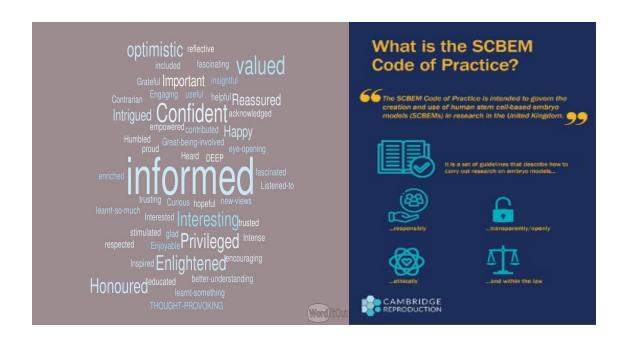


## **Cambridge Reproduction and UKRI Sciencewise**

# **Evaluation of a Public Dialogue on Stem Cell Based Embryo Models**

### **Evaluation report**

November 2024









## **Quality Management**

URSUS Consulting Ltd has quality systems which have been assessed and approved to BS EN IS9001:2008 (certificate number GB2002687).

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#### **Executive summary**

<u>Cambridge Reproduction</u>, <u>Progress Educational Trust</u> (PET) and <u>UKRI Sciencewise</u> commissioned a public dialogue process on Stem Cell Based Embryo Models (SCBEMs) in late 2023, which has been delivered by public dialogue contractors <u>Hopkins Van Mil</u> (HVM). This report summarises the key findings of an independent evaluation of the quality and robustness of the dialogue design and delivery, and its potential to impact on research policy and practice.

#### **Background**

SCBEMs (hereafter embryo models) are a fast developing area of scientific research which aims to improve IVF outcomes, help address conditions that develop at the earliest stages, and understand early human development (EHD). The term covers a plethora of different types of model which vary in how they are made (using either embryonic stem cells (ESCs) or induced pluripotent stem cells (iPSCs)) and in what they attempt to mimic (from single organs to complex integrated models). What all these models have in common is that they are not currently covered by EHD regulation in the form of the <u>UK Human Fertilisation and Embryology Act</u>, (HFE Act, 2008). Nevertheless, UK and international researchers tend to err or the side of caution: they apply the 14-day rule limit (set in the HFE Act) to all their work, despite the fact that embryo models do not necessarily follow the same developmental stages as classic human embryos.

#### **Dialogue purpose and outputs**

Cambridge Reproduction and PET jointly launched a project called Governance of Stem Cell-Based Embryo Models (G-SCBEM) in 2023. This involved assembling an interdisciplinary working group of experts drawn from institutions across the UK, to develop a governance framework for research involving SCBEMs. The working group decided that in the first instance, this should take the form of drafting a Code of Practice. The hope is that the Code will address grey areas in the legislation and will be widely adopted by researchers, funders and publishers. This will give researchers confidence to pursue research in the knowledge that it addresses scientific, ethical and wider societal hopes and concerns.

G-SCBEM seized the opportunity to commission a rapid dialogue on the back of a larger <u>public dialogue on early human embryo research</u> commissioned by the <u>Human Development Biology Initiative</u> (HDBI) and Sciencewise earlier in 2023. The objectives of this dialogue were to add to current understanding of the public's hopes and concerns for the technology, and to ensure that the public's views are reflected in the Code. The commissioners were able to draw on both a group of public participants and contractors who had already acquired some starting knowledge of the topic. The process was overseen by a small Oversight Group (OG). The dialogue report - <u>Addressing the Dialogue Gap</u> - was published in April 2024 and fed into the <u>Code of Practice on Stem Cell Based Embryo Models</u> published on 4<sup>th</sup> July 2024.

#### Dialogue design and delivery

Some 38 participants were selected (from 70 who were keen to take part) and reflected national demographic and socio-economic characteristics, while also representing a mix of attitudes and religious beliefs, including some strongly opposed to EHD research. Each participant attended four online workshops (totalling 9 hours) on weeknight evenings across a fortnight. They also undertook a few activities on a shared site (Recollective) in their own time. Participants heard background information from specialists (scientists, ethicists and legal experts) via videos, PowerPoints and specialist panels. They deliberated about the science, how it might be used, and how they would like to see it regulated in the future.



