be opposed to this (34%) than those in the North-West (21%), the West Midlands (21%) or the East of England (20%).

**\* GDPR (General Data Protection Regulation) guidelines describe genetic data as follows: "Genetic data" means personal data relating to the inherited or acquired genetic characteristics of a natural person which give unique information about the physiology or the health of that natural person and which result, in particular, from an analysis of a biological sample from the natural person in question.'**



'Opposition to a "universal DNA database" remains significantly higher than opposition to ID cards when those were first announced, and dissent only grew after that. Forensic use of everyone's genetic data, especially if gathered for health purposes, would be catastrophic for public trust.'

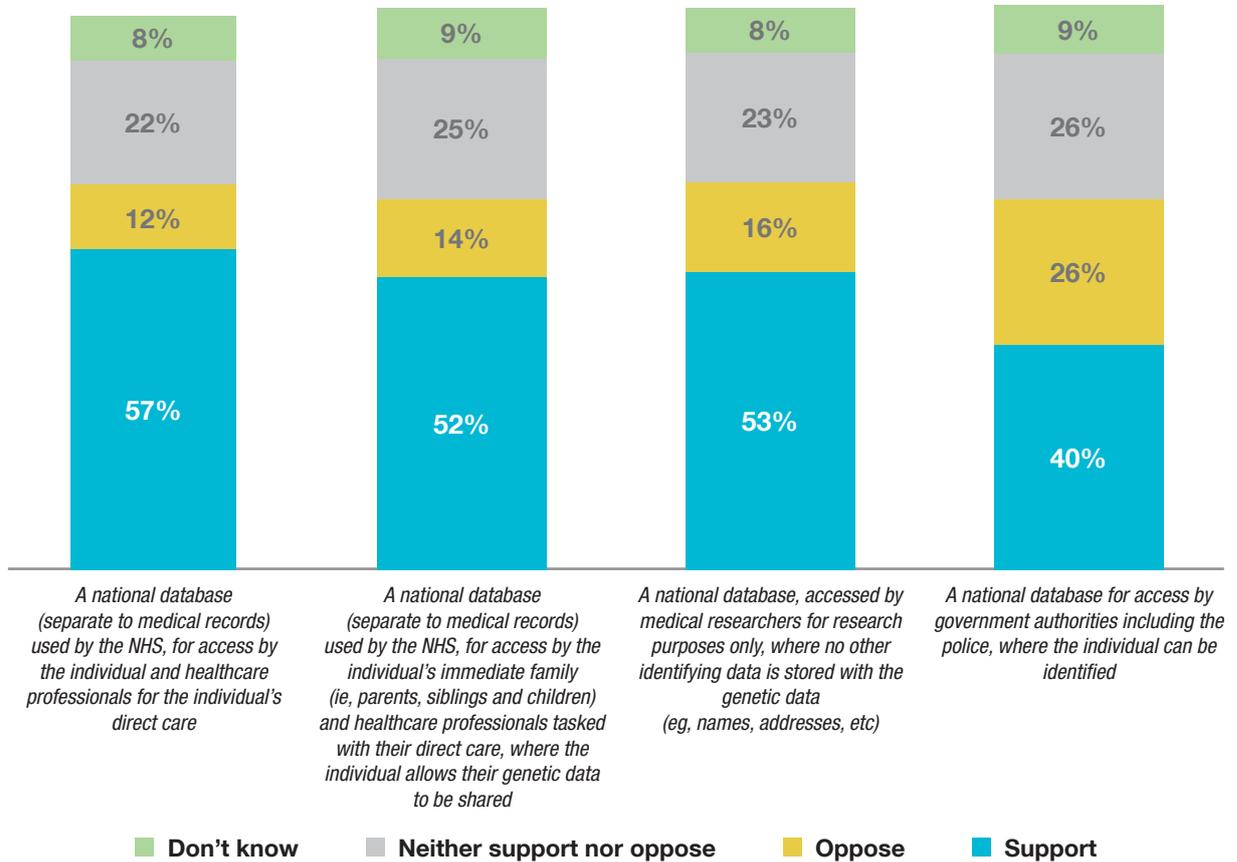
**Phil Booth**  
Coordinator of med Confidential

### PET says:

It is unsurprising that people are circumspect about this sort of access to their stored genetic data.

This highlights the importance of clear rules about who can access such data and why. The public must be reassured that any data collected will only be used for the stated purpose.

## 2.2 - 2.5 Summary of results: To what extent do you support or oppose an individual's genetic data\* being stored in each of the following ways?



Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.



‘This key report from PET demonstrates clear UK public support for the use of genomic data for research. This public trust makes it more likely that our NHS will continue to benefit from the most

advanced genomic medicine, and that patients will see the earliest benefits in their clinical care.’

**Professor Sir Mark Caulfield**  
Chief Executive of Barts Life Sciences

### PET says:

It is encouraging to see that so many people are comfortable with their genetic data being used for the good of others – either family members, or the wider community through research.

It is important that distinctions between different possible uses of genetic data are explained clearly to the public.

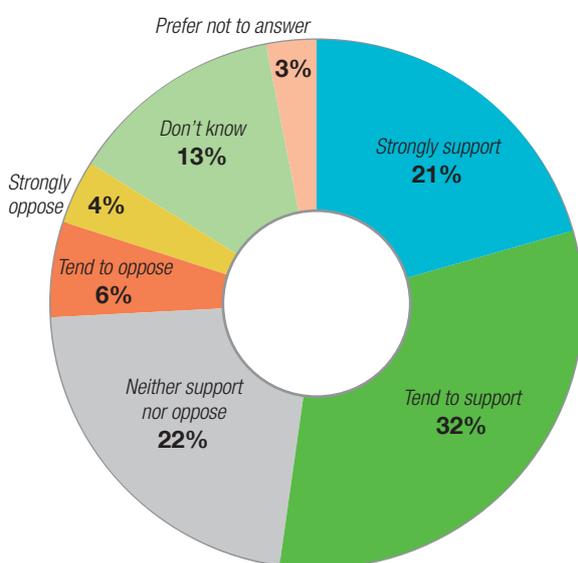
Failure to explain these matters clearly risks a loss of public trust, to the detriment of us all.

\* GDPR (General Data Protection Regulation) guidelines describe genetic data as follows: “Genetic data” means personal data relating to the inherited or acquired genetic characteristics of a natural person which give

unique information about the physiology or the health of that natural person and which result, in particular, from an analysis of a biological sample from the natural person in question.’

**2.6 Currently the NHS offers blood spot screening, also known as the ‘heel prick test’, for all newborn babies. This genetic test screens for the presence of nine different rare health conditions. It is possible to conduct a ‘whole genome test’ for newborn babies that is aimed at screening for a larger number of rare conditions than the nine that the current ‘heel prick test’ screens for. This would also include testing for rare conditions for which there is currently no available treatment.**

**Would you support or oppose the NHS offering this ‘whole genome test’ to all newborn babies in the UK?**



Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

The majority of respondents (53%) supported the idea of whole genome testing at birth, and just 10% were opposed.

Over a fifth of those surveyed neither supported nor opposed this (22%), with a further 13% saying ‘Don’t know’.



‘Having worked with children with rare diseases for over a decade, I am acutely aware there is more the NHS can and should do for the nine babies born every day in the UK with a treatable rare genetic condition. However, the ethical issues are complex, and it’s essential that any newborn sequencing is done with the backing and support of families who might take part. This is why the Newborn Genomes Programme is listening carefully and gathering a wide range of public views to inform its research pilot, which we hope to launch next year.’

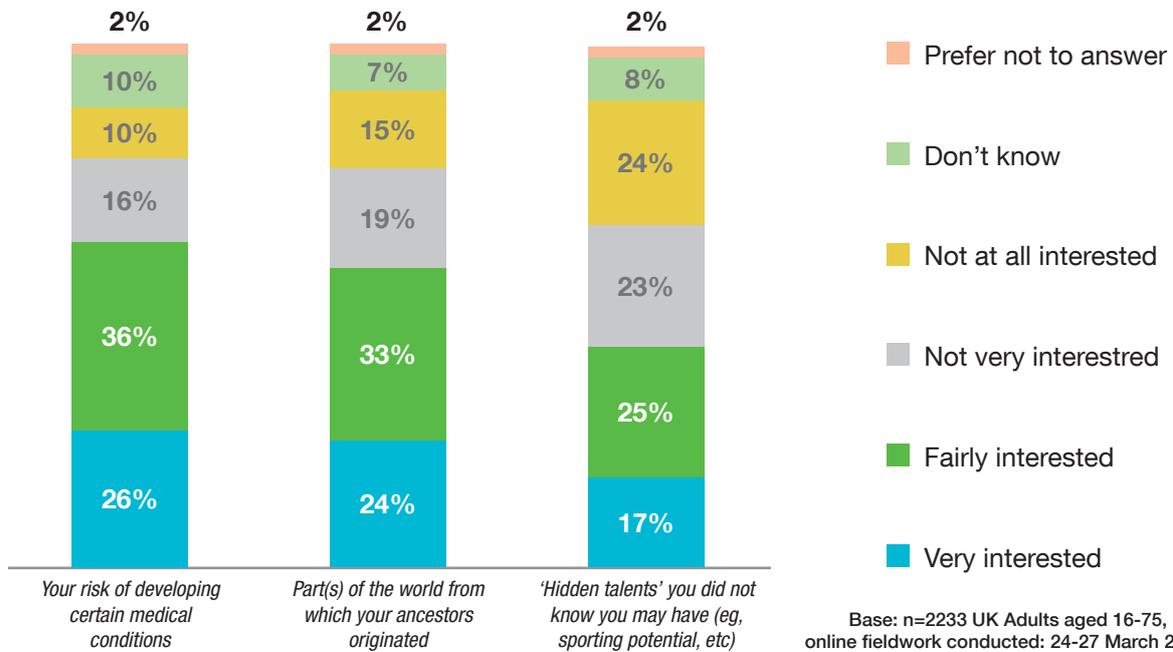
**Sarah-Jane Marsh**  
*Chair of the Newborn Genomes Programme’s NHS Steering Group*  
*Chief Executive of Birmingham Women’s and Children’s NHS Foundation Trust*

**PET says:**

This level of support is particularly encouraging, given the launch of Genomics England’s Newborn Genomes Programme research pilot, and given the lively public debates that PET has been producing with Genomics England to explore the issues involved.

