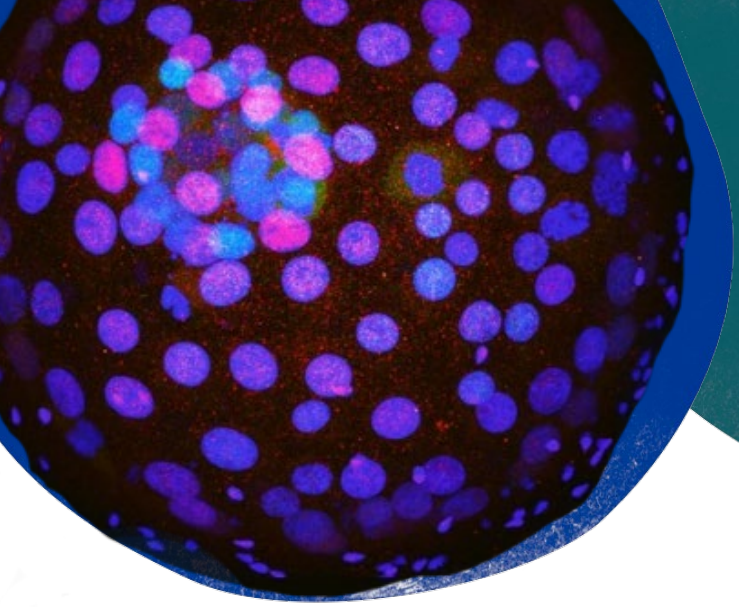

Public dialogue on research involving early human embryos

October 2023

Hopkins Van Mil

Human Developmental Biology Initiative

UK Research and Innovation

sciencewise

www.hopkinsvanmil.co.uk

Bringing people together to inform the future

Contents

Foreword

Our understanding of the earliest stages of human development and the application of this knowledge to benefit society have advanced at an impressive rate over the last few decades. Following the pioneering development of IVF almost fifty years ago, research has continued to illuminate the remarkable processes that enable a single fertilised egg to give rise to all of the different cell types in our bodies. These discoveries have led to unforeseen benefits including improved success rates of IVF treatment, the provision of mitochondrial donation therapies, and better understanding and preventative measures for developmental conditions such as spina bifida.

Advances in human embryo research have also raised important ethical questions. Broad societal discussions in the 1980s, by the Warnock Committee, defined some of these ethical considerations and informed the direction and limits of scientific research and applications. These discussions led to the introduction of regulations that included restrictions on the number of days that human embryos can be developed in a laboratory, establishing in law the '14-day rule'. Similar limits were introduced in many other countries around the world.

Since those important and wide-ranging discussions, human embryo research has continued at pace, with occasional discoveries capturing broad interest but otherwise remaining largely out of the public eye, like many other scientific disciplines. For several decades, the lack of suitable methods meant that the technical possibility of being able to develop human embryos in a laboratory up to 14 days seemed far-fetched, however recent scientific reports from around the world demonstrated the ability of newly developed technologies to maintain embryos up to and potentially beyond the UK limit of 14 days. Together with rapid progress of research using stem cell-based embryo models, these advances open up new opportunities to study stages of human development that are poorly understood potentially leading to human health benefits. At the same time, they also raise the possibility that future research based on these new discoveries could become out of step with societal expectations and values.

The Human Developmental Biology Initiative recognises the need to better understand society's current hopes and concerns for embryo research to ensure that research continues to be carried out responsibly, transparently and with societal consent. We have therefore come together with the UK Research and Innovation's Sciencewise programme to commission this dialogue project to explore the views of the UK public on these issues, with a primary focus on the 14-day rule.

This project is one of the first of its kind worldwide to provide a platform for the public, scientists, law makers and ethicists to engage with this topic in a two-way deliberative manner, and we are enormously grateful to all who took part. Participants of the dialogue have shown amazement at the progress of embryo research. They also voiced their support for continued societal engagement in these discussions and raised important recommendations for how this research is regulated and communicated. The

findings of this project will be used to inform future research programmes and we hope that this initial step to understand people's current views can inspire further work to engage the public in this important area of research.

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Executive Summary

Background to the dialogue

The aim of this public dialogue has been to engage a diverse group of the public to deliberate on how early human embryo research can be used to its fullest in the future, within a framework of public hopes, fears, aspirations and concerns.

Discussions explored current research and regulation and how they might develop and change in the future. The dialogue involved 70 members of the public engaging with scientists, regulators, ethicists, philosophers and people with lived experience to consider the ethical questions and societal implications of early human embryo research.

The Human Developmental Biology Initiative (HDBI) and UKRI Sciencewise co-funded this public dialogue. The dialogue was commissioned in light of recent innovations in techniques to culture human embryos in the laboratory. In the UK, human embryo research is regulated by the Human Fertilisation & Embryology Authority (HFEA). Since 1990, when the UK Human Fertilisation and Embryology Act was introduced, the culturing of human embryos in vitro for scientific research has been restricted to a maximum of 14 days. Based on recent studies, scientists now believe it is possible to culture human embryos in a laboratory beyond 14 days. In response to these developments, the 2021 guidelines of the International Society for Stem Cell Research called for meaningful public engagement to understand how people feel about the 14-day rule today.

The dialogue was designed and delivered by Hopkins Van Mil. Challenge and advice was provided by an Oversight Group comprising scientists, regulators, third sector organisations and those involved in early human embryo research policy.

This foundational piece of work provides an initial step to inform wider public involvement on the topic of early human embryo research and the 14-day rule, in the UK and internationally. The findings provide direction to future public engagement and research by highlighting where there are hopes, concerns and topics that need more exploration.

About the dialogue

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 in each group were as follows:

- Pilot group: 9
- Lived experience group: 19
- Broad public north: 21
- Broad public south: 21

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. This approach was intended to ensure a reflective group of public participants and mitigate against the issue

that can affect engagement processes - that only people with a high interest and campaign groups take part.

The dialogue process for the pilot and lived experience groups involved a webinar and three online workshops. For the broad public groups, the last two workshops were held in-person on a Friday evening and Saturday in Newcastle and London. Specialist speaker presentations, lived experience films and infographic material were used as stimulus for the discussions.

The findings

Early perceptions of human embryo research

Many participants came into the dialogue process knowing very little about early human embryo research. Many quickly became fascinated by what they were hearing. This fascination led to considerable admiration and respect for the science and the people behind it. The ability to study and potential to understand the early stages of human development by looking at something smaller than the width of a human hair is 'mind-blowing' for most participants.

The current gap in knowledge of how an embryo develops between 14 days (the legal limit for embryo research) and 28 days (when embryo material from miscarriage or abortion is available) was easily grasped. This gap was referred to by specialists as 'the black box' during the dialogue, a phrase used in many of the journal and media articles shared with participants.

Many participants see the potential for significant benefits in the future in terms of increasing fertility treatment success rates, reducing miscarriage and improving health outcomes - from further research that seeks to unlock this box.

Ethical, moral and religious considerations featured from an early stage of the discussions, with some participants keen to understand what alternatives might exist that do not involve human embryos.

Early perceptions of the regulation of early human embryo research

Most participants had not heard of the HFEA or the 14-day rule when coming into the dialogue. Many were learning about the legislation and work of the HFEA for the first time during the introductory webinar. What they heard from the HFEA representatives – about the use of Research Ethics Committees (RECs) to review research applications and the licensing process for laboratories, for example - gave most participants a high level of confidence in the current regulatory and legislative structures that surround early human embryo research.

Hopes for the future of early human embryo research

Early human embryo research is a complex, sensitive and emotive subject. Participants were mindful of this as they explored their responses to the research.

The strongest hopes for future early human embryo research focus on those issues that participants either have a personal connection to or where the opportunity for improvement is perceived to be strongest, specifically miscarriage, IVF and health

conditions such as spina bifida which are known to have significant development milestones during 'the black box' period.

The hope that IVF techniques can be improved to achieve higher success rates leads to hopes for related benefits such as reduced cost of treatment (fewer rounds) and raising the age of eligibility for NHS treatment.

The potential to understand, prevent and treat serious health conditions are also strong hopes. During the discussions many shared aspirations for the prevention of disease (such as childhood cancer) but views were more divergent on the prevention of disability (such as Down's syndrome).

A strong theme when discussing hopes for the future of research was that the research would always treat embryonic material with respect due to its link to the origins of human life.

Concerns and ethical dilemmas for the future of early human embryo research

The most significant concerns for the future of early human embryo research focused on eugenics. Some participants worried that enhanced techniques to detect health conditions could then lead to their elimination – with scientists making decisions on which conditions should be 'discontinued' without society's input.

In a similar vein, some participants were wary of extending human embryo research beyond 14 days because it could lead to what they termed 'genetic engineering'. Some feared that this could lead to a desire to create 'perfect' humans, a fear they considered reasonable given the history of eugenics in the not so distant past.

Thinking about who might be involved in the research, particularly in how it is funded, led some participants to feel concerned about a potential profit motive. They thought commercial funding of human embryo research into new IVF techniques could lead to treatments only accessible to those who could afford to pay for them.

However, whilst these concerns were strongly held by a few participants, they were also balanced by a strong belief that if this area of research continues to be robustly regulated and scientists work in harmony with society's expectations – such as around disability and accessibility of treatments - then beneficial outcomes for health and fertility can be achieved and should therefore be supported by society.

Stem cell-based embryo models

Stem cell-based embryo models are astonishing and complex to participants. They were a new discovery for almost all participants. Indeed, during the dialogue there was extensive media coverage about their development following scientific presentations at an international stem cell conference in June 2023[1].

Participants held a range of views on their ethical status - from being the same as a human embryo, to being 'biological material' similar to DNA.

[1] International Society for Stem Cell Research (ISSCR) Annual Meeting 2023, see: https://www.isscr.org/upcoming-programs/isscr-2023

The models are seen to offer benefits such as supplementing the scarce resource of human embryos, enabling learning about human development and in the future reducing or potentially replacing the need for human embryos in research.

Many participants want to see these models regulated. They are concerned that without regulation, scientists could use models as alternatives to human embryos in ways that could harm society, such as using models for experiments for well beyond 14 days or even creating an alternative form of human life.

A summary of responses to changing the 14-day rule

It is important to note that participants were not given a specific set of options for changes to the 14-day rule to consider during this process. Given the exploratory and foundational nature of this dialogue that would not have been appropriate. Rather, participants heard views from a range of scientists, ethicists and philosophers as well as each other's perspectives.

Many participants support some form of extension to the number of days or a change to the rule if it is informed by society's expectations about respect for the embryo and the research continues to be robustly regulated.

Participants have high expectations of scientists, regulators and the need to involve the public in future decision making on the research and the 14-day rule. They believe that greater transparency is necessary across all aspects of this work so as to raise public awareness of the need for research in this area prior to any national conversations on potentially changing the 14-day rule.

The most compelling reasons to explore some form of change to the rule are that there is potential to improve IVF success rates, reduce multiple miscarriages and to better understand, treat or prevent serious health conditions.

Views differed between and within groups on how the 14-day rule should change. Some participants believe that change should be taken in small steps, such as a 3-4 day extension, followed by review. They want a cautious approach that may result in a gradual extension beyond 14 days based on research learnings and in consultation with society. The idea of a trial extension appeals to some for the same reasons. These suggestions were made in particular by those in the broad public south group, where participants' interests often led them to prioritise the process of how decisions about extending the rule are made and communicated.

Other participants, particularly those in the broad public north group, believe extending to 28 days should be considered because it offers the opportunity to unlock 'the black box' and deliver significant new discoveries, such as the causes of and treatment for spina bifida. For many of these participants, the prospect of carrying out research on an embryo at 28 days posed no significant new ethical considerations when compared with an embryo at 14 days. The adoption of 28 days as a future milestone is also seen to benefit from having a relevant biological marker, in this case the closure of the neural tube, which could function in a similar way to the emergence of the primitive streak around 14 days. Some also based their support for 28 days on a perception that this is a preference among researchers in the field, whose views they wanted to take into account.

A few participants want no change to the rule – either because they thought research efforts should continue to focus up to 14 days if there were still discoveries to be made or because they opposed all forms of early human embryo research.

At the other end of the spectrum, a few participants want to see the rule abolished or extended considerably to allow research studies and the length of time they need to study human embryos to be considered on their individual merits. Some of these participants worry that the process of parliamentary debate to change legislation would turn the complex issue of regulating human embryo research into a political football and delay or prevent future research.

The following points should be taken into account when considering how participants reflected on changing the 14-day rule:

- Uncertainty for some about what benefits can accrue from extending the limit – noting the nature of 'the black box' - can the benefits of unlocking be further clarified before the key is turned?
- Some participants are concerned about developmental milestones in the embryo and, for example, when the embryo will feel pain.
- Some participants think it is important for donors to have a say on how long research can happen on the embryos they donate.
- Thinking about how to ensure the UK is not out of step with other countries if the 14-day rule is change/ or is not changed – how could global scientific collaboration be supported and not damaged?

Proposals for further explorations of the topic

Given some participants' serious concerns about eugenics, discussions about genetic testing should be separated from discussions about the 14-day rule and it may be appropriate to explore the former via a further deliberative exercise.

Early human embryo research is a developing area of science, and essentially new to many people across society. Analysis of the language used by participants in their responses to the topic was beyond the scope of this dialogue. However, we recommend that HDBI builds on the work they have already done to explore public and scientist use of language in the area of early human embryo research. Understanding more about differences in the language used by citizens and scientists, in particular what words are used to describe early human development will inform national conversations on the topic. Such a research study[2] would provide valuable insights for scientists as they engage with people across society in this field of research in the future.

Proposals for further public dialogue

As a result of their deliberations, participants see the need for further national conversations on the science and the regulation. Three such proposals are made:

[2] Middleton, A et. al. The legacy of language: What we say, and what people hear, when we talk about genomics: August 2023, is a useful example of the use of language in genomics research.

1. A forum to understand the views and perspectives of scientists

Hold a forum for scientists and researchers in which the various changes to the 14-day rule are mapped out, with pros and cons for each established. Hold a deliberative space within the forum for the above to be discussed and so that the hopes, concerns, expectations and perspectives of scientists, both as researchers and people in society, can be better understood.

2. A wider public dialogue

Hold a dialogue with a greater number of people in different settings, for example in communities and youth groups across the country. Participants see dialogue as useful in raising the profile of this research and its regulation, engaging civil society in the conversation, including community and faith groups. It will be important to engage equally with those likely to oppose change, those who would not know what their view is until taking part and those who naturally support scientific research.

3. Hold separate conversations about stem cell-based embryo models and genetic testing

The newness and complexity of stem cell-based embryo models and the current lack of specific regulation merits a separate, more in depth public conversation. Engagement on these models, how they differ and how they could be used in research would allow them to be explored and understood and lead to recommendations on how these entities should be regulated.

1. Introduction

1.1 Background

The Human Developmental Biology Initiative (HDBI) and UKRI Sciencewise co-funded this public dialogue to better understand public hopes and concerns around research involving human embryos.

In the UK, human embryo research is regulated by the Human Fertilisation & Embryology Authority (HFEA). Since 1990, when the UK Human Fertilisation and Embryology Act was introduced, the culturing of human embryos in vitro for scientific research has been restricted to a maximum of 14 days. It applies to early human embryos that are donated with consent to be used in research because they are no longer needed or because they are unsuitable for fertility treatment.

The dialogue was commissioned in light of recent innovations in techniques to culture human embryos in a laboratory. Based on recent studies, scientists now believe it is possible to culture human embryos in a laboratory beyond 14 days. In response to these developments, the 2021 guidelines of the International Society for Stem Cell Research called for meaningful public engagement to understand how people feel about the 14-day rule today.

This foundational public dialogue is planned to be an initial step that informs wider UK public engagement on this topic and will provide direction to future public consultations and research.

1.2 Project partners

The Human Development Biology Initiative (HDBI) is a Wellcome-funded research consortium based across multiple research institutions in the UK and two in Europe. The consortium brings together several of the leading research labs in the UK who are working on early embryos. HDBI aims to better understand how humans develop before birth, looking at four particular areas of development: the early human embryo, the brain and spinal cord, the blood and immune system, and the heart and lungs. HDBI researchers work with human foetal and embryonic tissues that are donated to research after abortions or fertility treatment as well as eggs and sperm donated specifically for research.

UKRI Sciencewise is an internationally recognised public engagement programme which enables policy makers to develop socially informed policy with a particular emphasis on science and technology. Sciencewise helps to ensure policy is informed by the views and aspirations of the public. The programme is led and funded by UK Research and Innovation (UKRI).

Hopkins Van Mil is an independent social research agency specialising in public deliberation methodologies. HVM creates safe, impartial and productive spaces to gain an understanding of people's views on what matters to society. HVM's work brings people from across society together to hold a lens up to issues which are contentious, emotionally engaging and on which a broad range of viewpoints need to be heard.

This public dialogue was conducted in line with Sciencewise Guiding Principles and Quality Framework[3]. The work was supported by a Sciencewise dialogue and engagement specialist. An independent evaluation was commissioned from URSUS Consulting providing a formative and summative evaluation of the process.

As with all Sciencewise public dialogues an Oversight Group (OG) was established for the project. Members of the OG included scientists, academics and third sector organisations who provided challenge, guidance and advice on the dialogue scope, design and delivery[4].

1.3 Aims and objectives of the dialogue

The overall aim of the public dialogue has been to engage a diverse and inclusive group of the public to deliberate on what conditions should be in place to ensure that early human embryo research can be used to its fullest in the future within a framework of public hopes, fears, aspirations and concerns. In line with this aim, the dialogue sought to:

- Develop a holistic understanding of participants' views of the societal and ethical issues around human developmental biology research.
- Identify participants' views of the research questions and outcomes of human developmental biology research that reflect societal priorities.
- Enable scientists and public participants to engage in a constructive dialogue to hear, reflect, consider and respond to issues around the research.

To contribute to these objectives, the dialogue considered research questions posed by HDBI at the beginning of the project:

- What do participants perceive to be societal implications of research with early human embryos?
- What ethical questions do participants raise around research with early human embryos?
- What implications / applications of research with early human embryos are most important to participants? Where should scientists be focusing in this area?
- What should the future of embryo research in the UK look like?
- What do participants think about the trade-offs for possible medical/healthcare implications of this research and where do the red lines exist?
- How does the 14-day rule factor into their thinking about possible outcomes?
- How do emerging alternative research models in this field affect their views?

1.4 Participant involvement

A total of 70 participants from across the UK took part in the dialogue: 9 in a pilot process; 19 people with lived experience of the topic (see bulleted list on the next page); 42 participants broadly reflecting the demographics of the UK population.

All participants were recruited using purposive sampling against a specification agreed by the project team. This approach ensures that the issue that affects many traditional consultation processes - that only people with a high interest and campaign groups take

[3] https://sciencewise.org.uk/about-sciencewise/our-guiding-principles/
[4] See Appendix 2 for the full membership list

part – is avoided. Sampling ensured a balanced spread across factors including age, gender, geographic location, life stage and multiple socio-economic indicators. For the lived experience group, we specifically recruited people with the following characteristics:

- Experience of fertility treatment for a range of reasons.
- Experience of recurrent miscarriage.
- Living with long term health conditions.

We set minimum recruitment numbers for some factors to achieve the required levels of participation among people experiencing racial inequalities and people with a range of religious beliefs. We also specified a range of levels of awareness of the Human Fertilisation & Embryology Act (HFE Act) and the 14-day rule and a range of support and opposition for early human embryo research.

All participants received a payment in recognition of the time commitment made. The majority[5] of participants took part in over 15 hours of deliberation (13 hours in workshops and an estimated minimum 2.5 hours reviewing and responding to material on the online space). Further detail on the recruitment process and specification is provided in Appendix 4.

Research on early human embryos is a complex and sensitive topic. From the very start of the dialogue process participants were offered several different sources of support if they were troubled by anything raised. This included access to a counsellor for individual one-to-one support, speaking with the dialogue facilitators or accessing helplines through details provided in the participant handbook.

The participant handbook was sent to all participants in advance of their first workshop. In addition to guidance on support, it contained practical details for taking part. This included how to join Recollective, an online space which participants used in their own time to take part in activities designed to enable participant reflection and comment on the dialogue topics and stimulus materials. Information on what to expect during each workshop was also provided in the handbook, such as session aims, a programme of activities and information about the facilitation team.

1.5 Why public dialogue?

Before describing the dialogue process in detail, it is worth reflecting on why a public dialogue approach is appropriate for a complex and sensitive topic such as early human embryo research and its regulation. Public dialogue does not use quantitative techniques or engage large numbers of people. It is not a transactional information exchange, or a public understanding initiative, nor does it set out to test what people do and do not know about a subject.

Dialogue works when small groups of participants interact on a level playing field with specialists: scientists, academics, ethicists, those that inform, challenge and make policy, and those with lived experience of the issue under discussion. This specialist evidence is then viewed through the lens of participants' own lived experience, acting as

[5] All those except pilot participants, who took part in a condensed process comprising 8 hours of workshop time and approximately 1 hour on the online space.

a provocation which leads to rich and powerful insights. Such an approach enables participants to engage and explore a topic in-depth, regardless of prior knowledge.

In public dialogue, citizens come together, with sufficient time to reflect, to:

- Learn about the issues.
- Talk with, not past, each other.
- Consider diverse points of view.
- Discover key tensions and values.
- Spark new thinking and ideas.

This process leads to a deep understanding of what people value, what they are concerned about, their priorities and the principles they apply to this prioritisation. HVM facilitators are key to gaining this understanding. They ensure there is a balance in small group discussions which allows people freedom to express their views whilst not allowing the process to lose the important focus on the dialogue scope or for the discussions to be derailed. This report sets out the findings that have emerged from this public dialogue process. How we designed and facilitated the process is set out in the next section.

1.6 The dialogue process

The pilot group tested the stimulus materials and the narrative flow of the project in advance of the full rollout. Their views and opinions on the topic were valuable, even though delivered in this testing mode, and we have therefore included the data gained from their work in the qualitative analysis. To have effective small group workshop discussions, the participants broadly reflective of the UK worked in two groups which we called broad public north and broad public south. Participants were allocated to these groups based on the location it was most convenient for them to attend in-person.

The dialogue process of a webinar and three workshops took place on Zoom for the 19 members of the lived experience group. The broad public north and south participants took part in the webinar and workshop 1 online (using Zoom). For the final two workshops, the groups met in person: the broad public north group in Newcastle and the broad public south group in London, meeting on a Friday evening and all-day on Saturday.

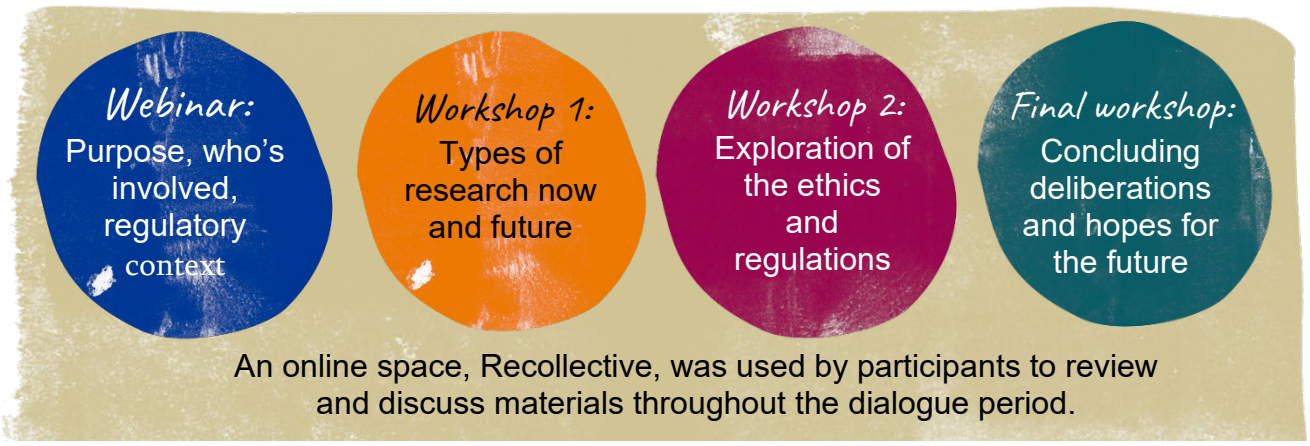


Figure 1: An overview of the dialogue process

Workshops were spaced over a two-week period to ensure they were not overwhelming. This schedule also gave participants time to think and consider the issues outside of the scheduled workshops. Workshops were designed using Plain English materials and with frequent summaries of what had been shared and discussed previously to keep participants focused on the dialogue scope, and to enable the discussions to develop based on what had previously been discussed.

Throughout the dialogue the online space, Recollective, was available for participants to review and discuss materials. These included short films, news articles, presentations, answers to questions raised during the dialogue and summaries of small groups discussions.

Speakers who took part in the dialogue included researchers, clinicians, people with lived experience of the topic, ethicists, philosophers and regulators. A full list of speakers is provided in Appendix 3, a fuller description of the process is available in Appendix 6.

The dialogue included exploration of concepts and research terms unknown to many at the beginning of the dialogue. A glossary of the terms used in the process and in this report is included at Appendix 1.

1.7 About this report

Public dialogue reports are qualitative in nature. As such we do not report on the number of times something was said, but rather the strength of feeling expressed across the methods used. For this project we used grounded theory, which means we read, and re-read, the transcripts many times. We collated what was said into key themes and used those themes to draw out meaning from the discussions. We chose this approach to ensure the findings are rooted in what participants tell us, guided by the dialogue objectives and the research questions, rather than looking for confirmation of preconceived ideas.

As such we use the following quantifiers in the report:

- ‘Many’ or ‘most’ when it is clear that all or almost all participants shared a similar view.
- ‘Some’ when a reasonable number of participants shared a similar view.
- ‘A few’ when a small number of participants shared a similar view.

Bullet points are used to summarise key points made. These mostly reflect areas of agreement and where points were made by many participants across many groups.

Anonymised quotations are used to highlight points made by a number of participants and to underline points made by a range of people. They also highlight points of particular significance to participants.

Reading this report

Those reading this report will find:

An icon like this illustrating a key topic or theme. 

*"**Quotes** set out like this. Quotes are used throughout the report to illustrate points, not replace narrative. These are provided verbatim in participants' own words, we remove filler words, but do not make changes to spelling or grammar so as not to distort the participants' meaning".*

Key messages

Are presented throughout the report in text boxes with a coloured frame like this one. They highlight key points made on the topic being described in the chapter.

The findings are presented from the following chapter onwards.

2. Early human embryo research and regulation: where we are now

In this chapter we set out participants' initial perceptions of the dialogue topic and the views they shared towards the beginning of the process. We summarise participants' early responses to stimulus materials. Early views on both the research and regulation are explored. This includes participants first thoughts on the 14-day rule and regulation including the role of the HFEA and Research Ethics Committees (RECs)[6].

In the recruitment questionnaire for the dialogue, participants were asked about their awareness of the HFE Act, the 14-day rule and 'to what extent they support or oppose the use of early human embryos (up to 14 days after fertilisation that are donated from fertility treatment) in scientific and medical research, for example to help understand and develop treatments for infertility or developmental conditions?' The aim was to achieve a mix of awareness and attitudes. Figure 2 illustrates the early level of awareness of the Act and the 14-day rule.

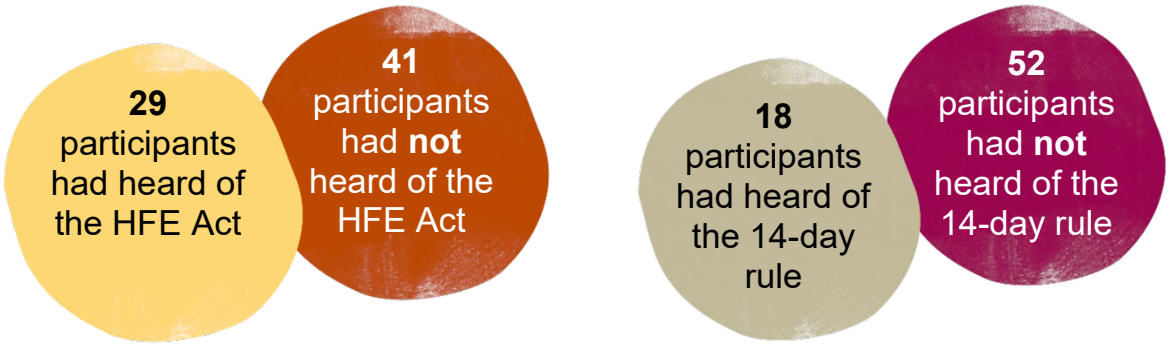


Figure 2: Initial awareness of the HFE Act and 14-day rule.