#### The dialogue fully met its objectives

- 1. To understand public views on the value and potential risks of research using embryo models. Despite the complex science, participants felt well enough informed to share their hopes and concerns for the research in some depth. Their previous exposure to EHD research, and the engaging way that the information was shared helped them navigate the topic without feeling too overwhelmed. Participant's familiarity with the process, each other and a small team of facilitators helped them to feel comfortable in a wholly online process. The attention put into ensuring that support was available for anyone who found topic emotionally distressing was appreciated by participants. Only about a third needed to use the support but all appreciated knowing it was there. There was very little drop-out between sessions.
- 2. To understand whether and/or how public participants expect embryo models to be regulated in future, including legal and governance structures. Legal specialists and ethicists helped participants understanding current legal frameworks and the pros and cons of potential future approaches. Participants quickly grasped the wider societal issues and came to clear positions on how they hoped to see embryo models governed (how stringently, which aspects and who should be involved) in the near future and longer term. A consensus emerged on the need for some immediate governance framework (such as a voluntary Code of Practice). However, many participants were also interested in a stepwise approach leading to statutory legislation (such as the HFE Act) at some point in the future if embryo models started to closely resemble human embryos (e.g. visible spinal cords, heartbeats or the ability to feel pain).
- 3. To help make sure that public views are reflected in the Code of Practice being developed by G-SCBEM for research using stem cell based embryo models. Participants studied an early draft of the Code of Practice and most were supportive of the underlying principles and how quickly such an approach could be put in place compared to legislation. As a result of the public dialogue the section on ethics in the final version of the Code was much strengthened. Four of the five key recommendations on governance made by the participants were either already covered (such as the need for regular review) or incorporated directly (including some types of models in legislation in the future, if necessary; involving the public in governance; and increasing awareness of the science including what it is trying to achieve and its benefits). A fifth recommendation was to have time limits for research using embryo models. Most participants wanted fixed limits but the Code authors opted for a case-by-case approach, with limits to be determined during the course of application to the SCBEM Oversight Committee. This decision was made because models cover such a wide spectrum that no one limit (analogous to the 14-day rule applicable to human embryo research) seemed workable. However, the Code does urge researchers 'to be aware of and sensitive to concerns' in relation to features (such as spinal cord or heartbeat) that 'may have ethical significance' in proposing appropriate limits for their own work.

#### There is the potential for significant impacts on research policy and practice

Even before the dialogue report was published the team were able to share insights gained from the dialogue and how these were feeding into their early thoughts on the Code. Events aimed at public audiences included a Science Museum Late and a workshop at the Cambridge Festival. The published dialogue report was then disseminated by the commissioners and by a few OG members: press releases and social media comments highlighted the usefulness of the process and the importance of capturing the public's hopes, concerns and recommendations in the final version of the Code.



The Code – despite being published on election day – attracted coverage in the UK press (Guardian), science publications (Science, Nature), academic websites, blogs and articles and social media. The coverage highlighted the importance of the public's views and principles being reflected in the Code, and on occasion cited the dialogue directly. The tone of coverage suggests that the Code is welcomed as a clear, transparent and ethical framework which will support researchers to progress their work, confident that they are in step with public opinion.

Over the next year G-SCBEM hope to set up an Oversight Committee, website and central register of embryo model research (as laid out in the Code) and publicise the Code more widely. Key actors in the UK research community – including research institutions, funders and publishers – will be encouraged to start endorsing and implementing the Code. The dialogue findings and Code approach also have the potential to feed into longer term UK thinking about regulations via G-SCBEM member inputs to the Nuffield Council on Bioethics (NCoB) review which will help inform the thinking of the Human Fertilisation and Embryology Authority (HFEA) when they make recommendations on how SCBEM should be covered in other types of regulation.

There is also potential for wider international impact. Indeed, the International Society for Stem Cell Research (ISSCR) welcomed a presentation by the PET lead (on both the dialogue and Code drafting processes) at their annual meeting in July: ISSCR attendees included international scientists and ethicists who showed an interest in the process including how the dialogue has informed the Code. In the next year a key member of G-SCBEM will sit on the ISSCR's working group to update its own guidance for the international research community, with an opportunity to influence both the process and content of the ISSCR guidance.

#### **Key factors which contributed to success**

- A carefully tailored process and timetable ensured that dialogue insights could feed into the Code and vice versa.
- A small multi-disciplinary Oversight Group proved agile to meet at short notice with
  the Sciencewise adviser stepping in as Chair when necessary to make sure their inputs or
  review came at the most useful points of the process.
- Purposeful overlap between the members of the OG, core management team and related processes (the HDBI dialogue, G-SCBEM working group and NCoB task force) allowed the team to draw on a pool of multi-disciplinary specialists.
- The involvement of Cambridge Reproduction and PET project managers in all public workshops helped build participant's trust in the process. Participants unanimously agreed that they had been heard and were confident that their insights would be reflected in drafting the Code. The project managers were able to take what they heard in workshops directly to G-SCBEM meetings and feed into the policy drafting from the earliest stages.
- Working with an experienced group of participants made it possible to run all
  workshops online. Participants were already confident with the technologies, understood
  the process and how to work together, and had an established interest in the topic. Without
  this and the continuity provided by an experienced facilitation team, it is likely that the dropout rate would have been higher and participants would have been less engaged.
- Scheduling sessions a few days apart over a fortnight allowed participants some time
  to reflect on what they had heard and for the team to make minor design adjustments.
  An alternative approach would have been to run full-day workshops at weekends. However,



- such meetings would have needed to be face-to-face, which would have not been practical with such a geographically dispersed group of participants.
- A mix of information sharing formats worked well to help participants feel informed
  without overwhelming them. PowerPoints presentations were supplemented with
  unscripted reflections and an expertly moderated panel discussion. The latter worked
  particularly well to juxtapose the perspectives of a scientist, ethicist and legal specialist and
  participants welcomed this as an interesting way to hear such views.
- A dedicated share site proved invaluable for participants to review materials.
   Participants found the chance to revisit materials between meetings gave them confidence that they were keeping up with the complex topic. Those that had time also shared individual reflections which added another layer of evidence for the analysis.