If whole genome testing of newborns is rolled out more widely following the research pilot, then greater awareness and engagement will be vital.

## 2.7 If it was available to you, to what extent would you be personally interested, or not, in taking a genetic test (usually requiring a saliva sample) that the test provider claimed would identify the following?



There were notable levels of interest for all three of the genetic tests described.

A test identifying the risk of developing certain medical conditions was the test out of the three presented which garnered the highest proportions of those 'very' (26%) or 'fairly' (36%) interested. A test identifying 'hidden talents' had the lowest proportion saying they were interested in this (42% either 'very' or 'fairly' interested).

There was a higher proportion of female than male respondents 'Not interested at all' in a test to identify

'hidden talents' (28% vs 20%). Older age bands were more likely to say they were 'not at all' or 'not very' interested in a test like this (63% of 55-75s, 54% of 45-54s, 44% of 35-44s – all three of these groups were more likely to say they were 'not at all' or 'not very' interested than the 18-24s and 25-34s).

A test identifying the risk of developing certain medical conditions received a significantly higher level of 'Don't know' responses than the other tests (10% said 'Don't know' when asked about this test).



'The interpretation of genetic tests sold directly to the consumer is often unreliable, and may be misleading. This might not matter much for ancestry testing, or even for tests that supposedly identify hidden talents. But it can cause serious problems if

people are concerned about predisposition to inherited diseases.'

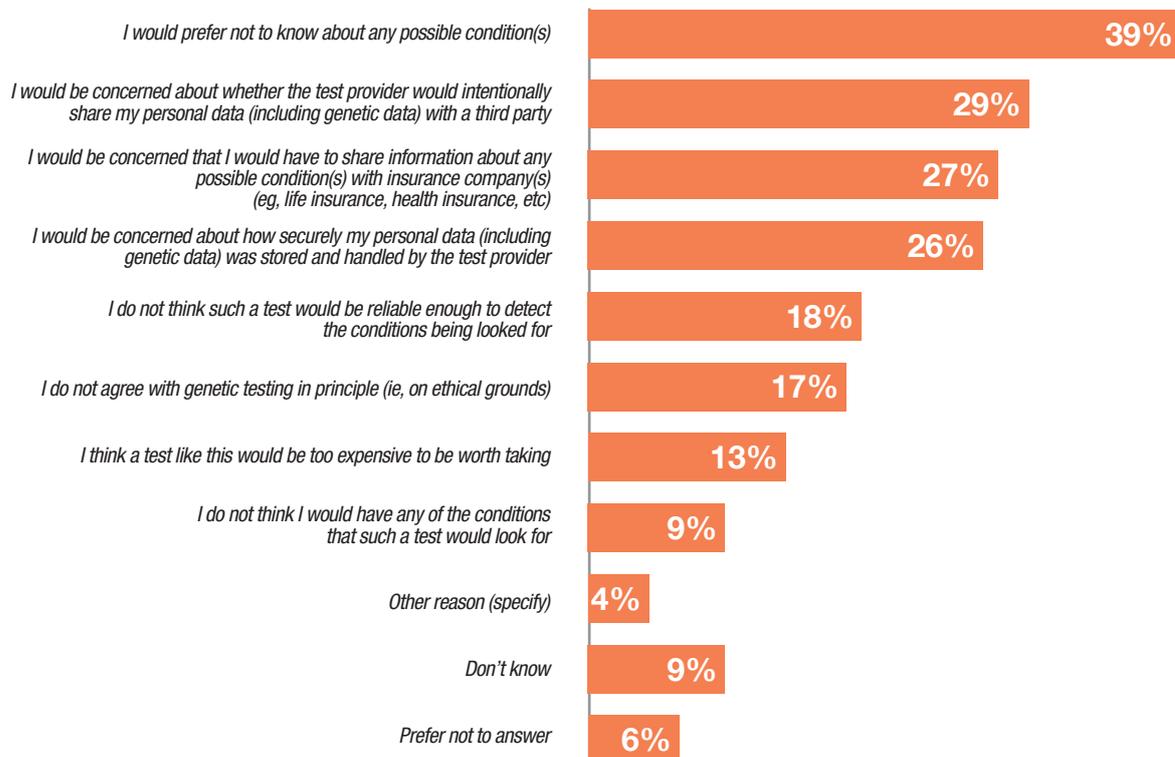
**Professor Frances Flintner - Trustee at PET**  
Member of the HFEA and of the Nuffield Council on Bioethics

### PET says:

These sorts of direct-to-consumer genetic tests have become widely available, and may often be of dubious value. In particular, tests claiming to identify 'hidden talents' are supported by little or no scientific evidence.

Meanwhile, tests claiming to identify the risk of developing certain medical conditions can cause unnecessary distress, especially if the test results cannot be meaningfully acted upon.

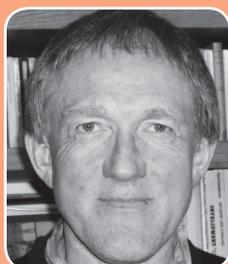
## 2.8 Which, if any, of the following describe why you are *not* interested in taking a genetic test that would identify your risk of developing certain medical conditions? (Please select all that apply.)



Base: n=564 UK Adults aged 16-75, who were not very/not at all interested in taking a genetic test that the test provider claimed would identify their risk of developing certain medical conditions, online fieldwork conducted: 24-27 March 2022.

This follow-up question was put to those who were 'not very' or 'not at all' interested in taking a genetic test that the test provider claimed would identify their risk of developing certain medical conditions (see p26).

The most commonly given reason was a preference not to know of any possible condition(s), with 39% of respondents selecting this answer from those listed above.



**'I would not want to take a direct-to-consumer genetic test to look at my risk of developing a serious condition, because I would not trust the company's interpretation of my laboratory test findings, and I would not even trust the simple, bare (uninterpreted) findings**

**themselves. The track record of direct-to-consumer companies with the accuracy or utility of the tests on offer has not been good.'**

**Professor Angus Clarke**  
Professor of Clinical Genetics at Cardiff University

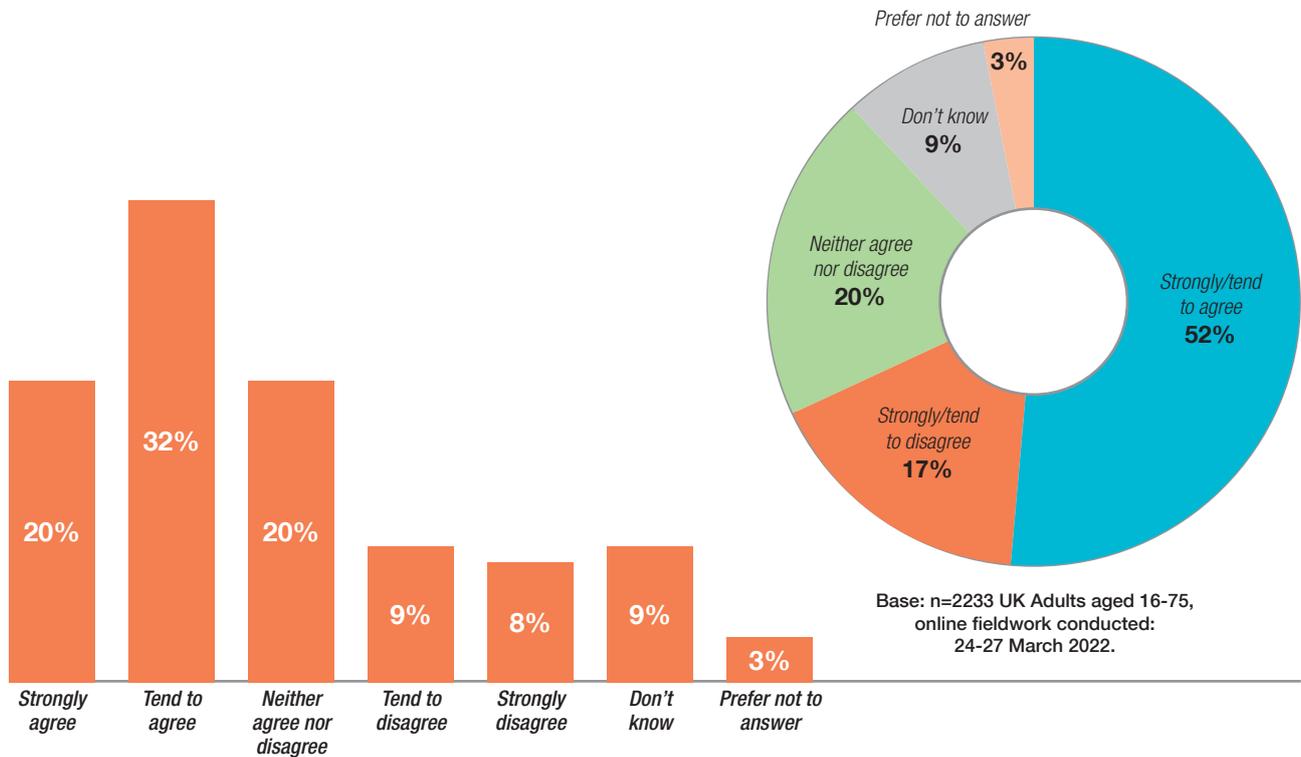
The next three most commonly given reasons concerned the security or sharing of data and information. These answers were selected by a higher proportion of respondents than concerns over the reliability or cost of the test.