When asked about the use of early human embryos (up to 14 days and when donated from fertility treatment) in scientific and medical research:

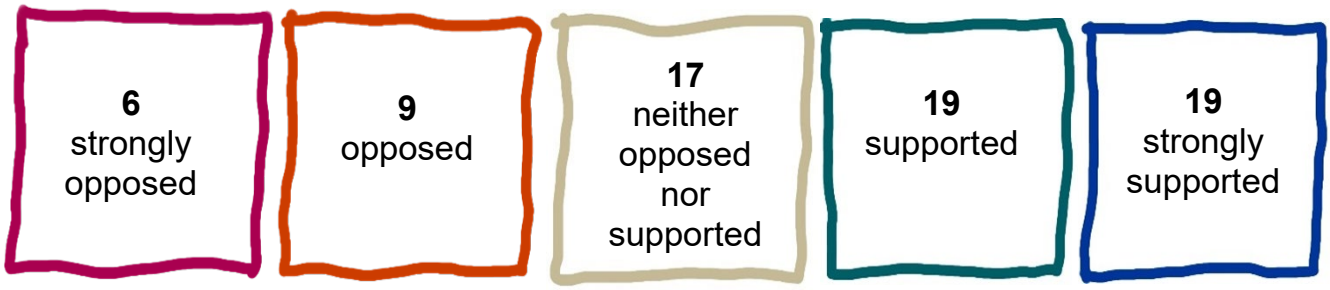


Figure 3: Initial views about the use of early human embryos in scientific research

There is very little difference in the subgroups in terms of support or opposition to this research, except that slightly more people in the broad public north group initially expressed neither opposition nor support; and slightly more people in the lived experience group strongly opposed the research.

[6] A REC is a diverse group of people appointed to review research proposals to assess formally if research is ethical. This means the research must conform to recognised ethical standards, which includes respecting the dignity, rights, safety and well-being of the people who take part.

A representative from the HFEA explained its role in the research process and the wider regulatory framework. In between the workshops, lived experience films[7], newspaper articles, podcasts and responses to participants' questions were also posted on Recollective to help participants absorb the current landscape of research and regulation.

The workshop discussions prompted participants to start sharing their initial reactions to what they had heard about early human embryo research and its regulation, including any positive or negative thoughts and associations. Participants also had the opportunity to pose questions to the experts to help clarify their understanding.

This section of the report presents the findings from these initial perceptions and summarises what participants felt about:

- Current early human embryo research.
- Current regulation of early human embryo research.

2.1 Initial perceptions of early human embryo research

Current research: key messages

There were low levels of pre-existing knowledge amongst dialogue participants on all aspects of early human embryo research and the regulation.

- Participants quickly became fascinated by what they were hearing and have considerable admiration and respect for the science and the people behind it.
- The current gap in knowledge between 14 and 28 days was easily grasped, and participants see the potential for significant benefits in the future from further research.
- Ethical, moral and religious considerations featured from an early stage of the discussions and participants are keen to understand what alternatives might exist that do not involve human embryos.

In order to contextualise current early human embryo research, the presentations and materials explained that there are two main types of research in human development biology:

- **Blue sky research** which aims to generate fundamental new knowledge about how embryos develop, with the potential to impact on healthcare in the future – for example, in understanding the causes of spina bifida, and childhood cancers.
- Research with **near-term applications** which aim to improve treatments in the next five to ten years – for example, improving fertility treatments and reducing early miscarriage.

[7] These included people who have experience of fertility treatment and/ or recurrent miscarriage; researchers on disability in this context; those who oppose early human embryo research; a member of a Research Ethics Committee; researchers working on early human embryos and their motivations for doing so. Examples of these stimulus materials can be found provided alongside this report post-publication.

Examples of the practical application of research shared with participants included: advances in IVF; mitochondrial donation; the discovery of the role of folic acid supplementation in reducing the risk of congenital disorders; and pre-implantation genetic testing for those with an increased susceptibility to certain types of conditions. This was important to participants who were fascinated by the real-world examples, some of which they had been aware of, particularly the role of folic acid in pregnancy.

Initial awareness of research and the 14-day rule

There was generally a low level of awareness of early human embryo research at the start of the dialogue, including who is involved, how it takes place, and what it is trying to achieve. Based on the questions all participants answered as they joined the dialogue, almost half of the participants recruited to the process overall have some lived experience of IVF, miscarriage or are living with, or are closely related to people with, long-term health or childhood development conditions. However, this did not necessarily translate into knowing about the broader landscape of early human embryo research. It was common for participants to express that it was something they had not fully appreciated or given much thought to.

> *"I don't really know a lot about embryo research. I'm really interested in the information that we're going to hear… When I was reading some of the information I was quite curious about the stages of the embryo."* **Broad public group, north**

> *"There's a huge amount of research in the cancer field, but it didn't even occur to me that embryo research could potentially benefit that more generally. I certainly wasn't aware of that. I'm sure that's probably not widely known."* **Broad public group, south**

The presentations and background materials explained the 14-day rule to participants, outlining how the limit to current research on early human embryos is at 14 days, or when the primitive streak forms.

Initial reactions to the 14-day rule were mixed, which can be attributed to different levels of understanding coming into the dialogue. Some participants were aware of the 14-day rule and could explain a bit about what it entails. Others were aware of the rule, but did not know any detail, or what it meant in the context of human embryo research. A few participants had not heard about it at all or said they had initially connected it to abortion limits before realising the difference.

Reflecting on the 14-day limit, participants expressed some surprise that the rule has been in place for over 30 years and that there have not been attempts to extend it before now.

> *"I just wondered, had the attempt to extend the 14 days ever happened before or is this the first time that this research surrounds that?"* **Pilot group**

Fascination and amazement

There was a sense of excitement and fascination that came out of early exposure to the topic. Comments along the lines of "*it blows my mind*" and "*it has opened my eyes*" were frequent. Some participants were captivated by the idea that something so small and imperceptible to the human eye could do so much in a short space of time. Participants

were particularly interested in how "*intelligent*" cells are by dividing and forming different parts of the body. Questions raised at this point demonstrate that participants wanted to know more about how and why cells keep dividing, and how they know to change.

The presentation on stem cells from the Crick Institute piqued participants' curiosity in some of the breakout groups. Questions included:

- How are pluripotent cells identified?
- How are pluripotent cells converted into adult stem cells?
- Have there been any experiments using pluripotent cells to understand more about genetic conditions?

This fascination and amazement led many to speak of their respect and admiration for scientists working in this area. Some participants considered scientists to be 'brilliant' as a result, and seem to implicitly trust them:

> *"There are loads [of people] involved in this. Loads of highly intelligent people that know what they're talking about. Sit back, listen, and learn."* **Broad public group, north**

Early human embryo research achievements

The workshops involved discussions on how early human embryo research has developed so far. Many participants wanted to know what has been discovered already, and what might be possible in the future.

In the early familiarisation period, discussions around IVF tended to dominate when reflecting on research achievements. The low rates of IVF success (1 in 3) [8], and high rates of miscarriage were a surprise for some participants.

> *"I'm somewhat surprised at the low success rate of IVF. Even after 40 years of research, it leaves me a little bit stunned."* **Lived experience group**

Questions were raised across the broad public and lived experience groups about:

- Different types of miscarriage – what has happened and why?
- What can be done around implantation failure?
- Whether research into IVF can benefit understanding about natural conception at the same time?

> *"Hopefully it can lead to a more open-minded and a more informed science about embryos, and how they develop and how that can end up with fewer people struggling to become parents or losing children."* **Broad public group, north**

The realistic and practical applicability of early human embryo research clearly appeals to some participants. They considered it a route to more people carrying babies to term and being able to conceive in the first place using fertility treatments. These factors are seen as being part of the 'for the greater good' role of science and scientists. Participants talked about future benefits to quality of life for those trying to conceive.

[8] 'Preliminary average IVF birth rates using fresh embryo transfers for patients aged 18-34 were 33% per embryo transferred, compared to 4% for patients aged 43-50 when using their own eggs in 2021.' For further information, see the HFEA's reporting on this: Fertility treatment 2021: preliminary trends and figures | HFEA

Even when participants do not have lived experience of IVF or miscarriage, many know friends or family who do, and are aware of the emotional and physical impact it can have. Some participants reflected on whether if more was understood about miscarriage they would have seen people they know carry more babies to full term. This leaves them to wonder if the reasons for not being able to conceive and recurrent miscarriage could be somehow linked.

Participants also expressed interest in how early human embryo research might help to improve the detection of certain conditions, and lead to advances in both prevention and treatment.

Participants with lived experience in one breakout group focussed on how terrifying it can be to find out about conditions at a later stage of pregnancy, and the heartbreak of loss. They said they feel strongly that the potential for earlier diagnosis would be helpful.

> *"I lost a baby, due to spina bifida. If they had done maybe some research on this, potentially that baby could have lived… If there's anything that's going to help them to overcome some of these challenges that we have at early development, then I'm all for it. Obviously, I'd want it to be ethical, and I want it to be done in the right way."* **Lived experience group**

Questions included:

- What other conditions could be researched in the future?
- Could this include neurological conditions?
- Could some conditions be eradicated in the future?

Some participants on hearing of scientists asking for an extension to the 14-day rule assumed that all research on human embryos up to 14 days must have been exhausted. They understood this to be the reason for opening up new avenues beyond 14 days. Whenever this was raised, scientists spoke about research still needing to be done up to 14 days.

> *"From zero to 14 days now that they've learned everything that they're going to learn that they've done all their research. And now they need to go into the unknown."* **Broad public group, north**

'The black box' between 14 and 28 days

Participants understand the notion of 'the black box' between 14 (the limit for human embryo research) and 28 days (when embryos from miscarriage and abortions are first available), and the current limitations on knowledge about what happens during that period of development. This generated much discussion in the workshops from an early stage. Some of the questions were:

- What information are scientists looking for during that 14 to 28-day period? What do they know now, and where do they want to get to? What might they discover?
- Can scientists actually grow embryos beyond 14 days in the lab?
- Do scientists have a clear idea or consensus on how many additional days they would ideally like?

"If they were given the green light to go beyond that 14 days, I would say, what the science could find out would be absolutely fascinating." **Broad public group, south**

There were some participants who expressed hesitation from the outset about extending the 14-day rule. As a result of this hesitancy they want to see an incremental or trial approach to avoid the 'slippery slope' from happening.

"If we move it, does that open the floodgates to being able to move it indefinitely? Because we've set the precedent of 28 days? Well, we could make it 50. Or we could make it this and that. So my question is what are they actually proposing to move it to? And then what is that based on evidentially?" **Lived experience group**

2.2 Perceptions of the regulation of early human embryo research

Key messages on perceptions of current regulation

There is a high level of confidence in the current regulatory and legislative structures that surround early human embryo research.

- Having independent RECs, with a range of members drawn from science, law and the public, that spend considerable time and effort reviewing research applications is valued.
- The system of inspections and licensing run by the HFEA is seen as reassuring and gives participants confidence that research is closely monitored.
- Questions were raised about RECs some participants wonder whether lay members serve for too long and risk being institutionalised.

The UK's current regulatory framework around early human embryo research aims to allow ground-breaking research, but within tightly defined boundaries. Participants were given information to show the regulatory timeline from the start of IVF research in the 1940s through to the first babies being born following mitochondrial procedures in 2023.

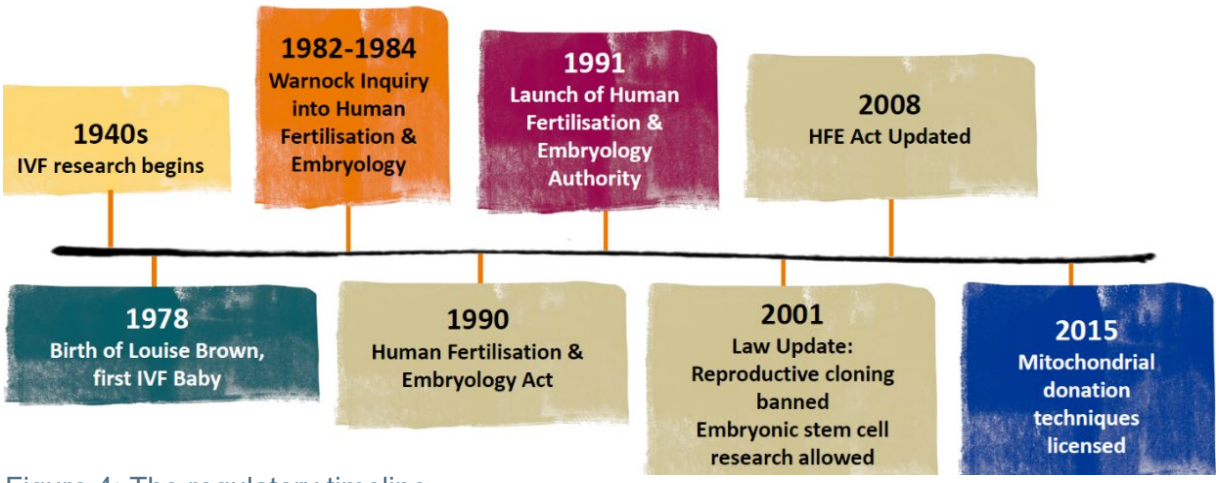


Figure 4: The regulatory timeline

The presentation given to each group by a representative from HFEA informed participants about the organisation's role and responsibilities in regulating early human embryo research as outlined by the HFE Act. The aim of this was to ensure participants understood:

- The HFEA's role.
- That there are strict laws in place about what human embryos can be used for.
- That scientists can only do research with human embryos if they have an HFEA licence for a specific project.
- Acquiring a licence can take around 18 months and applications are examined in great detail to ensure that the project has the potential to provide new knowledge about one of the permitted purposes, such as advancing the treatment of infertility.
- The HFEA regularly inspects labs to ensure research is carried out properly.
- RECs scrutinise applications and these are composed of research professionals, ethicists, statisticians and lay members.
- The 14-day rule is a clear red line in the regulations, and it is a criminal offence for scientists to grow embryos for more than 14-days, or beyond the appearance of the primitive streak, whichever is sooner.

Finally, participants were given a map showing some of the different rules and regulations across the world, and how these compare with the UK.

Reactions to the regulatory framework

As understanding of the legislative and regulatory frameworks grew, so did participants' confidence in them. There is general consensus that regulation is essential, and it is right that such a sensitive area is tightly controlled. There is a strong belief that it should not be easy to get a licence, that scientists should be able to justify what they are doing and be prepared to open their plans to scrutiny and transparency from a very early stage.

Many participants feel reassured that there are essentially two limits in place. A chronological limit, expressed in the 14-day rule, and a biological limit: the formation of the primitive streak. These are both reassuring limits because they can be monitored. Participants also believe that those who might review the legislation in the future should think about this two-limit reassurance and factor it into any change to the law.

> "*I think it's quite easy for us to focus on time but actually the physical makeup of the embryos is really key as well because they develop at different rates… The more I reflect on it, the more the morphology feels more important than the time.*"
> **Lived experience group**

HFEA and RECs

The independence of the HFEA is widely seen by participants as an asset, particularly its inspection powers and its separation from Government. Some participants also focussed on the fact that the HFEA is involved throughout the licensing, meaning they can help suggest changes or improvements to applications and ensure they are within the limits of what is permitted in law.

The existence of RECs and the role they play in approving research was new to many participants. As more information about RECs was shared via stimulus and speakers, they likewise came to be seen as an important and reassuring aspect of the regulatory system. They are viewed as an additional way of aligning embryo research with ethical and societal considerations, not just scientific standards.

With this in mind, participants support the inclusion of people with a range of different perspectives on RECs. Participants consider that if the committees only had a scientific membership, then ethical debates would risk being lost. At the same time, some participants express concern over the length of time people serve on RECs, particularly lay members who they feel should rotate more frequently to prevent sole individuals from establishing close ties or a long-term influence.

Donor consent

Participants heard about the informed consent process, counselling on offer, and that donors are given as much time as they need to decide what to do with their embryos.

A few participants in the lived experience group shared positive reflections on the consent process and its overall clarity. They believe it is clear to donors what will happen to their embryos. They feel that people are given wraparound support, understand what will happen to their embryos and are aware that licensed clinics operate to high standards.

> *"It's not just about the sort of physical, the scientific, it's about the emotional, about the ethical. And everybody in the clinic that we went to was really working to these high standards."* **Lived experience group**

Despite the positive experience some could share, other participants wanted to understand more about whether donors have a choice about which research programme they can donate to, and whether they have the option to withdraw their consent to donate to research.

The risk of regulation restricting scientific advancement

Whilst many participants welcome the rigour of the UK's regulatory framework, some participants feel that it is out of date and too inflexible. Some participants wanted to understand if the regulation is getting in the way of the science progressing, or if the research itself is limited at this stage by what is scientifically possible.

There is fear that if other countries go further, that the UK will lose scientists to work overseas.

> *"The other thing is, say, for instance, the USA decided they were going to go for 20 to 28 days, and we don't, where does that leave us?... If I was an embryologist, I'd be going and working in the US."* **Broad public group, south**

Some participants expressed frustration with the 14-day rule as it stands, believing that it is a block to improving some health outcomes and stifles the development of technology.

> *"I feel that the 14-day rule is holding back technological development, which could speed up if it's allowed to progress, it could speed up the research."* **Lived experience group**

3. Hopes and concerns for the research

In this chapter we explore the hopes and concerns participants have for early human embryo research and what it could lead to in the future. It also covers how participants responded to stem cell-based embryo models.

3.1 Research: Hopes for the future

Research – hopes for the future: key messages

The strongest hopes for future early human embryo research focus on those issues that participants either have a personal connection to or where the opportunity for improvement is perceived to be strongest, specifically miscarriage and IVF and health conditions which are known to have significant development milestones during the 'black box period' such as spina bifida.

- The hope that IVF techniques can be improved to achieve higher success rates, leads to hopes for related benefits such as reduced cost of treatment (fewer rounds) and raising the age of eligibility for NHS treatment.
- The potential to understand, prevent and treat serious health conditions are strong hopes, but views differ on the prevention of disease vs disability.
- The 14-28 day black box of embryo development is, for participants, a compelling example of a knowledge gap about human development that many participants hope can be unlocked and yield a wide range of learnings that lead to improved health outcomes.

Improving the success rate of IVF

Improvement to IVF is one of the clearest areas in which participants place their hopes for research with early human embryos. They view this as an area of research in which researchers' intentions are good and the potential breakthroughs it offers could reduce suffering. This is understandable given that IVF was one of the main ways in which participants shared awareness or connection to the topic in their initial discussions.

Participants hope to see wide-ranging improvements to IVF. At the core of these is an expectation that its success rates could improve significantly from the current one in three. Improvements here feel like a tangible prospect.

> *"We also just said that we want IVF to be more successful than one in three, because we don't think that's like a good number. So that's like a big push."* **Broad public group, north**

Some suggest improvements to IVF are important for people to feel like they are getting something back from this research and it can deliver positive outcomes for society.

> *"More success with IVF, we all agree that we need something positive that we expect from the research."* **Broad public group, north**

> *"I'd say my views have changed through the workshops. I originally didn't really agree with the extension of the days. But now hearing the videos and different people's views. I'm for it, because I think if it can improve the success rate of IVF I think it's a good thing."* **Broad public group, north**

Many, particularly those in the lived experience group who have had fertility treatment, consider the current system to be unfair and inequitable. They would like to see IVF become more affordable and can see this being made possible by improvements to the technique itself. In line with this, participants hope IVF could become more widely accessible on the NHS - by virtue of becoming more efficient and less costly.

For some participants, an important outcome of extending the 14-day rule would be more inclusive access to IVF and wider availability on the NHS, particularly for people:

- Aged 40-42.
- Wherever they live in the country.
- Whether or not they already have children.

Participants spoke about it becoming more common for people to have children in their forties and consider the wider trends in society that make this more likely, including the cost of living and house prices. They would like to see research undertaken which improves the success rates of techniques such as IVF at this age, because it is currently much lower than for women under 40. Some therefore also suggested the assistance available on the NHS, including in the form of IVF, should reflect this shift towards more people trying to have children over forty. One participant suggested such a change in policy could have circular benefits by increasing the number of embryos available to research and therefore supporting research which may in turn directly benefit patients too.

> *"The NHS don't fund after a certain age. I think the age limit should increase. Because if women have the ability to conceive naturally after that date, then I think that should also increase the age limit for the funding as well. And many women don't go ahead with IVF, just because of this reason. If that happens, you may end up having more donations for the embryos as well, to be honest. And it will help not only with the research, but also with the success of IVF.* **Lived experience group**

Understanding and preventing miscarriage

Participants expressed similar levels of hope about the impact research could have on people who experience miscarriage. Participants identified two key issues which they feel research on early human embryos should address in relation to miscarriage: reducing the rates of multiple or recurrent miscarriages and understanding the causes of miscarriage. Some participants spoke of their own experience of miscarriage and the influence this has on how they view the significance of research in this area and the potential impact it can have.

> *"After having four miscarriages and giving my samples to the lab constantly for many years, they failed to find the cause. And then finally, I ended up having a successful pregnancy and I gave birth to my boy. After that, I tried having another baby, but I was not successful. I continued having miscarriages. And the last one I had was just in April this year. Prior to having a miscarriage I went through IVF. So my belief now has changed, even though I was not in favour of doing this*

research altogether at one point, but things have changed in the last few years, especially because I think researchers need more time." **Lived experience group**

Participants would like greater understanding of the causes of miscarriage in order to try to prevent them from happening in the first place. They also consider this knowledge important for the well-being of people who experience miscarriage.

> *"It would maybe be good for the person who has had the miscarriage for them to know 'well there would be such and such wrong and would your body reject it' because it could be a lot of people out there - I blamed myself for a long, long time. What did I do wrong? Did I lift something heavy? Did I do this? Did I do that? It can be quite daunting so I think it would put a lot of people's minds at rest, if we could, maybe one day find out."* **Broad public group, north**

Understanding and treating health conditions

Human health and illness is the third key area in which participants place their hopes for early human embryo research. This strikes many participants as an area through which increasing the scope of early human embryo research could clearly translate into benefits for society. Participants referred to a variety of specific conditions, including Down's syndrome, spina bifida, Alzheimer's disease and motor neurone disease, as well as illness and disease in more general terms.

Participants spoke broadly about the need for research which leads to improvements in the prevention of disease, as well as treatments and cures for people who need them. They would like to see research develop insight into the causes of conditions, particularly cancer, heart disease and spina bifida, and in doing so improve the range of options available to people with the potential to be affected by them. There is also hope that findings from research can be applied to interventions during pregnancy, such as with the use of folic acid supplements to promote healthy development.

> *"They were saying that spina bifida occurs between 14 and maybe 28 or more days, which is when the neural tube is forming and should be closing, but maybe they don't understand why it doesn't. That was a really interesting thing that could be possibly achieved by the 14-day rule being extended, because at the moment it's an area of disease that we think does happen in that window, but we don't know. I think it's one of the areas that there is a genuine societal need and societal interest in."* **Lived experience group**

Participants expressed distress in relation to witnessing the suffering of people with various conditions and the helplessness felt by family members. They hope that research in this field can reduce or prevent this.

> *"A friend who recently lost their son to cystic fibrosis, and a friend whose sister also died from the effects of spina bifida. So it made me a little emotional, like listening to (scientists) say that it could be prevented from such an early age or find that out from such an early stage. I know that I'm already quite positive towards early embryo testing. But I just think someone that's been in that situation, if they knew that there could be a prevention from such an early stage to stop other families experiencing what they experience, that they will be very pro, this sort of testing."* **Lived experience group**

Many participants said they feel it is important to distinguish between different conditions as well as recognise the diverse needs and wants of people who live with them. This informed discussions on hopes for research in this area, as some cautioned against the universal promotion or application of the prevent, treat and cure approach. This is a hard red line for some participants, and they also believe that it is a topic for another, separate, societal discussion.

> *"I think there does need to be sort of that differentiation between testing for a disease or a disability. I think that needs to be quite like a strict line before that kind of debate goes out to society. So that opens a whole new can of worms, if you start saying, we can test Down's Syndrome and things like that before an embryo is implanted or anything like that, I think there needs to be like a stronger focus on a disease, like a curable disease, like cancer, rather than this whole general thing that we can test for and see for and stop going further."* **Lived experience group**

In some groups there were intense but respectful discussions where contrasting views were shared on the importance of better understanding versus outright prevention of some health conditions. A few participants hope that early human embryo research could identify and prevent developmental conditions. They believe that preventing these conditions would save resources and prevent families from the agony of living with such life limiting conditions.

> Participant 1: *"Secure fewer people with disabilities, which is a drain on finances and other resources…it is uncomfortable to discuss"*
>
> Participant 2: *"I think we're looking at the extremes. We want a society where it's inclusive, we are becoming better at understanding, accepting, looking at each other's differences. We see that there's lots of people that have conditions or disabilities, and they have got a lot to give us as a society. But it's when people are born into the world with such life limiting conditions."* **Lived experience group**

In response, many more participants question the right of scientists or society to decide if a condition is a burden, or whether or not that condition should be eradicated from the population. We explore these ethical concerns further in section 3.2.

Understanding human development

For those wishing to engage with people in the future on research into fundamental topics such as human development it is important to know that the term 'basic science' did not resonate with participants, 'blue sky research' is a more helpful term for participants to explore. The concept of early human embryo research leading to greater understanding of human development came up most in relation to:

- 'The black box' of 14-28 days where little is known.
- Hopes that understanding human development can lead to more understanding of conditions such as cancer, Down's Syndrome and spina bifida.
- Understanding how and why humans are different from other species.

There is a sense among some participants that an improved fundamental understanding of human development could lead to a wide range of breakthroughs across different health and fertility issues.

3.2 Research: Concerns and ethical dilemmas

Research – key concerns for participants are:

Eugenics: the potential for conditions to be eradicated from the population as a result of the research and the need for a distinction to be made between people rather than diseases to be cured.

- Genetic engineering and a potential desire to create perfect humans.
- The moral status of the embryo together with the idea that this research experiments with human life.
- Risks that IVF becomes less accessible rather than more.
- How possible it is to evade the law.

In this section we explore each of these concerns.

Eugenics: concerns about the eradication of conditions from society

We have seen in section 3.1 that there were detailed discussions during the dialogue on early human embryo research into diseases and disabilities. Many participants believe there needs to be more considered discussion across society on the implications of early human embryo research for different types of health conditions, notably disease vs disability. Participants often referred to Down's Syndrome[9] as an example of a condition that they many of them see as a difference between people, rather than a disease to be cured / prevented. They reflect that there is screening for Down's Syndrome currently and use this example when thinking of a hypothetical future where embryo research leads to the development of screening for other conditions, that they see as differences between people (rather than diseases to be cured). They feel this would be a misuse of the technology for society. As a result they want to see clearer distinctions being made throughout the research process and for there to be separate societal discussions to establish where this sometimes blurred line should rest.

> *"There is a difference between disease and disability, and I guess this is where my concerns would come in. What is it we're trying to cure? I've been quite vocal about how I believe pre-implanted embryo testing could help with fertility and curing disease. But then yes, to begin trying to prevent a disability, especially one where you can mostly live a normal life. I'm not on board with that."* **Participant, Recollective**

For some this concern is unfounded. They assume scientists would not be trying to use research findings for eugenics. Some based this on their own experience of genetic testing and their desire, not to prevent a child with a genetic condition from being born, but rather to ensure that they are equipped as parents to plan for a baby being born with such a condition.

[9] Participants heard from Felicity Boardman, Professor of Social Science in Medicine at the University of Warwick, about her research with parents of children with Down's Syndrome before the last workshop.