## **Lessons for future dialogues**For Sciencewise and Commissioners

- Where opportunities arise consider whether commissioning a small online dialogue as a follow up to a larger process may be a cost effective and efficient way of informing a specific policy drafting process.
- Consider whether reconvening participants who have already gained some dialogue experience and topic knowledge could be helpful in enabling a wholly online and/or more intensive process than would otherwise be practical.
- Where a process is focused on a specific policy drafting process, encourage those involved to
  participate in workshops as specialists or observers (while ensuring that they do not
  compromise the independence of the process). A visible presence of well briefed
  commissioner representatives can both help foster trust in the process and help ensure that
  findings feed directly into policy drafting.
- For a pacy process, such as this, consider the pros and cons of a small, agile oversight group who can represent key stakeholder perspectives (with others feeding into the process via the workshop specialists and materials) and be able to convene quickly to make inputs at the most useful points in the process.
- Plan for dialogue findings to be shared more widely via the networks of all those involved (e.g. as OG members or specialists).

#### For delivery contractors

- Build in opportunities for participants to experience the diversity of experiences and views within the group (e.g. mixing up small groups between sessions, feedback in plenary, ePolling etc). This is particularly important for an online process where there are not the opportunities for informal social interactions offered by face-to-face workshops.
- Consider running a dedicated online share space alongside the workshops as a repository for workshop materials. Such a space could also allow those who are interested and have time to contribute individual reflections to enrich the evidence for analysis.
- Even where time is tight for developing stimulus materials, ensure a mix of information sharing formats to suit different learning styles and keep participants engaged.
- Aim for continuity in the facilitation team so that all facilitators are up to speed on the topics and can probe beneath the surface of what people say.



- Consider varying the length of workshop sessions to suit the stage of the process. In this case starting with a shorter information giving sessions (an online webinar) and building up to longer workshops for deliberative and reflective stages worked really effectively.
- If the topic is likely to be emotionally upsetting, provide support options (such as opportunities for time out, talking to an empathetic listener or links to external support organisations) for those that need them.
- Use a mix of techniques during online meetings to capture participant views as a group (e.g. transcriptions, visible note taking on interactive whiteboards) and individually.
- Allow a realistic timeframe for analysis and report drafting. In this case time spent getting
  the narrative and structure right at the outset helped streamline the drafting process and
  ensure that the final report was well written, put the participant's voices front and centre and
  produced clear recommendations for the policy drafting team.



### Contents

Acronyms	1
Executive Summary	2
1 Introduction	3
1.1 Introduction	3
1.2 Context	3
1.3 Dialogue design and delivery	4
1.4 Evaluation objectives and methods	4
2. Potential impacts of the public dialogue	6
2.1 Overview	6
2.2 Publication and dissemination of the dialogue findings	6
2.3 The dialogue's influence on the Code of Practice	10
2.4 Potential for influence on research practice and policy	12
3. How the dialogue has met is objectives and lessons on contributi	ng factors17
3.1 Overview	17
3.2. Key factors which contributed to meeting the objectives	18
4. Conclusions and Recommendations	24
4.1 Conclusions	24
4.2 Recommendations for Sciencewise and commissioners	24
4.3 Recommendations for delivery contractors	25

#### **ANNEXES**

Annex A Oversight Group and specialists involved

Annex B Evaluator observations

**Annex C** Feedback from participants



#### **Acronyms and Abbreviations**

BBSRC Biotechnology and Biological Sciences Research Council

**Code** Code of Practice

**EHD** Early human development

**EHE** Early human embryo

**ESC** Embryonic Stem Cell

**G-SCBEM** Governance of Stem Cell-Based Embryo Models

**HFE Act** Human Fertilisation and Embryology Act

**HFEA** Human Fertilisation & Embryology Authority

**HDBI** Human Developmental Biology Initiative

**iPSC** Induced Pluripotent Stem Cell

**IVF** In vitro fertilisation

MRC Medical Research Council

NCoB Nuffield Council on Bioethics

**PET** The Progress Educational Trust

SCBEM Stem Cell Based Embryo Model



#### 1 Introduction

#### 1.1 Introduction

This report has been prepared by URSUS Consulting Ltd and is an independent evaluation of a public dialogue commissioned by <u>Cambridge Reproduction</u> in collaboration with the <u>Progress Educational Trust</u> (PET) with support from <u>UKRI's Sciencewise</u> and <u>Biotechnology</u> and <u>Biological Sciences Research Council (BBSRC) Impact Acceleration Account</u>. The dialogue process was delivered by public dialogue contractors <u>Hopkins Van Mil</u> (HVM).

#### 1.2 Context

Stem Cell Based Embryo Models (SCBEMs - hereafter embryo models) are a fast developing area of early human development (EHD) research. Models differ in how they are made - using either embryonic stem cells (ESCs) or induced pluripotent stem cells (iPSCs) - and in what they attempt to mimic (from single organs to complex integrated models which closely resemble human embryos). What these models have in common is that they are not currently covered by existing regulations in the UK or much of the world. Most scientists using embryo models currently err on the side of caution and work within the limits of the UK <u>Human Fertilisation and Embryology Act</u>, (HFE Act, 1990, substantially amended in 2008). However, key aspects of the act such as the 14-day rule are not strictly translatable since embryo models do not follow the exact same stages as early human embryo (EHE) development.