### PET says:

We must listen to and respect some people's preference not to know about their possible risk of developing a medical condition.

We should also work to ensure that even when people *do* wish to know of such risks, any genetic tests that they take are of a high standard, with the results clearly and accurately explained and with clear signposting to relevant further information and appropriate support.

**2.9 To what extent do you agree or disagree with this statement – ‘I would willingly share my genetic data (assuming my name and other personal details are withheld) for medical research’.**



More than half (52%) of those surveyed agreed with this statement, with 20% strongly agreeing. Only 17% of respondents disagreed with this statement.

Responses to this question were broadly consistent regardless of age band, geographical region or whether respondents were male or female.

**PET says:**

It is heartening to see that a majority of those surveyed would willingly share their genetic data for medical research.

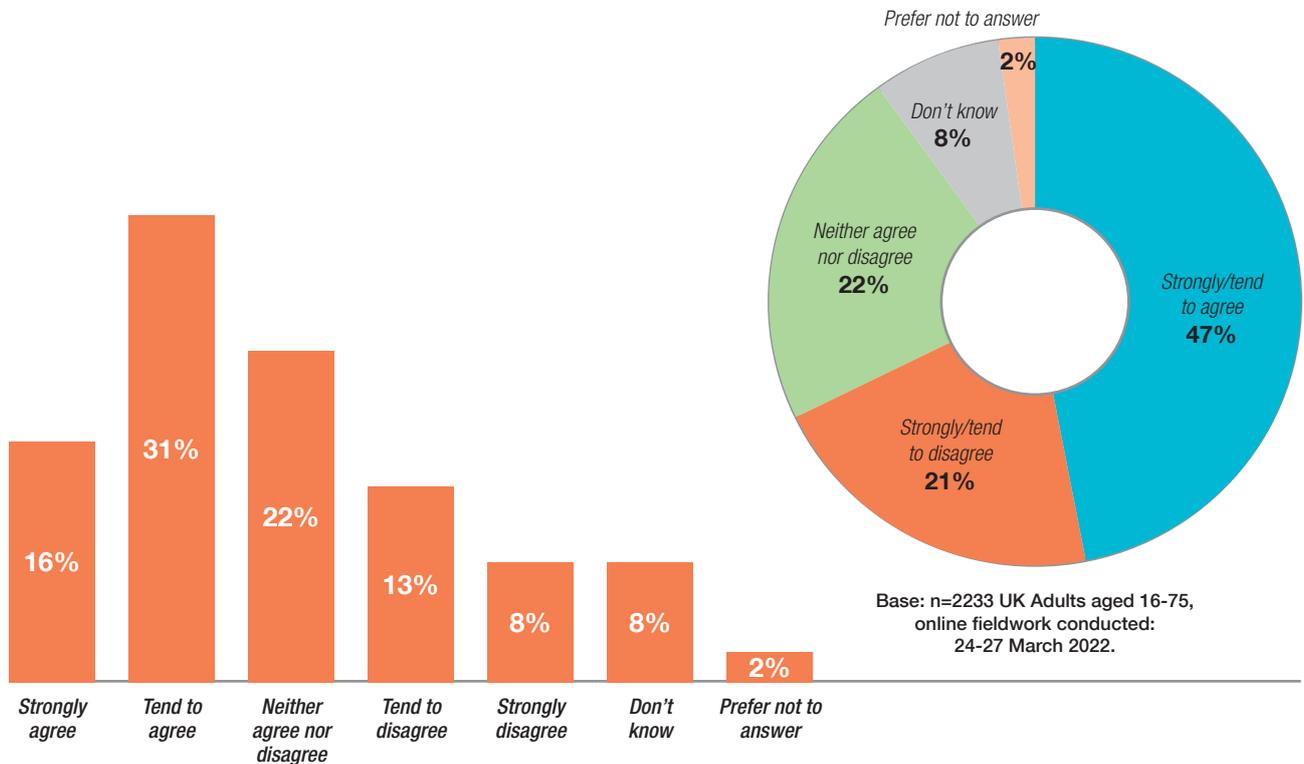
Such public altruism, which we see with blood donation (to give one well-known example), is becoming evident in relation to genetic data as well.



‘Traditionally, we have seen research as something separate from clinical practice. As we now better understand the importance of the close link between research and practice, it is vital that sharing of medical data becomes commonplace. These findings suggest that many of the respondents may already recognise the value of this. More work will need to be done to maintain and build upon this trust, so that medical research can flourish for the benefit of us all.’

**Professor Michael Parker**  
Director of the University of Oxford's Ethox Centre

**2.10 To what extent do you agree or disagree with this statement – ‘I am confident that any data (eg, genetic data, medical records, etc) held by the NHS will be kept confidential’.**



47% of respondents agreed to some extent that they are confident that their data (eg, genetic data, medical records, etc) will be kept confidential by the NHS, while 21% disagreed.

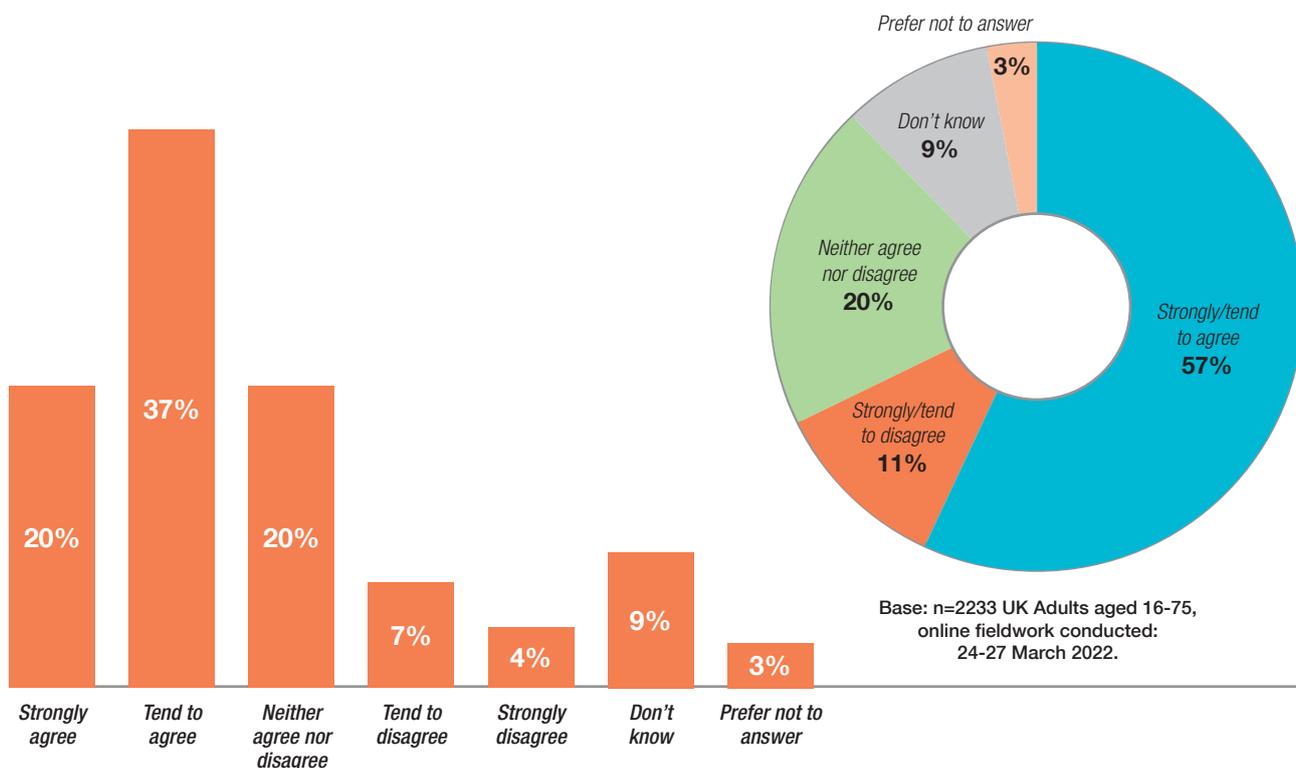
Female respondents (50%) were more likely to agree with this statement than male respondents (44%).