> *"I had genetic testing performed on 11 of my embryos on the fifth and sixth days of their growth, and I knew from this that none of my potential children would have Down's syndrome. This wasn't to 'breed out' or eliminate the condition, this was done simply to equip me with early knowledge about the needs and possible lived experiences of my future children. I don't think anyone is proposing the changes to the 14-day rule to allow for the total eradication of genetic disorders. More to understand further about how they arise and what brings them about."* **Participant, Recollective**

As we see throughout this report, the slippery slope is an argument for some against extending the 14-day rule. For some of these participants, the worst place this slope can take science is towards the eradication of a human life.

> *"The debate then goes, some people would then say, 'take it further and eradicate dwarfism or whatever and start to take away asthma'. I know it sounds ridiculous, but it could happen."* **Broad public group, south**

> *"I guess we're potentially talking about possibly eliminating embryos if they show that they have a certain problem. Certainly that's morally questionable. And I've certainly come across this idea amongst the deaf community. Why do we want to get into that, that's a problem for society, not a problem for biology."* **Broad public group, north**

Many participants want it to be clear that there should be a hard red line drawn which science cannot cross. They believe the research should be used to investigate and understand genetic and other conditions, but it should not always be used to prevent them, rather focus on those conditions which are life-limiting or lead to a life with ongoing pain. In this case some participants concluded that there should be separation between two distinct cases.

1. They consider that **research should be used** to improve IVF outcomes and minimise the incidence of miscarriage; plus develop cures and treatments for cancer and other life-limiting and life-threatening diseases such as spina bifida; and understand human life and development.
2. In the second case **it should not be used** to remove certain conditions from society such as Down's syndrome or autism, where people can thrive and live fulfilling lives with these conditions.

They would like the second option to be part of a separate societal discussion and do not feel it should be for consideration as part of the 14-day rule being extended or not.

> *"I still can't get around the fact that I think it's a twofold (issue). And it seems to have just been lumped into one, I understand the benefits and the research for IVF. That's life changing for people. That's something we're blessed that we're at the stage of human advancement, that we can actually do that. But then there's this other side of it again, that I think needs to be broken away and discussed separately. And that's this screening for illnesses and diseases and ailments and conditions and hereditary stuff, I just don't see where that's going to stop. And it really concerns me that, I mean, obviously, it's been brought up about Down syndrome, I understand that…But I have a health condition, which is a lifelong condition. It's a reasonably serious condition, which could end my life early. I'd feel if we take in this second issue here you could be saying, 'Let's just remove*

that person, let's stop them being born.' It's very, very dangerous ground." **Lived experience group**

Genetic engineering and a potential desire to create perfect humans

Linked to the previous point, some participants are also concerned that early human embryo research could pave the way for dystopian scenarios involving the creation of 'perfect' humans or adapting humans for certain jobs or situations. Participants feel this is unlikely given their admiration for the work of the scientists in this field and the trust they place in them to do the right thing. However, they want to flag it as a route that the science should never take.

> *"Hidden in the background here, is there a researcher who wants to create a new, Brave New World? I think that's when you have to sort of consider. Aldous Huxley described it back in the early 30s. When all births were done from embryos, and they were divided into different scales depending on how, where they were destined."* **Broad public group, north**

Some participants reflected on the fact that eugenics has a real history, including during the Nazi regime, and would like to be reassured that it cannot be repeated through early human embryo research.

> *"I feel like it would be going back to the Nazis trying to create the perfect Aryan, is that the word? It feels like it could just be twisted and distorted and just used for the wrong reasons if it ends in the wrong kind of hands."* **Pilot group**

The moral status of the embryo

Some participants shared their views on when they believe the embryo becomes a life. Discussion reflected different faith perspectives, from life beginning at conception in the Catholic faith, to the soul arriving at 42 days, in the Muslim faith, and of recognised diverse opinions under the banner of the same faith.

> Participant 1: *"I'm from a Christian Catholic background. So life begins at conception and that's that. It's something we don't really discuss, to be honest with you. You know, because it's just seen as 'No, you shouldn't do that.'"*
>
> Participant 2: *"I am a Catholic, and I do practise the faith, but that doesn't mean I agree with everything the church says. I have been through two IVF cycles with a clear conscience and don't see this early bundle of cells as life, they are the precursor to life, but not quite life yet."*
>
> Participant 3: *"So as Muslims we believe when a soul goes into the body that's when you can't do anything to the foetus, or anything. That happens at day 42. So that's why, from my point of view, I don't want anyone going past day 42, for me, that's my, that's my go to. That's when the soul goes into the body. So God sends down an angel and then the angel develops muscles and tissues. Yeah, on day 42. But then some sects within our religion cite from 100 days or something along those lines, so, it's different schools of thought."* **Broad public group, south**.

Others expressed their views on the embryo's status in terms of 'humanity'. They want to stress that science should treat embryos with great respect and dignity, because even if they aren't considered anything more than a tiny collection of cells prior to the 14-day

limit, they are the roots of a human life. Some participants found some presentations on the status of the embryo in this period rather clinical.

> *"So it comes across as very cold and gloomy. You know, you need to be talking about people. We're talking human, humanity. We're not, we're not dealing with, you know, a pet, a pet rabbit, or something. The lady said it's just, you know, it's just a pinprick. You know, in my opinion, the point of conception, that's life. So just the way she was referring to it. I just found it a bit cold and clinical.* **Lived experience group**

Some participants shared religious convictions about what research should be done and until what stage of the development of the embryo.

> *"I have strong religious views on embryology research, because I believe or know, that life begins at conception. I firmly believe and know that it should not be messed around with. I think what comes into play a lot of times, a lot of the scientists say, 'I think, I think, I think', Well, I think we have to listen to our consciences sometimes, about how we get on this slippery slope of going beyond this research."* **Lived experience group**

For others, they expressed feelings of disquiet at the thought of experiments, which they see as potentially harmful, being carried out on something which has the potential in time to become a human being.

> *"I feel like it's experimenting on human beings, and I don't even agree with animal experiments. Although some good has come from this research I believe 14 days is as far as it should go."* **Participant, Recollective**

We therefore see a difference in view between those who have a conviction that early human embryo research is in conflict with the embryo as a life that is forming, and those who do not believe that the collection of cells has the status of a life.

Inaccessible and unaffordable IVF services

Many participants welcome researchers working with early human embryos in the hope of improving IVF success rates and find this impressive. However, some participants worry that improvements in fertility treatment arising from this research will become an elite option. They consider that with the squeeze on NHS budgets, the number of IVF rounds that are available will be reduced. This might be acceptable if the treatment success rate improves dramatically, but will cause harm if it creates more expensive treatment options which are only open to those who can afford private healthcare and so creating a dystopian class divide in the future.

> *"What is most important to us, is accessibility to it all. As you know, we all pay a set amount of a prescription if we need it, you know, medicine, whether it's medicine, whether it's knowledge or anything like that. Again, happy to pay for a bit, but it has to be accessible. There has to be a realistic system for the many and not the few. It can't be a tiered system."* **Lived experience group**

Some participants shared concerns that the benefits of such improvements in fertility treatment will only benefit those living in developed countries rather than the global south.

> *"This throws up socio economic questions. Is this available to all in society or a select group, and if so then it's a privilege that is not afforded to others and in that sense it's a commercial venture. That makes me question whether the risks and costs to humanity are justified, just to benefit a small minority of the population and really is this just a thing for developed countries."* **Participant, Recollective**

Who or what is driving the research agenda?

It was not clear to participants initially how early human embryo research is funded. Whilst participants heard about HDBI and the consortium of academic and funding institutions behind it, they did not necessarily accept that there is no private funding, or commercial agendas behind the research and what it focuses on. This led to discussions about who is driving the research agenda if commercial entities are involved.

> *"You were saying that the scientists, they're really keen, and upright about it all, they are clearly brilliant. But somewhere along the line, someone's got to fund this. And this is where all these things come unstuck. That the money's got to come from someone who wants to make even more money. And that just kills the moral probity of it all. I've been around 75 years. So I've seen a lot of corruption."* **Lived experience group**

There is also a concern that, just as in the field of artificial intelligence, the technology seems to be driving the research agenda because of what is possible in a rapidly developing field. Participants asked if the same thing could happen in this sphere, with technological advances driving the research rather than human need – and could that push the research over the bounds of what is acceptable?

> *"I also worry that, you know, AI, it has really advanced, we wouldn't have been able to do this, only 3 or four years ago. But now we're at a point where we're actually saying we're worried about AI. We're saying we're a bit concerned how far we've gone with it. So there is that. Could we go too far with this research as well?"* **Lived experience group**

A few think that the blue sky research that they admire may be stifled by trying to fulfil the agendas of charities focused on specific health conditions.

> *"They've been at the 14-day (rule) for so long now and there must be sorts of grand reasons perhaps why they want to extend it, but are there any outside pressures, you know? Is there pressure on them from (charities) I don't know, like the British Heart Foundation desperately want them and they've got more money and they're putting pressure on the scientists to look at things."* **Lived experience group**

Concerns about rogue scientists

Although participants are largely positive about the current regulation, there are some concerns that rogue scientists could evade laws and regulations. This is an underlying theme in the discussions around regulation - the sense that it could still be possible for scientists to push the boundaries and conduct research which breaks the law or goes outside what is permissible – particularly if this involves genetic engineering.

A lot of this mistrust centred on the news story about He Jiankui, a Chinese scientist who used preimplantation gene editing on twin embryos[10]. As a result of reading about this case, some participants expressed concern that he had been able to work in this way undetected for a long period of time. This fed into a more general fear among some participants that not everyone involved in early human embryo research globally can be trusted and that research could 'get into the wrong hands.'

> *"How can we trust really those regulations? And how can we really be sure that nothing crazy might happen despite those regulations? Because we're all humans. You know, scientists just have a scientist brain… and they might like to experiment a bit more."* **Pilot group**

This led participants to discuss scientists in the UK evading the law and ask:

- How regular and transparent are the HFEA checks that take place?
- Who checks that the HFEA is fulfilling this role?
- How many licences are actually turned down?
- How many scientists have been prosecuted for not adhering to the law around human embryo research?
- Can people who are not experts in the field apply for licences for research?

3.3 Stem cell-based embryo models

Key messages on stem cell-based embryo models

Stem cell-based embryo models are astonishing and complex to many participants, some remained uncertain about them at the end of the dialogue.

- There are a range of views on their ethical status, ranging from being the same as a human embryo, to being 'biological material' similar to DNA.
- Many participants want to see these models regulated. They are concerned that without regulation, scientists could use them as alternatives to human embryos in ways that could harm society, such as using them for experiments for extended periods of time or even creating an alternative form of human life.
- The models are seen to offer benefits such as supplementing the scarce resource of human embryos, enabling learning about human development and in the future potentially replacing the need for human embryos in research.

Although the focus of this public dialogue has been on research using early human embryo research, we included stem cell-based embryo models in our stimulus materials and questions for discussion for the following reasons:

- The development of these models is highly relevant to the future direction of early human embryo research and is important contextual information for participants to be aware of when considering the future of this area of science
- At the International Society for Stem Cell Research (ISSCR) Conference, which took place during the dialogue, a presentation on these models generated

[10] This article was shared with participants in the online space Scientists who edited babies' genes says he acted 'too quickly' The Guardian, 4 Feb, 2023

significant media coverage[11]. Following the conference presentation, several other labs also published pre-print papers on their work developing stem cell-based embryo models.

There was limited time in this dialogue to discuss these models alongside the wider topic of early human embryo research, so these findings should be seen in that light. But as will be seen in this section, many participants were extremely interested in the 'what, how and why' of the models and their regulation and there is clearly interest in further engagement on this new area of science.

> *"I'm now wondering, is it not possible for researchers to continue improving on the non-embryonic models, such as stem cell-based organoids, or animal models to study early human development?"* **Broad public group, north**

The trajectory of reactions to stem cell-based embryo models

When first introduced, there was widespread astonishment among participants that an 'embryo model' could be created without using a sperm and egg. The concept of triggering stem cells through 'chemical nudges'[12] to create something was both unfamiliar and complex for many participants and hard to make sense of. For some this information immediately triggered science fiction or dystopian associations: could this be the end of natural conception and childbirth, could this lead to the creation of 'synthetic', 'parentless' children who could be subject to prejudice?

> *"I'm shocked. I just think it's crazy that we don't need an ovule and a sperm to create an embryo. That's like alien creation of a new sort of human?"* **Pilot group**

The ability of stem cells to replicate themselves almost infinitely was seen as a key benefit by participants. Such replication means that there would, as the technology improves, be an unlimited supply for research, enabling more research to be carried out. However, this benefit took some participants time to understand, as illustrated by this question about why create a model from an embryo and then dispose of the embryo.

> *"If they've taken the cells from it, and they've created this synthetic embryo, and they throw away the other embryo, wouldn't it have been easier to use the other one to work with? We do that in life, don't we, where we will try and create something different, but you could just use the original in the first place."* **Lived experience group**

As conversations continued, participants thought more of the benefits these models could bring, such as being a solution to the low numbers of embryos available for research and, in time, potentially being a more ethically acceptable replacement for human embryos in research.

> *"Stem cells are kind of like embryos, but they're not the same. So you can get an idea by cultivating stem cell synthetic embryos, but they're not seen as a real embryo. So, when you first look at it, stem cell embryos are brilliant. You can use them and they're not really embryos, but (can) enhance knowledge..."* **Lived experience group**

[11] https://www.theguardian.com/science/2023/jun/18/model-embryo-with-heartbeat-replicates-cells-in-early-pregnancy https://www.bbc.co.uk/news/health-65914934
[12] https://www.scientificamerican.com/article/new-human-embryo-models-spark-needless-controversy/

> *"I go with the fact that there clearly aren't that many embryos or enough embryos, human embryos, donated for research. And based on the fact that (they are) used in the right way to improve IVF or cure diseases, then perhaps stem cell-based embryos may be a better option than real human embryos. As long as they always stay like a replica of an embryo of a human embryo, just for the purpose of research."* **Lived experience group**

Participants who oppose early human embryo research want to know if stem cell-based embryo models could be created by extracting stem cells from an embryo in the womb without causing it any harm. They saw this as a way of creating models without needing to culture embryos in the lab and dispose of them.

Questions that arose during the discussions were:

- How are the embryo models created?
- What happens to the source material after they are created?
- How realistic are these models compared to human embryos?
- Do they differ in properties and qualities from human embryos?
- How human do the stem cell-based embryo models become?
- Have scientists been able to find similar things from the stem cell-based embryo models as they would do from human embryos?
- Are the stem cell-based embryo models also governed by the 14-day rule?
- Can these models be used to create artificial organs for transplant?

Many participants are concerned that currently, given their very recent development, these models are not regulated. Some thought that if this remained the case, it could lead to a 'Frankenstein' moment, where the knowledge gained through unrestricted development of these models could lead to a malign source of power.

> *"Watching that (stem cell video) made me think about Frankenstein if it were taken to the end of what is possible and the question of then who controls all this knowledge and power."* **Broad public group, south**

Other participants continued to wrestle with how they feel about stem cell-based embryo models that weren't created from a sperm and an egg. The notion that the source of the material was different but still human was a conundrum:

> *"It's been bugging me since the start of this two weeks ago. The difference between a stem cell embryo and an actual sperm egg embryo. I'm still uncertain as to what the differences between them are. If one of these has been created from something else. Stem cells and stem cell embryos they don't have the same connection to me as a genuine human embryo. So the confusion is still there. And I don't have the same feeling towards the stem cells as I do the human embryo."* **Lived experience group**

How to validate stem cell-based embryo models given the 14-day rule?

Participants recognised the catch-22 facing stem cell-based human embryos – that to reliably and accurately supplement, or even replace, early human embryos in research – scientists need to compare them to the 'real thing' over the same time period.

> *"I guess without the 14-day rule, we don't know what human embryos are doing between that 14 days and that six weeks to know whether the synthetic ones are*

developing in line with the human ones, because we don't know." **Lived experience group**

A range of views on the ethical status of stem cell-based embryo models

During the discussions participants were asked to compare their views on the ethical status of stem cell-based embryo models to that of early human embryos. Three distinct perspectives emerged from these discussions:

1. Same: Because they are sourced from a human embryo, a few participants think stem cell-based embryo models share the same qualities as human embryos and are therefore ethically the same. The few participants who expressed this view worry that if models are classified differently to human embryos there will be a freedom to manipulate them in worrying ways.

   "Between the embryo-based models, and the normal embryos, in terms of ethics they are still coming from humans. So in fact they are still the same in essence. And yes, you can multiply you can create these stem cell-based ones more, but they do come from the same (source). So that is a concern, if we look at one as a thing, and one is a human, then that can go down a bit of a concerning road. If it doesn't feel as important as a human life to (the scientist), then they can do anything with them. **Lived experience group**

2. Similar: They are sourced from a human embryo but are created artificially and in a different way, so merit respect but not to the same extent as a human embryo. As such many participants want to see a balance between respect and utility. They are concerned that if they are seen on a par with human embryos their usefulness to science will be limited.

   "(I'm) just saying maybe somewhere in the middle? I do think, of course, any of these models should be treated with respect, given that they are similar to human embryos and do what embryos do." **Lived experience group**

3. Different: They are seen in the same class as a DNA sample, such as a hair sample. For some participants the models are akin to a piece of biological evidence – not something they saw as a potential human.

   "As they seem to be laboratory generated… I don't think they require the same general respect or consideration as a proper, full human embryo. Even if it is human tissue. I just think it's somewhere along, I mean, the police they'll pull your hair and know they'll manipulate your DNA to get a result in a crime or stuff like that." **Lived experience group**

The need to regulate stem cell-based embryo models

Many participants expressed a desire for stem cell-based embryo models to be regulated and were surprised that they do not fall within current regulations. They see this as a risk, where scientists can work with impunity and without oversight.

"I still think there should be some sort of regulations. At the minute there's absolutely nothing, I think (scientists) can do what they like." **Broad public group, south**

Some participants expressed fear that a lack of specific regulation could lead to the models being taken to full term and the creation of 'synthetic humans'. Their unknown nature, that they could be developed to cause harm to humanity, that they could be subject to prejudice and that they would be 'parentless' underpinned these concerns.

Participants heard during the dialogue that taking models to full gestation wasn't the intention of the scientists currently developing them. For many this was raised as something they feel is more akin to science fiction and dystopian visions of a future with clones and replicants. Some participants feel that both technological advancements, such as artificial intelligence; and what they had heard about the actions of He Jiankui, meant that this was not fiction, but a real and deeply troubling risk. It is also a clear red line for participants who are extremely concerned about the ethical and social implications of such a development.

> *"If you go back to the 70s, people wouldn't believe that you could work with a 14-day embryo. If it moves that quick, within a decade or so, we're getting to this stage where stem cell derived embryos will just go full term. So it could be parentless in a way."* **Lived experience group**

> *"There was a suggestion that stem cell models could ultimately go right through to full term. We thought that that should definitely be beyond a red line, that stem cell embryos should have an absolute limitation that should not go through to full-term. There's too much scope for irresponsible science, when we call it a stem cell model rather than we call it an embryo and we wanted to put a limit to say that they're not allowed to go ever to even close to full term. We don't want to fall into things that people say, 'Oh, it's only stem cell model so we can do what we like, it doesn't matter that it's twitching and saying ouch."* **Broad public group, north**

The purpose of stem cell-based embryo models

If properly regulated, there are significant hopes for the potential uses of stem cell-based embryo models. They include:

- Providing opportunities for learning more about human development

  "It seems like there's a lot of potential there for learning. I remember reading that one stem cell can go on indefinitely and make loads of more stem cell-based embryos. So that for me was really interesting." **Lived experience group**

- Creating organs for transplant

  "If the intention is to change the research so that (scientists) are able to make organs from stem cells, it can drastically decrease the waiting list for people who need new organs. **Broad public group, north**

- Replacing human embryos in research

  "If the technology was there to evolve the models, then, in an ideal world, you wouldn't have to research on real human embryos. **Broad public group, south**

4. The 14-day rule

This section of the report starts by exploring the specific reasons why participants support, oppose or question extending the 14-day rule. It goes on to look at views on what it could be extended to and participants' thoughts on involvement in future decision making on changes to human embryo research regulation.

4.1 Reasons to support a change to the 14-day rule

Key messages on reasons to support changing the rule

Many participants support some form of extension to the number of days or a change to the rule.

The potential to improve IVF success rates, reduce multiple miscarriages and better understand, treat or prevent serious health conditions are seen to be the most compelling reasons to explore some form of change to the rule.

- Supplementary reasons to change the rule include:
    - unlocking the black box of human development of 14-28 days.
    - the rule being in place for 30+ years so a review is due.
    - disposing of a human embryo at 14 days is a waste of a precious resource.
    - confidence that a slippery slope can be avoided.
- Some participants said a swift discovery resulting from a change to the rule that improves a health outcome will be important to placate opposition to change.

Improving health outcomes

For many participants, the opportunity to better identify, understand, prevent, treat and potentially cure serious, life limiting conditions such as cancer and spina bifida, to reduce the rates of multiple miscarriage and increase IVF success rates are together compelling reasons to extend the 14-day rule. For some, this range of benefits helped them overcome their initial concerns about early embryo research.

> *"I didn't think 14-day rule should be extended because I thought it could potentially be a baby and that is human life. But then I thought if they can do research on the embryo to try and find out where people who have diseases and cancers and to help ladies stop having miscarriages. I think the pros outweigh the cons. So I think it could potentially be a good thing."* **Broad public group, south**

For these participants there is a positive trade-off to be made. The deliberations resulted in those with potential ethical concerns around research on an embryo which they see as a human life being diminished when consideration is given to the benefits from the outcomes of the research.

For others, learning about what research so far has yielded gives confidence that yet more could be discovered in the future if the rule changed.

> *"From the research that they've done on zero to 14-day embryos, if they're then given permission to go to 28 days it would be massive. If more things were found out it's got to be a benefit I think."* **Broad public group, north**

A few participants put themselves into the shoes of scientists and feel frustrated on their behalf. They understand that there is research that scientists wish to do that could benefit humankind, but they are prevented by the current 14-day limit from taking it further.

> *"Unfair terms for the scientists, the ethical scientific community, worked really hard to make things better for humankind. And then when it's like, oh, 14-day rule. They have to fight to get those better things."* **Broad public group, north**

Going beyond 14 days and making new discoveries could trigger 'a domino effect' of one finding leading to another, so multiple health benefits could stem from an extended number of days.

> *"Kids are born with cancer. It gets your mind thinking. Could this research open up different doors, like the domino effect. It just knocks on different things where if you think of it, we could maybe help more kids who are born with cancer, leukaemia."* **Broad public group, north**

A few participants shared even more ambition for early human embryo research, expressing the hope that all health conditions that are detectable in a human embryo could be understood and treated.

> *"I wouldn't expect the research to be extended up to a day before full term. But it needs to be extended gradually, up to the point when most if not all of the inflictions that children and adults are suffering and which can be screened out if you like, on the embryo. The extension of the 14-day rule needs to be to such a point that each of these developments in the embryo can be sorted."* **Lived experience group**

Seeing fairly rapid health benefits resulting directly from an extension or change to the rule is important to some participants who believe this could help to reduce opposition to an extension.

> *"If there are amazing results found quickly, say if the 14-day rule is increased, then that would perhaps convince others who weren't sure that extending the rule gives us real benefits, the research brings benefits to everyone."* **Broad public group, south**

Some participants prioritised embryo research for health conditions over improving IVF success rates and reducing miscarriage. The reasons given for this were that there are existing (although not perfect) techniques for resolving infertility, but some health conditions have no means of early detection or cure and are matters of life or death, such as some forms of childhood cancer.

> *"If research can be done to prevent some of these life limiting diseases, it has to be a priority. My personal journey is I've had several miscarriages, but I would much rather that time was focused on trying to find cures for some of the diseases and improving people's way of life, than more research being done on*

why people miscarry, even though that's my personal journey." **Lived experience group**

The rationale for extending the 14-day rule to better understand spina bifida is clear and positive for some participants – because it is understood that the closure of the neural tube happens after 14-days. However, whilst it is seen as important to find treatments and cures for conditions such as childhood cancer, there is less clarity for some participants on why extending the 14-day rule may be helpful.

> *"Going back to the whole spina bifida area, the neural tube only develops after the third to fourth week. So we wouldn't necessarily know why that happens before the 14th day, so I am pro extending it because of that. So if we can figure out any of that detail, I don't know when everything else developed. So you know, children's cancer and all these other…conditions. It would make me hopeful for that to give us some information and some data."* **Lived experience group**

Supplementary reasons to support changing the rule

While not seen as primary reasons for change, participants see the following supplementary reasons for changing the 14-day rule as significant:

1. 'The black box' needs exploring:

'The black box' remained an area of interest for participants throughout the dialogue. There is a sense amongst many that this gap in basic knowledge about human development needs addressing. They believe that extending the 14-day rule would mean an end to 'the black box' period.

> *"It sounds like that's very much like a blind spot in terms of just basically understanding anything about the human embryo. Because I think 28 days is when you can start getting tissue from terminations and miscarriages. So I think, my hope is that we would have just basic knowledge about that time period."* **Lived experience group**

2. It is wasteful to destroy an embryo at 14-days:

A few participants thought about the current disposal of early human embryos at 14 days of development as a wasted resource. This is particularly so if continued research could lead to useful benefits for humankind.

> *"It's first difficult to grow out an embryo until these limits. Secondly, when you manage it, it will be a waste to destroy an embryo and waste from an analytical and moral point of view."* **Broad public group, north**

For these participants, reasons for extending the 14-day rule are driven partly by the sense that embryos are a highly valuable resource which can provide known and unknown benefits for humankind in the future.

3. No change since the rule was introduced in 1990

Among those participants who commented on the rule being in place since 1990, some expressed mild surprise that the rule hasn't been comprehensively reviewed in the thirty years since it was brought in, given changes in science and technology. Others are frustrated that it has been in place for so long and that this may have prevented earlier improvements to IVF and decreased miscarriage.

"I think I'm a bit surprised as to why it hasn't been reviewed for that long, long time. Because obviously, a lot of other regulations like data protection, a few other ones have been reviewed recently." **Pilot group**

"Science has improved since 1990. We've gone a long way. So I think it's definitely about time we looked into that." **Broad public group, south**

4. The value in international collaboration

The fact that science is often undertaken by researchers collaborating internationally is welcomed by participants, and they feel that this area of research would benefit from continued working across country borders. For some participants, extending the 14-day rule in the UK could pave the way for this country to become a centre of innovation, attracting scientists from around the world to work here. They see the pace of developing a Covid vaccine, and the role of UK science in that process, as a model for such collaborative innovation.

"We're hoping there will be more kind of international collaboration that might attract more top scientists to the UK, attract more students to universities in the UK. It will be one of the only countries working beyond that 14-day rule." **Broad public group, north**

"I mean if the decision does get passed in this country, maybe we can come up with centres of innovation with countries collaborating and maybe the research time or whatever time can be significantly reduced like the way we did in COVID." **Broad public group, north**

4.2 Concerns and opposition to extending the 14-day rule

Key messages on concerns with and opposition to extending the rule

- Taking the step to extend the limit once, could lead to a slippery slope of more and more extensions, leading to fundamental and irreversible changes to the creation of human life.
- Extending the limit could lead to a societal backlash and a ban on all human embryo research.
- Life begins at conception and so research that would end the life of any embryo is not acceptable at any point.
- There is still research to be done up to the 14-day limit, exhausting this research would help legitimise reviewing the limit.
- There is no clear, specific benefit to extending the limit, for example that will lead to a diagnosis or treatment for a specific condition.
- Early human embryo research is a scientific luxury which is the preserve of western/high income nations – it is an area of science that doesn't have global benefits.

Extending the limit risks a slippery slope with a range of consequences

For some participants the slippery slope[13] argument is really challenging, leading to the use of words such as 'Pandora's box' and 'Floodgates' in relation to extending the rule beyond 14 days. For these participants there is a genuine concern that the limit on the number of days for when research can be undertaken will continue to increase, and perhaps not stop. They feel this is just information for information's sake.