Cambridge Reproduction is an interdisciplinary research centre which aims to explore pressing issues and convene different stakeholders to offer fresh perspectives on broad issues which affect individuals, society and policy formulation. Cambridge Reproduction and PET jointly launched a project called Governance of Stem Cell-Based Embryo Models (G-SCBEM) in 2023. This involved assembling an interdisciplinary working group of experts drawn from institutions across the UK, to develop a governance framework for research involving SCBEMs. The working group decided that in the first instance, this should take the form of drafting a Code of Practice. The intention was that a voluntary Code of Practice (hereafter the Code) could immediately be applicable by UK researchers in order to address some of the legal concerns while not unnecessarily holding back such a fast moving area of research.

G-SCBEM's working group met on 27 occasions between March 2023 and June 2024: stakeholders were consulted through a survey, policy workshops, and by sharing early drafts of the Code in Spring 2024. G-SCBEM was also keen to involve lay members of the public and took the opportunity to build on the HDBI public dialogue on early human development (EHD) funded by Sciencewise and the Human Development Biology Initiative (HDBI) in 2023. The plan was to reconvene a smaller group of participants who had taken part in this dialogue: they would understand the research context and have a starting understanding of embryo models and how they are currently being used. The opportunity to work with the same dialogue delivery team, independent evaluator and a few of the specialists was also expected to make the scoping process quicker so that it could feed into G-SCBEM's drafting timeline at key points. This would allow public views to be considered alongside those of



other stakeholders such as scientists, legal experts and ethicists. The dialogue was delivered between December 2023 and February 2024.

The three dialogue objectives were to:

- Understand public views on the value and potential risks of research using embryo models:
- Understand whether and/or how public participants expect embryo models to be regulated in future, including legal and governance structures; and
- Help make sure that public views are reflected in the Code being developed by G-SCBEM for research using stem cell based embryo models.

#### 1.3 Dialogue design and delivery

The process was steered by a small Advisory Group (7 individuals listed in *Annex A*) who provided some continuity with the previous HDBI dialogue steering group and some overall with G-SCBEM's working group. The process was managed by a small core group consisting of the two commissioner project managers (Cambridge Reproduction and PET), the HVM team, the Sciencewise Dialogue and Engagement Specialist (DES) and the independent evaluator.

From the 70 participants in the HDBI dialogue who volunteered to reconvene, 38 were selected to reflect UK demographics and socio-economic characteristics, and a range of religious beliefs and attitudes to early human development (EHD) research. Each participant received a thankyou payment (£275) for attending 9 hours of online workshops and completing up to an hour of individual activities at a dedicated share site (Recollective). The four online workshops varied in length from 90 minutes (an initial webinar) to 165 minutes (the final workshop). All workshops were held on weekday evenings over a two-week period.

Participants received background information in a range of formats including an advance participant pack, online presentations, articles, videos and panel discussions with specialists. They were gradually introduced to the different types of embryo models, how they are or could be used for research, and options for their future governance. A group of nine specialists (see *Annex A*) shared their perspectives as scientists, ethicists and legal experts. During the final workshop the participants reviewed a summary early draft of the Code and shared their thoughts on where it aligned with their thinking and where they felt amendments were needed.

#### 1.4 Evaluation objectives and methods

The objectives of this evaluation were to provide an independent assessment of the quality and robustness of the public dialogue and the credibility and impact of its findings. The scope included assessing the delivery methods; the mix of participants; the design of events; quality and balance of information provided; the role of specialists involved and professionalism and independence of the facilitation.

Evidence has been gathered through observation (of Oversight Group meetings and public workshops) and through written feedback from the participants in the process including



public via Recollective and an online survey (SurveyMonkey) and from specialists (via an online survey). The impacts of the process have been assessed on the basis of desk research and interviews with G-SCBEM's working group members. Quotes from the participants, specialists and wider stakeholders are shown throughout the text and *highlighted in blue*.



### 2. Potential impacts of the public dialogue

#### 2.1 Overview

This section describes the impact so far of the dialogue on the SCBEM Code and its potential to have an impact on scientific research practice and to influence UK and international practices and policy in the longer term.

The <u>Addressing the Governance Gap</u> (the public dialogue report) was published in April 2024 in advance of the <u>Code</u> published in July. From the end of the fieldwork in February there were plenty of opportunities for the emerging insights and recommendations to feed into the Code drafting process via the project management team, oversight group and G-SCBEM working group members involved as specialists. G-SCBEM members also talked about the dialogue and its links to the Code at public science events.

As a result of the public dialogue the section on ethics in the final version of the Code was much strengthened. Four of the five key recommendations on governance made by the participants were either already covered (such as regular review) or incorporated directly (including some types of models in legislation in the future, if necessary; involving the public in governance; and increasing awareness of the science including what it is trying to achieve and its benefits). A fifth recommendation was to have time limits to research using embryo models. Most participants wanted fixed limits but the Code authors opted for a case-by-case approach, with limits to be determined during the course of application to the SCBEM Oversight Committee. This decision was made because models cover such a wide spectrum that no one limit (analogous to the 14-day rule applicable to human embryo research) seemed workable. However, the Code does urge researchers 'to be aware of and sensitive to concerns' in relation to features (such as spinal cord or heartbeat) that 'may have ethical significance' in proposing appropriate limits for their own work. Researchers must adhere to this limit and may not go beyond this point without further review by the SCBEM Oversight Committee.

The Code has been widely circulated via social media and picked up by the national and trade press. It is referenced by academics, think tanks and policy makers such as the HFEA and has been welcomed in all circles for providing some immediate clarity on how to proceed ethically with this research.