**PET says:**

It is striking that despite several high-profile/health-related data lapses in recent years, almost half of those surveyed agree that they are confident their data will remain confidential in the hands of the NHS.

Trust is hard to win and easy to lose. The NHS and other bodies must work to maintain current levels of public trust.

**2.11 To what extent do you agree or disagree with this statement – ‘More scientific and medical research into human genetics is needed, otherwise we will miss out on new treatments for life-limiting conditions such as cancer’.**



Respondents who supported the use of laboratory-created human embryos in research (see p34) were more likely to agree with this statement than those who were opposed (81% either strongly agreeing or tending to agree, compared with 38% selecting either of these among those who opposed the use of embryos in research).

Furthermore, those who supported Government funding of research that uses human embryos (see p35) were also more likely than those who opposed the funding to agree here (84% vs 34%).

**PET says:**

Our survey results suggest that people recognise the need for more scientific and medical research into human genetics, with over half of respondents appearing to support such research.

PET hopes that funders of such work will feel emboldened by this response. With so much goodwill, scientists and doctors can feel confident that their endeavours are supported by the public, as we move from the era of genetics into the era of genomics.

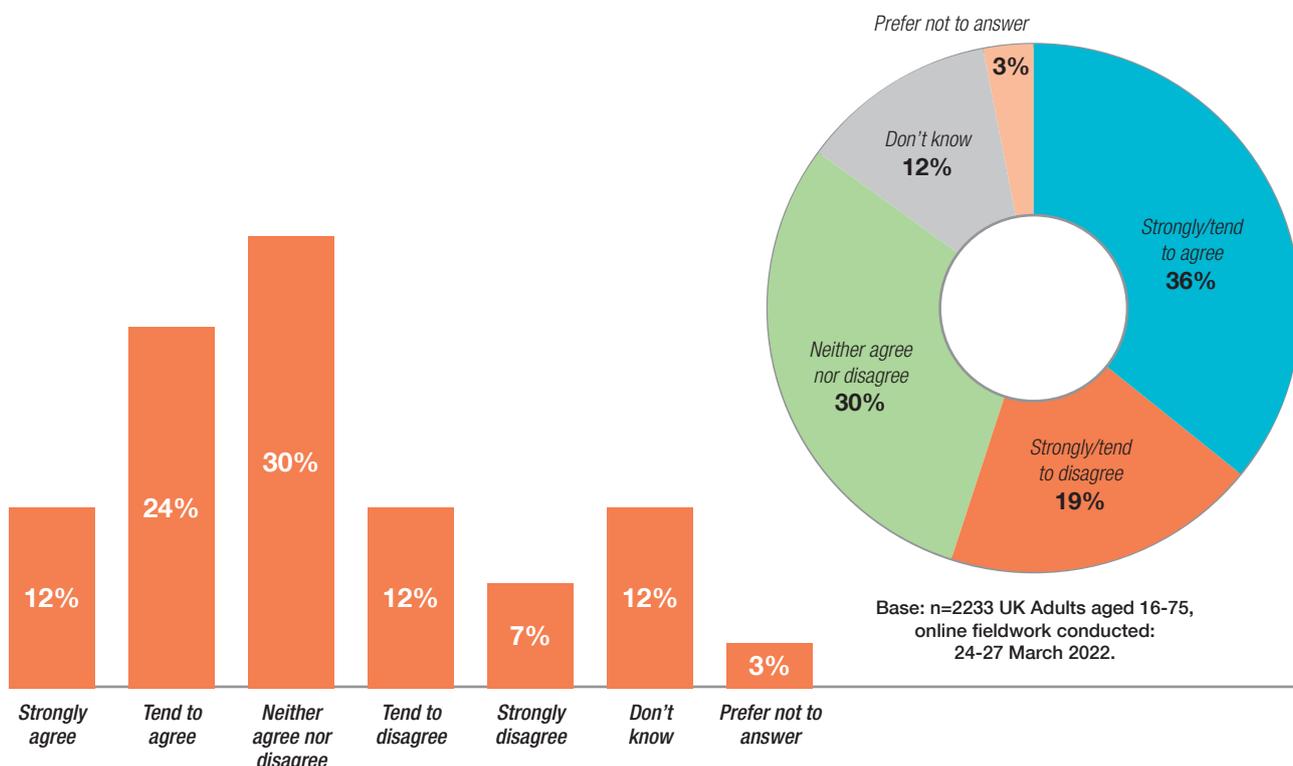


‘Technological advances enable the ready generation of vast amounts of genomic data. Only with research studies using human samples and data will we understand properly

what these genomic changes mean. This research will enable us to use the technologies prudently, producing clinical tests that genuinely optimise how we treat and prevent disease. Trust is essential.’

**Professor Clare Turnbull**  
Professor of Translational Cancer Genetics  
at the Institute of Cancer Research

## 2.12 To what extent do you agree or disagree with this statement – ‘I am excited about the potential for new medical treatments which involve genome editing’.



A high proportion of respondents selected either ‘Neither agree nor disagree’ (30%) or ‘Don’t know’ (12%) in response to this question, with female respondents more likely to respond ‘Don’t know’ than male respondents (14% vs 9%).

36% of respondents either strongly agreed (12%) or tended to agree (24%) that they are excited about the potential for new medical treatments which involve genome editing.

Male respondents were particularly likely to respond ‘Strongly agree’ (14% compared with 10% of female respondents), as were respondents in the 16-24 age band (20%, compared with between 9% and 13% across the other age bands).



‘There’s clearly a need for more education and outreach to inform more people about genome editing – particularly and specifically what is possible in the realm of human health, and what the benefits and risks might be. With so much unmet health need in genetic and rare conditions, this is a source of potential progress that we must explore.’

**Nick Meade**  
Director of Policy at Genetic Alliance UK

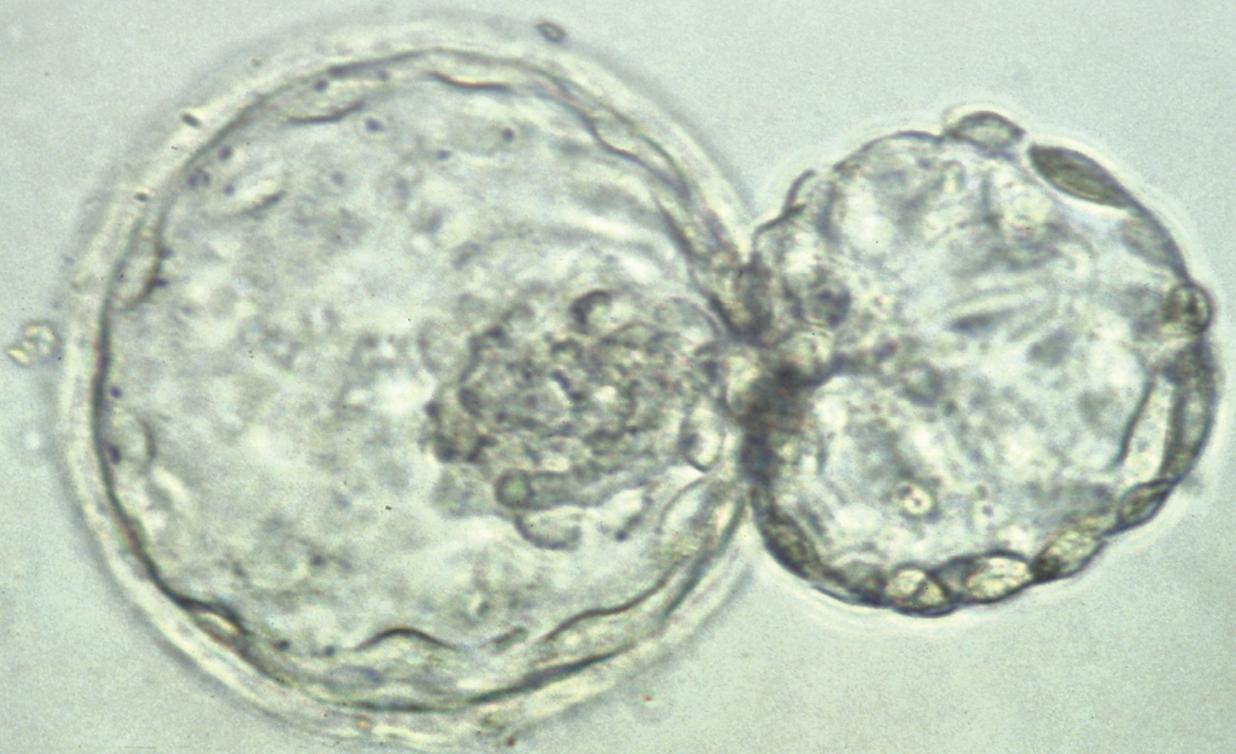
### PET says:

Some treatments involving genome editing will be more controversial than others, and there are important distinctions to be drawn between (for example) somatic and germline genome editing.