> *"(It could) open the floodgates to things which are just for curiosity, not need."* **Lived experience group**
>
> *"We will be sent down the slippery slope and into the unknown and have significant moral and ethical impacts."* **Lived experience group**

Those participants that travelled down the slippery slope in their minds saw a number of potential consequences to extending the limit on early human embryo research.

• Extending the limit once will lead to multiple extensions in the future	*"My problem is, I have no idea if they do extend the 14 days to say 21 or 22 , then is that the Pandora's box, and then it will be another 28 days? That's my concern. We're going to extend it to 21 days, and everyone agrees, that's fine. But in another five years, 10 years are they're going to say, 'well, actually, we'd be better off with 56 days.' It's going to upset a lot more people who are more concerned about when life begins."* **Broad public group, south**
• Further extensions to the limit could create a backlash that could lead to a total ban on all human embryo research	*"I personally don't agree with extending it. I believe that the limit was introduced for public trust, and essentially represented a lack of compromise between the utilitarian argument and people's views that embryos deserve some sort of protection. What if someone then says two weeks, four weeks, maybe 20 weeks? And when you think about it, when ectogenesis becomes an option? The whole thing then becomes unsound. And then people will just want to ban it entirely.* **Broad public group, south**
• Reasons to extend the limit will be found repeatedly and what may seem like a specific and reasonable step at the time, could lead to a	*What I assume is going to happen is that we're going to find something, if we can extend to 28 days, they're going to keep researching until they find something that they want to continue doing. And they'll ask to extend it again and again, until it gets to the point where now there's a viable organism, and we've essentially just started ectogenesis, we're now normalizing. Obviously, that*

[13] The slippery slope concept was introduced by some participants early in the dialogue. It was also raised by the ethicists and philosophers who gave 'ethical briefings' in each workshop. It was generally used to convey the idea that developments are not viewed in isolation, but as the potential beginning of a trend.

major change in how human life is created	*wouldn't be the intention but that could possibly happen.* **Broad public group, south**
• The slippery slope may be steeper than we think – the speed of technological advancement is ever increasing	*"I just feel that once we open this, the floodgates will just open. The technology is moving so fast that it won't be decades, I think it'll be countable in a period of months or years, that they're going to say, 'well we've exhausted that, we're going to move on' and I just think we're on rocky ground. I've got a great concern about that."* **Lived experience group**
• Changing the limit could lead to an irreversible, negative impact on future generations	*My point is that when we get to near perfection, I do believe they will get that. That's when concerns really start. That point in future, and whether that's five years, 10 years, 50 years down the line, that's when future generations will have to deal with the fall out of decisions now."* **Lived experience group**

For some the slippery slope is a concept that calls for caution and a reason not to change the rule. But some other participants question the concept or think about it in different terms.

> *Participant 1: "My fear is how far does this go before you stop, so in another 30 years' time there's another review of our public data and then we say tell you what just extend it indefinitely. Where does it end?"*
>
> *Participant 2: "But there is a bridge to cross now, before you get to that."*
>
> *Participant 1: "Yeah but where does it stop?"*
>
> *Participant 2: "You could say that about any scientific sort of endeavour couldn't you? where does anything stop?"* **Broad public group, south**

Some participants re-frame the 'slippery slope' as evolution:

> *"The slippery slope (point) has gone for me, because I'm sure back in the day, when it first started, they were probably worried about the slippery slope, but you've got to evolve and it's more really about the benefits that it brings."* **Broad public group, south**

Others see the slippery slope as an alarmist argument that isn't based in reality

> *"I'm not very convinced about that slippery slope type of argument. I don't think that because we're deciding that we may gain more knowledge and we may reduce the overall level of suffering in the world as a result, it doesn't mean to say that in five years' time, we'll be growing monsters in a lab. I'm just not convinced that we'd suddenly start essentially murdering people."* **Broad public group, south**

Changing the limit is premature, there is still research to be done

Some participants came to the end of the dialogue asking why some scientists want to extend the 14-day rule now, when there is still research to be done within the existing

time limit. They feel that because of the ethical sensitivity of extending the limit, all research questions should be exhausted beforehand.

> *It worries me that scientists are discussing maybe getting this 14-day rule extended when they haven't explored already all of the possible discoveries within the 14-days. And they don't even have the technology in place to keep the embryos longer than 14-days. Why are they wasting time even talking about extending it at the moment when they've literally not exhausted all avenues within the 14-days.* **Lived experience group**

No clear benefit or reason

A few participants in the lived experience group spoke of feeling either less certain or completely unconvinced about the merits of extending the 14-day rule because they felt they hadn't heard of any concrete benefits that would stem from an extension.

> *"I would have liked it to be more of a specific hypothesis or some specific proposal in terms of, we want to do this research up to this number of days for these specific reasons. It's all quite hypothetical, which obviously, I understand. But I think that can make it difficult to kind of fully understand the implications and the reasoning behind all of this. I would have liked it to be maybe more concrete.* **Lived experience group**

> *"I want to know how many scientists want to extend the rule. If we don't know that we can't be sure what the reasons are for changing it really, not really."* **Broad public group, south**

Only benefits Western nations

A few participants see early human embryo research as a kind of 'scientific luxury' of the 'western world'. They wondered if considerations about the impact of extending the 14-day rule are being reviewed on a global or just a Western basis. They asked if the benefits of this research are shared and used globally and suspect that because fertility treatment isn't affordable for many people in different parts of the world, that its relevance is limited.

> *"I'm a Hindu. I've had some experiences working in pharmaceutical research, health care. So I'm aware of processes around research and the protocols and the regulation. I think 14 days is enough. Because truly we're talking about humanity, and the whole world population, most of the research is carried out in western technologically advanced countries. That research doesn't benefit humankind as a whole.* **Lived experience group**

> *"The average person in Southeast Asia or Africa or south America won't (be exposed to this research), it won't be an issue for them. Because they ain't got the money. And the research probably ain't happening in those countries. If we're talking about humanity and humans, is it all humans? Or is it specific ones? And if it's specific ones, say, so. Be honest. Because it's not a global thing is it really?* **Lived experience group**

4.3 Views on changing the 14-day rule

It is important to note that participants were not given a specific set of options for changes to the 14-day rule to consider during this process. Given the exploratory and foundational nature of this dialogue that would not have been appropriate and might have implied that a full review of the 14-day rule is already officially underway.

However, during the course of the dialogue, participants heard a range of views from speakers and media reports on whether the 14-day rule should be changed and, if so, what the rule should be changed to. There were a range of views shared by speakers during the dialogue on changing the rule which can be summed up in four main points:

- Keep at 14 days for now to allow technology to culture embryos longer to develop.
- Extend to 28 days to unlock 'the black box' of human development.
- Remove the 14-day rule and allow scientists to make a case for each research programme for the length of time, based on their research need and potential outcome.
- Keep at 14 days but allow scientists to go beyond the 14 days if they can justify the need to do so with the regulators.

Key messages on changing the 14-day rule

Many participants are positive but cautious about changing the 14-day limit:

- There is uncertainty about what benefits can accrue from extending the limit.
- Some participants are concerned about key development points in the embryo and, for example, when the embryo will feel pain and the state of knowledge about when that is.
- This leads many participants to advocate for small changes to the limit, combined with regular reviews.
- Some participants think it is important for donors to have a say on how long research can happen on the embryos they donate.
- A few participants propose taking early human embryo research out of legislation, only regulating it via the HFEA/ expert groups, to avoid political polarisation and legislative delay.
- A few participants want the rule to remain as it is.
- A very few participants want early human embryo research to stop completely.

Small steps towards a 3-4 day extension, and then review

As we drew towards the end of the dialogue process uncertainty and caution were strong characteristics of the discussions about changing the 14-day rule. Uncertainty about changing the rule stemmed from some participants feeling that they do not have enough, or definitive enough information about an embryo's development, such as its ability to feel pain. Caution stems from the perceived robustness of the 14-day rule: the length of time it took to agree, how long it has remained in place and its partner measure, the primitive streak.

> *"Where do you draw the line? Is it the ability to feel pain, a basic level of consciousness or something? If it is one or both those things or something similar, how would we know how we would measure it? Presumably we'd have to do some research, ironically enough to find out whether we can do the research. I just think it's a big minefield that we've barely touched upon so far."* **Broad public group, north**

> *"One of my main concerns was if the White Paper went to Parliament, to put the law forward, to go to 28 days, if that became law, and they started research up to 28 days, they still don't know what effect that's going to have and how that's going to look, how the embryo's going to be between these stages. Is it still non-sentient? Because they don't know. So you can't just put the law down there and all of a sudden, everybody goes and does research at the 28 days, there needs to be some sort of trial basis."* **Broad public group, south**

In light of this, many participants - particularly in the Broad public south group – wish to see a 'small steps and review' approach to changing the 14-day rule. Others suggest that bigger changes to the rule are required to future proof against the fast pace of advancements given how long it takes to enact change to the law.

> *"After the last 30-40 years, having change now would be the time, excuse the pun, for baby steps, to go forward slowly to the next level and give it a shot. If it can be proved that this is the right thing, not that we necessarily think it's the right thing, but the scientists and everybody else can prove that there's only a very minimal, if not negligible, downside should we progress further."* **Broad public group, south**

Some spoke about a trial period, before any fixed or legislated change. Research could happen a few days beyond the 14-day limit and the results reviewed and shared publicly. This is seen as an important first step to many in order to justify a change to the legislation.

> *"I think that we couldn't just run with the law and start doing this, there will have to be trial and error for a time to try and find out what they can find out."* **Broad public group, south**

For some participants, reviewing the limit doesn't necessarily mean reviewing it to extend it. It could also be appropriate to review and bring the limit back to 14 days, particularly if promised research outcomes are not being seen.

> *"It was like we re-evaluated or reassessed after a year or so to see if actually, it has been worth extending it more has been discovered, if anything? If anything positive would come from it. I guess if nothing further has been developed, then maybe it needs to be reevaluated."* **Lived experience group**

The importance of a biologically observable limit

The dual nature of the current limit for research on early human embryos - number of days and the visible indicator of the primitive streak - is important and robust for many participants. They feel it recognises the organic nature of human development and balances the binary/fixed nature of a number. Some participants wonder how moving away from the primitive streak can be justified if it was seen as a significant biological milestone 30 years ago. Others want to know if there are equivalent, significant

milestones at other timepoints being considered if the day rule is extended. Some mentioned the closing of the neural tube in this light.

> *"What's going to happen? If we do move it to 28 days, if the primitive streak still takes place at a certain point in time? Are we just going to dismiss that primitive streak now and just carry on to 28 days?"* **Lived experience group**

> *"Up to 14-days, and you have the primitive streak. And then if you're extending it, say another, 28 days. That they'd heard that, after 28 days, the primitive streak then disappears. So think within the regulations that will need to be a similar (point), something that you can notice."* **Lived experience group**

Consider moving to a 28-day limit

When discussing an alternative day limit to the current 14 days, 28 days is the one most often considered and, in some cases, supported by participants. This was more evident in the Broad public group, north and Lived experience groups than the south group.

Section 4.1 of this report describes how compelling 'the black box' is for some participants and this underpinned some support for opening up this 14-28 day period. A few participants talked about their confidence that if 28 days is the scientists' choice of extension, that is sufficient for them to support it.

> *People who are more knowledgeable than me in the subject are saying 28 days well, I don't have a benchmark myself so if that's what they suggest, then that's probably the right idea. And 14 to 28 days is not an enormous amount of time. It's not eternity. 28 days.* **Broad public group, north**

The biological milestone of the neural tube closure around 28 days, alongside the potential to better understand spina bifida in the 14-28 day time period are also reasons participants give to support this extension. This provides both the dual marker (time and a visible sign) that they admire in the current limit and a specific benefit that could be achieved through an extension.

> *"When we can see the closure of the neural tube, that will give them an insight on how to extend a bit further."* **Broad public group, north**

28 days was a maximum limit for some participants because of the embryo developing a basic human body structure at that point.

> *"When an embryo gets to 28 days, they started taking a human form. And for me, that really, it was like, 'Well, now you are really experimenting on humans rather than embryos'. You know, it's not just cells now, is it? It's actually something that we would recognize."* **Lived experience group**

In the Lived experience group there were conversations that sought to quantify the nature of a move from 14 to 28 days. One participant noted that 28 days was a 100% increase in the limit and also 10% of a pregnancy and therefore likely to be seen as a significant extension that could be hard to justify to some parts of society.

> *"So they want to make that initial jump. It doesn't seem much when it's just said in a passing comment. But it is, in essence, a 100% increase. Going back to the facts and figures, but 28 days is 10% of the total pregnancy, that's quite a lot of*

development in my eyes of an actual human being, it's quite a jump that." **Lived experience group**

A limit beyond 28 days

A few participants spoke about their support for early human embryo research to take place across months rather than weeks. For some this was because they were hopeful of significant scientific breakthroughs through extensive human embryo/foetus research, and they did not attach 'personhood' to the research material.

For others a longer extension was justified or permitted by their religious faith.

> *"I come from an Islamic background and being a Muslim, what we have been told and what we believe is that a soul is only put into the foetus or maybe to the embryos when it's gone past three months or 12 weeks. So if it stays under the limit of maybe 12 weeks, I'm happy with it, I don't have any issues."* **Lived experience group**

Influence of technology on regulation of human embryo research

How might technology develop and what implications might it have on early human embryo research and how it is regulated? These questions were considered by participants in different respects. Some hope that technology might develop in such a way that would allow early human embryo research to take place 'in utero'.

> *One of the technologies that may become available that isn't yet. There's much more ability to non-invasively look at embryos. And once that has been discovered how to do that so that you could look at a living embryo without disturbing its gestation or anything else, then you can get a lot more knowledge at that stage. That technology isn't available yet. But it may well be in the future.* **Broad public group, north**

Others thought about the potential for artificial intelligence, or other new and dramatic technological developments, to influence or change how early human embryo research is done and should be regulated. Leading to a belief that the regulations should be reviewed regularly.

> *"After x amount of time, say, three, five years, it's revisited. So if there's been a sudden explosion of say AI, or they're able to do all the sudden new- like the stem cell… in other words, somebody comes up with some idea of splitting the atom, so to speak. There's maybe perceived a need then to revisit it. But you have a set time you say, five years, or 10 years or whatever."* **Lived experience group**

Donors input on research time limits

The proposal was made by some participants that the donor should have the right to decide how long research should be carried out on the embryo that they are considering donating. They foresee that different donors may have different views on how long research should be carried out for. For some it may be a short time limit, but other donors may have an interest in a specific health condition that a longer time limit of research could benefit.

"Even if the law just changed and the law said, 'Okay, we're going to extend it by two days' I still think the person signing the consent should have the final choice on whether it is extended by five days or whatever." **Broad public group, south**

Other considerations for the limit: when embryos feel pain and the abortion limit

A powerful and important question for many participants was 'When does an embryo feel pain' and research that would take the embryo beyond that point is an absolute red line for many. They also worry about how scientists can know definitively if the embryo does feel pain.

"Some people were saying that's 27 days and somebody's saying 28 days well that's after we develop a nervous system. How do we do know that for sure? What can we research so we're ready to know exactly what days there is? **Broad public group, south**

"I had mentioned about primitive streak, like embryo feeling pain and stuff. That's something I've thought about quite a lot. Just because obviously, we're doing this in terms of improving, you know, like human health and IVFs and everything. But obviously, you equally don't want to cause any unnecessary pain or suffering." **Broad public group, north**

The time limit for abortions was raised by some participants who juxtaposed that limit with the research limit. They asked that if an abortion could take place up to 23 weeks, why shouldn't research be allowed for the same period?

"When does that embryo become a person when you can have an abortion after 23 weeks? And I'm thinking well, if you give people the right to have an abortion up to that timescale, if technology allows why not have (the research) on similar timescales?" **Lived experience group**

4.4 Views on deciding the future of the 14-day rule

Key messages on who makes decisions about the 14-day rule:

- There is recognition of the legislative process that will need to be followed if an extension to the 14-day rule is to be considered, but there is a lack of trust in Government and politicians, and a concern about them making a decision on their own.
- Participants feel strongly that members of the public should be engaged in the process of deciding whether the 14-day rule is extended or not.
- In addition many participants want government to listen carefully to scientists and experts, including philosophers and ethicists, when considering whether or not to extend the 14-day rule. Civil society, such as different religious scholars, should also be consulted as part of the decision-making process.
- Many participants want there to be a broad / national conversation with a diverse range of people, which includes in-depth conversations with groups that are representative. This needs to be an informed conversation, that respects differences of opinion.
- There is some concern about the potential for backlash against a change to rule and consider how this might be managed.

Members of the public

Participants feel strongly that people across society should be engaged in the process of deciding whether the 14-day rule is extended or not. They argue that it is important to involve a range of perspectives and provide opportunities for discussion on the ethical aspects of the topic. They would like to see decision-makers hear the diversity of public views directly. They consider it essential to hear from those with lived experience of issues connected to early human embryo research, such as IVF and miscarriage.

> *"Everyone has personal interest, and everyone's been targeted, people have been affected by say, a miscarriage or IVF treatment so I think the public would have a good view."* **Broad public group, north**

A few participants said that it's positive that this dialogue is asking diverse people from across the UK their views on early human embryo research and recommend that the findings are a starting point for understanding societal views.

Civil society

Some participants highlighted the importance of engaging civil society, particularly religious scholars. They believe this will give decision makers a richer understanding of the different perspectives across society. In addition, participants reflected on the value of members of the public hearing different perspectives as part of a process.

> *"I'd be interested in hearing different viewpoints because this has been really thought provoking to me, this process. We've heard so much information, and just reflecting on it I'd be interested in hearing other philosophical or religious views (that) might open my mind to things I hadn't considered."* **Lived experience group**

Scientists and experts

Participants consider that the government and regulators should also be listening carefully to scientists and other experts including philosophers and ethicists when considering whether or not to extend the 14-day rule.

> *"So from my perspective, I think that the regulators should also listen to the experts. So yes, we should have more of a collective and there should be different ideas, different debates and everything going on there. But I do think, you know, particularly (the) government needs to really kind of listen to the experts in the fields on advice."* **Lived experience group**

A few participants argue that it should be the experts who should decide on the 14-day rule and embryo research more generally.

> *"The thing that's been going through my mind is that it should be up to experts to actually decide on the 14-day rule. And the research in general."* **Pilot group**

Some participants reflect on the value of scientists hearing directly from members of the public, as part of a wider conversation with society.

> *"It is only when this kind of format and forum happens that you're able to see the actual, physical practical impact upon people's lives. And that has more weight than somebody wanting to explore something."* **Lived experience group**

Parliament and the Government

There is a recognition that there is a legislative process that will need to be followed if it is decided that an extension to the 14-day rule is to be considered. Some comment on the importance of a potential change to the 14-day rule being debated in Parliament and relevant committees, given Members of Parliament (MPs) represent the views and opinions of the public.

> *"I think this should be debated in the parliament. Because your point was that it's for the people, it's about the people. It's where things are discussed for the good of everyone."* **Lived experience group**

Specific suggestions included producing a Green Paper as part of a wider consultation or establishing committees to explore ethical issues alongside the scientific case.

However, many participants believe there is currently a lack of trust, and negativity, around the government and politicians. They argue that it is wrong to leave the decision in the hands of politicians alone and worry that they will not make an informed decision.

> *"I wouldn't want the parliament to make the decision on it. I wouldn't want them, they're the last people I'd want."* **Broad public group, south**

> *"Two or three people have already said, 'Oh, I don't trust the government anyway'. They think they're doing a bad job. And I include myself in that. But at the end of the day these are men and women have made decisions for us. So this is where conscience and ethics and morals come in. How many people in parliament are moral? How many people in parliament are ethical? How many are emotional? How many are not? How many have experienced miscarriage?"* **Lived experience group**

Some questioned what impact the current composition of the Houses of Parliament and the House of Lords might have on the 14-day rule. For example, if there are more men in Parliament than women, or given the number of Church of England representatives in the House of Lords (based on understanding that the Church of England's current position is not to extend beyond 14 days).[14]

Many participants believe that decision-makers and MPs will need to listen carefully to the opinions of wider society and be well educated on the topic (including hearing evidence from a wide range of sources) before making a decision.

A broader / national conversation with society

When participants discussed how wider society should be engaged in deciding the future of the 14-day rule, an extensive national conversation on the topic, building on what has been discussed in this foundational programme was put forward. They see this national conversation as one which engages as many people as possible. Participants emphasised the importance of a process that allows time for discussion and deliberation, and which respects differences of opinion, so that the range of perspectives can inform the decision, even though it is unlikely a consensus will be reached.

> *"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."* **Broad public group, south**

> *"We won't all agree, but the Warnock Committee had a period of extended consultation and public dialogue. We can say we don't all agree, we can understand what the different viewpoints are, what the difference or considerations are for different groups of religions. I think they understand and then make a decision."* **Lived experience group**

Many participants commented that people will come with different opinions and values. They reflect on the importance of carefully listening to and respecting diverse views, and finding ways to compromise, so that sections of society don't feel neglected or ignored.

Some participants recommend engaging as many people in the decision-making process as possible, while others suggest bringing a group of people together that is reflective of the population. Others feel that a combination of depth and breadth will be needed to ensure that everyone has the opportunity to share their views.

> *"Some people do have very strongly held beliefs. I just think everybody needs an opportunity to share their views."* **Lived experience group**

> *"But I do think society does need to be involved in it, maybe in a forum. And then it's collating all that data of each individual's voice and feedback and making that a valid decision around it… taking everyone's view into account."* **Lived experience group**

[14] Based on a description of the Church of England's Mission and Public Affairs (MPA) position that "under certain circumstances, embryo research may be permissible as long as the intention is to alleviate human suffering, no viable alternative method is available, that all embryos are treated with respect and not permitted to develop beyond the UK legal limit of 14 days." See the Church of England's webpage on this for more detail: https://www.churchofengland.org/sites/default/files/2017-11/embryology-and-related-topics.pdf

Taking part in this public dialogue gave confidence that public engagement on this complex topic will be possible as part of the next steps.

A specialist attending the dialogue explained what a regulatory sandbox is to one group, and they immediately felt it could be a valuable next step to better understand what extending the 14-day rule might involve.

> *"Regulatory sandbox, a diverse Committee, filled with trusted people who know what they're talking about, right."* **Broad public group, south**

A referendum on the 14-day rule

A few participants considered whether it would be appropriate to have a referendum on extending the 14-day rule. They think it would be a good way to reach a large proportion of the population, but question whether people will be adequately informed. They also expressed concern about the potential for voter manipulation and the impact of misinformation.

> *"That's a great idea for any major decisions that are made, that there is actually a public vote [a referendum], because then that does consider everyone. Although then there's the issue that not everybody is very well informed. And they need to be clear exactly what they're voting for."* **Lived experience group**

Concerns about a backlash

While recognising the importance of allowing space for all perspectives, a few participants are concerned about the potential for backlash and the importance of managing this.

> *"I'm all for this research, I want to see positive results coming out of this research, but I feel what's going to be challenging is there's going to be people that are going to be protesting against it. You know, just like you've seen in the news about the oil protesters and gluing themselves to the road and blocking traffic and all that. That's going to delay things I feel. And not everyone's going to see the positives. Not everyone's going to agree on things, which is natural."* **Pilot group**

> *"One of the things is backlash from different places, for example, media sources. Like anti-abortion campaigns, religious feelings, this could be quite a controversial subject."* **Broad public group, north**

Some participants are concerned about the impact of potentially violent protests during discussions about extending the 14-day rule, particularly the safety of scientists.

> *"What about around safety and security of researchers and labs from, you know, sort of potentially violent protesters. Because I think this is a very contentious issue. There's already protesters in this area. But I think if you know, if the law was extended, I imagine that there are certain groups that would be not very happy about it.* **Lived experience group**

> *"I'd be concerned about personal attacks on scientists. We saw that with scientists researching animals. It wasn't safe for them, and they had to get police protection."* **Broad public group, south**

5. How participants would like to see early human embryo research taken forward

Many participants are ambitious for this research and as such have expectations of the scientists engaged in the work and in the regulations governing it. As we have seen they also expect ongoing public involvement in decision making in this area, and also, as we describe in this chapter, ongoing awareness raising so that in future this area of research is not something that comes as a surprise to people.

Key messages about participant expectations

Participants expect scientists to:

- Undertake research which meets a need, not just because the technology exists to extend the period of research beyond 14 days.
- Maintain a strong ethical basis for their work, not driven by profit or commercial interests, prioritising respect for the embryo.
- Act with transparency, sharing breakthroughs swiftly demonstrating their practical application in society.
- Potentially share any early breakthroughs that arise if the rule is extended beyond 14 days to convince those who are uncertain about the extension that it has resulted in important findings.

Participants expect regulators to:

- Maintain strong ongoing regulation with substantial punishments for those who break law (or the spirit of the law).
- Act with transparency on their regulatory work including licensing.
- Reduce the politicisation of the issue basing decisions in evidence and fact, not what might go down well with voters.
- Involve donors in decision-making and ensure Research Ethics Committees are inclusive and diverse.
- Consider establishing a mechanism for regulation globally.

In addition participants expect society to be better informed about early human embryo research, its outcomes, its implications and the regulation.

5.1 Expectations of scientists

At the heart of participant expectations of scientists is that they will maintain a strong ethical basis for their work, which is driven by meeting societal needs, and no other motivation.

Working ethically to meet societal needs

Many participants expect that scientists will be driven by their own consciences in this work, that they will devise research programmes because they have identified a societal need for the research to be done. They place a high value on research which could alleviate suffering from serious medical conditions such as cancer and from infertility and recurrent miscarriage and they expect these to be the drivers of the research agenda.

> *"The way I see it is that scientists are doing this because they want to help families, they are making discoveries (to help people). And they're doing it for the good of humanity, I'm guessing. And I'd like to believe that a lot of the scientists have a moral compass which guides their work."* **Lived experience group**

This thinking means that participants do not expect science to be driven by profit or the technology. They do not want a, 'we can, so we will' approach to infiltrate the science. The value of the embryos that this research is working with and the fact that they are in limited supply and come from donors who may have struggled with the decision to donate to science, gives them a status above other research material. For many participants, particularly those in the lived experience groups, this means that they want to know that scientists will work towards research findings which inform treatments available to all, not an elite with the money to pay for them.

> *"I strongly, strongly think that if they do, I mean, come up with treatments for any kind of long term illness or just illness in general. It should be available for everyone, not just for rich people. They've used our precious eggs and sperm to create the research material after all."* **Lived experience group**

Some participants questioned the intentions of others in the research context, for example the Government who may be more profit-focused. Participants expect scientists to push back against such a motivation and stick to their research ethics and principles.

> *"I'm starting to sort of question what the Government, and the broader intentions might be outside of actually coming up with cures or helping IVF and whether there's more of a profit intention or other types of intentions there. I hope scientists will stick to their guns and work for the right motives."* **Lived experience group**

> *"My hope is that the scientific community can get through that. They will show that they are above what we see in other parts of higher society if you're like, you know, they're not part of your government apparatus. You know, they're not part of the big business."* **Broad public group, south**

Participants stress that they expect the research to be driven by the 'common good' so that it benefits society as a whole in areas of crucial importance such as health and fertility.

> *"It's important whether it's for the common good, isn't it? I mean we've just lived through a pandemic, and lots of people made lots of money through the pandemic and that could have been to a different argument. But ultimately, the development of a vaccine was done for the common good."* **Lived experience group**

> *"I just have the hope that if they are successful in extending the rule, any discoveries or breakthroughs they make are shared, for the good of science and not sold for profit."* **Lived experience group**

Having an ethical basis for their work is essential. Participants prioritise this given that the research is done using human embryos. Many appreciated that the scientists they heard from showed respect for the embryo and they want to ensure that this approach

continues if the rule is extended, keeping in mind at all times the source of the research material.

