

**EMBARGOED until 00:01 (BST) Wednesday 25<sup>th</sup> October 2023**

Public support for extending the 14-day rule on human embryo research indicated by foundational dialogue project

Key points:

- Most of the dialogue's 70 participants support some form of extension or modification of the 14-day rule, provided it is guided by society's expectations about respect for the embryo and as long as the research continues to be robustly regulated.
- The dialogue highlighted the need for national conversations on reviewing and changing the 14-day rule, informed by greater transparency and public awareness of human embryo research.
- The use of stem cell-based embryo models in research was welcomed by the dialogue participants, recognising the value of these models in better understanding human development, but the majority of participants want to see regulation put in place.
- The dialogue findings provide an initial snapshot of public opinion on human embryo research, and that of stem cell embryo models, and aim to inform future public consultation, policy development and research governance.

The findings of a foundational UK public dialogue on human embryo research are published today, Wednesday 25<sup>th</sup> October 2023, as part of the Wellcome-funded Human Developmental Biology Initiative (HDBI). The HDBI is an ambitious scientific endeavour to advance our understanding of human development. The dialogue project, which was co-funded by UKRI Sciencewise programme, engaged a diverse group of the public to consider how early human embryo research can be used to its fullest, the 14-day rule and the fast-paced field of stem cell-based embryo models.

Headline findings include:

- **Appetite for review of the 14-day rule:** Participants recognised that extending the 14-day rule could open up ways to achieve benefits in fertility and health, with participant support for reviewing this, including national discussion.
- **Confidence in regulation:** There was a high level of confidence in how human embryo research is regulated, despite a low level of awareness of the regulators and statutes themselves. This included strong desire to see robust regulation governing any changes to the 14-day rule and further regulation for the use of stem cell-based embryo models.
- **Support for improved fertility and health outcomes:** The strongest hopes for future human embryo research were where new knowledge would deliver improvements in understanding miscarriage, preventing health conditions such as spina bifida and raising the success rates of IVF procedures.
- **Concerns about genetically engineering humans:** The public expressed concerns on the application of developments in this field to genetically alter or engineer humans.

The dialogue engaged a group of 70 people broadly reflective of the UK population in over 15 hours of activities including a series of online and face-to-face workshops with scientists, ethicists, philosophers, policy makers and people with relevant lived experience (such as embryo donors from IVF procedures).

**Dr Peter Rugg-Gunn**, scientific lead for the HDBI and senior group leader at the Babraham Institute, said: “Recent scientific advances bring incredible new opportunities to study and understand the earliest stages of human development. To ensure this research remains aligned with society’s values and expectations, we must listen and respond to public desires and concerns. This public dialogue is an important first step and as a scientist I am reassured by the findings but there is still a long way to go to fully understand this complex issue.”

The report is exceedingly timely, following notable scientific advances in human developmental biology presented at conferences and in leading scientific journals in recent months. As well as generating excitement in scientific fields and with the public, announcement of these breakthroughs also prompted some concerns and criticisms, with the view that these findings raised significant ethical issues. The dialogue provides insight into public considerations following deliberation on early human embryo research. The hope is that it will act as a foundational reference point that others in the sectors can build upon, such as in any future review of the law on embryo research.

**Professor Robin Lovell-Badge**, co-chair of the HDBI Oversight group, senior group leader and head of the Laboratory of Stem Cell Biology and Developmental Genetics at the Francis Crick Institute, said: “We have learnt a lot about human development before 14 days, but there are areas of investigation that could change how we understand development, and associated diseases, that lie beyond our current window of knowledge. Despite low awareness of current laws, members of the public quickly recognised many of the critical issues researchers are keenly aware of when it comes to growing embryos beyond the current limit. This dialogue also reinforced the fact that the public are in support of research that will yield better health outcomes, and in this case, increase the success of IVF procedures.

Other countries will be looking to the UK to see how we deal with the 14-day rule; we are not there yet with any mandate to make a change, but this does give a strong pointer. The next step will be to delve deeper into some of the topics raised through this dialogue as they apply to specific areas of research, as well as feeding into policy changes.”

### **The 14-day rule and the regulation of stem cell-based models**

When considering the regulation of research involving human embryos, the dialogue explored participant’s views on the 14-day rule. Introduced in 1990, the 14-day rule is a limit enforced by statute in the UK. It applies to early human embryos that are donated by consent to research and embryos that are created for research from donated sperm and eggs. It limits the amount of time early human embryos can be developed in a laboratory for scientific study to 14 days after fertilisation. Due to technical advances, it is now possible to grow embryos in the lab past 14 days, but researchers are not allowed to by the law. If the law changed, it would open up this ‘black box’ of development with researchers able to investigate this crucial time in development from 14-28 days after fertilisation.

**Professor Bobbie Farsides**, co-chair of the HDBI Oversight group and Professor of Clinical and Biomedical Ethics at the Brighton and Sussex Medical School, said: “It has been a fascinating experience to support HDBI in the undertaking of this exercise. I commend the participants for the care and mutual respect they have shown throughout. Their engagement and commitment to a subject few of them had previously considered allowed for a wide range of views to be expressed and considered. I hope the scientists involved will be encouraged by the high level of interest in their work, and will want to keep the public conversation going around these important subjects.”

The dialogue included participant discussion on what a change to the 14-day rule might look like, and identified points that should be considered, such as defining what the benefits of extending the rule would be and potential mis-alignment with human embryo research regulations in other countries.