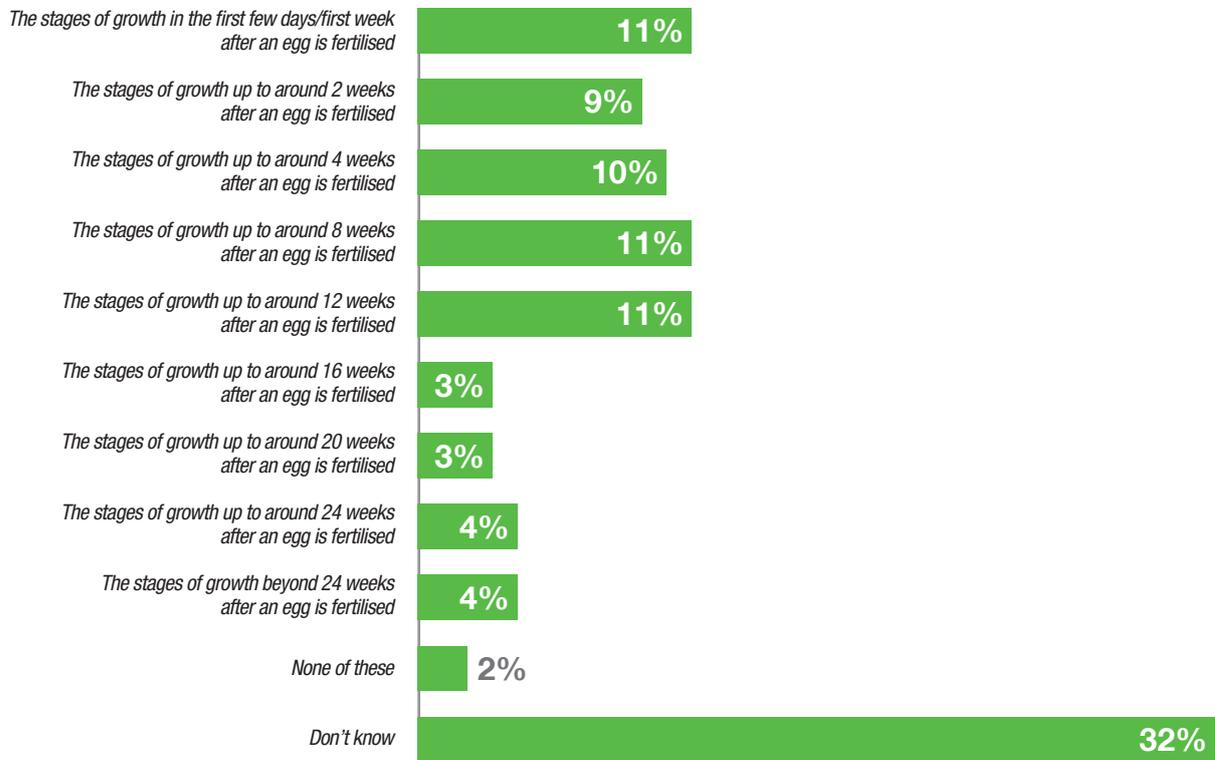
Even so, we are glad to see a significant level of public enthusiasm about genome editing treatments, which have already saved lives and have enormous future potential.

Section 3

# Human Embryos in Research and Treatment



### 3.1 A human egg fertilised by a human sperm becomes a human embryo. How long do you think the term ‘embryo’ is applicable for?



Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

Only 11% of respondents selected the scientifically correct answer – the term ‘embryo’ applies to the stages of growth up to around eight weeks after an egg is fertilised.

Almost a third of those surveyed (32%) responded ‘Don’t know’ to this question. A further 57% gave scientifically incorrect answers.

The proportion of ‘Don’t know’ answers increased with the respondents’ age, with 38% of 55-75s saying ‘Don’t know’, compared with 21% of 18-24s and 25% of 25-34s.

#### PET says:

There is clearly a huge knowledge gap here, which PET needs to address in its future work.

Understanding early human development is an important prerequisite for understanding what fertility treatment and embryo research involve.

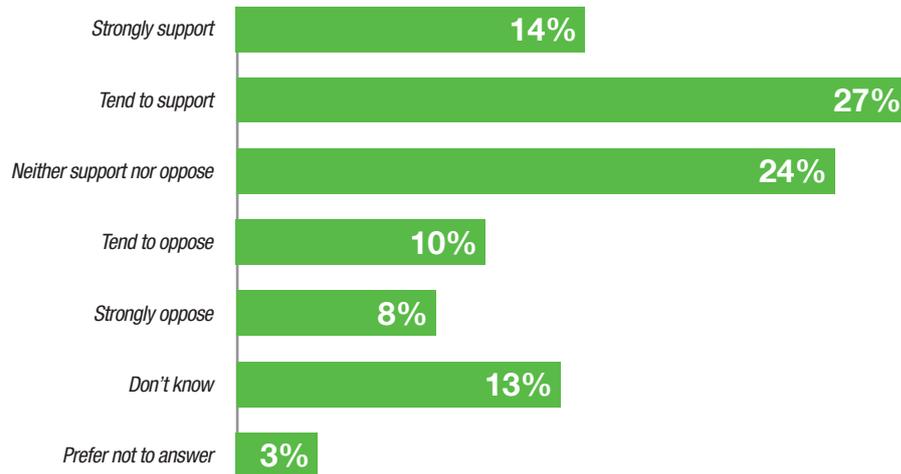
This area is made more complicated by legal definitions of a human embryo, which are not always in alignment with scientific definitions.



‘Confusion can arise when a term like “embryo” is adopted for various purposes outside science. Usage in some circles can then conflict with usage in other circles.’

**Professor Andrew Copp**  
Professor of Developmental Neurobiology  
at the UCL/GOSH Institute of Child Health

### 3.2 To what extent do you support or oppose the use of human embryos in scientific and medical research to help understand, and develop treatments for, congenital disease?



Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

The use of human embryos for scientific and medical research was supported by 41% of respondents. This exceeded the 19% of people who indicated opposition.

The level of strong support was boosted by statistically higher levels of support from male (17% among male respondents, 10% among female respondents) and younger respondents (the 16-24 age band – 19% – was more likely to support than respondents in the groups aged 35 and over).

Overall, however, when combining those selecting ‘Strongly support’ and ‘Tend to support’, there was no significant difference in the level of total support between male and female respondents.

#### PET says:

It is encouraging that more than 40% of those surveyed said they supported the use of human embryos in scientific and medical research.

However, with almost a quarter remaining neutral and a further 13% giving a ‘Don’t know’ answer, there is still a long way to go.

Education is vital, and PET will keep working to help people engage.

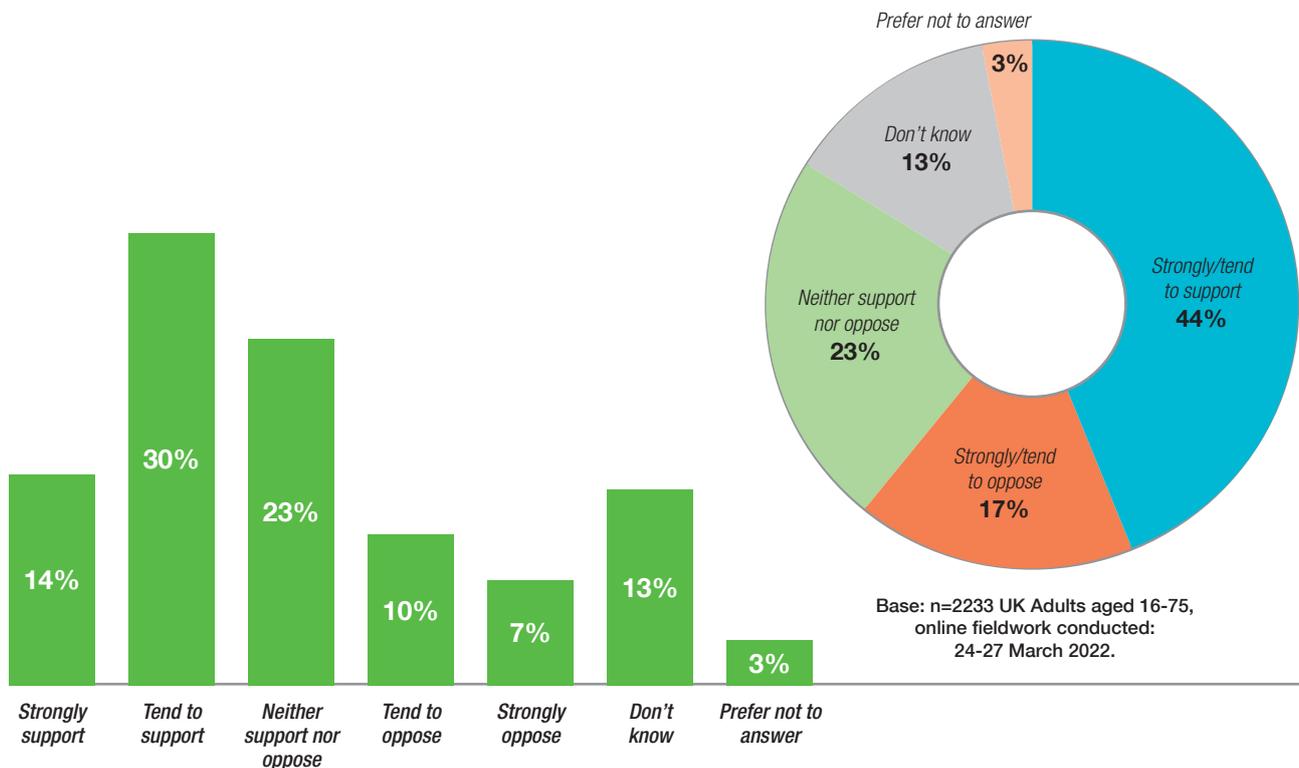


‘The development of IVF relied upon good quality embryo research, which underpins more effective fertility treatments in the future. Embryo research is also critical for the use of stem cells in regenerative medicine. While it is encouraging that many respondents were supportive of human embryo research, there is still room for continued engagement. PET is perfectly positioned to lead future discussions of this important topic.’