> *"You know, it sounded from the scientists, both of them, that they handle (the embryos) with care, you know, they're not just freezed, unfreezed, refreezed, you know, not just being used just as a product if you like. They are taking care of them. And it's encouraging that they are looking after them in the best way possible."* **Broad public group, north**

> *"Keep your morals and integrity intact and put yourself in the shoes of the women donating the embryos ensuring they are taken care of as best as possible."* **Lived experience group**

Given this ethical basis for the work it is equally important to participants that researchers strictly abide by the UK regulations. Some feel that even if 'rogue' scientists operate in other countries where the UK has no control, UK researchers should meet the highest ethical and legal standards for their work. Others suggest there are always bad elements in every situation but strict adherence to the regulations is expected by those working within the profession.

> *"Most scientists are looking at finding cures or helping understand disease. There is, of course, the risk of your mad scientists. This is the whole point to regulation. If you ask a huge group of scientists if they would work on sensitive subjects like this, if they want regulation, I think you'll find the vast majority would say yes, of course, they'd feel safer. Because they're properly regulated."* **Pilot group**

One participant sums up the view of many in relation to caring for this previous research resource by saying,

> *"I guess for me the expectation is that every single care is taken with these embryos. I expect that everything is done to the regulations, and I expect that they are all kept safe and cared for in controlled environments."* **Lived experience group**

Act with transparency, promoting the research to demonstrate its value

Transparency is an important aspect of participants' expectations of scientists. Participants want to know that there are no hidden agendas, that the motivations of the researchers are open and obvious and focused on the themes of fertility and health treatment as already discussed. There is a belief amongst many participants that acting with transparency will improve societal knowledge of the research being done which will benefit society.

> *"Be open about it as well, no hidden games. Be open at every stage. Sometimes I feel that's where things have got messed up in the past, when society didn't know what was happening behind laboratory doors."* **Broad public group, north**

> *"A lot of us didn't necessarily have much knowledge about this. And I think a societal expectation might just be that the findings of the research are better communicated, or the rationale behind the research is better communicated. I think transparency in general with society. If we're doing research for the benefit of society then society should be informed about it."* **Broad public group, south**

Acting with transparency includes sharing the findings of the research in accessible ways. They discussed using the media, writing news articles, and presenting their research in ways that are engaging to the public, not only in academic journals. They want to know that people across society can find out more about the outcomes of the research, not just scientists and academics. This includes not only sharing significant breakthroughs, but showing how the research was done to achieve these outcomes.

> *"I think transparency, so we understand the research and to give people hope on the achievements and the successes. I think really the successes are the most important. Yeah, we don't really know what they succeeded in doing really until we came here."* **Broad public group, south**

If the 14-day rule, is extended, some participants, particularly in the broad public group, south, were eager, for any significant outcomes that come from opening up 'the black box' to be shared swiftly. They feel this would provide a justification for having extended the rule and demonstrate the value of the research.

> *"My expectation is, if this does go through which I'm sure at some stage it will, extending it to 28 days, they very quickly find a benefit for it to justify; that they quickly and not just in 20 years' time, but quickly find a definite benefit that can justify why they've done it."* **Broad public group, south**

5.2 Expectations of the regulations and regulators

A strictly regulated system

Above all, many participants expect that the regulations governing early human embryo research are strong, robust and have effective measures in place to punish those who break the rules and regulations. There is much agreement that robust regulations will continue to make clear what is acceptable and what is not in this field of research. This gives the public reassurance that the research is being conducted ethically and can be trusted to focus on the areas that will bring benefit to society.

> *"I would want to make sure that (the regulations) are fairly tight, that they couldn't be taken to another level of designer babies or somebody with a lot of money could choose to eradicate hereditary conditions. Everything has a flip side. It does seem very positive and it's for the greater good, but there must be a dark side or a sinister side or could be open to being used wrongly. I think the governance would have to be really tight."* **Broad public group, north**

> *"Ethically, it all has to be regulated in the right way. Otherwise, everyone can just go off and do their own thing, and the world will crash and burn. The regulators need to think all the time that this is a human embryo. It's just making sure that we are doing the right thing for the right people and the right reasons."* **Lived experience group**

There is also a belief amongst some participants that if the 14-day rule is extended to as much as 28 days then the regulations must be even more stringent, or at least more rigorously monitored, to ensure they are being abided by.

> *"If the 14-day rule were to be extended to 28 days, there should be more regular checks, and oversight. Because inevitably that research is going to be somewhat developed. So it should have more regular checks."* **Broad public group, south**

For some participants the regulations need to encompass not just how and when the research is done, but also how it is funded. They feel that there is a role to be played by the regulators in framing who is able to fund this research and to ensure that the focus is not on profitability but on ethically conducted research.

> *"Research does need to be funded. I appreciate that. But this just kind of hammers home to me the importance of regulation. Because there will be a profit element, you know, IVF costs massive amounts of money, you can go private, you can spend money. People are always looking to exploit if there's profit to be made aren't they? Changes to regulation should take profits into account, they obviously need to be carefully considered."* **Lived experience group**

Some participants looked at the Warnock report[15] as a model for how the regulation should continue to develop. They feel that considerable effort was made in showing how the Committee had reached its conclusions and what they had considered. They find this impressive and as a result they want to know that any changes to existing regulations will be developed as seriously creating specific clauses for specific situations. They also described a framework around the regulation which ensures all the relevant elements of the rule, and the regulations, are held together to give researchers a clear and coherent structure for their work.

> *"In some of the stuff in the Warnock report, the reasoning behind the regulations such as where and how you can use embryos should be carried forward. I think they are really robust around what you can do research on and how. And all those sort of specific rules. That would be an important sort of scaffolding to have around, especially if the time were to change just to make sure that there is that really robust, like an umbrella of regulation."* **Lived experience group**

A transparent regulatory system

As much as participants feel that people in society know very little about this area of research, they also feel that society does not know about the system that regulates it. In their view this should change. Some suggested that there has been no outcry about the research or its regulation because people do not know enough about it.

> *"Do the public really know that much about it? Really there hasn't been an outcry over all these years that the 14-day rule has been in place. Why? Because people don't really know. I mean, most of us here didn't know anything about it. Why is that? Maybe regulators are worried that if they say something about it there'll be an outcry."* **Broad public group, south**

Many participants want the HFEA to be more visible to "*everyday people*" so that there are clear assurances that the regulations exist and are enforced.

> *"Put it out there in the public domain. Not just what happens in the lab, but also the guidelines that it is regulated by. It will show that there are ethical policies in place. I keep thinking back to when genetics started with, say, Dolly the sheep, and the outcry. Well, it doesn't have to be like that, the more transparent the regulations are, the more it shows they are working in the public interest."* **Broad public group, north**

[15] Warnock, M, Report of the Committee of Inquiry into Human Fertilisation and Embryology, London, HMSO 1984

Other reassurances that participants expect to show that the regulations are being managed with transparency include:

- Publishing regular, publicly accessible (including in accessible language and formats) reports on which laboratories have been licensed for which pieces of work and, when that work is complete, an evaluation report showing how the regulations have been met.
- More clarity for donors on the kinds of research that is being done with embryonic material and what the outcomes of that research has been. This could include:
    - Updates from the research institutions targeted at donors.
    - Stories from donors on their experience to give support and clarity to potential donors.
    - The potential for discussions and exchanges between donors and the institutions receiving the donated material, an invitation to open days for example, allowing donors access to the researchers.
- Communicating to the public when the rules have been breached and what the repercussions have been for those that breached them, to give assurances that robust action is taken if the regulations are broken.

The potential for global regulation

As we have seen participants place value on international collaboration for this research. Some participants therefore expect the regulations to operate globally. They discussed ways of facilitating international collaboration including:

- Having a database of all the research being done on early human embryos so that partners and collaborators could easily be identified, and researchers could identify those that operate within the same ethical framework.

    "With that in mind, it is extremely utopian, but there will be a world central database of all research. Then you will find some labs. Some countries might just withhold the research anyway, so it wouldn't be up to date. But in an ideal world that's what I'd have a worldwide database on all research and guarantees to be up to date and honest." **Lived experience group**

- Establishing a system of global regulation so that all the signatory countries abide by the same timelines, regulations and ethical standards. They propose this because of the importance of the subject for humanity.

    "It does feel like there should be some sort of worldwide agreement, because particularly, you know, in the minds of scientists, you want them to be able to collaborate together from country to country. The different rules and regulations get in the way. It just feels, you know, we're all human, we should be able to have a common regulation and global laws for the good for all of humankind." **Lived experience group**

5.3 Expectations for future understanding of the research

The important and groundbreaking nature of early human embryo research leads many participants to expect that society will in the future be better informed about the work and its significance. They feel that if discussions are to be opened up about the possibility of extending the 14-day rule then society should be prepared, the ground work done, so

that this area of research is not seen as new and surprising but something that has a history right back to the 1940s when IVF research began.

Laying the foundations for engagement on changing the 14-day rule

There is a concern amongst some participants that if foundations are not laid for a public conversation before it is held, then misconceptions and misinformation will take the place of fact and evidence, and this will lead to a misinterpretation of the research and how it is regulated.

> *"If you don't tell me what you're doing, then I'm allowed to speculate. I mean, if you don't inform me very well, some other people will and I might get a handle on the wrong information. Right. So the importance of information can never, never be over emphasised."* **Broad public group, north**

> *"It's a shame that the people that are worried about this topic are potentially misinformed, they haven't benefited from the subject experts, they don't know what the research is doing."* **Broad public group, south**

Involving young people

Many participants also want young people, who will be most affected by any advances in fertility and health treatments and other research outcomes to be at the centre of this drive to raise awareness about the science. Proposals for what could improve societal understanding about the research include:

- Including early human embryo research, its achievements and potential future outcomes, in the National Curriculum.
- Communications on research institutes websites and social media channels sharing new breakthroughs, and also day-to-day work and what researchers do.
- Communications from regulators on licensed laboratories and their studies.
- More opportunities for people to encounter the work at public events and institutions such as science festivals and in museums.
- More opportunities for researchers, at all stages in their careers[16], to share information about what they do and their motivations for doing it.

> *"The public dialogue should be widened. Have debates, evening workshops online. Massively encourage young people to get involved. And then even extending it into schools and these sort of things that people want in the curriculum, to educate kids."* **Broad public group, south**

Participants feel an added bonus to raising awareness of the science in society is that it will inspire people to join the research community by becoming scientists or doctors.

> *"Awareness and education raising for young people, because these young people are going to benefit more from this because it might take 10, 15 or 20 years to demonstrate results. The young people can then grow with that knowledge and they're more open to going a little bit further. It's to inspire the new generation because they might want to be doctors and scientists."* **Broad public group, south**

[16] Participants valued the fact that in the dialogue they heard from and interacted with early career as well as very senior researchers working in the field.

6. Conclusions and next steps

The breadth and depth of our participants' discussions, summarised in this report, demonstrates people's capacity to engage with complex and potentially controversial subjects and respond with sensitivity and nuance.

6.1 A summary of reflections on changing the 14-day rule

To conclude we summarise where participants land in terms of the 14-day rule and its regulation.

Many participants support some form of extension to the number of days or a change to the rule if it is informed by society's expectations about respect for the embryo and the research continues to be robustly regulated.

Participants have high expectations of scientists, regulators and the need to involve the public in future decision making on the research and the 14-day rule. They believe that greater transparency is necessary across all aspects of this work so as to raise public awareness of the need for research in this area prior to any national conversations on potentially changing the 14-day rule.

The most compelling reasons to explore some form of change to the rule are that there is potential to improve IVF success rates, reduce multiple miscarriages and to better understand, treat or prevent serious health conditions.

Views differed between and within groups on how the 14-day rule should change. Some participants believe that change should be taken in small steps, such as a 3-4 day extension, followed by review. They want a cautious approach that may result in a gradual extension beyond 14 days based on research learnings and in consultation with society. The idea of a trial extension appeals to some for the same reasons. These suggestions were made in particular by those in the Broad Public south group, where participants' interests often led them to prioritise the process of how decisions about extending the rule are made and communicated.

Other participants, particularly those in the Broad Public north group, believe extending to 28 days should be considered because it offers the opportunity to unlock 'the black box' and deliver significant new discoveries, such as the causes of and treatment for spina bifida. For many of these participants, the prospect of carrying out research on an embryo at 28 days posed no significant new ethical considerations compared with an embryo at 14 days. The adoption of 28 days as a future milestone was also seen to benefit from having a relevant biological marker, in this case the closure of the neural tube, which could function in a similar way to the emergence of the primitive streak around 14 days. Some also based their support for 28 days on a perception that this is a preference among researchers in the field, and therefore a useful guide.

A few participants wanted no change to the rule – either because they thought research efforts should continue to focus up to 14 days if there were still discoveries to be made or because they opposed all forms of early human embryo research.

At the other end of the spectrum, a few participants wanted to see the rule abolished or extended considerably to allow research studies and the length of time they needed to study human embryos to be considered on their merits. Some of these participants

worried that the process of parliamentary debate to change legislation would treat the complex issue of regulating human embryo research into a political football and delay or stymy future research.

The following points should be taken into account when considering how participants reflected on changing the 14-day rule:

- Uncertainty for some about what benefits can accrue from extending the limit – noting the nature of the black box - can the benefits of unlocking be further clarified before the key is turned?
- Some participants are concerned about development milestones in the embryo and, for example, when the embryo will feel pain.
- Some participants think it is important for donors to have a say on how long research can happen on the embryos they donate.
- Thinking about how to ensure the UK is not out of step with other countries if it changes the 14-day rule – how could global scientific collaboration be supported and not damaged?

For some participants there are serious concerns that early human embryo research and pre-implantation genetic testing could pave the way to the eradication of certain disabilities and conditions from the population. This is an area of respectful, but nevertheless challenging, discussion for participants. **Some are very concerned that an area of research that they value for the benefits it brings, could become a route to eugenics.**

6.2 Proposals for further explorations of the topic

Given some participants' serious concerns about eugenics, discussions about genetic testing should be separated from discussions about the 14-day rule and it may be appropriate to explore the former via a further deliberative exercise.

This is a developing area of science, and essentially new to many people across society. Analysis of the language used by participants in their responses to the topic was beyond the scope of this dialogue. However, we recommend that HDBI builds on the work they have already done to explore citizen and scientist use of language in the area of early human embryo research. Understanding more about differences in the language used by citizens and scientists, in particular what words are used to describe early human development, would be a valuable contribution towards future dialogue. For example:

- Are there differences in the language used by citizens and scientists?
- The use of gendered language
- What is acceptable language (for example to disabled people) when describing disability, and the disabling aspects of some developmental conditions in the context of early embryo research?
- Terms to use for the disposal of embryos when fertility treatment/ research programmes end
- Terms to describe when a human forms, what makes a human and what do the words 'becoming human' used in this dialogue mean?

Such a research study[17] would provide valuable insights for scientists as they engage with citizens in this field of research in the future.

6.3 Proposals for further dialogue

This dialogue was commissioned as a first step intended to encourage other organisations in the UK and around the world to involve people in similar discussions. The foundational nature of the dialogue was recognised and appreciated by participants. Their discussions indicate a number of further areas for engagement and involvement which are set out below.

Some participants were surprised that we did not share during the process a breakdown of how scientists researching in this field feel about changing the 14-day rule in the dialogue stimulus. To some extent, and in some groups, specialists did give their personal view, but participants learnt that no such data exists, although it is clear that there is no consensus in the scientific community on the approach to take for future regulation.

> *"So we hear that scientists differ in their opinion on this 14-day rule. I would love some idea of a Congress, of the scientists involved in this research. And during that they have a way of discovering a percentage of scientists that are for it, and the percentage of scientists who are against it. And the kind of reasoning for that."*
> **Broad public group, south**

Equally surprising to some was that we did not provide a list of options for changing the 14-day rule to which they were asked to respond. This was done purposefully and was intended to enable a subtle discussion on the issue rather than a debate on the pros and cons of various potential options. Allowing a free exploration of possible futures gave helpful scope for questions, what ifs and thoughts on alternatives. Both these points lead to the first proposal for further research.

1. A forum to understand the views and perspectives of scientists

- Hold a forum for scientists and researchers in the field in which the various changes to the 14-day rule are mapped out, with pros and cons for each established.
- During this forum, survey scientists to understand what their view is on any potential change to the rule and its regulatory context.
- Hold a deliberative space within the forum for the above to be discussed and so that the hopes, concerns, expectations and perspectives of scientists, both as researchers and people in society, can be better understood.

Participants saw this dialogue as significant across social, ethical, philosophical and faith dimensions, as well as being critical for considerations for health and fertility treatment outcomes. They believe, as we have seen in chapter 3, more and wider dialogue would be welcome. They suggest:

[17] Middleton, A et. al. The legacy of language: What we say, and what people hear, when we talk about genomics: August 2023, is a useful example of the use of language in genomics research.

2. A wider public dialogue

- Hold a dialogue with a greater number of people in different settings for example in communities and youth groups across the country.
- Facilitate different modes of dialogue such as online, in-person, in the evenings, over several weekends, replicating the model of longer form deliberation over several weeks.
- Use the dialogue process as a way of raising the profile of this research and its regulation, for example calling it 'A national conversation' and working with the media to have an open and transparent conversation.
- Engaging civil society in the conversation, including community and faith groups.
- Continue to work with scientists on the design and delivery of the dialogue so that they can explain their work and the motivations behind it.
- Engaging equally those who are likely to oppose change as much as those who would not know what their view is until taking part, or those who naturally support scientific research.

  "That there is no scientific consensus on the proposed cut-off for embryonic age for research which makes the opinion of the public of even greater importance."
  Broad public group, south

3. Hold separate conversations about stem cell-based embryo models and genetic testing

The newness and complexity of stem cell-based embryo models and the current lack of specific regulation merits a separate, more in depth public conversation. Engagement on these models, how they differ and how they could be used in research would allow them to be explored and understood and lead to recommendations on how they are regulated.

Acknowledgements

Hopkins Van Mil is enormously grateful to participants from across the UK who shared their time and thoughtful reflections as part of this public dialogue. Their commitment to engaging with this complex and sensitive subject and the respect they showed each other when, at times, their views differed quite significantly was both impressive and inspiring and made this a valuable and insightful process.

Particular thanks are due to Oversight Group (see Appendix 2) members, and its Co-Chairs Bobbie Farsides, University of Sussex and Robin Lovell-Badge, the Crick Institute.

Our speakers and those who gave their time for lived experience interviews greatly enhanced participant understanding of the topic. We are therefore most grateful to

Mag Aushev, Newcastle University; Felicity Boardman, University of Warwick; Sarah Chan, University of Edinburgh; Katrien Devolder, Oxford University; Stephanie Ellis, Central Cambridge Research Ethics Committee; Clare Ettinghausen, HFEA; Bobbie Farsides, University of Sussex; Katarina Harasimov, Cambridge University; Insoo Hyun, Harvard Medical School Center for Bioethics; Emily Jackson, London School of Economics; David Jones, Anscombe Bioethics Centre; Elselijn Kingma, King's College London; Robin Lovell-Badge, the Crick Institute; Sarah Milosevic, HDBI Insights Group; Matteo Mole, Babraham Institute; Naomi Moris, the Crick Institute; Kathy Niakan, Cambridge University; Emma Rawlins, Gurdon Institute; Elizabeth Robertson, University of Oxford; Peter Rugg-Gunn, Babraham Institute; Seetal Salva, Independent; Natalie Silverman, The Fertility Podcast; Venessa Smith, Guy's & St. Thomas' Hospital; Desislava Staneva, Cambridge University; Peter Thompson, HFEA; Amy Wilkinson, Babraham Institute.

We would also like to pay thanks to additional members of the HDBI Insights Group, who provided valuable input during the design of the dialogue process.

Our special thanks go to Naomi Clements-Brod of the HDBI and Mike Norman of Babraham Institute; Suzannah Lansdell and Diane Beddoes at Sciencewise; Anna MacGillivray and Hilary Livesey, the independent evaluators from Ursus Consulting. The support and guidance of everyone on the project team has been crucial to designing and delivering this project effectively and it has been a pleasure to work with them over the last 8 months.

Appendix 1 – Glossary of terms used in this report

Note: The definitions given here are based on our interpretation of the terms drawing on a) what specialists told us and b) what participants discussed. As such, they should not be considered comprehensive or definitive explanations of each term.

'14-day rule' This is a legal limit applied to research on human embryos which forbids the in vitro development of human embryos beyond the first 14 days, or until the first appearance of the **primitive streak**, whichever comes first. It is a feature of science policy and regulation in many jurisdictions around the world. In the UK it is set out in law under the **Human Fertilisation & Embryology Act (HFE Act)**.

'Black box' A term commonly used by researchers working in the field of early human embryo research to refer to the period of embryo development between 14 and 28 days. There is less knowledge about this period due to two constraints: on the one hand the **14-day rule**, and on the other the earliest that embryo material from miscarriage or abortion typically becomes available is 28 days.

Eugenics means the selection of certain heritable characteristics above others because they are seen as more desirable, so as to improve future generations.

Foetus An embryo becomes a foetus about 8 weeks after conception. By then, all of the major organs and body parts have begun to form and the foetus is about 3cm long, with the head making up about half of this size.

Human Fertilisation & Embryology Act (HFE Act) This is an Act of Parliament of the United Kingdom that was first passed in 1990. It has been subject to updates, including in 2008, but the laws it established remain largely the same. It led to the founding of the **Human Fertilisation & Embryology Authority** and sets out rules for regulating the use of human embryos, including for research.

Human Fertilisation & Embryology Authority (HFEA) is the UK's independent regulator fertility treatment and research using human embryos. It was established via the **Human Fertilisation & Embryology Act (HFE Act)** as an 'arm's length body' of the Department of Health, meaning its work is independent but on behalf of the Government. Its role includes licensing, monitoring and inspecting fertility clinics and research centres.

In-Vitro Fertilisation (IVF) is a technique in which an egg is removed from the ovaries and fertilised with sperm in a laboratory. The fertilised egg, now an embryo, is then returned to the person's womb to grow and develop. Surplus IVF-made embryos that are not used for family-building purposes are sometimes donated to individuals to research following informed consent.

Mitochondrial donation treatment This has been developed more recently than **IVF** and is designed to help people with severe mitochondrial disease to avoid passing the condition onto their children. Two techniques have been approved by Parliament in the UK, both of which use donated mitochondrial DNA alongside the parent-to-be's own genetic material.

Neural tube This is a hollow structure from which the brain and spinal cord form. It starts to develop in early pregnancy and closes about 4 weeks after conception. If it doesn't develop as expected this can result in congenital conditions such as spina bifida.

Pluripotent stem cells are a type of unspecialised **stem cell** that can be cultured in the laboratory. Like cells in the early human embryo, pluripotent stem cells can specialise into many of the different cell types of the human body. They are often the starting point for building **stem cell-based embryo models**.

Pre-implantation genetic testing This is a technique which can sometimes be applied as part of **In-Vitro Fertilisation (IVF)** to identify embryos which are affected by one or more specific health conditions. It allows embryos which are not affected by these conditions to be taken forward during IVF and implanted in the womb, making it unlikely for the condition to occur in the next generation. In the UK this testing is regulated by the **Human Fertilisation & Embryology Authority (HFEA)**.

Primitive streak This is a formation in the early embryo which establishes its 'axis', identifying a future 'head' and tail' at each end. It is also a visual indication that the embryo is starting to develop specialised cells, those which will go on to develop into the various types of cells that make up the body. As set out in the **Human Fertilisation & Embryology Act (HFE Act)**, human embryos are not allowed to continue developing in research settings once the primitive streak has emerged (usually around 14 days).

Regulatory sandbox is a tool to enable the exploration of new and innovative products, researchers, services or businesses under a regulator's supervision in a simulated situation which mimics a real world situation.

Research Ethics Committee (REC) A REC is a diverse group of people appointed to review research proposals to assess formally if research is ethical. This means the research must conform to recognised ethical standards, which includes respecting the dignity, rights, safety and well-being of the people who take part.

Stem cells are unspecialised cells that help to grow and repair tissues in our bodies, and can also be cultured in the laboratory where they retain their potential to give rise to specialised cell types. There are two broad categories of stem cells: **pluripotent stem cells** that can give rise to many different types of cell, and tissue-restricted stem cells that can typically only give rise to cell types within a particular tissue.

Stem cell-based embryo models are a recent scientific advance that use stem cells, usually **pluripotent stem cells**, to create cellular structures that share features with early embryos. Scientists study stem cell-based embryo models as a means to better understand how human embryos might grow and develop. These models are associated with a fast-moving area of science and raise important considerations for ethics, science policy and regulation.

Warnock report Also known as The Report of the Committee of Inquiry into Human Fertilisation and Embryology, this is a report published in 1984 following a governmental inquiry into issues of fertility and embryology in the UK, named after its chair Mary Warnock. It laid the groundwork for the **Human Fertilisation & Embryology Act (HFE Act)** which was passed in 1990.