Over the next year G-SCBEM hope to set up governance arrangements (an Oversight Committee to review relevant UK research proposals), a website and research register and to get research institutes and funders to sign up to the Code. In the longer term the Code has the potential to influence UK regulatory policy and overseas research practices by informing the work of the International Society for Stem Cell Research (ISSCR) which is developing its own governance framework.

#### 2.2 Publication and dissemination of the dialogue findings

#### 2.2.1 Early sharing of the dialogue findings

The public dialogue report - available at <u>Sciencewise</u> and <u>HVM</u> websites - was finalised in March and published on 11<sup>th</sup> April 2024. The dialogue report highlights a number of key



findings. These included the excitement that most participants felt about the opportunities to use embryo models for research to improve IVF, understand congenital disease and further understanding of early human development. The report also highlights participants' concerns about embryo model's equivalence to human embryos: this strongly shaped how they felt research of embryo models should be governed. Even before the dialogue report was published the team were able to share insights gained from the dialogue and how these were feeding into their early thoughts on the Code. Events aimed at public audiences included a Science Museum Late and a workshop at the Cambridge Festival (see *Box 2.1*).

#### 2.2.1 Dissemination of the public dialogue report

Addressing the Governance Gap (the public dialogue report) was shared with all participants and with wider audiences by HVM, Sciencewise, Cambridge Reproduction and Progress Educational Trust (PET). Blogs, tweets and news pieces were shared across each organisations websites, newsletters and social media (See *Table 2.1*). A number of the G-SCBEM's working group members disseminated the dialogue report when it was published (Francis Crick Institute, Hull York Medical School and Manchester University): others waited to share the published Code, at which point they also referred to the public dialogue that had helped to inform it (see *Table 2.2*).

#### Box 2.1: Exploring dialogue messages with the wider public

- Science Museum Late event (7<sup>th</sup> March 2024) entitled 'Stembryos: the future of reproduction' run by a panel of G-SCBEM members (all of whom had been involved in the dialogue) mentioned the dialogue and members of the public asked questions about options for governance of embryo models which resonated with issues raised by the dialogue participants.
- A Parliamentary Office for Science and Technology (POST) report on <u>Human stem cell-based embryo</u> models, <u>Research Briefing</u><sup>1</sup> (29 Feb 2024) to inform parliamentarians on the issue mentions both the Human Developmental Biology Initiative (HDBI) and this dialogue but without a full reference since the SCBEM report had not yet been published. Key insights on the public's hopes and concerns helped inform the report via the contributions of nine specialists who were involved in the dialogue via the Oversight Group or as specialist contributors.
- <u>Cambridge Festival</u> panel discussion on 'Reproductive Futures: SCBEMs' (17 March 2024) included an
  exhibition and panel discussions led by the HDBI public engagement team and three academics (Dr Peter
  Rugg-Gunn (Babraham Institute), Professor Sarah Franklin (Department of Sociology, University of
  Cambridge) and Professor Kathy Liddell (Faculty of Law, University of Cambridge) who had all been involved
  in the HDBI or SCBEM dialogues. Nearly 200 visitors took part in events or discussions asking a broad range
  of questions similar to those raised by dialogue participants.

The dialogue process and its findings were also mentioned at events such as the Science Policy Forum for policy specialists run by the Royal Society (April), but the dialogue report did not attract much wider press attention. Nevertheless, the commissioners and funders emphasised the importance and timeliness of the report:

"We're delighted that we've been given the opportunity to carry out this public dialogue, as it has allowed us to listen to wider public views, as well as those of researchers, policy makers and funders. By giving us a better understanding of public hopes, concerns and sensitivities around embryo models, the dialogue findings will help to ensure that our Code of Practice is as robust, transparent and trustworthy as possible." Cambridge Reproduction

<sup>&</sup>lt;sup>1</sup> POST Note, Human stem cell-based embryo models Research Briefing, Published Thursday, 29 February, 2024, Jahnavi Bhaskaran and Natasha Mutebi



<sup>&</sup>quot;It is an ideal time to find out what the general public has to say about this fast-moving area of research." **PET** 

They consider that the dialogue is a first in the UK - and probably internationally - that has engaged the public in such depth on embryo models. It has added value not just in providing a foundational understanding of what participants think about the science, but also in developing recommendations on its future governance.