**Professor Kathy Niakan**

Director of the University of Cambridge’s Centre for Trophoblast Research

### 3.3 To what extent do you support or oppose the UK Government funding scientific and medical research that uses human embryos to understand, and develop treatments for, congenital disease?



Overall, the Government funding of research using human embryos for scientific and medical research was more supported than opposed. There was more than twice the number of people strongly supporting than strongly opposing.

However, this situation could change if the 39% who said 'Don't know', 'Prefer not to answer' or 'Neither support nor oppose' form an opinion, become outspoken or stop remaining neutral on the subject.

#### PET says:

We are heartened that 44% of respondents support Government funding of research involving human embryos.

Such levels of support could pave the way to establishing a national embryo bank, which in turn would enable better use to be made of the embryos that are donated to research by fertility patients, after they have completed their treatment.

Donated embryos are a precious resource, that can give researchers new insights into congenital disease.



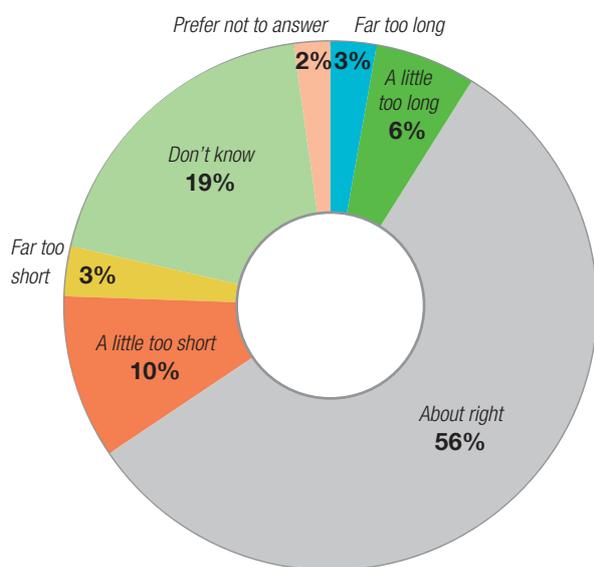
'Many of the most serious congenital diseases have unknown causes. If these causes are to be understood, and new treatments for these diseases discovered, it will sometimes be

necessary for scientists to study human embryos at early stages of development. It is reassuring to see that 44% of respondents support UK Government funding for embryo research, suggesting that these research goals align with societal values. However, it is important to continue to have open, two-way conversations and to build trust, particularly with those who are currently neutral or oppose this research.'

**Dr Peter Rugg-Gunn**  
Group Leader and Head of Public Engagement  
at the Babraham Institute

**3.4 In the UK, human embryos created in a laboratory can currently be used in scientific and medical research (eg, to help understand, and develop treatments for, congenital disease) for 14 days from fertilisation (this is often called the ‘14-day rule’). After this, they must be destroyed. The 14-day rule refers to the first 14 days of the embryo’s development, and does not include any time for which the embryo is frozen.**

**Do you think this ‘14-day rule’ is too long, too short, or about right?**



Base: n=1462 UK Adults aged 16-75, who support or neither support nor oppose the use of embryos in research, online fieldwork conducted: 24-27 March 2022

This question was asked to respondents who said they supported (or neither supported nor opposed) the use of laboratory-created human embryos in research (see p34).

The majority of respondents in this group (56%) felt that the 14-day rule was ‘About right’. When compared with the 16-24s and 25-34s, this was significantly higher in the older age bands, with 61% of both 45-54s and 55-75s selecting this option.

With this in mind, although the most commonly selected answer among 16-24s was still ‘About right’, a higher proportion of respondents in the younger age bands selected ‘too long’ (either ‘Far too long’ or ‘A little too long’) in response to this question (20% of 16-24s and 19% of 25-34s selected one of these options, which is significantly more than the older age groups in the sample).

In addition, more 16-24s in the survey selected ‘too short’ compared with some of the other age bands (19% in this group compared with 11% of 55-75s, for example).



**‘Better fertility services evolve through better science. The 14-day rule not only regulates research, it provides a foundation for enabling science to work for the benefit of society. The 14-day rule is the *de facto* global standard for research**

**in this area, and no other feature of the original HFE Act has been so influential or widely emulated. It has not only stood the test of time, but benefited millions of IVF users, by providing a sound foundation for treatment. The 14-day rule is not only a uniquely effective regulatory instrument, it embodies the vital principle of social consensus in support of scientific innovation for the benefit of all.’**

**Professor Sarah Franklin**

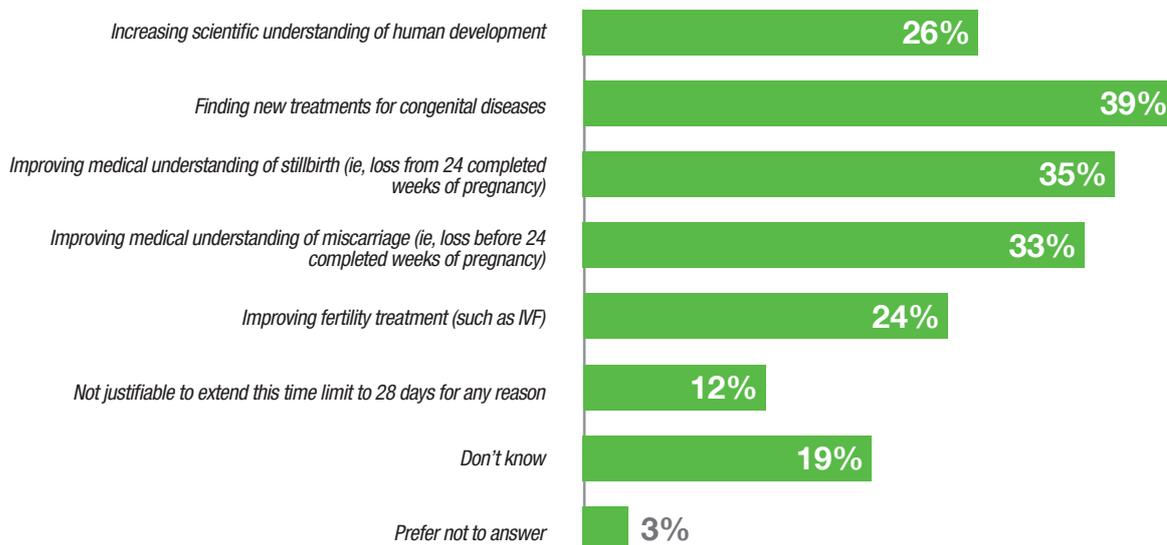
*Director of the University of Cambridge’s Reproductive Sociology Research Group*

**PET says:**

**We would like to pay tribute to our former Patron, the late Baroness Mary Warnock, who was largely responsible for establishing the 14-day rule in UK law. The rule was subsequently adopted by many countries and institutions around the world.**

**Baroness Warnock’s work on this issue gave confidence to scientists and the wider public alike. This is a tradition that PET aspires to uphold, by seeking to ensure that if the 14-day limit is extended – in the UK or elsewhere – then reasons for the extension are explained clearly, and we bring the public along with us.**

### 3.5 For which, if any, reasons do you think it would be justifiable to extend the embryo research time limit\* from 14 days to 28 days? (Please select all that apply.)



Base: n=1462 UK Adults aged 16-75, who support or neither support nor oppose the use of embryos in research, online fieldwork conducted: 24-27 March 2022

This question was asked to respondents who said they supported (or neither supported nor opposed) the use of laboratory-created human embryos in research (see p34).

Among this group, the most popular answers selected for extending the 14-day rule to 28 days were 'Finding new treatments for congenital diseases' (39%), 'Improving medical understanding of stillbirth' (35%) and 'Improving medical understanding of miscarriage' (33%). 'Increasing scientific understanding of human development' and 'Improving fertility treatment' were less likely than these top three to be selected by the respondents (26% and 24% respectively).

12% selected 'Not justifiable to extend this time limit to 28 days for any reason', and 19% responded 'Don't know'.

\* In the UK, human embryos created in a laboratory can currently be used in scientific and medical research (eg, to understand, and develop treatments for, congenital disease) for 14 days from fertilisation (this is often called the '14-day rule'). After this they must be destroyed. The 14-day rule refers to the first 14 days of the embryo's development and does not include any time for which the embryo is frozen.



'This is a stage in our development that is tremendously important, but about which we know so little, due to its relative inaccessibility. Extending the limit to which we can culture human embryos will have a profound impact on our ability

to advance our understanding of human development.'