Appendix 2 – Membership of the Oversight Group

Name **Co-chairs of the group* *In alphabetical order by name of organisation, beginning with Co-chairs.*	**Role(s)**	**Organisation(s)** **Members sharing representation of a specific organisation have been collated together.*
Professor Bobbie Farsides*	Professor of Clinical and Biomedical Ethics	Brighton and Sussex Medical School
Professor Robin Lovell-Badge*	Group Leader and Head of the Laboratory of Stem Cell Biology and Developmental Genetics	The Francis Crick Institute
Dr Peter Rugg-Gunn	Human Developmental Biology Initiative Scientific Lead; Research Group Leader and Head of Public Engagement	The Babraham Institute; Human Developmental Biology Initiative
Professor Sarah Franklin	Professor of Sociology and ReproSoc Research Director	University of Cambridge
Professor Nick Hopwood	Professor of History of Science and Medicine; Deputy Chair, Cambridge Reproduction	University of Cambridge
Professor Kathy Niakan	Group Leader and Head of the Human Embryo and Stem Cell Laboratory; Human Developmental Biology Initiative Research Group Leader	The Francis Crick Institute; Human Developmental Biology Initiative; University of Cambridge
Dr Marcin Smietana	Senior Research Associate, Cambridge Reproduction	University of Cambridge
Dr Catherine Hill Sharon Martin	Interim Chief Executive Business Development Manager	Fertility Network UK
Georgie Ariaratnam	Public Engagement Manager	The Francis Crick Institute
Clare Ettinghausen Angharad Thomas	Director of Strategy and Corporate Affairs Head of Communications	Human Fertilisation and Embryology Authority
Subhadra Das	Researcher and storyteller	Independent
Sarah Milosevic	HDBI Public Insights Group Member	Independent
Professor Emily Jackson	Professor of Law	London School of Economics
Sarah Dickson	Head of MRC Regulatory Support Centre Research and Policy Manager	Medical Research Council
Ranveig Berg Danielle Hamm Rebecca Mussell	Research and Policy Manager Director Associate Director	Nuffield Council on Bioethics
Sarah Norcross	Director	Progress Educational Trust
Dr Ros Williams	Senior Lecturer in Digital Media and Society	University of Sheffield

Professor Felicity Boardman	Deputy Head of Social Science and Systems in Health in Health Unit	University of Warwick Medical School
Dr Alessia Costa	Senior Social Scientist	Wellcome Connecting Science
Haidee Bell	Public Participation Lead	The Wellcome Trust

Appendix 3 – Dialogue Speakers

Lived Experience group

Speaker	Organisation	Topic
Webinar		
Dr Katarina Harasimov	University of Cambridge	The Embryo – Part 1
Dr Peter Rugg-Gunn	The Babraham Institute	What is Early Human Embryo Research?
Peter Thompson	Human Fertilisation and Embryology Authority (HFEA)	Introducing the HFEA
Workshop 1		
Dr Emma Rawlins	HDBI	Early Human Embryo Research: Examples and Outcomes
Dr Naomi Moris	The Francis Crick Institute	The Embryo – Part 2
Dr Katarina Harasimov	University of Cambridge	Contributor on scientific research – Speaker panel
Dr Sarah Chan	University of Edinburgh	Contributor on philosophy and ethics – Speaker panel
Workshop 2		
Amy Wilkinson	HDBI	Contributor on scientific research – Speaker panel
Dr Katarina Harasimov	University of Cambridge	Contributor on scientific research – Speaker panel
Dr Robin Lovell-Badge	The Francis Crick Institute	Contributor on scientific research – Speaker panel
Venessa Smith	Guy's and St Thomas' NHS Foundation Trust	Contributor on IVF and donation of embryos to research – Speaker panel
Dr Sarah Chan	University of Edinburgh	Contributor on philosophy and ethics – Speaker panel
Workshop 3		
Dr Sarah Chan	University of Edinburgh	Contributor on philosophy and ethics – Speaker panel
Dr Katarina Harasimov	University of Cambridge	Contributor on scientific research – Speaker panel
Amy Wilkinson	HDBI	Contributor on scientific research – Speaker panel

Broad Public groups

Speaker	Organisation	Topic
Webinar – Both groups		
Dr Magomet Aushev	University of Newcastle	The Embryo – Part 1
Dr Peter Rugg-Gunn	The Babraham Institute	What is Early Human Embryo Research?
Clare Ettinghausen	HFEA	Introducing the HFEA
Workshop 1 - Broad public group, south		
Dr Emma Rawlins (pre-recorded)	HDBI	Early Human Embryo Research: Examples and Outcomes
Dr Naomi Moris	The Francis Crick Institute	The Embryo – Part 2 Contributor on scientific research – Speaker panel
Dr Desislava Staneva	University of Cambridge	Contributor on scientific research – Speaker panel
Professor Bobbie Farsides	Brighton and Sussex Medical School	Contributor on philosophy and ethics – Speaker panel
Workshop 1 – Broad public group, north		
Dr Robin Lovell-Badge	The Francis Crick Institute	Early Human Embryo Research: Examples and Outcomes Contributor on scientific research – Speaker panel
Dr Naomi Moris (pre-recorded)	The Francis Crick Institute	The Embryo – Part 2
Dr Magomet Aushev	University of Newcastle	Contributor on scientific research – Speaker panel
Dr Katrien Devolder	University of Oxford	Contributor on philosophy and ethics – Speaker panel
Mike Norman	Babraham Institute	Contributor on HDBI – speaker panel
Workshop 2 - Broad public group, south		
Dr Elselijn Kingma	King's College London	Contributor on philosophy and ethics – Speaker panel
Dr Desislava Staneva	University of Cambridge	Contributor on scientific research – Speaker panel
Venessa Smith	Guy's and St Thomas' NHS Foundation Trust	Contributor on IVF and donation of embryos to research – Speaker panel
Naomi Clements-Brod	HDBI	Contributor on HDBI – Speaker panel
Workshop 2 - Broad public group, north		
Dr Peter Rugg-Gunn	The Babraham Institute	Contributor on scientific research – Speaker panel

Dr Katrien Devolder	University of Oxford	Contributor on philosophy and ethics – Speaker panel
Dr Magomet Aushev	University of Newcastle	Contributor on scientific research – Speaker panel
Amy Wilkinson	The Babraham Institute	Contributor on scientific research – Speaker panel
Alex Faulkner	University of Newcastle	Contributor on scientific research – Speaker panel
Mike Norman	Babraham Institute	Contributor on HDBI – speaker panel
Workshop 3 - Broad public group, south		
Dr Elselijn Kingma	King's College London	Contributor on philosophy and ethics – Speaker panel
Dr Kathy Niakan	University of Cambridge	Contributor on scientific research – Speaker panel
Dr Desislava Staneva	University of Cambridge	Contributor on scientific research – Speaker panel
Vanessa Smith	Guy's and St Thomas' Hospital NHS Foundation Trust	Contributor on IVF and donation of embryos to research – Speaker panel
Naomi Clements-Brod	HDBI	Contributor on HDBI – Speaker panel
Workshop 3 - Broad public group, north		
Dr Katrien Devolder	University of Oxford	Contributor on philosophy and ethics – Speaker panel
Dr Peter Rugg-Gunn	The Babraham Institute	Contributor on scientific research – Speaker panel
Dr Magomet Aushev	University of Newcastle	Contributor on scientific research – Speaker panel
Amy Wilkinson	The Babraham Institute	Contributor on scientific research – Speaker panel
Alex Faulkner	University of Newcastle	Contributor on scientific research – Speaker panel
Dr Meena Choudhary	Newcastle Hospitals NHS Foundation Trust	Contributor on reproductive medicine – Speaker panel
Mike Norman	Babraham Institute	Contributor on HDBI – speaker panel

Filmed Contributors

Name	Role(s)	Organisation(s)
Dr Peter Rugg-Gunn	Human Developmental Biology Initiative Scientific Lead; Research Group Leader and Head of Public Engagement	The Babraham Institute
Dr Matteo Mole	Postdoctoral Research Scientist	The Babraham Institute
Professor Elizabeth Robertson	Professor Developmental Biology	University of Oxford

Natalie Silverman	Founder of The Fertility Podcast & Co-founder Fertility Matters at work	The Fertility Podcast
Sarah Milosevic	HDBI Insights Group Member	Independent
Seetal Savla	Fertility Patient Advocate	Independent
Professor Emily Jackson	Professor of Law	London School of Economics
Stephanie Ellis	Committee Chair	Cambridge Central Research Ethics Committee
Venessa Smith	Quality Manager, Assisted Conception Unit | Women's Services	Guy's and St Thomas' NHS Foundation Trust
Professor Felicity Boardman	Deputy Head of Social Science and Systems in Health in Health Unit	University of Warwick Medical School
Professor David Jones	Director; Research Fellow in Bioethics	Anscombe Bioethics Centre, Oxford; St Mary's University

Appendix 4 – Recruitment Specifications

Lived Experience - Recruitment Specification

1. Background

The Human Developmental Biology Initiative (HDBI) is a Wellcome-funded research consortium based across multiple research institutions in the UK and two in Europe. HDBI aims to better understand how humans develop before birth. This public dialogue project focuses on research with early human embryos donated from fertility treatment as well as early human embryos created specifically for research from donated sperm and eggs.

The dialogue will engage a group of people broadly reflective of the UK population, some of whom may have particular views or perspectives on the topic. The objectives for the dialogue are to:

- Develop a holistic understanding of participants' views of the societal and ethical issues around HDBI research.
- Identify participants' views of the research questions and outcomes of human developmental biology that reflect societal priorities.
- Enable scientists and public participants to engage in a constructive dialogue to hear, reflect, consider and respond to issues around the research.

As a consequence, those involved in human developmental biology research will:

- Use this initial evidence base to inform future public engagement, policy decisions and reviews such as around the 14-day rule in laboratory embryo culturing.
- Improve the quality of scientific research in this area by ensuring it is in greater alignment with participants' priorities.

This is a complex and potentially contentious area. The role of the dialogue is to more clearly hear public hopes, concerns, and aspirations to inform where science goes, not to shape public views.

2. Recruitment summary

We are recruiting 70 people to the dialogue (8 pilot participants, 20 with specific lived experiences of the issue, 42 from a broad demographic). This recruitment specification is focused on the recruitment of 20 participants who have lived experience specific to the research topic. This will include some or all of the following experiences:

- People who have experienced recurrent miscarriage.
- Parents of children who have developmental conditions (e.g. Spina Bifida)
- People who have experienced fertility treatment (e.g. IVF, mitochondrial replacement, pre-implantation genetic testing) potentially including for different reasons (e.g. difficulty conceiving naturally, LGBT+ reproduction, reproducing as a single parent, to avoid passing on known inherited genetic conditions)
- People who have at least been approached about donating tissue for research after receiving fertility treatment.
- People (who may or may not have had the above experiences) who have different religious/spiritual beliefs.

Our workshops will run as one group of 20 people, who will mostly work in sub-groups of 6-7 people supported by a dedicated HVM facilitator.

Participants in the group will, in addition to having the experiences listed above, also broadly reflect the UK population in terms of age, gender, life stage, social grade, household income, geography and ethnicity. We will be gaining informed consent from participants in terms which comply with Data Protection Act 2018 - the UK's implementation of the General Data Protection Regulation (GDPR). Recruitment for this cohort will be done by the HVM team, data will be held securely in password protected sheets at all times. HVM is registered as a data controller with the Information Commissioner's Office no: Z2969274.

Participants are required to take part in all the activities listed below for which a payment of £350 per participant has been allocated.

Please note support will be provided for participants who need either equipment or data to take part, they will not be excluded for not having access to a laptop, tablet or insecure/ no internet connection.

The following summarises the commitment participants will be making. All workshops will be held online using Zoom. In addition, participants are invited to spend time thinking about the project outside of this workshop time. To do this they will be asked to review materials and make a contribution to an online space. Participants are likely to spend no more than 30 minutes in the online space before each dialogue workshop. A maximum of 2 hours in total.

Activity	Dates
Main workshops	
Optional tech support session for all participants	4-5pm Monday 12th June
Online context webinar for all participants	6-7:30pm Wednesday 14th June
Online exploratory workshop 1	6-8:30pm Monday 19th June
Online exploratory workshop 2	6-9:00pm Monday 26th June
Online final workshop	10am-4pm Saturday 1st July

3. Screener to include:

Criteria for 20' participants	Target – lived experience participants
Fertility treatment	At least 3 people who have, or are a partner of someone who has, experienced fertility treatment (there may be overlap with the miscarriage criteria below): • IVF • Mitochondrial replacement • Pre-implantation genetic testing And for different reasons (e.g. difficulty conceiving naturally, LGBT+ reproduction, reproducing as a single parent, to avoid passing on known inherited genetic conditions) The screener should therefore gather information on: • The type of treatment

	• Reason for treatment • When the treatment took place/ or if it is ongoing (and if so, what stage) • If the treatment was successful And include people who have at least been approached about donating tissue for research after receiving fertility treatment.
Miscarriage	At least 2 people who have experienced recurrent miscarriage (there may be overlap with people who have received IVF)
Developmental conditions	At least 2 people who have, or are the parents of a child with, a developmental condition e.g. spina bifida
Religion	At least 2 people (who may or may not have had the above experiences) who hold religious beliefs.
In addition to the specific criteria above, this group should also broadly reflect the UK population, the following specification criteria are therefore also included:	
Gender	Appropriately balanced mix of people who identify as male / female / non-binary.
Age	Good age distribution across age groups from every adult life stage from 18 upwards.
Minority ethnic groups	A boosted sample of up to 5 participants are from communities experiencing racial inequalities (CERI) above current census data. Asian, Asian British x 1 Black, Black British, Caribbean or African x 2 Mixed or Multiple ethnicities x 1 Other ethnic group x 1
Disabilities/ those with long-term chronic health conditions.	A boosted sample of 5 participants who are disabled/ have chronic illness.
Current working status and type	A range of people who are employed (part-time/ full time/ self-employed) and unemployed, plus those who are retired.
Social Grade	A mix of social grades where possible.
Geographic location	The group should be drawn from a UK sample.
Sexual orientation	Appropriately balanced mix LGBTQIA+ identities, boosted above current census data.
Experience of market research/ dialogue	Should not have taken part in a public deliberation/ Citizens' Jury/ Citizens' Assembly or public dialogue in the last **24** months particularly those run by HVM such as WGS for newborn screening; or heath and data use public dialogues for the National Data Guardian; and dialogues for Genomics England on researcher access to discovery research.
Perspectives on screening/ data access	**Awareness** Awareness questions should be asked in the screener to make sure we include a range of people who are and who are not aware of HFE Act/ 14 day rule. Q1. I have heard of the Human Fertilisation and Embryology Act (HFE Act) Yes No

	Q2. I have heard of the 14-day rule. Yes No **Attitude** Attitudinal questions should be asked in the screener to make sure we include a range of views. Q1. On a scale of 1-5 (where 1=not at all interested and 5=extremely interested) please state how interested you are in scientific research on human biology? Q2. To what extent do you support or oppose the use of early human embryos (up to 14 days after fertilisation that are donated from fertility treatment) in scientific and medical research, for example to help understand and develop treatments for infertility or developmental conditions? Strongly oppose/ oppose/ neither oppose nor support/ support/ strongly support.

4. Exclusion criteria

Given the specification of this project, please do **not** recruit people currently or recently (in the past 12 months) working for

- Any of the Human Developmental Biology Initiative research partners
- People working in the life sciences industry.
- Journalists or people working in the media.

Lived Experience - Participant Breakdown

Total number of participants (19)		
Age	18 – 29	3
	30-39	5
	40-49	5
	50-59	3
	60 +	3
Gender	Female	9
	Male	9
	Non-Binary	1
Lived experience (participants select all that apply)	Child with developmental condition	2
	Developmental condition	2
	Fertility	7
	Long-term chronic health condition	7
	Miscarriage	5

Religious beliefs – Do you hold any religious beliefs that are against the use of early Human Embryos research, using embryos donated from fertility treatment, as well as early human embryos created specifically for research from donated sperm and eggs?	Yes	3
	No	16
Ethnicity (self-described)	Asian	1
	Black British	2
	Black Caribbean	1
	Mixed – White & Black	1
	White British	14
Employment status	Full-time	10
	Part-time	2
	Registered disabled / long-term sickness	2
	Retired / semi-retired	4
	Student	1
Geographic location (by region)	East of England	2
	north West	8
	south East (including London)	5
	south West	1
	Yorkshire and the Humber	1
	Scotland	1
Sexual orientation	Straight / Heterosexual	16
	Lesbian / Gay	2
	Bisexual / Pansexual	1
Awareness Q.1 – I have heard of the Human Fertilisation and Embryology Act (HFE Act)	Yes	10
	No	9
Awareness Q.2 – I have heard of the 14-day rule	Yes	7
	No	12
Attitude Q.1 - On a scale of 1-5 (where 1=not at all interested and 5=extremely interested) please state how interested you are in scientific research on human biology	1	
	2	1
	3	6
	4	6
	5	6
Attitude Q.2 - To what extent do you support or oppose the use of early human embryos (up to 14 days after fertilisation that are donated from fertility treatment) in scientific and	Strongly oppose	2
	Oppose	3
	Neither oppose nor support	3
	Support	7

medical research, for example to help understand and develop treatments for infertility or developmental conditions?	Strongly support	4

Broad Public - Recruitment Specification

1. Background

The Human Developmental Biology Initiative (HDBI) is a Wellcome-funded research consortium based across multiple research institutions in the UK and two in Europe. HDBI aims to better understand how humans develop before birth. This public dialogue project focuses on research with early human embryos donated from fertility treatment as well as early human embryos created specifically for research from donated sperm and eggs.

The dialogue will engage a group of people broadly reflective of the UK population, some of whom may have particular views or perspectives on the topic. The objectives for the dialogue are to:

- Develop a holistic understanding of participants' views of the societal and ethical issues around HDBI research.
- Identify participants' views of the research questions and outcomes of human developmental biology that reflect societal priorities.
- Enable scientists and public participants to engage in a constructive dialogue to hear, reflect, consider and respond to issues around the research.

As a consequence, those involved in human developmental biology research will:

- Use this initial evidence base to inform future public engagement, policy decisions and reviews such as around the 14-day rule in laboratory embryo culturing.
- Improve the quality of scientific research in this area by ensuring it is in greater alignment with participants' priorities.

This is a complex and potentially contentious area. The role of the dialogue is to more clearly hear public hopes, concerns and aspirations to inform where science goes, not to shape public views.

This is often seen as controversial research with potentially widespread health and societal implications. As such, it is crucial for researchers to listen to public voices when deciding on future research directions.

2. Recruitment summary

This recruitment specification is focused on the recruitment of 50 participants reflecting a broad demographic. Our workshop groups will be as follows:

1. 8 people from a UK sample to pilot the process
2. 21 people from Northern England, Scotland and Northern Ireland
3. 21 people from Southern England and Wales

These groups will broadly reflect the UK population in terms of age, gender, life stage, social grade, household income, geography and ethnicity. We will be gaining informed consent from participants in terms which comply with Data Protection Act 2018 - the UK's implementation of the General Data Protection Regulation (GDPR). Data shared between HVM and our fieldwork agency will be password protected at all times. HVM is

registered as a data controller with the Information Commissioner's Office no: Z2969274.

Participants are required to take part in all the activities listed below for which a payment of £400 per participant has been allocated. HVM will arrange and pay for participant travel and overnight accommodation for the final in person workshops.
Please note support will be provided for participants who need either equipment or data to take part, they will not be excluded for not having access to a laptop, tablet or insecure/ no internet connection.

The following summarises the commitment participants will be making. The majority of workshops are online using Zoom. The exception is the final workshop set. These are marked 'in person' on the table below. In addition, participants are invited to spend time thinking about the project outside of this workshop time. To do this they will be asked to review materials and make a contribution to an online space. Participants are likely to spend no more than 30 minutes in the online space before each dialogue workshop. A maximum of 2 hours in total.

Activity	Dates
Main workshops	
Optional tech support session for all participants	4-5pm Monday 3rd July
Online context webinar for all participants	6-7:30pm Monday 3rd July
Online exploratory workshop 1 for all participants	6-9pm Wednesday 5th July
In person workshop Newcastle (for UK Northern Group) & London (for UK Southern Group)	6-9pm Friday 14th July
In person workshop Newcastle (for UK Northern Group) & London (for UK Southern Group)	10am-4pm Saturday 15th July

3. Screener to include:

Criteria for 46 for 42 participants	Target – a broad diversity of UK demographics
Gender	Appropriately balanced mix of people who identify as male / female / non-binary.
Age	Good age distribution across age groups from every adult life stage from 18 upwards.
Life stage	A broad range of life stages from students, those at the beginning of working lives, those raising young children, people without children, empty nesters and those who are retired.
Minority ethnic groups	A boosted sample of 8 participants (e.g. 16 of 42) are from communities experiencing racial inequalities (CERI) above current census data. Asian, Asian British x 2 Black, Black British, Caribbean or African x 3 Mixed or Multiple ethnicities x 2 Other ethnic group x 1
Disabilities/ those with long-term chronic health conditions.	A boosted sample of 8 participants in each cohort of 21 - above current census data - who are disabled/ have chronic illness.

Sexual orientation	A boosted sample of LGBTQIA+ identities, weighted above current census data in each group.
Religion	A boosted sample of people, above current census data, who confirm they have a religious faith.
Current working status and type	A range of people who are employed (part-time/ full time/ self-employed) and unemployed, plus those who are retired.
Social Grade	Mix of AB (4 participants) C1C2 (7 participants) DE (10 participants) for each group of 21 people
Geographic location	The group should be drawn from a UK sample. We are running each workshop in two parallel groups Northern UK/ Southern UK. Each group should include those from rural, urban and suburban regions. At least 5 participants should live in/ near Newcastle. At least 5 participants should live in/ near London.
Experience of market research/ dialogue	Should not have taken part in a public deliberation/ Citizens' Jury/ Citizens' Assembly or public dialogue in the last **24** months particularly those run by HVM such as WGS for newborn screening; or heath and data use public dialogues for the National Data Guardian; and dialogues for Genomics England on researcher access to discovery research.
Perspectives on screening/ data access	**Awareness** Q1. I have heard of the Human Fertilisation and Embryology Act (HFE Act) Yes No Q2. I have heard of the 14 day rule Yes No Q3. I have, or have a close friend or family member who has, experience of fertility treatment Yes No Don't know If yes to Q3. Please explain which type of fertility treatment: • IVF (in vitro fertilisation) • ICSI (intra cytoplasmic sperm injection) • Mitochondrial replacement • Pre-implantation genetic testing • Don't know • Other – please explain And for which reason (e.g. difficulty conceiving naturally, LGBT+ reproduction, reproducing as a single parent, to avoid passing on known inherited genetic conditions).

	When the treatment took place/ or if it is ongoing (and if so, what stage)/ if it was successful. If yes to Q3. If you have direct experience of successful fertility treatment, were you offered the option to donate embryos to research at any point? Yes No Don't know Q4. I have, or have a close friend or family member who has, experience of a developmental condition such as spina bifida Yes No **Attitude** Attitudinal questions should be asked in the screener to understand the range of views, and confirm that we have a range of views, in the sample. Q1. On a scale of 1-5 (where 1=not at all interested and 5=extremely interested) please state how interested you are in scientific research on human biology? Q2. To what extent do you support or oppose the use of early human embryos (up to 14 days after fertilisation that are donated from fertility treatment) in scientific and medical research, for example to help understand and develop treatments for infertility or developmental conditions? Strongly oppose/ oppose/ neither oppose nor support/ support/ strongly support. Q3. Of those who have confirmed they have a religious faith: • Which faith? Drop down list • Do you consider yourself someone who actively practises your faith?

Important note: please **do not** recruit friendship pairs or use snowballing techniques.

4. Exclusion criteria

Given the specification of this project, please do **not** recruit people currently or recently (in the past 12 months) working for

- Any of the Human Developmental Biology Research partners
- Those working in the life sciences industry
- Journalists or people working in the media

Broad Public - Participant Breakdown

Total number of participants (42)		
Age	18 – 29	7

	30-39	8
	40-49	9
	50-59	13
	60 +	5
Gender	Female	18
	Male	24
Religious beliefs – How do you identify your religious beliefs?	None/Atheist	13
	Agnostic	1
	Buddhism	1
	Christianity	12
	Hinduism	5
	Islam	3
	Judaism	4
	Prefer not to say	3
Ethnicity (multiple choice and/or self-described)	Any other Asian background	1
	Any other White background	2
	Asian British	1
	Black or Black British - African	5
	Black or Black British - Caribbean	2
	British Indian	2
	British Pakistani	1
	Caribbean – Black / African / Caribbean / Black British	1
	Chinese – East Asian / East Asian British	1
	Indian	1
	Mixed – White and Asian	1
	Other Mixed Background	1
	south Asian / Asian British - Indian	1
	south Asian / Asian British - Pakistani	1
	White English, Welsh, Scottish, Northern Irish or British Irish	21
Employment status	Full-time employed	23 (13)
	Part-time employed	4
	Other – Homemaker / stay-at-home	1
	Registered disabled / long-term sickness	2
	Retired / semi-retired	7
	Student	3
Geographic location (by region)	north East	5
	north West	2
	East Midlands	2
	West Midlands	1
	East of England	1
	south East (including London)	15

	south West	1
	Yorkshire and the Humber	4
	Northern Ireland	3
	Scotland	7
	Wales	1
Sexual orientation	Straight / Heterosexual	30
	Lesbian / Gay	4
	Bisexual / Pansexual	5
	LGBTQ or other	3
Awareness Q.1 – I have heard of the Human Fertilisation and Embryology Act (HFE Act)	Yes	17
	No	25
Awareness Q.2 – I have heard of the 14-day rule	Yes	9
	No	33
Attitude Q.1 - On a scale of 1-5 (where 1=not at all interested and 5=extremely interested) please state how interested you are in scientific research on human biology	1	2
	2	5
	3	13
	4	7
	5	15
Attitude Q.2 - To what extent do you support or oppose the use of early human embryos (up to 14 days after fertilisation that are donated from fertility treatment) in scientific and medical research, for example to help understand and develop treatments for infertility or developmental conditions?	Strongly oppose	4
	Oppose	5
	Neither oppose nor support	11
	Support	12
	Strongly support	10

Appendix 5 – Stimulus Materials

Dialogue Films

The project team worked with filmmaker Paul Wyatt to produce a number of films to act as stimulus for participants to consider during the dialogue. Examples of these can be found provided alongside this report post publication.

Summary of Asynchronous Activities

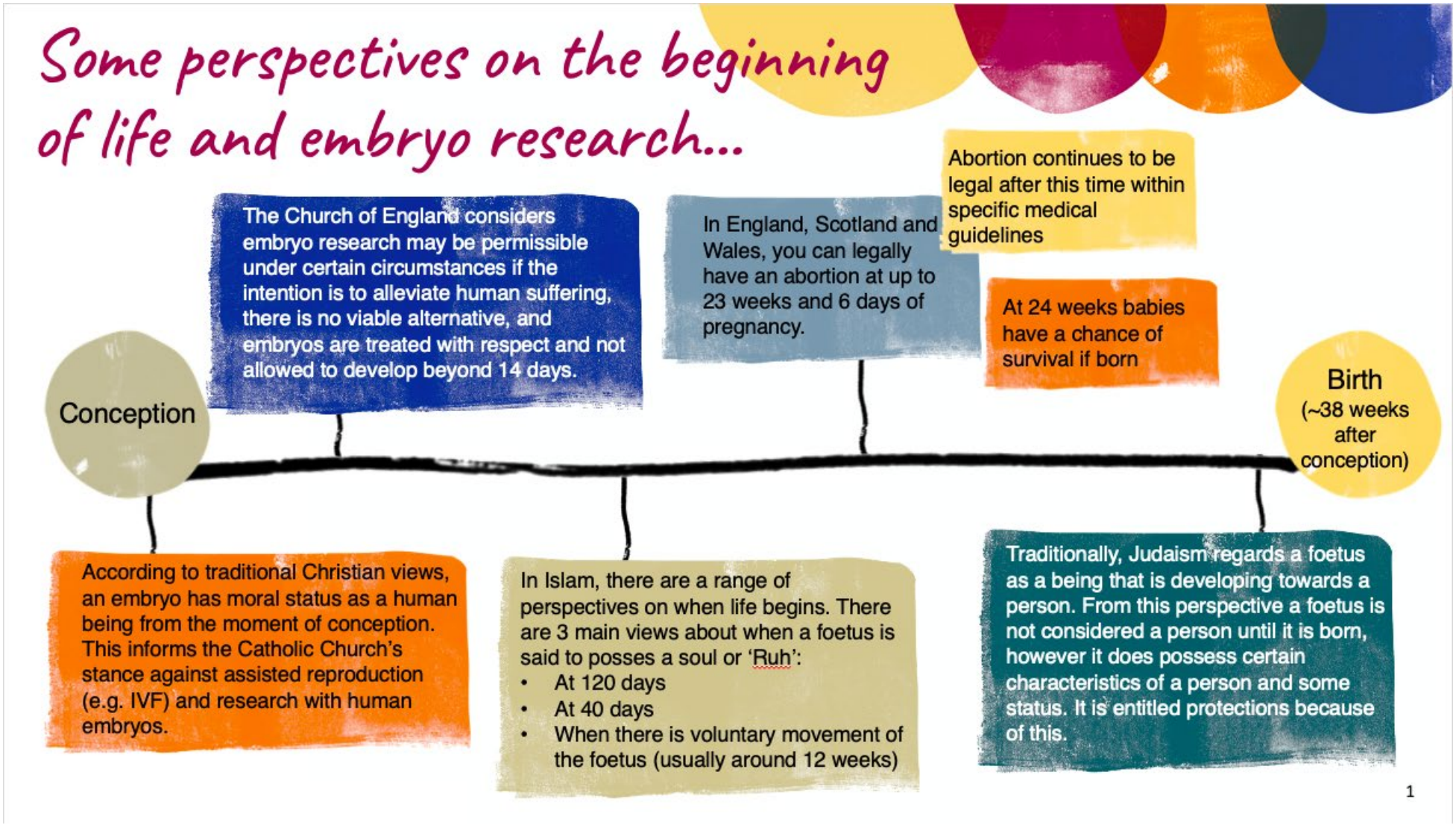
Before and between each of the workshops, participants reviewed activities in their own time using an HVM tailored dedicated online workspace using the qualitative research platform Recollective. Short summaries of these activities are listed in chronological order below.

Task	Description
1. An introduction to public dialogue.	Participants were asked to watch a short film explaining what a public dialogue is, so they knew what to expect throughout the process.
2. Who's involved in this public dialogue?	This activity broke down the various parties involved in the public dialogue, from the funders to those who ran it.
3. An introduction to the purpose of this public dialogue.	Participants were shown a short film about the purpose of the public dialogue to inform the future of early human embryo research.
4. HDBI – Fact Sheet	This task contained a PDF of frequently asked questions so participants could easily clarify any gaps in their understanding of the topic.
5. Listen to Insoo Hyun – An explanation of early embryo development and the 14-day rule.	Participants were asked to listen to this audio clip of Insoo Hyun, Harvard Medical School, explain early human embryo development. The clip talks about the 14-day rule, how early embryos develop and what is observable during the first 14 days of development. The clip also talks about the 'black box' time period between 14 and 28 days of development.
6. Newspaper report on "synthetic human embryos".	In this activity participants reviewed a report talking about stem cell-based embryo models and how they have caused a breakthrough in early human embryo research.
7. Look at how embryo research is regulated across the world.	This activity provides a summary of regulation around early embryo research in some other countries around the world.
8. Watch again – the webinar presentations.	This activity gave participants the opportunity to watch the presentations that were shown in the webinar again to refresh their memories.