Table 2.1: Dissemination of public dialogue findings by the commissioners

Organisation	Media	References to the dialogue
Sciencewise	Twitter – <u>series of 5 posts</u> 11.04.2024.	Announcing the dialogue and the key 5 findings. About 500 views in the first week.
Cambridge Reproduction	Commissioner reflections blog post	"I was deeply impressed by the thoughtfulness and nuance that the dialogue participants brought to these discussions. Even where opinions differed – and there was a wide range of views expressed during the dialogue! – the discussions remained respectful and open-minded."
	Cambridge Festival panel discussion on 'Reproductive Futures: SCBEMs' 17.3.2024	Tweet: Nearly 200 visitors came to our <u>@Cambridge Fes</u> eventsand talked stem cell based embryo models with <u>@BabrahamInst</u> and <u>@PDN Cambridge</u>
	News item: First UK public dialogue on stem cell-based embryo models suggests considerations for research and governance 11.04.2024	Link to the <u>public dialogue</u> . "commissioned to ensure that public voices – as well as those of researchers and policy makers – were taken into account while the Code of Practice was being written"
	Pioneering Code of Practice released for use of stem cell-based embryo models in research 4.7.2024	"A public dialogue enabled us to include public voices during the development of the Code, taking account of their hopes, concerns and sensitivities around research involving stem cell-based embryo models. Participants were excited by the potential of embryo model research, but also strongly supportive of oversight."
	Retweet of Sciencewise post and Retweet of @PET_BioNews article	What do members of the public think about the governance of research involving stem cell-based embryo models? Find out in the report of the public dialogue
	A <u>Policy Workshop Case Study:</u> <u>Cambridge</u> for Science and Policy (CsaP) Univ Cambridge	Sharing of lessons learnt on drafting the Code, including on the dialogue process via a professional development seminar
Progress Comment piece: If Educational Trust publication: Stem	Comment piece: BioNews publication: <u>Stem Cell based embryo</u> models addressing the governance	Link to dialogue report "we are keen that the views of the wider public, as well as the views of the other stakeholders in our orbit, should inform the Code of Practice at the very outset. It is thanks to the public dialogue that we will be able to ensure that this is the case."
	Newsletter lead comment piece: <u>Stem-cell-based embryo models:</u> <u>addressing the governance gap</u> (4 minute read) (15.4.2024)	Link to dialogue report "participants were asked to consider some of the most cutting-edge achievements and conundrums in present-day research and policy, thinking through and weighing up both the related opportunities and the related risks. This was no easy task, but the insights that they offered in response were – and are – invaluable."
	Science Policy Forum, Royal Society (April 2024)	Presentation on SCBEMs by Sandy Starr
	Annual conference of the ISSCR, Hamburg (13.7.2024). Presentation Identifying the ethical complexities and governance implications for embryo model research	Attended by >60 participants including ethicists from UK, Japan, China and US. Mentioned the dialogue, its findings and how these helped to inform the Code. The current president of the ISSCR asked questions about the scope of the Oversight Committee (to research applications outside the UK): others asked about public engagement and how often the Code should be revised.

<sup>&</sup>quot;Once again dialogue participants have shown they are able to grapple with the most complex, cutting edge science and give clear messages to help shape the way forwards." **UKRI** 



Table 2.2: Dissemination of the findings by others involved in the dialogue

Organisation	Dissemination route	Mention of the dialogue or its findings
Babraham	Pioneering Code of Practice	"Informed by <u>a public dialogue</u> to explore public attitudes
Institute,	released for use of stem cell-based	towards research involving embryo models."
Prof Peter Rugg-	embryo models in research 4.7.2024	"enabled us to include public voices during the
Gunn	Quotes in blogs and news articles	development of the Code, taking account of their hopes, concerns and sensitivities around research involving stem cell-based embryo models. Participants were excited by the potential of embryo model research, but also strongly
	LinkedIn Boot	supportive of oversight."  "Creat to see this report published. It serves as an
	<u>LinkedIn Post</u> X (twitter ) post - 1,926	"Great to see this report published It serves as an important and valuable contribution to current discussion
	Views – now removed	about how research involving stem cell-based embryo models should be governed in the UK, which will also inform our work on this issue."
Hull York Medical	LinkedIn posts on launch of	"Really proud to have played a small part in this excellent
School/ Univ Manchester Prof Roger Sturmey	dialogue report (April)	endeavour to try to capture how the public perceive hashtag#scbems stem cell based embryo modelsReally grateful to all the participants who have given us much to consider but with lots of support for research in this area.
	Quoted in other blogs and press articles Article in Nature (see <i>Table 2.3</i> )	"Because the guidelines reflect the public's voice and have had input from a wide range of stakeholders, I'm confider that UK researchers and institutions will follow them"
Francis Crick	Tweet X (April)	"I strongly believe that what we need most in the field of
Institute		embryo models, is more public engagement and public
Dr Naomi Moris	Researchers develop pioneering Code of Practice for use of stem cell-	dialogue. Initiatives like this show some fascinating examples of how the public feel about research &
	based embryo models 4.7.2024	regulation, take a look!  "incorporates public feedback through a Public Dialogue
	Also widely quoted in other blogs and news articles	"incorporates public feedback through a Public Dialogue that was held alongside the project, I am hopeful that it
	and news articles	will be well-received and that researchers will make use o the improved clarity around what is expected of them when it comes to such experimental projects."
<b>Biolawgy</b> Julian Hitchcock	LinkedIn follower comment	"Such important work. Crucial to understand public perceptions and that the public understand and trust the science."
Nuffield Council on Bioethics Ranveig Svenning Berg	<u>LinkedIn posts</u> on publication of public dialogue and then on Code of Practice	"Really proud to have played a small part in this excellent endeavour to try to capture how the public perceive <u>#scbems</u> stem cell based embryo models Really grateful to all the participants who have given us much to conside but with lots of support for research in this area."
<b>Exeter University</b> Louise Vennells	Pioneering new Code of Practice on stem cell-based embryo models in research 4.7.2024	Mentions the public dialogue and the role of Prof Austin Smith who contributed to the Code
<b>Durham University</b> Prof Emma Cave	Kellogg College Lecture: A history of the UK's 14 day rule governing human embryo research, 24 <sup>th</sup> June 2024, YouTube	Includes slides on SCBEM from the HDBI dialogue and mentions this dialogue as ongoing "the principle that public dialogues can strengthen trust and openness to more radical scientific research was very much confirmed by this exercise"
Kings College Centre of Medical Law and Ethics, Rosamund Scott	First UK Code of Practice for stem cell-based embryo models in research 4.7.2024	Mentions the importance the public having trust but not the dialogue directly
Brighton and Sussex Medical School	Pioneering Code of Practice released for use of stem cell-based embryo models in research 4.7.2024	No mention of public dialogue
London School of Economics Prof Emily Jackson	Journal of Law and the Biosciences , Regulating embryo models in the UK Vol 11, Issue 2, July 2024	References HDBI dialogue and its findings on SCBEMs and how this dialogue will add further understanding on publi attitudes
<b>Univ of Cambridge</b> Prof Sarah Franklin	Talking embryos: changing public perceptions of embryo research   The Royal Society May 9 <sup>th</sup> 2024	Lecture shares findings from HDBI dialogue and mention SCBEMs but not the dialogue specifically, 1,299 views