**Professor Shankar Srinivas**

Professor of Developmental Biology at the University of Oxford

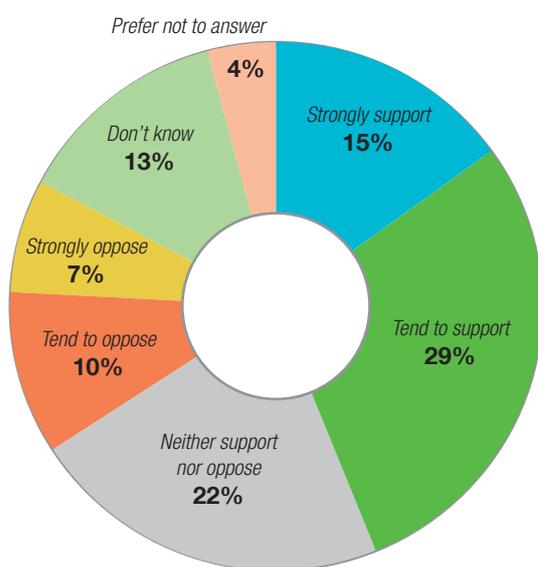
#### PET says:

It is reassuring that for the most part, even those who do not think the 14-day rule should be changed are willing to consider extending the rule – in fact, doubling the time limit – if there is a sufficiently good reason to do so.

That said, we need to do more to explain the importance of improving scientific understanding of human development in general. Such basic research must usually precede work that fulfils more specific objectives, such as tackling disease.

### 3.6 Genome editing technologies enable scientists to make changes to DNA by altering sections of DNA.

Thinking about this, to what extent do you support or oppose the use of human genome editing in human embryos for scientific and medical research to help understand, or develop treatments for, congenital disease? (The research embryos will never be used to establish a pregnancy in a human being.)



Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

45% of respondents supported the use of genome editing in human embryos to help understand, or develop treatments for, congenital disease. Male respondents were more likely to support than female respondents (47% strongly supporting or tending to support, vs 42%).

16% of those surveyed were opposed, and more than a third (35%) remained neutral (neither supported nor opposed) or answered 'Don't know'.

Respondents who supported the use of laboratory-created human embryos in research (see p34) were significantly more likely to support the use of human genome editing in this scenario (79%), compared with those who opposed (13%) or who neither supported nor opposed (30%).

Those who supported Government funding of research that uses human embryos (see p35) were also significantly more likely to support the use of human genome editing in this scenario (77%), compared with those who opposed (13%) or who neither supported nor opposed (30%).



'The use of techniques such as genome editing provides an opportunity to understand many aspects of how the human embryo begins to develop, and the critical importance of specific genes and processes, where the knowledge gained may be

useful to improve IVF and reduce the incidence of miscarriage and congenital disorders. However, decisions around any limits of what scientists can do need to be informed by the public, who themselves first need to be informed about the possibilities. It is a challenge to do this well, but it has to start with conversations, something that PET is very good at initiating.'

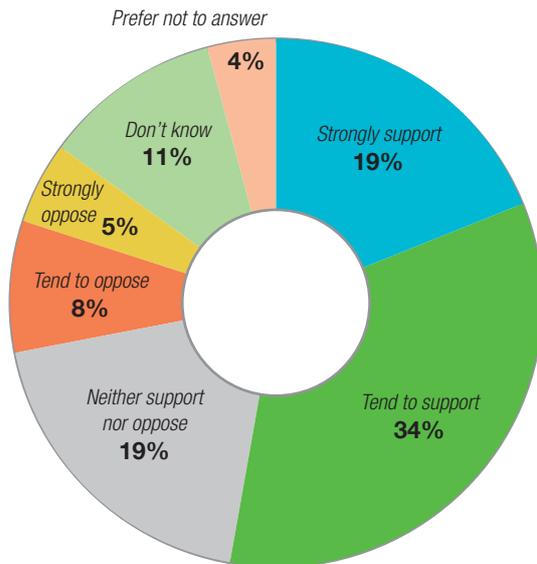
**Professor Robin Lovell-Badge**  
**Chair of Trustees at PET**  
*Group Leader at the Francis Crick Institute*

### PET says:

The UK has led the world in this area. The first research that involved editing the genomes of human embryos in order to study the function of a gene was conducted in the UK.

More than 4 in 10 respondents taking our survey showed support for such research. It is clear that greater public engagement is needed, so that the one-third who are undecided can form a view.

### 3.7 To what extent do you support or oppose the use of human genome editing\* in human embryos that will be transferred into a woman to establish pregnancy, to help eliminate a severe or life-threatening condition (such as cystic fibrosis) in the resulting child, where there may otherwise be a predisposition for that child to have the condition?



Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

The majority of respondents (53%) supported this use of human genome editing. Only 14% of those surveyed responded either 'Strongly oppose' or 'Tend to oppose'.

\*Genome editing technologies enable scientists to make changes to DNA by altering sections of DNA.

#### PET says:

It is very striking that more than half of those surveyed support the use of germline genome editing, to try to ensure that a child is not affected by a life-threatening condition.

We are glad to see that the 2018 scandal in China, where three children's genomes were edited in a way that breached scientific and ethical standards, has not turned the public against this technology.

We must now do our best to ensure that if germline genome editing is put to medical use, this is done in a scientifically and ethically rigorous way.



'It is encouraging to see that only a minority of respondents objected to the potential use of germline genome editing, when the objective is to prevent future human suffering. This public view aligns with the recommendations of several international expert groups, who have been exploring responsible pathways towards a clinical translation of this revolutionary technology. It is critically important to engage in a broad public conversation about how to characterise various genetic conditions, and how to decide what conditions are considered severe enough to warrant such unprecedented intervention.'

**Professor Vardit Ravitsky**  
President of the International Association of Bioethics

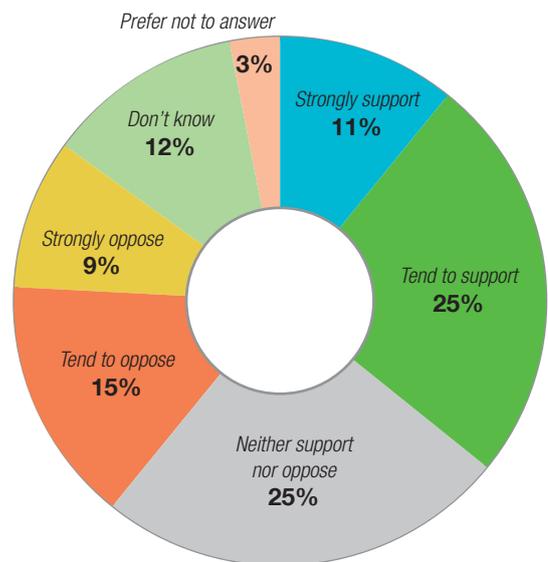
### 3.8 To what extent do you support or oppose the use of human genome editing\* in human embryos that will be transferred into a woman to establish pregnancy, to help eliminate a common medically manageable condition (such as asthma) in the resulting child?

36% of respondents supported the use of the use of genome editing in human embryos to help eliminate manageable medical conditions. A similar proportion (36%) remained neutral (neither supported nor opposed) or answered 'Don't know'. 24% of respondents were opposed.

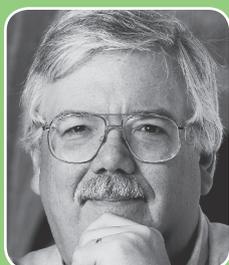
Respondents who supported the use of laboratory-created human embryos in research (see p34) were significantly more likely to support the use of human genome editing in this scenario (57%), compared with those who opposed (18%) or who neither supported nor opposed (28%).

Those who supported Government funding of research that uses human embryos (see p35) were also significantly more likely to support the use of human genome editing in this scenario (58%), compared with those who opposed (16%) or who neither supported nor opposed (26%).

**\*Genome editing technologies enables scientists to make changes to DNA by altering sections of DNA.**



Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.



**'Embryo editing may turn out to be a good way to avoid disease, but much research will be needed to show that it is safe and effective compared with other approaches.'**

**Professor Henry Greely**  
*Director of Stanford University's Centre for Law and the Biosciences*

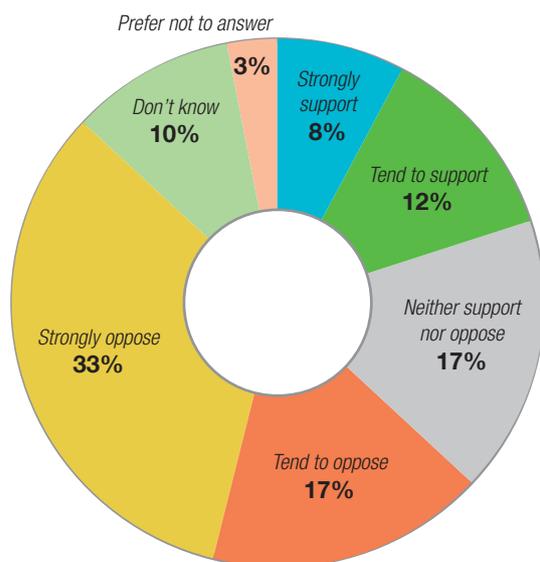
### PET says:

It is understandable that people may be cautious about the use of germline genome editing to address more common and more manageable conditions.

However, it is also worth taking account of the lived experience of people with particular conditions, and their families and carers. Even a condition that is nominally manageable can be debilitating to live with day-to-day, or can involve treatments which are themselves onerous.

We must keep an open mind about potential future applications of germline genome editing.