Participants acknowledged the astonishing possibilities of stem cell-based embryo models. The majority of participants would like to see these models further regulated. Work in establishing potential governance mechanisms is already underway. In recognition of the need for additional guidance and regulation in this area, the Cambridge Reproduction initiative launched a project in March 2023 to develop a governance framework for research using stem cell-based embryo models and to promote responsible, transparent and accountable research.

### **Future steps**

A key outcome from the public dialogue is the identification of areas for further exploration, with participants proposing how future national conversations might be shaped. It is hoped that the project acts as a reference base for both widening engagement with the subject and also prompting deeper exploration of areas of concern.

**Dr Michael Norman**, HDBI Public Dialogue coordinator and Public Engagement Manager at the Babraham Institute, said: “This dialogue shows that people want the public to work closely with scientists and the government to shape both future embryo research legislation and scientific research direction. It is crucial that others in the sector build on these high quality, two-way engagement methodologies that allow for a genuine exchange of views and information to ensure that the public’s desires and concerns are listened to and respected. Transparency and openness around science is vital for public trust and through this we, as a society, can shape UK research in way that enriches the outcomes for all.”

**Public Participant (Broad public group, south) said:** “I do think that an extension of this public dialogue, and educating a wider society has a benefit in itself. This is really complex and sensitive and the wider you talk about it before decisions are made, the better.”

### **Notes to Editors**

#### **Publication reference**

Before embargo, a copy of the report can be obtained by emailing: [comms@babraham.ac.uk](mailto:comms@babraham.ac.uk).

After publication on 25<sup>th</sup> October, the report can be access from:

- HDBI website: <https://hdbi.org/public-dialogue>
- Sciencewise website: <https://sciencewise.org.uk/projects/early-human-embryo-research/?portfolioCats=43%2C44%2C45%2C46%2C15>
- Hopkins Van Mil website: <http://www.hopkinsvanmil.co.uk/social-research-deliberation>

### **Press contact for enquiries and requests for interviews**

Honor Pollard, Communications Officer, Babraham Institute, [comms@babraham.ac.uk](mailto:comms@babraham.ac.uk), +44 (0)1223 496093, +44 (0)7833 481170

### **Available project spokespeople**

- Dr Peter Rugg-Gunn, scientific lead for the HDBI, senior group leader and Head of Public Engagement at the Babraham Institute
- Professor Robin Lovell-Badge, HDBI Oversight group co-chair, senior group leader and head of the Laboratory of Stem Cell Biology and Developmental Genetics at the Francis Crick Institute
- Professor Bobbie Farsides, HDBI Oversight group co-chair and Professor of Clinical and Biomedical Ethics at the Brighton and Sussex Medical School

### **About the HDBI public dialogue project**

This project was commissioned by the Human Developmental Biology Initiative with dialogue workshops taking place in summer 2023 designed to explore public hopes and concerns around the regulation of research involving human embryos.

The dialogue project was funded by Wellcome and UK Research and Innovation's (UKRI) [Sciencewise](#) programme. It is managed by a team including members of HDBI and the Babraham Institute, with support from UKRI Sciencewise, and is advised by an oversight group, established to provide both challenge and advice to the dialogue design, co-chaired by Prof. Bobbie Farsides and Prof. Robin Lovell-Badge.

The dialogue was delivered by Hopkins Van Mil and evaluated by Ursus Consulting.

Learn more about HDBI public engagement mechanism at: <https://hdbi.org/public-engagement>

### **Dialogue participant recruitment and involvement**

A total of 70 participants from across the UK took part in the dialogue. They participated in one of three ways: the pilot group, the lived experience group (with experience of developmental conditions; fertility treatment and/ or recurrent miscarriage) and broad public north and broad public south groups. The numbers and engagement mechanisms in each group were as follows:

- Pilot group: 9 (engaged in a webinar and three online workshops)
- Lived experience group: 19 (engaged in a webinar and three online workshops)
- Broad public north: 21 (engaged in a webinar and one online workshop followed by two in-person workshops)
- Broad public south: 21 (engaged in a webinar and one online workshop followed by two in-person workshops)

All participants were recruited using a specification agreed by the project team. This included recruiting a range of levels of awareness of the HFEA, the 14-day rule and a mix of those who support and oppose early human embryo research.

### **About the HDBI**

The Human Developmental Biology Initiative (HDBI) is a 5-year, Wellcome-funded £10 million research project involving 25 research groups from across the UK and Europe. <https://hdbi.org/>

The overall goal of the project is to support wider research in human development, which is needed to better understand how humans grow and develop, and how problems with these processes can sometimes arise and lead to miscarriages and developmental conditions. The project's research focuses on four complementary systems: the early embryo, the developing heart and lung, the central nervous system and the blood and immune system.

### **About the Babraham Institute**

The Babraham Institute undertakes world-class life sciences research to generate new knowledge of biological mechanisms underpinning ageing, development and the maintenance of health. Our research focuses on cellular signalling, gene regulation and the impact of epigenetic regulation at different stages of life. By determining how the body reacts to dietary and environmental stimuli and manages microbial and viral interactions, we aim to improve wellbeing and support healthier ageing. The Institute is strategically funded by the [Biotechnology and Biological Sciences Research Council](#) (BBSRC), part of UK Research and Innovation, through Institute Strategic Programme Grants and an Institute Core Capability Grant and also receives funding from other UK research councils, charitable foundations, the EU and medical charities.

### **About Sciencewise**

[UKRI Sciencewise](#) is an internationally recognised public engagement programme which enables policy makers to develop socially informed research and policy with a particular emphasis on science and technology. Sciencewise helps to ensure research and policy is informed by the views and aspirations of the public. The programme is led and funded by UK Research and Innovation (UKRI). It provides co-funding and support for organisations to undertake public dialogue.