9. What are stem cells? Watch this video to find out.	Participants were asked to watch this 3-minute BBC video explaining what both human and plant stem cells are.
10. Regulation and science timeline.	This graphic shows some key dates in the history of embryo research.
11. Researcher stories – The people behind the science.	Participants watched this video on the experience of researchers who work in early human embryo research.
12. Answers to your questions from the webinar.	During the webinar any questions which were not answered in the allotted time were collected, subsequently answered, and posted on recollective for participants to review.
13. Answers to your questions from workshop 1.	During workshop 1 any questions which were not answered in the allotted time were collected, subsequently answered, and posted on recollective for participants to review.
14. Lived Experience Film: Donating embryos to research.	This short film on an individual's lived experience of IVF and her thoughts on donating embryos to research was shown in workshop 1. It was then posted on recollective in case participants wanted to watch it again.
15. Perspectives on when life begins and embryo research.	This task showed the range of different perspectives on the beginning of life and embryo research. Participants were asked to review and give their thoughts if they had any.
16. What did the other groups talk about? Notes from workshop 1.	This activity showed the workshop notes of other groups for participants to review.
17. Views opposing changes to the 14-day rule and early human embryo research.	This film shares some views opposing early human embryo research and reasons against extending the 14-day rule. Participants were asked to watch and give their thoughts.
18. Watch again – the workshop 1 presentations.	The task contained recaps of the different presentations given across both groups in workshop 1. Each group of participants were encouraged to review the presentations given to the other group.
19. News article on He Jiankui who edited the genes of twins.	Participants were asked to review an article on the Chinese scientist He Jiankui who "announced in 2018 that he had edited the genes of twin girls before birth". This procedure is illegal in both China and the UK.
20. Lived Experience of genetically inherited conditions.	Participants reviewed this 4-minute film in which an individual talks about having a family history of the condition 'Muscular Dystrophy".

21. Lived experience of IVF.	Participants were asked to review this 5-minute film in which an individual talks about her and her husband's experience of IVF and thoughts on embryo donation to other potential parents and to research.
22. Regulations and Laws around Human Embryo Research.	Participants were asked to watch a short film on the various regulations and laws around human embryo research.
23. Research Ethics Committees.	In this film participants heard from the Chair of a Research Ethics Committee about the ethical review process for research on early human embryos.
24. Consent for donating to embryo research.	In this task participants from someone who works at an Assisted Conception Unit on the consent process for embryo donation.
25. Perspectives of people living with genetic conditions.	Participants were asked to review this 10-minute film in which a researcher talks about interviews they have done with parents of children with Down's Syndrome. They talk about their views on health, disease, disability, and identity.
26. Regulatory Review of Research	Participants were asked to watch a short film about the regulatory review of research with early human embryos. It talks about what an application involves and who is involved in reviewing it

Religious Perspectives Graphic



Some perspectives on the beginning of life and embryo research...

In general, most Hindus believe that the beginning of personhood coincides with the occurrence of reincarnation at the moment of conception, and that the earliest human embryo deserves respect. However, Hinduism is intrinsically flexible, and the destruction of a human embryo can be justified under certain circumstances – for example, to save a mother's life. When potential benefits to humankind could result, Hindu scholars generally favour embryonic stem cell research, but only with surplus embryos from fertility clinics.

Under Buddhist teachings, an embryo acquires personhood after implantation in a mother's uterus, and research may be conducted on human embryos *in vitro* if intended '…to help humankind'.

Appendix 6 – Process Plans

Pilot Webinar – Monday 22nd May

Scope and research questions

In referring to 'early human embryos' the scope of this dialogue will only cover research involving embryos donated following fertility treatment and embryos created specifically for research purposes with donated sperm and eggs. This dialogue **will not** cover research which uses embryonic, and tissue donated following pregnancy terminations.
Research questions include:

- What do participants perceive to be societal implications of research with early human embryos?
- What ethical questions do participants raise around research with early human embryos?
- What implications / applications of research with early human embryos are most important to participants? Where should scientists be focusing in this area?
- What should the future of embryo research in the UK look like?
- What do participants think about the trade-offs for possible medical/healthcare implications of this research and where do the red lines exist?
- How does the 14-day rule factor into their thinking about possible outcomes?
- How do emerging alternative research models in this field affect their views?

Time	Agenda	Process	Process Tools
6:00-6:10 (10 mins)	Introduction to this webinar and the overall dialogue programme	The webinar has two purposes: 1. To give you initial information to start thinking about our topic 2. To pilot this public dialogue which will take place from the beginning of June. 1. HVM/ HDBI team introduce themselves 2. Evaluator to introduce themselves and the evaluation process End with a reminder of the 'what is public dialogue' film.	PP Purpose & Agenda Slide Intro PP
6:10-6:15 (5 mins)	Menti questions set 1	QM1: Share where in the country you are zooming in from QM2: When I say the word 'research' what comes to your mind?	Menti.com

Time	Agenda	Process	Process Tools
6:15-6:30 (15 mins)	An introduction to our subject	LF introduces HDBI representative LF to introduce Naomi – explain Naomi's role in the dialogue and confirm that she isn't a scientist in this field. Explain that in the main dialogue this will be presented by scientists and participants will also hear live from ethicists, regulators and those with lived experience. **1. Naomi Clements-Brod, intro presentation** • Why this dialogue now • What the dialogue will inform/ the influence it will have as a foundational piece of work • Clarity on size/ scale • What is an embryo (inc: cell as building block of body) • Visualisation an early embryo timeline • What is the primitive streak • What is human developmental biology? • Examples of HDB research – early embryo and being clear what's in scope for our dialogue.	Animations Visualisations PP presentation **Record presentations**
6:30-6:50 (20 mins)	Chat questions	Participants asked to share questions in the Chat: about the public dialogue and their role in it; the embryo; early human embryo developmental research. Naomi and Suzannah/ others present answer questions where possible. Where not possible, take the questions away and get answers during the week. LF confirmation that this is our first introduction to these topics. We'll be learning more as we go along.	CF to review Chat questions as necessary
6:50-6:55 (5 mins)	Menti.com – online polling Piloteers Wrap up and close	**With your participant hat on:** QM3: One thing that you have learnt or has particularly interested you from what you've heard this evening **With your piloteers hat on:** QM4: One thing that went particularly well for your this evening that you think should stay the same in the main public dialogue? QM5: One thing that didn't go well this evening that you think should change in the public dialogue?	Menti.com

Time	Agenda	Process	Process Tools
In own time	Online community space activities for next time	• Review the information/ presentations from this evening, add any questions you have • Look at the regulation timeline and the regulatory story graphic, add any questions you have • Review the graphic materials on the embryo and the primitive streak • Listen to BBC R4 Inside Science – Insoo Hyun/ Naomi Morris.	Activities on Recollective

Pilot Workshop 1 – Monday 22nd May – Piloting the process with a research focus

Time	Agenda	Process	Process Tools
6:00-6:10 (10 mins)	Introduction to this workshop and reminder of the overall dialogue programme	1. HVM team introduce themselves 2. Observers/ speakers present introduce themselves 3. Evaluator to introduce themselves and the evaluation process Reminders on the materials we shared in the webinar/ what we are doing together and how the online space works.	PP Purpose & Agenda Slide Intro PP
6:10-6:15 (5 mins)	Menti questions set 1	QM1: As we'll be spending some time together, tell us in a few words something about yourself. QM2: What comes to your mind when you think about what you heard at the webinar?	Menti.com
6:20-6:45 (25 mins) 6:20-6:30 (10 mins) 6:30-6:45 (15 mins)	Reflections on what we've shared so far	**Introductions** 1. Say hello to the group 2. Say where you are zooming in from 3. Briefly share one thing you are thinking about having attended the webinar/ reviewed materials in the online space. **Q1: What in those materials either surprised or interested you?** Prompts • Something that was new to you? • Something that made you think?	Jamboard Start taking notes on Jamboard to collect key points

Time	Agenda	Process	Process Tools
		• Why was that surprising or interesting?	
6:45-7:00 (15 mins) 6:45-6:55 (10 mins) 6:55-7:00 (5 mins)	An introduction to the research	Encourage participants to note down the questions they have as the presentation is given: **Presentation a brief summary from the LF of:** • Reminder of the information on the Act and the 14-day rule they've seen on Recollective • The progress timeline – outcomes/ developments as a result of this research including 1st IVF baby; importance of prenatal vitamins • How the research is done: lab, frozen embryos, examples Researcher motivations for the work (as we have been preparing for this work this is what we've heard). OR https://www.youtube.com/watch?v=301rB1dOa80 (35:00 to 37:18) OR Stem cell derived embryo models – what they are and why used – play Inside Science (second part after Insoo Hyun), Naomi Morris, Crick Institute explanation of the models. **Runs from 9:14-11:46.**	PPs Visualisations e.g. timeline
7:00-7:15 (15 mins)	Developing our questions	**Q2: What questions do you want to ask at this point to clarify your understanding?** Prompts: • What's news to you? • What do you want to know more about? • Was anything unclear: language/terminology? (We'll add new terms to the jargon buster)	List all the questions that come up on the Jamboard.
7:15-7:20	**Break**		

Time	Agenda	Process	Process Tools
7:20-7:40 (20 mins)	Initial exploration of the issues raised this evening	**Q4: What are your initial thoughts on this research now you know more about it?** Prompts: • What for you feels important about the research? • What for you is positive about the research? • What for you is challenging about the research? • What is your response to the motivations for conducting the research?	Jamboard for visible note taking
7:40-7:55 (15 mins)	Piloteers	**LF: Now we've experienced this workshop, let's focus on our role as piloteers, feeding back on the dialogue process.** Clear, helpful, relevant, missing? • What and how we discussed workshop 1 • What you've seen so far on the online space • Purpose of the dialogue and what it will influence • Information on the science/ the embryo • Other thoughts on what should be included/ covered in the main dialogue roll-out?	Jamboard
7:55-8:00 (5 mins)	Menti.com – online polling and close	QM3: Something that you have learnt or has particularly interested you from what you've heard and discussed this evening	
In own time	Online community space activities for next time	• Review Q&A Responses • Stimulus and visuals on the embryo part two	Activities on Recollective

Pilot Workshop 2 – Monday 25th May – The regulatory framework a pilot process

Time	Agenda	Process	Process Tools
6:00-6:10 (10 mins)	Introduction to workshop 2 and reminder of the overall dialogue programme	1. HVM team introduce themselves 2. Observers/ speakers present introduce themselves 3. Evaluator to introduce themselves and the evaluation process	PP Purpose & Agenda Slide Intro PP
6:10-6:20 (10 mins)	Menti questions set 1	QM1: One thing that you remember from what you read/ saw in the online space about the regulations regarding this research? QM2: What three words would you use to describe how you feel about the regulations for this kind of research? QM3: What comes to your mind when you think about the clips from the Radio 4 Inside Science recordings?	Menti.com

6:20-6:35 (15 mins)	Reflections on what we've shared so far	**Q1: What in the workshop 1 and online space materials either surprised or interested you?**
		Prompts
		• What have you been thinking about in relation to the dialogue since we last met on Tuesday?
		• Has anything in workshop 1 on Tuesday, or in the online space been:
		  ○ New to you?
		  ○ Made you think?
		  ○ Was particularly interesting to you?
			Jamboard
			
			Start taking notes on Jamboard to collect key points

6:35-7:05 (30 mins) 6:35-6:50 (15 mins) 6:50-7:05 (15 mins)	An exploration of perspectives on the regulations	**LF presentation – Reminders and new information on the embryo and regulation of research** • Reminder: why do embryo research • Reminder: regulation overview • More info on why 14 days: Primitive Streak explanation & Sarah Franklin Video explaining why 14 days/Primitive Streak • Researcher view on regulation: Kathy N at Cambridge Festival Video **Q2: What questions do you want to ask at this point to clarify your understanding?** Prompts:	PPs Visualisations e.g. timeline

Time	Agenda	Process	Process Tools
		• What's news to you? • What do you want to know more about? • Was anything unclear: language/terminology? (We'll add new terms to the jargon buster)	
7:05-7:10	**Break**		
7:10-7:40 (30 mins) 7:10-7:35 (25 mins) 7:35-7:40 (10 mins)	Exploring the regulatory context	**Q3: What is your current response to the existing regulations for research with early human embryos?** • To what extent do the regulations give you reassurance about how the research is approved/ conducted and how? • What feels particularly important to you about the regulations? • What should society be concerned about in relation to the regulations as they stand/ if they change? **Summary sheet:** • What's important? • What's a cause for concern? • What gives reassurance/ cause for optimism?	Jamboard divided into three: Important Cause for concern Cause for optimism Jamboard summary sheet.
7:40-7:55 (15 mins)	Piloteers	**LF: Now we've experienced this workshop, let's focus on our role as piloteers, feeding back on the dialogue process.** Clear, helpful, relevant, missing? • What and how we've covered what we have in this workshop • What you've seen so far on the online space • Purpose of the dialogue and what it will influence • Information on the science/ the embryo/ Or regulation, HFEA and the 14 day rule? • Other thoughts on what should be included/ covered in the main dialogue roll-out?	Jamboard
7:55-8:00 (5 mins)	Menti.com – online polling Evaluation	QM3: Share one thing you consider particularly important about this evening's discussions Give information on the evaluation form/ task which will be on Recollective.	

Time	Agenda	Process	Process Tools
	Wrap up and close		
In own time	Online community space activities for next time	• Review Q&A Responses • Space for Participant-driven information, what matters to you at this point? What do you want to make sure we include in our final deliberations on Saturday? • Watch this 6min video that touches on some of the key points that we've discussed.	Activities on Recollective

Pilot Workshop 3 – Saturday 27th May – Final deliberations

Time	Agenda	Process	Process Tools
10:00-10:10 (10 mins)	Introduction to final workshop and reminder of the overall dialogue programme	1. HVM team introduce themselves 2. Observers/ speakers present introduce themselves 3. Evaluator to introduce themselves and the evaluation process	PP Purpose & Agenda Slide Intro PP

<table>
<tr><th>Time</th><th>Agenda</th><th>Process</th><th>Process Tools</th></tr>
<tr><td>10:10-10:20
(10 mins)</td><td>Menti questions set 1</td><td>QM1: Share one concern you have for early human embryo research.
QM2: Share one hope you have for early human embryo research.</td><td>Menti.com</td></tr>
<tr><td>10:20-10:30
(10 mins)</td><td>Reminder of what we've covered/ what we have shared so far. Prompts</td><td>LF: Reminder of all we've discussed. Drawing out things from HDBI FAQs that will support our discussions today.
Re-cap on what we've covered so far
Reminder of our speakers and what they've shared
• Quick catch up on what's been reviewed in the online space
• Recap of what you have said in the online space about what we should discuss today
• Reminders of key points raised by the three groups of participants so far.</td><td>PP slides with visual reminders</td></tr>
<tr><td>10:30-11:30
(60 mins)
10:30-10:55 (25 mins)
10:55-11:20 (25 mins)
11:20-11:30 (10 mins)</td><td>Exploring hopes and concerns of participants</td><td>Q1: What are your concerns about research using early human embryos/ stem cell derived models?
Group to create list of concerns
Build on what has been discussed and what has been seen in Recollective (types of research/ use/ reasons for use are on Recollective)
Q2: What are your hopes about research using early human embryos/ stem cell derived models?
Group to create list of hopes
Build on what has been discussed
Q3: What are the most important concerns/ hopes that we've discussed this morning?
Group to create a summary sheet:<table><tr><td>Most important concerns
1.
2.
3.</td><td>Most important hopes
1.
2.
3.</td></tr></table></td><td>Jamboard: concerns
Types:
IVF, mitochondrial replacement, pre-implantation genetic testing
Reasons: LGBT+ reproduction, reproducing as a single parent, avoid passing on known inherited genetic conditions
Repeat Jamboard format for hopes</td></tr>
<tr><td>11:30-11:40</td><td colspan="3">Break</td></tr>
</table>

Time	Agenda	Process	Process Tools
11:40-12:40 (60 mins)	Expectations of the research/ researchers/ regulation	**Q1: What are your expectations of the research and the regulations which govern it?** **Q2: From what you have heard from others in your group and the presentations/ information received - what other expectations do you think society might have of the science and regulations**	Jamboard for visible notes A reminder is on screen of the legal limits of research in this area/ HFEA summaries (on Recollective).
12:30-12:40 (10 mins)	Reflections back	Mike Norman reflections back on what's been heard this morning. What such discussions will mean for the research: Highlight how the public input will support: • Generating an information base for us to use in regulatory discussion such as the HFEA consultation process. • How we build public views into our research strategies and link this through to funding applications for research and • How BI (as an example) is publicly funded so the PD is a mechanism to impact that.	
12:40-12:50 (10 mins)	Piloteers	**LF: Now we've experienced this final workshop, let's focus on our role as piloteers, feeding back on the dialogue process.** Clear, helpful, relevant, missing? • What and how went through our discussions in this final workshop • What you've seen so far on the online space • Purpose of the dialogue and what it will influence • Information on the science/ the embryo • Other thoughts on what should be included/ covered in the mail roll-out?	Jamboard
12:50-12:55 (5 mins)	Menti.com – online polling	QM5: One word of advice for those setting the regulatory framework for early embryo research covered by the 14-day rule QM6: One word for the project team as they finalise this process for the full roll-out of the dialogue in June	
12:55-13:00 (5 mins)	Wrap up and close	LF Thanks everyone	

Lived Experience Webinar – Wednesday 14th June

Time	Agenda	Process	Process Tools
6:00-6:15 (15 mins)	Introduction to this webinar and the overall dialogue programme	1. HVM team introduce themselves 2. Observers/ speakers present introduce themselves 3. Evaluator to introduce themselves and the evaluation process **1. Introduction to the Dialogue** End with a **reminder** of the 'what is public dialogue' film on Recollective. Including mentioning that people will hear from lots of speakers during the dialogue as a whole and will use that information to explore the issues that are important to them/ and ask questions.	PP Purpose & Agenda Slide Intro PP
6:15-6:25 (10 mins)	Menti questions set 1	QM1: Share where in the country you are zooming in from QM2: When I say the word 'research' what comes to your mind?	Menti.com
6:25-6:30 (5 mins)	Chat questions	Participants asked to share questions they have in the chat about the purpose of the dialogue. Quick points of clarification. Chat Prompt 1 (CP1): What questions do you have about the purpose of the dialogue/ your role in the dialogue?	**HI** to put Chat Prompt 1 in the Chat
6:30-6:50 (20 mins) 6:30-6:40 (10 mins) 6:40-6:50 (10 mins)	An introduction to our subject	**2. Presentation: Embryo – part 1: Katarina Harasimov, Cambridge University** • Clarity on size/ scale • What is an embryo (incl: cell as building block of body) • Visualisation an early embryo timeline • Include what is the primitive streak here **3. Presentation: What is early human embryo research: Peter Rugg-Gunn**, Group Leader HDBI and Head of Public Engagement, Babraham Institute introduces our topic: • Present on what is early human embryo research? • Types of research: basic/fertility/miscarriage/genetic conditions • How the research is done in the lab.	PP presentations (speaker view only – **start and stop the recording with each new speaker**)

Time	Agenda	Process	Process Tools
6:50-7:05 (15 mins)	Chat questions	Participants asked to share questions they have in the chat about the embryo, early human embryo developmental research, collated by CF. Chat Prompt 2 (CP2): What questions do you have about the embryo/ embryo research/ the purpose of embryo research?	**HI** to add Chat Prompt question to the Chat
7:05-7:15 (10 mins)	A focus the legislative framework	**4. Presentation: Introducing the Human Fertilisation & Embryology Authority Peter Thompson,** HFEA Chief Executive An explanation of the current regulatory and legal system including: • The role of the HFEA, its establishment with The Human Fertilisation and Embryology Act (1990) • How this relates to other organisations in the system • How the regulatory system has evolved since the work of the Warnock Committee in 1982	PP presentation as necessary (speaker view only – start and stop the recording with each new speaker)
7:15-7:25 (10 mins)	Chat questions	CP3: What questions do you have about the regulations and law?	**HI** to put the Chat Prompt into the Chat
7:25-7:30 (5 mins)	Menti.com Evaluation Close	QM3: One thing that you have learnt or has particularly interested you from what you've heard this evening	Menti.com
In own time	Online community space activities for next time	• Review the speaker presentations from this evening, add any questions you have • Look at the regulation timeline and the regulatory story graphic, add any questions you have • Review the graphic materials on the embryo and the primitive streak. • Listen to BBC R4 Inside Science – Insoo Hyun	Activities on Recollective

Time	Agenda	Process	Process Tools
6:00-6:10 (10 mins)	Introduction to this workshop and reminder of the overall dialogue programme	1. HVM team introduce themselves 2. Observers/ speakers present introduce themselves 3. Evaluator to introduce themselves and the evaluation process	PP Purpose & Agenda Slide Intro PP
6:10-6:20 (10 mins)	Menti questions set 1	QM1:Tell us in a few words something about yourself QM2: What comes to your mind when you think about what you heard at the webinar?	Menti.com
6:20	TS to move everyone to their pre-allocated small groups – 7 participants per group, based on a mix of demographics, 1 facilitator for each group, tech support available to all groups for immediate Zoom challenges.		
6:20-6:45 (25 mins)	Reflections on what we've shared so far	**Introductions** 1. Say hello to the group 2. Say where you are zooming in from 3. Briefly share one thing you are thinking about having attended the webinar and reviewed materials in the online space. **Q1: What in the webinar and online space materials either surprised or interested you?** Prompts • Something that was new to you? • Something that made you think? • Why was that surprising or interesting?	Jamboard No visible notes Start taking notes on Jamboard to collect key points
6:45-7:10 (25 mins) 6:45-6:55 (10 mins) 6:55-7:00 (5 mins)	An introduction to the research	**Presentation 1: Early Human Embryo Research: Examples and Outcomes: Emma Rawlins, HDBI** • An overview of types of early (pre-14 day) human developmental research to include: blue sky and near term applications e.g. improving IVF techniques • The progress timeline – outcomes/ developments as a result of this research including 1st IVF baby; importance of prenatal vitamins, mitochondrial donation	PPs Visualisations e.g. timeline PW Film

Time	Agenda	Process	Process Tools
7:00-7:10 (10 mins)		• Speaker own motivations for their work. **Film 1 – Researcher Stories** Paul Wyatt film **Presentation 2: Naomi Moris, Crick Institute** Embryo part two: • Embryo availability (challenges/limitations) • Stem cell derived embryo models – what they are and why used (How to come overcome challenges using alternatives)	
7:10	TS to move everyone to their pre-allocated small groups – 7 participants per group, based on a mix of demographics, 1 facilitator for each group, tech support available to all groups for immediate Zoom challenges.		
7:10-7:25 **(15 mins)** 7:10-7:20 (10 mins) 7:20-7:25 (5 mins)	Developing our questions	**Q2: What questions/reflections do you want to ask at this point to clarify your understanding?** Prompts: • What's news to you? • What do you want to know more about? • Was anything unclear: language/terminology? (We'll add new terms to the jargon buster) Create a long list of questions **Q3: What are the 2 main questions/reflections we want to explore with the whole group after the break?** Select two main questions, explain that all the questions will be answered on Recollective, we've picked the two questions that feel most important to get an answer to know.	List all the questions that come up on the Jamboard. Select two questions from the list – ready for screen sharing.
7:25-7:35	**Break**		
7:35-8:00 **(25 mins)** **7:35-7:55** **(20 mins)**		LF go round each group. Ask one question first, then do a second round with the second question. Pick up questions that can be answered. Questions that can't be answered either for time/ content reasons will be responded to, as far as possible, before the next workshop. Questions that are more complex, or need a number of	F's to do off-screen note taking on Jamboards to identify main unanswered questions

Time	Agenda	Process	Process Tools
7:55-8:00 (5 mins)		people to respond to them may take a little longer. Answers will be shared on Recollective. Speaker panel responds to the questions. Panel includes: • Emma Rawlins; Naomi Moris; Katarina Harasimov (researchers) • Sarah Chan (ethicist). End with Sarah Chan - a **short ethical briefing** – 5 minutes highlighting some of the ethical dimensions/ questions that arise from what we've heard so far.	
8:00-8:05 (5 mins)	Lived experience	**Lived experience film 1**	Paul Wyatt film
8:05	TS to move everyone to their pre-allocated small groups – 7 participants per group, based on a mix of demographics, 1 facilitator for each group, tech support available to all groups for immediate Zoom challenges.		
8:05-8:25 (20 mins)	Initial exploration of the issues raised this evening	**Q4: What are your initial thoughts on early human embryo research now you know more about it?** • What for you feels important about this research? • What for you could be positive about early human embryo research? • What for you is negative or challenging about early human embryo research? • What is your response to the motivations for conducting early human embryo research?	Jamboard for visible note taking
8:25-8:30 (5 mins)	Menti.com Close	QM3: Something that you have learnt or has interested you this evening	
In own time	Online community space activities for next time	• Review Q&A Responses as they become available • Lived experience stories • Religious/moral perspective on when life begins	Activities on Recollective

Time	Agenda	Process	Process Tools
6:00-6:10 (10 mins)	Introduction to workshop 2 and reminder of the overall dialogue programme	1. HVM team introduce themselves 2. Observers/ speakers present introduce themselves 3. Evaluator to introduce themselves and the evaluation process	PP Purpose & Agenda Slide Intro PP
6:10-6:20 (10 mins)	Menti questions set 1	QM1: One thing that you remember from what you heard so far about the regulations regarding this research? QM2: What three words would you use to describe how you feel about the regulations for this kind of research?	Menti.com Tech support to put menti link/ code in the Chat
6:20	TS to move everyone to their new pre-allocated small groups – 7 participants per group, based on a mix of demographics, 1 facilitator for each group, tech support available to all groups for immediate Zoom challenges.		
6:20-6:45 (25 mins) 6:20-6:30 (10 mins) 6:30-6:45 (15 mins)	Reflections on what we've shared so far	**Introductions** 1. Say hello to the group 2. Briefly share one thing you have been thinking about embryo research dialogue since workshop 1 last Monday. **Q1: Regulation of embryo research: what do you remember from the webinar/online space?** Prompts • What are you interested in discussing or learning more about? • 14 day rule/primitive streak? • How scientists work with the regulations • Who's involved in reviewing the science?	Jamboard No visible notes Start taking notes on Jamboard to collect key points
6:45-7:10 (25 mins) 6:45-6:55 (10 mins) 6:55-7:10 (15 mins)	An exploration of perspective on the regulations	**Film 1:** Where embryos come from – including the consent process • How they are stored • The facts on the regulations around licensing/ donation/ storage **Film 2: Research Ethics Committee view on embryo research:** **Film 3: Experience of the fertility treatment/ donation/ consent process**	PW film 6 Mins PW Film 6:10mins PW Film 5mins
7:10-7:20	**Break**		

Time	Agenda	Process	Process Tools
7:20	TS to move everyone to their pre-allocated small groups		
7:20-7:35 (15 mins) 7:20-7:30 (10 mins) 7:30-7:35 (5 mins)	Developing our questions	**Q2: What questions do you want to ask to clarify your understanding or explore a point that interests you?** Prompts: • Questions about how the regulations might change in the future? • What do you want to know more about? • Questions about what you found surprising? • Was anything unclear: language/terminology? (We'll add new terms to the jargon buster) **Q3: What are the 2 main questions we want to explore with the whole group after the break?**	List all the questions that come up on the Jamboard. Select two questions from the list – ready for screen sharing.
7:35-7:55 (20 mins)		LF go round each group. Ask one question first, then do a second round with the second question. Pick up questions that can be answered. Questions that can't be answered either for time/ content reasons will be responded to before the next workshop and answers shared on Recollective. Speaker panel responses to the questions. Panel includes: Sarah Chan (ethicist); Amy Wilkinson (researcher – everyday practicalities); Katarina Harasimov (researcher – setting up a project); Robin Lovell-Badge (the science) and Venessa Smith (embryo/ consent).	Off-screen note taking to record main unanswered questions
7:55-8:00	**Quick Break**		
8:00-8:20 (20 mins) 8:00-8:15 (15 mins) 8:15-8:20 (5 mins)	An exploration of perspectives on the regulations	**Speaker panel** discusses the experience of the 14-day rule. Panel includes: Sarah Chan (ethicist); Amy Wilkinson (researcher – everyday practicalities); Katarina Harasimov (researcher – setting up a project); Robin Lovell-Badge (the science) and Venessa Smith (embryo/ consent). Points to bring out – • The current status of early embryo research - what its achieved • Your thoughts on any changes to the 14 day rule • Your reflections of what you've heard from participants in the dialogue so far	PW Film 10 mins