### 3.9 To what extent do you support or oppose the use of human genome editing\* in human embryos that will be transferred into a woman to establish pregnancy, to help ensure that child has a particular preferred characteristic (eg, physical traits like eye colour, height, hair colour, etc)?



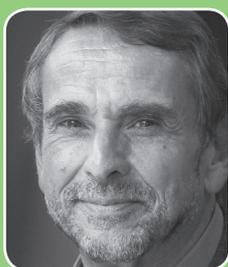
Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

This is the least supported scenario for the use of human genome editing, out of the four that were presented to the respondents in our survey. Overall, a larger proportion of respondents opposed than supported this use of genome editing (49% vs 20%), with nearly a third of all respondents selecting 'Strongly oppose'.

Male respondents and younger age bands were more likely to be supportive. 25% of male respondents strongly supported or tended to support, compared with 16% of female respondents. 38% of 16-24s and 31% of 25-34s strongly supported or tended to support, significantly higher than any of the older age bands in the survey.

In contrast, female respondents and older age bands were significantly more likely to be opposed. 56% of female respondents strongly opposed or tended to oppose, compared with 42% of male respondents. 63% of 55-75s and 60% of 45-54s strongly opposed or tended to oppose, significantly higher than any of the younger age bands in the survey.

**\*Genome editing technologies enable scientists to make changes to DNA by altering sections of DNA.**



**'I support the maximum possible parental choice in human reproduction, including choice of physical traits which are not in themselves harming – such as hair colour, eye**

**colour or height within normal limits. If it is not harming to be (for example) a bonnie, bouncing, brown-eyed baby girl, how can it be wrong to deliberately create such a person by reasonably safe means? Bear in mind that normal sexual reproduction is far from being a safe reproductive modality. Every year, an estimated 7.9 million children are born with a serious birth defect of genetic or partially genetic origin.'**

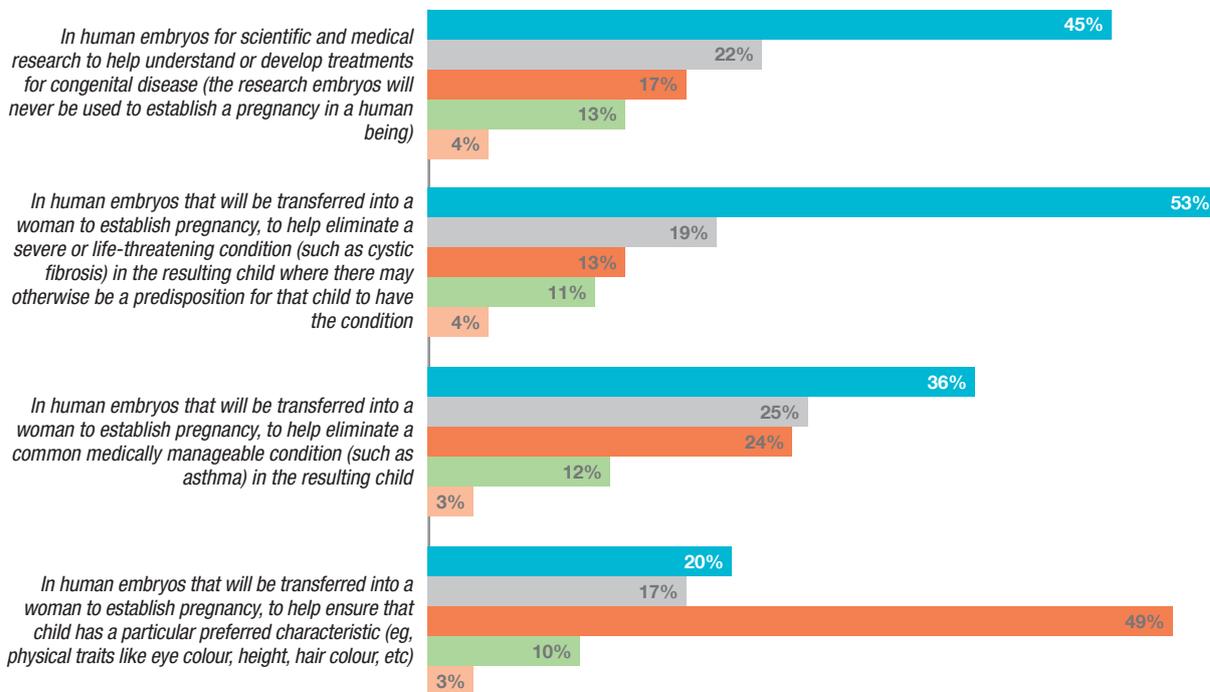
**Professor John Harris**  
Emeritus Professor of Bioethics at the University of Manchester

### PET says:

It is unsurprising that half of those surveyed were opposed to the use of germline genome editing for non-medical purposes. These technologies always involve some degree of risk, even once they have been refined, and it is difficult to justify this risk if there is no clear medical benefit to be had.

However, it is striking that younger respondents were more willing to countenance germline genome editing for the purpose of ensuring preferred characteristics. It is worth paying attention to these views, but we should continue to prioritise medical needs in the first instance.

### 3.6 - 3.9 Summary of results: To what extent do you support or oppose the use of human genome editing\* in each of the following scenarios?



- Strongly/tend to support
- Neither support nor oppose
- Strongly/tend to Oppose
- Don't know
- Prefer not to answer

Base: n=2233 UK Adults aged 16-75, online fieldwork conducted: 24-27 March 2022.

## PET says:

More than half of those surveyed support the idea of establishing a pregnancy with a genome-edited embryo, in a scenario where this is done to help eliminate a severe or life-threatening condition.

Understandably, a smaller (but still significant) proportion support this if it is done to eliminate a less severe condition, or if it is done for a non-medical reason.

We are pleased by these findings, but we are concerned that the results suggest that public support for the use of genome-edited embryos in research may be slightly lower than it is for the use of genome-edited embryos to avoid severe disease.

These technologies can only be considered for use in the clinic following thorough studies using research embryos – the one is not possible without the other. PET will work to ensure that this important link between research and treatment is better understood.

The most supported of the scenarios is genome editing in a human embryo to eliminate a severe or life-threatening condition (53%), followed by genome editing in embryos where a pregnancy would not be established, in order to help develop treatments for congenital diseases (45%).

Less supported is the use of genome editing in human embryos for common medically manageable conditions (36%), and least supported is the use to select for preferred characteristics (20%).

\* Genome editing technologies enable scientists to make changes to DNA by altering sections of DNA.

## Survey details

Ipsos interviewed a sample of 2,233 adults aged 16-75 in UK using its online i:omnibus between 24 and 27 March 2022.

Data has been weighted to the known offline population proportions for age, working status and social grade within gender and Government office region.

The questionnaire was developed by PET and its advisers with the input of Ipsos survey research experts. All research was carried out in accordance with the requirements of the international quality standard for market research, ISO 20252, and in accordance with the Ipsos Terms and Conditions.

All percentage calculations are rounded up to the nearest whole number. Where percentages do not add up to 100%, this is due to rounding.

## Image details

The scientific images used in this report are from the Wellcome Collection, and are also used on PET's recently redeveloped website at [www.progress.org.uk](http://www.progress.org.uk)

PET is grateful to Wellcome, which has funded PET's digital transformation with a Sustaining Excellence Award.

## Credits

### Cover image

Image by Ezequiel Miron/University of Oxford via the Wellcome Collection.

Depicts the misreplication of DNA in a human fetal lung fibroblast nucleus (super-resolution optical micrograph of DNA stain acquired with a 3D structured illumination microscope).

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### Section 1: Assisted Conception

Image by Alan Handyside via the Wellcome Collection.

Depicts a human egg soon after fertilisation, with the two parental pronuclei clearly visible.

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### Section 2: Genetics and Genomics

Image by Peter Artymiuk via the Wellcome Collection.

Depicts the shadow of a DNA double helix, on a background that shows the fluorescent banding of the sequencing output from an automated DNA sequencing machine.

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### Section 3: Human Embryos in Research and Treatment

Image by K Hardy via the Wellcome Collection.

Depicts a human embryo at the blastocyst stage (about six days after fertilisation) 'hatching' out of the zona pellucida.

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## Contributors

### PET would like to thank everyone who has contributed commentary to this report:

Nina Barnsley, Phil Booth, Louise Brown, Professor Sir Mark Caulfield, Julia Chain, Professor Angus Clarke, Professor Andrew Copp, Professor Frances Flinter, Professor Sarah Franklin, Professor Henry Greely, Professor John Harris, Professor Nick Hopkins, Professor Pali Hungin, Sarah Jones, James Lawford Davies, Professor Robin Lovell-Badge, Professor Anneke Lucassen, Sarah-Jane Marsh, Nick Meade, Professor Alison Murdoch, Professor Kathy Niakan, Professor Michael Parker, Professor Marcus Pembrey, Professor Vardit Ravitsky, Dr Peter Rugg-Gunn, Professor Julian Savulescu, Dr Richard Scott, Professor Shankar Srinivas, Professor Clare Turnbull and Professor Stephen Wilkinson.



PET provides impartial and accurate information to people affected by infertility or genetic conditions, and provides platforms for them – and relevant experts and practitioners – to discuss scientific, ethical, legal and policy developments in these areas.

#### Our vision

To improve choices for people affected by infertility or genetic conditions.

#### Our mission

To educate and to debate the responsible application of reproductive and genomic science.



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