#### 2.3 The dialogue's influence on the Code of Practice

#### 2.3.1 How the dialogue findings fed into the drafting process

Careful planning and delivery of the dialogue report to the agreed schedule meant that by the time the <u>Code of Practice for SCBEMs</u> was published on 4<sup>th</sup> July 2024, the dialogue findings had permeated the wider conversation around drafting and helped inform the text itself via a number of routes:

- The Cambridge Reproduction and PET project managers were closely involved as contributing authors for the Code and were able to feed back to the drafting group on how the dialogue was progressing and the emerging hopes and concerns of participants.
- Half of G-SCBEM working group members were also involved in the public dialogue either as OG members or as specialists at workshops allowing them a direct route to hear participants hopes and concerns.
- An infographic prepared by the Cambridge Reproduction project manager summarised an early draft of the Code to share with participants. Participants found the format easy to understand and were able to make concrete suggestions about where they agreed, disagreed or thought gaps needed to be addressed. The same infographic was then shared alongside the full draft with 100+ stakeholder consultees (of whom about 55 shared comments). These insights came at a time when the working group was ready to hear different ideas, have their views on key issues challenged, and to discuss them with wider stakeholders. Comments from the dialogue participants fed into the Code alongside those from specialist stakeholders.

#### 2.3.2 How the dialogue findings are reflected in the Code

Through a combination of the above a G-SCBEM author noted that: "the dialogue was referred to in almost every G-SCBEM meeting...the results came at a time when the working group really needed input on some 'knotty issues.' We wouldn't have been able to take on so much if it had been any earlier." **Commissioner** 

This is also formally recognised in the text of the Code: "We are also indebted to the participants in the SCBEM public dialogue (see Appendix 4), who gave us feedback on a lay summary of an early draft of the Code. Their views were an important counterpart to those of the reviewers above, and have shaped both the form and the content of the final document." Code p16

Those involved in G-SCBEM's working group report that the dialogue has "informed the document in a very important way" and the findings are "quite deeply embedded in thinking" while also noting that a public dialogue can not give easy answers to a drafting process and also needs to be weighed with perspectives collected from other processes: "The dialogue report is long and nuanced, and the reflections captured cannot easily be directly imported into a Code of Practice. The report identifies areas of tension, where participants were split between two or more views. In other areas, the public participants expressed views that differed from other stakeholders that we have consulted, or they weighted key considerations very differently." I Commissioner blog.



The extent to which the dialogue has been taken into account by Code authors is evident in the introduction and the 7 footnotes (of a total 26) each referencing a specific section of the dialogue report. The dialogue is also described in Appendix 4, p24. *Figure 2.1* summarises how the dialogue's five headline recommendations are reflected in the text of specific sections and in the underlying principles. Contributing authors of the Code note that these and other insights were "definitely at the forefront of the group's thinking...and led to more rigorous thinking in some areas where the public's responses were different from [what the group] expected."

The ethics section (chapter 3 p7-9) was substantially rewritten and extended from a half to over two pages which highlight many of the participants' concerns about the links between SCBEMs and human embryos: this section references the dialogue report five times. Specifically, public dialogue participant's concerns are highlighted about: the balance between benefits of research and concerns related to human embryos; their support for time limits of some sort; and concerns about the models developing to the stage where they might feel pain or display recognisable features such as a spinal cord or heartbeat. Finally this chapter recognises the need to revise the Code as the science develops, as recommended by the participants (but already foreseen in early drafts of the Code).

Figure 2.1: Key dialogue findings and how they have informed the Code of Practice

Overall references to the importance of the public dialogue

- •Intro describes the Code as founded on principles of trust, transparency and accountability & overall public support for research using SCBEMs
- Annex 4 describes the dialogue
- •7 footnotes reference different sections of the report
- 1. More consideration needed on time or developmental limits for embryo model research
- Core Principles section does not set a single time limit but notes that researchers should be sensitive & provide clear justification for how long the model will be allowed to develop on a case-by-case basis
- 2. Recognising the Code value in filling the current governance gap, but that there may be a need to include some types of models in legislation in
- Ethics section recognises that if at any point embryo models become capable of developing into humans they should be treated as embryos and regulated as such
- Trust, transparency, accountability section echoes these concerns
- 3. Regular reviews of governance arrangements to keep pace with the progress of the research
- Recognises a need to keep the Code under review as the science develops
- 4. Public involvement in governance and awareness of the science will be key
- Dedicated **Oversight Committee** (OC) will review each proposed research project
- Public included as lay members on the OC
- and also recognises lay public as stakeholders with an interest
- 5. Describe clearly what the research is trying to achieve and benefit
- Aim to develop a website and a public register of research projects to increase transparency and public understanding



Where the final document embodies different choices from those recommended by the participants – most notably in not setting a single fixed term limit for how long embryo models can be used in research - the drafting team are confident that the arguments have been strengthened and the justification made more transparent as a result of bringing public voices into the process.