Time	Agenda	Process	Process Tools
		• Ethical and research points you'd like participants to consider End with **short ethical briefing** – 5 minutes highlighting some of the ethical dimensions/ questions that arise from what we've heard so far.	
8:20	TS to move everyone to their pre-allocated small groups		
8:20-8:40 (20 mins)	Exploring the regulatory context	**Q2: What is your current response to the existing regulations for research with early human embryos?** • Do the regulations give you reassurance about how the research is approved/ conducted and how? • What feels particularly important to you about the regulations? • What should society be concerned about in relation to the regulations as they stand/ if they change?	Jamboard divided into three: Important Cause for concern Cause for reassurance
8:40-8:45 (5 mins)	Menti.com Close	QM3: Share one thing you consider particularly important about this evening's discussions	
In own time	Online community space activities for next time	• Review Q&A Responses – as they become available. • Space for Participant-driven information, what matters to you at this point? What do you want to make sure we include in our final deliberations on Saturday? • Film: on families with experience of genetic conditions • Film: perspectives opposing early embryo research • He Jianku scandal – Guardian article • Blastoids/ cattle research – other current news	Activities on Recollective

Lived Experience Final workshop – Saturday 1st July – Final deliberations

Time	Agenda	Process	Process Tools
10:00-10:10 (10 mins)	Introduction to final workshop and reminder of the overall dialogue programme	1. HVM team re-introduce themselves 2. Observers/ speakers present introduce themselves 3. Evaluator to introduce themselves	PP Purpose & Agenda Slide Intro PP
10:10-10:20 (10 mins)	Menti questions set 1	QM1: Share one concern you have for early human embryo research. QM2: Share one hope you have for early human embryo research.	Menti.com
10:20-10:50 (30 mins)	Reminder of what we've covered/ what we have shared so far.	**Show Perspectives Film 1** **Show Perspectives Film 2** **Speaker** – the ethical/ philosophical dimension Sarah Chan reflects on some key questions to consider given all that has been reviewed/ discussed so far.	PP slides with visual reminders + Perspectives Film 1 & 2
10:50	TS to move everyone to their pre-allocated small groups – 7 participants per group, based on a mix of demographics, 1 facilitator for each group, tech support available to all groups for immediate Zoom challenges.		
10:50-12:00 (70 mins)	Exploring hopes and concerns of participants	**Introductions** 1. Say hello to the group 2. Briefly share one question or thought about human embryo research that is in your mind at this point in our process? **Q1: What are your concerns about research using early human embryos/ stem cell derived models?** • Group to create list of concerns • Build on what has been discussed • Note differences between embryos and models **Q2: What are your hopes about research using early human embryos/ stem cell derived models?** • Group to create list of hopes	Jamboard: **concerns – types and reasons up on Jamboard** **Types**: IVF, mitochondrial replacement, pre-implantation genetic testing **Reasons**: treating infertility, avoid passing on known inherited genetic conditions

<table>
<tr><th>Time</th><th>Agenda</th><th>Process</th><th>Process Tools</th></tr>
<tr><td></td><td></td><td>• Build on what has been discussed
• Note differences between embryos and models
○ In relation to providing new treatments/ interventions for medical conditions (e.g., childhood cancers, spina bifida, heart conditions.)
Q3: What are the most important concerns/ hopes that we've discussed this morning?
Group to create a summary sheet:<table><tr><td>Most important concerns
1.
2.
3.</td><td>Most important hopes
1.
2.
3.</td></tr></table></td><td>Repeat Jamboard format for hopes</td></tr>
<tr><td>12:00-12:20 (20 mins)</td><td>Feedback from each group</td><td>LF invites each group in turn to share their important concerns/ hopes.
Sarah Chan, Amy Wilkinson and Katarina Harasimov reflect back on what they've heard.
Give further thoughts on what will be important to think about, given these hopes/ concerns as we go into our final deliberations this afternoon.</td><td>Fs to share Jamboards with summary sheets</td></tr>
<tr><td>12:20-13:00</td><td colspan="3">Lunch break</td></tr>
<tr><td>13:00</td><td colspan="3">LF welcomes people back - TS moves everyone straight back to their pre-allocated small groups – 7 participants per group, based on a mix of demographics.</td></tr>
<tr><td>13:00-14:10 (70 mins)
13:00-13:25 (25 mins)

13:25-13:50 (25 mins)</td><td>Expectations of the research/ researchers/ regulation</td><td>Q1: What are your expectations of early human embryo research?
Prompts – to support the discussion to cover:
• What do you expect in terms of the fertility treatments/ healthcare treatments?
• What do you expect from the researchers working with early human embryos?
• Do you expect different things when the work is being done with stem cell derived embryo models? And if so what are they/ why?
• What would you never want to see happen as a result of this research?</td><td>Jamboard for visible notes
Research heading – summary of broad areas of research for fertility/ healthcare
Regulatory heading – the legal limits of research – summarised from the Warnock report (1984)/ HFEA</td></tr>
</table>

Time	Agenda	Process	Process Tools
13:50-14:10 (20 mins)		**Q2: What are your expectations of the regulations governing early human embryo research?** A reminder is on my screen of what the Warnock report said should be the legal limits of research in this area/ HFEA summaries (on Recollective). Prompts – to support the discussion to cover: • What do you expect from governing bodies? E.g., HFEA (for licensing/ work within the 1990 Act) – HRA (for ethics reviews) • Do you expect input from people across society in how this work is regulated/ governed/ overseen? And if so why? • What are your views on the 14-day rule for research on early human embryos? **Q3: What other expectations do you think society might have of the research and the regulations, including the 14-day rule?** Prompts – to support the discussion to cover: • What else do you think society might expect from governing bodies? E.g., HFEA (for licensing/ work within the 1990 Act) – HRA (for research approvals) • What does society expect from the research community/ the science e.g., to find alternatives to human embryos; to respect ethical codes; to respect religious perspectives; to understand the causes of/ reduce risk of miscarriage, understand human development to inform new treatments for fertility, medical conditions, innovations in the field? • Where do you think lines should be drawn which should not be crossed in this research? • What does society expect from those regulating the science/ the research? • What are the ethical considerations we need to think about as a society? • How much should people across society be involved in these ethical discussions?	consultation summaries are up on the Jamboard (also on Recollective)
14:10-14:25	**Break**		

<table>
<tr><th>Time</th><th>Agenda</th><th>Process</th><th>Process Tools</th></tr>
<tr><td>14:25-15:05
(40 mins)
14:25-14:50
(25mins)

14:50-15:05
(15mins)</td><td>Recap and prioritisation of before break activity</td><td>Q3: What are the most important expectations that we've discussed this afternoon?
Prompts:
• What is most important for you?
• What is most important for society?
• Why are these things important?
• To what extent are there trade-offs here e.g., to understand better why miscarriages occur, research needs to be done on early human embryos.
Group to create a summary sheet:<table><tr><td>Important expectations of researchers
1.
2.
3.</td><td>Important considerations of the regulators/ legal framework
1.
2.
3.</td></tr></table></td><td>Jamboard with summary sheet.</td></tr>
<tr><td>15:05-15:45
(40 mins)</td><td></td><td>LF invites each group in turn to share their expectations. Giving enough time to explain clearly their key points.
Researchers/ ethicists/ philosophers reflect back on what they've heard.
Whole group discussion/ reflections on the work we've done together.
To end – Naomi Clements-Brod: HDBI, shares final reflections back on what they have heard today.
• Key points heard
• Reflections on what this means
• Sum up next steps as a result of the dialogue.</td><td>Fs to share Jamboards with summary sheets</td></tr>
<tr><td>15:45-15:55
(10 mins)</td><td>Menti.com – online polling</td><td>QM5: Keeping the 14-day rule as it is would…
QM6: Changing the 14-day rule would…
QM7: One word of advice for those setting the regulatory framework for early embryo research covered by the 14-day rule</td><td></td></tr>
<tr><td>15:55-16:00
(5 mins)</td><td>Wrap up and close</td><td>LF thanks everyone</td><td></td></tr>
</table>

Time	Agenda	Process	Process Tools
In own time	Online community space	Evaluation task	Activities on Recollective

Broad Public Webinar – Monday 3rd July

Time	Agenda	Process	Process Tools
6:00-6:15 (15 mins)	Introduction to this webinar and the overall dialogue programme	1. HVM team introduce themselves 2. Observers/ speakers present introduce themselves 3. Evaluator to introduce themselves and the evaluation process End with a **reminder** of the 'what is public dialogue' film on Recollective. Including mentioning that people will hear from lots of speakers during the dialogue as a whole and will use that information to explore the issues that are important to them/ and ask questions.	PP Purpose & Agenda Slide Intro PP LF to make a note of question to answer
6:15-6:25 (10 mins)	Menti questions set 1	QM1: Share where in the country you are zooming in from QM2: When I say the word 'research' what comes to your mind?	Menti.com
6:25-6:30 (5 mins)	Chat questions	Participants asked to share questions they have in the chat about the purpose of the dialogue. Quick points of clarification. Chat Prompt 1 (CP1): What questions do you have about the purpose of the dialogue/ your role in the dialogue? LF to answer questions directly related to the dialogue. Questions more related to our topic than the process will be covered in the next Q&A we have after our next presentations.	**HH** to put Chat Prompt 1 in the Chat

Time	Agenda	Process	Process Tools
6:30-6:50 (20 mins) 6:30-6:39 (9 mins) 6:39-6:50 (11 mins)	An introduction to our subject	**Reminder** – you've seen a short film from one of our speakers, Peter Rugg-Gunn on Recollective. This has explained the purpose of the dialogue and why it's happening now. **2. Presentation: Embryo – part 1: Mag Aushev** • Clarity on size/ scale • What is an embryo (incl: cell as building block of body) • Visualisation an early embryo timeline • Include what is the primitive streak here **3. Film: What is early human embryo research: Peter Rugg-Gunn**, Group Leader HDBI and Head of Public Engagement, Babraham Institute introduces our topic: • Present on what is early human embryo research? • Types of research: basic/fertility/miscarriage/genetic conditions • How the research is done in the lab	PP presentation Film (speaker view only – **start and stop the recording with each new speaker**)
6:50-7:05 (15 mins)	Chat questions	Participants asked to share questions they have in the chat about the embryo, early human embryo developmental research, collated by CF. Chat Prompt 2 (CP2): What questions do you have about the embryo/ embryo research/ the purpose of embryo research? **Mag Aushev & Amy Wilkinson** to answer questions as directed by LF. LF confirmation that this is our first introduction to these topics. We'll be learning more as we go along.	**HH** to add Chat Prompt question to the Chat
7:05-7:15 (10 mins)	A focus the legislative framework	**4. Presentation: Introducing the Human Fertilisation & Embryology Authority Claire Ettinghausen,** HFEA Director of Strategy & Corporate Affairs An explanation of the current regulatory and legal system including: • The role of the HFEA, its establishment with The Human Fertilisation and Embryology Act (1990) • How this relates to other organisations in the system • How the regulatory system has evolved since the work of the Warnock Committee in 1982	PP presentation as necessary (speaker view only – start and stop the recording with each new speaker)

Time	Agenda	Process	Process Tools
7:15-7:25 (10 mins)	Chat questions	CP3: What questions do you have about the regulations and law? Claire & other speakers to answer questions prioritised by the LF.	**HH** to put the Chat Prompt into the Chat
7:25-7:30 (5 mins)	Menti.com Close	QM3: One thing that you have learnt or has particularly interested you from what you've heard this evening	Menti.com
In own time	Online community space activities for next time	• Review the speaker presentations from this evening, add any questions you have • Look at the regulation timeline and the regulatory story graphic, add any questions you have • Review the graphic materials on the embryo and the primitive streak • Listen to BBC R4 Inside Science – Insoo Hyun	Activities on Recollective

Broad Public Group, south - Workshop 1 – Monday 5th July – Research[18]

Time	Agenda	Process	Process Tools
6:00-6:10 (10 mins)	Introduction to this workshop and reminder of the overall dialogue programme	1. HVM team introduce themselves 2. Observers/ speakers present introduce themselves 3. Evaluator to introduce themselves and the evaluation process	PP Purpose & Agenda Slide Intro PP
6:10-6:20 (10 mins)	Menti questions set 1	QM1:Tell us in a few words something about yourself QM2: What comes to your mind when you think about what you heard at the webinar?	Menti.com Tech support to put menti link/ code in the Chat
6:20	TS to move everyone to their pre-allocated small groups – 7 participants per group, based on a mix of demographics, 1 facilitator for each group, tech support available to all groups for immediate Zoom challenges.		

[18] The Broad Public Group, north followed the same process as the Broad Public Group - South with different live speakers. See Appendix 3 for a breakdown of the speakers allocated to each group.

Time	Agenda	Process	Process Tools
6:20-6:45 (25 mins) 6:20-6:30 (10 mins) 6:30-6:45 (15 mins)	Reflections on what we've shared so far	**Introductions** 1. Say hello to the group 2. Say where you are zooming in from 3. Briefly share one thing you are thinking about having attended the webinar and reviewed materials in the online space. Remind participants of what LF said in the intro about sharing personal information – more about your perspectives on current and future of early human embryo research and how your life experience informs them. **Q1: What in the webinar and online space materials either surprised or interested you?** Prompts • Something that was new to you? • Something that made you think? • Why was that surprising or interesting?	Jamboard No visible notes Start taking notes on Jamboard to collect key points
6:45-7:10 (25 mins) 6:45-7:00 (15 mins) 7:00-7:10 (10 mins)	An introduction to the research	**Film 1: Early Human Embryo Research: Examples and Outcomes** An overview of types of early (pre-14 day) human developmental research to include blue sky and near-term applications e.g. improving IVF techniques • The progress timeline – outcomes/ developments as a result of this research including 1st IVF baby; importance of prenatal vitamins, mitochondrial donation. • Speaker own motivations for their work. **Presentation 1: Naomi Moris, Crick Institute** Embryo part two: • Embryo availability (challenges/limitations) • Stem cell derived embryo models – what they are and why used (How to come overcome challenges using alternatives)	PPs Visualisations e.g. timeline
7:10-7:20	**Break**		

Time	Agenda	Process	Process Tools
7:20	TS to move everyone to their pre-allocated small groups – 7 participants per group, based on a mix of demographics, 1 facilitator for each group, tech support available to all groups for immediate Zoom challenges.		
7:20-7:35 (15 mins) 7:20-7:30 (10 mins) 7:30-7:35 (5 mins)	Developing our questions.	**Q2: What questions/reflections do you want to ask at this point to clarify your understanding?** Prompts: • What's news to you? • What do you want to know more about? • Was anything unclear: language/terminology? (We'll add new terms to the jargon buster) Create a long list of questions. **Q3: What are the 2 main questions/reflections we want to explore with the whole group after the break?** Select two main questions, explain that all the questions will be answered on Recollective, we've picked the two questions that feel most important to get an answer to know.	List all the questions that come up on the Jamboard. Select two questions from the list – ready for screen sharing.
7:35-8:00 (25 mins) **7:35-7:55 (20 mins)** **7:55-8:00 (5 mins)**		LF go round each group. Ask one question first, then do a second round with the second question. Pick up questions that can be answered. Questions that can't be answered either for time/ content reasons will be responded to, as far as possible, before the next workshop. Questions that are more complex, or need a number of people to respond to them may take a little longer. Answers will be shared on Recollective. Speaker panel responds to the questions. Panel includes: **Naomi Moris; Desislava Staneva (researchers), Bobbie Farsides (ethicist).** End with **Bobbie Farsides** - a **short ethical briefing** – 5 minutes highlighting some of the ethical dimensions/ questions that arise from what we've heard so far.	F's to do off-screen note taking on Jamboards to identify main unanswered questions
8:00-8:05 (5 mins)	Lived experience	LF introduces film: someone with experience of fertility treatment and deciding to donate embryos to research. **Lived experience film 1**	Paul Wyatt film

Time	Agenda	Process	Process Tools
8:05	TS to move everyone to their pre-allocated small groups – 7 participants per group, based on a mix of demographics, 1 facilitator for each group, tech support available to all groups for immediate Zoom challenges.		
8:05-8:25 (20 mins)	Initial exploration of the issues raised this evening	**Q4: What are your initial thoughts on early human embryo research now you know more about it?** Prompts: • What for you feels important about this research? • What for you could be positive about early human embryo research? • What for you is negative or challenging about early human embryo research? • What is your response to the motivations for conducting early human embryo research?	Jamboard for visible note taking
8:25-8:30 (5 mins)	Menti.com Close	QM3: Something that you have learnt or has interested you this evening.	
In own time	Online community space activities for next time	• Review Q&A Responses as they become available. • Lived experience stories. • Religious/moral perspective on when life begins. • Researcher stories	Activities on Recollective

Broad Public Group, south Workshop 2 – Friday 14th July – The regulatory framework

Time	Agenda	Process	Process Tools
6:00-6:10 (10 mins)	Introduction to workshop 2 and reminder of the overall dialogue programme	1. HVM team introduce themselves 2. Observers/ speakers present introduce themselves 3. Evaluator to introduce themselves and the evaluation process	PP Purpose & Agenda Slide Intro PP
6:10-6:20 (10 mins)	Menti questions set 1	QM1: One thing that you remember from what you heard in the webinar or in the online space about the regulations regarding this research?	Menti.com

Time	Agenda	Process	Process Tools
		QM2: What three words describe how you feel about the regulations for this kind of research?	
6:20-6:35	Participants collect a plate of food and bring it back to their table – conversation over supper		
6:35-7:00 (25 mins) 6:35-6:45 (10 mins) 6:45-7:00 (15 mins)	Reflections on what we've shared so far	**Introductions** 1. Say hello to the group 2. Share where you've come from today 3. As you travelled here, what were your thoughts on how this workshop would be? **Q1: Regulation of embryo research: what do you remember from the webinar/ online space?** Prompts • What are you interested in discussing or learning more about? • 14 day rule/ primitive streak? • How scientists work with the regulations • Who's involved in reviewing the science?	Flip charts No visible notes Only take notes on flip of really key points/ or use post-its and add them to the flip.
7:00	Participants to turn out to face the speaker area		
7:00-7:20 (20 mins) 7:00-7:05 (5 mins) 7:05-7:20 (15 mins)	An exploration of perspectives on the regulations	**Film 1: Where embryos come from – including the consent process** • How they are stored • The facts on the regulations around licensing/ donation/ storage **Film 2: Research Ethics Committee view on embryo research** **Film 3: Experience of the fertility treatment/ donation/ consent process**	PW film – 5 mins PW Film – 5 mins PW Film – 5 mins
7:20-7:35	**Break**		
7:35	Participants turn into their groups		

Time	Agenda	Process	Process Tools
7:35-7:50 (15 mins) 7:35-7:45 (10 mins) 7:45-7:50 (5 mins)	Developing our questions	**Q2: What questions do you want to ask at this point to clarify your understanding about the regulations and about the issues that they raise for you?** • Questions about how the regulations might change in the future? • What do you want to know more about? • Questions about what you found surprising? • Was anything unclear: language/terminology? Create a long list of questions. **Q3: What are the 2 main questions we want to explore with the panel and the whole group?**	List all the questions that come up on the Flip chart. Select two questions from the list. Have the questions visible/ written out for the volunteers to read out
7:50-8:25 (35 mins) 7:50-8:05 (15 mins) 8:05-8:20 (15 mins) 8:20-8:25 (5 mins)	Plenary Q&A Speaker panel	LF go round each group. Ask one question first, then do a second round with the second question. Pick up questions that can be answered. Questions that can't be answered either for time/ content reasons will be responded to where possible during tomorrow's workshop/ on Recollective. **Speaker panel London** • Elselijn Kingma-Vermeer, King's College London • Desislava Staneva, Cambridge University • Venessa Smith, Guys & St Thomas' • Naomi Clements-Brod, HDBI We now move from questions to our panel discussion. Our panel will now share experience of the 14 day rule. End with **short ethical briefing**: Elselijn Kingma-Vermeer, King's College London	
8:25	Participants turn into their groups		
8:25-8:55 (30 mins) 8:25-8:50 (25 mins) 8:50-8:55 (5 mins)	Exploring the regulatory context	**Q2: What is your current response to the existing regulations for research with early human embryos?** • Do the regulations give you reassurance about how the research is approved/ conducted and how? • What feels particularly important to you about the regulations? • What should society be concerned about in relation to the regulations as they stand/ if they change?	Flip chart divided into three: 1.Important 2.Cause for concern 3. Cause for optimism

Time	Agenda	Process	Process Tools
		Summary sheet: • What's important? • What's a cause for concern? • What gives reassurance/ cause for optimism?	Flipchart summary sheet.
8:55-9:00 (5 mins)	Menti.com – online polling	QM3: Share one thing you consider particularly important about this evening's discussions	

Broad Public Group, south Workshop 3 – Saturday 15th July – Final deliberations

Time	Agenda	Process	Process Tools
10:00-10:10 (10 mins)	Introduction to final workshop and reminder of the overall dialogue programme	1. HVM team re-introduce themselves 2. Observers/ speakers present introduce themselves 3. Evaluator to introduce themselves	PP Purpose & Agenda Slide Intro PP
10:10-10:20 (10 mins)	Menti questions set 1	QM1: Share one concern you have for early human embryo research. QM2: Share one hope you have for early human embryo research.	Menti.com
10:20-11:00 (40 mins)	Reminder of what we've covered/ what we have shared so far.	Then each group is invited to review what else we've seen by doing a carousel activity to remind everyone of what we've covered. Chairs around the images for those that would rather not stand. Each facilitator goes round the room with their group. Image reminders of the presentations/ films/ recollective tasks up on the wall/ on flip stands. Facilitator notes what was discussed in each workshop/ presentation set/ films. Reminder of all we've discussed. Drawing out things from HDBI FAQs that will support our discussions today. LF Plays range of perspectives **Film** 2 **Speaker** – the ethical/ philosophical dimensions **London** Elselijn Kingma **or** Play Sarah Chan **Film**	PW film A1 sheets up on the wall with reminders of key information.

<table>
<tr><th>Time</th><th>Agenda</th><th>Process</th><th>Process Tools</th></tr>
<tr><td>11:00</td><td colspan="3">Participants turn into their groups</td></tr>
<tr><td>11:00-11:25
(25 mins)</td><td>Exploring hopes and concerns of participants</td><td>Q1: What are your concerns about research using early human embryos/ stem cell derived models?
• Group to create list of concerns
• Build on what has been discussed
Prompts – to be used as necessary:
• What specific concerns do you have for this research and how it is regulated and why?
• To what extent do you have specific concerns about the research:
○ In relation to fertility treatment?
○ In relation to different types of fertility treatment? (list the types on flip)
○ When used for different reasons (list potential reasons on flip
○ In relation to providing new treatments/ interventions for medical conditions (e.g., childhood cancers, spina bifida, heart conditions.)
• How does this differ for models?</td><td>Flipchart: concerns
Types – on a flip near the table:
IVF, mitochondrial replacement, pre-implantation genetic testing
Reasons – on a flip near the table:
avoid passing on known inherited genetic conditions, infertility, health conditions</td></tr>
<tr><td>11:25-11:40</td><td colspan="3">Break</td></tr>
<tr><td>11:40-12:10
(30 mins)

11:40-12:00
(20 mins)

12:00-12:10
(10 mins)</td><td></td><td>Q2: What are your hopes about research using early human embryos/ stem cell derived models?
• Group to create list of hopes
• Build on what has been discussed
Q3: What are the most important concerns/ hopes that we’ve discussed this morning?
Group to create a summary sheet:
<table><tr><td>Most important concerns
1.
2.
3.</td><td>Most important hopes
1.
2.
3.</td></tr></table></td><td>Repeat Flip format for hopes

Summary sheet for review later in the day</td></tr>
</table>

Time	Agenda	Process	Process Tools
12:10-12:40 (30 mins) 12:00-12:10 (10 mins) 12:10-12:30 (20 mins)	Feedback from each group	LF invites each group in turn to share their important concerns/ hopes. Speaker panel reflect back on what they've heard: **London** • Elselijn Kingma, KCL • Kathy Niakan, Cambridge University • Desislava Staneva, Cambridge University • Venessa Smith, Guys • Naomi Clements-Brod, HDBI	Fs to share Flips with summary sheets
12:40-1:20	**Lunch break**		
1:20	LF welcomes people back – Groups to turn back to their tables for discussion		
1:20-2:25 (65 mins) 1:20-1 :25 (5 mins) 1:25-1:35 (10 mins) 1:35-1 :55 (20 mins) 1:55-2:05 (10 mins) 2:05-2 :25 (20 mins)	Expectations of the research/ researchers/ regulation	**Q1: What are your expectations of the research?** *We are first focusing on the research itself – we will discuss regulation of research in a moment.* Prompts – to support the discussion to cover: • What do you expect in terms of the fertility treatments/ healthcare treatments? • What do you expect from the researchers working with early human embryos? • Do you expect different things when the work is being done with stem cell derived embryo models? And if so what are they/ why? • What would you never expect to happen as a result of this research? **Q2: What are your expectations of the regulations governing this research area?** Prompts – to support the discussion to cover: • What do you expect from governing bodies? E.g., HFEA (for licensing/ work within the 1990 Act) – HRA (for research approvals) • Do you expect input from people across society in how this work is regulated/ governed/ overseen? And if so why? • What are your views on the 14-day rule for research on early human embryos?	Flip to collect post it notes Research heading – summary of broad areas of research for fertility/ healthcare Regulatory heading – the legal limits of research – summarised from the Warnock report (1984)/ HFEA consultation summaries are up on the wall from the night before (also have been on Recollective)

<table>
<tr><th>Time</th><th>Agenda</th><th>Process</th><th>Process Tools</th></tr>
<tr><td></td><td></td><td>• How much should people across society be involved in these ethical discussions?</td><td></td></tr>
<tr><td>2:25-2:40</td><td colspan="3">Break</td></tr>
<tr><td>2:40-3:00
(20 mins)</td><td>Recap and prioritisation</td><td>Q3: What are the most important expectations that we've discussed this afternoon?
Group to create a summary sheet:<table><tr><td>Important expectations of researchers
1.
2.
3.</td><td>Important considerations of the regulators/ legal framework
1.
2.
3.</td></tr></table></td><td>Flip chart with summary sheet for sharing with the room</td></tr>
<tr><td>3:00-3:45
(45 mins)
3:00-3:10
(10 mins)
3:10- 3 : 20
(10 mins)
3:20-3:35
(15 mins)
3:35-3:45
(10 mins)</td><td></td><td>LF invites each group in turn to share their expectations. Giving enough time to explain clearly their key points.
Everyone stands up and goes round the sheets of the other groups.
Use a green sticky dot to note the things you found particularly important in the other groups' notes.
Use a blue sticky dot to note the things you think need addressing urgently
Researchers/ ethicists/ philosophers reflect back on what they've heard.
Whole group discussion/ reflections on the work we've done together.
To end – Naomi: HDBI representative, shares final reflections back on what she has heard today. Sum up next steps as a result of the dialogue.</td><td>Fs to share flips with summary sheets</td></tr>
<tr><td>3:45-3:55
(10 mins)</td><td>Menti.com</td><td>QM5: Keeping the 14-day rule as it is would…
QM6: Changing the 14-day rule would…
QM7: One word of advice for those setting the regulatory framework for early embryo research covered by the 14-day rule</td><td></td></tr>
<tr><td>3:55-4:00
(5 mins)</td><td>Wrap up and close</td><td>LF Thanks everyone</td><td></td></tr>
</table>

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