#### 2.4 Potential for influence on research practice and policy

#### 2.4.1 Dissemination of the Code of Practice

The Code was formally launched at a <u>Science Media Centre event on July 4<sup>th</sup></u> with presentations by four members of G-SCBEM drafting team – all of whom had been involved in the public dialogue. Despite coinciding with the day of the General Election, the launch and press release created opportunities for many of the authors and those with a policy interest to be quoted in the national and academic press (*Table 2.3*). The Code, blogs and quotes were also disseminated via wider academic networks, some of which mentioned the dialogue as well. Several academic articles and presentations also directly refer to the role of the public dialogue, but most simply note that public views were included alongside stakeholders.

Since July, G-SCBEM team members have also shared the Code and mentioned the role of the public dialogue with wider audiences such as through the Royal Society, International Society for Stem Cell Research ISSCR and Cambridge University professional development events. The Cambridge Reproduction team have plans to publicise the Code and the public dialogue more widely in late 2024.

Table 2.3: Press coverage of the Code of Practice and the role of public dialogue

Publication	Refence to public dialogue informing the Code of Practice
Science Media Centre	<u>Code of Practice launch</u> with presentations by Prof Roger Sturmey, Dr Peter Rugg-
Launch 4.7.2024	Gunn, Sandy Starr and Christina Rozeik presented and scientists response.
	"It adds to the Guidelines published by the International Society for Stem Cell
	Research in 2021, which include work with SCBEMs (although these are already a
	little out of date), but in a way that will mesh better with the UK's way of governing
	research on human embryology." Robin Lovell-Badge (lead author of ISSCR 2021
	guidelines)
Guardian	Work on synthetic human embryos to get code of practice in UK mentions issues
Ian Sample, 4.7.2024	from the public dialogue which have influenced the Code such as emotional
	responses to SCBEMs with heartbeats, spinal cords and other recognisable
	features and the need for researchers to be sensitive to these concerns but does
	not cite the public dialogue
BioWorld Medtech	UK experts offer new guidelines for stem cell-based embryo models.
Nuala Moran 5.7.2024	
Nature News,	<u>Lab-grown embryo models: UK unveils first ever rules to guide research</u> Corrections
Prof Roger Sturmey,	published on 10 July 2024 but, despite requests from the author, still does not
3.7.2024	include a link to the public dialogue report.
HFEA Website,	HFEA Statement: SCBEM Code of Practice Welcomes publication of the Code but
Peter Thompson 4.7.2024	makes no specific mention of the dialogue.
Medical Express	UK issues guidelines for use of stem cell-based embryo models in research
University of Cambridge	mentions the role of the public dialogue and includes quote from Christina Rozeik
3.7.2024	"A public dialogue enabled us to include public voices during the development of
	the Code, taking account of their hopes, concerns and sensitivities around research



	involving stem cell-based embryo models. Participants were excited by the potential of embryo model research, but also strongly supportive of oversight."
Cambridge Independent Article 12.7.2024	First UK Code of Practice for use of stem cell-based embryo models.
Clinical Laboratory Article	New Code of Practice for stem cell-based embryo models addresses ethical concerns.  "Importantly, the development process also included a public dialogue to explore public attitudes towards research involving embryo models."
Journal of Law and the Biosciences, Prof Emily Jackson 18.7.2024	Regulating embryo models in the UK, Volume 11, Issue 2, July-December 2024. References HDBI dialogue and its findings on SCBEMs and mentions this dialogue as ongoing.
<b>Book</b> Sarah Franklin and Emily Jackson, July 2024	<u>The 14 day rule and human embryo research</u> , mentions G-SCBEM work on the Code and the HDBI public dialogue.
Cambridge University Centre for Science and Policy (CsaP) Christina Rozeik	<u>Policy Workshop Case Study: Cambridge Reproduction</u> <u>describes the public dialogue and reports that "The findings from this dialogue will inform the final code of practice, resulting in more robust policy."</u>

#### 2.4.2 Potential Impact on UK researchers

#### **Increasing understanding of what the public thinks**

- Cambridge Reproduction recently submitted a report to funders BBSRC (September), highlighting the impacts of the dialogue on the research team and academia. This highlights how scientists involved in the public dialogue (via the Oversight Group and as specialists or observers) and G-SCBEM working group have been really heartened to hear how amazed participants are by the research and how supportive they are of its potential in general. Researchers were also interested and surprised to hear that participants do not automatically assume good faith on the part of all those involved in this type of research: but that they do tend to trust UK academic scientists, and that this may explained their acceptance of a voluntary approach to governance. These insights have given confidence to researchers, including post-doctoral scientists who presented their work at the Science Museum Late and Cambridge Festival in March that the public is interested in their work.
- G-SCBEM have also taken away lessons which will be valuable for their future public engagement: "The public dialogue has given us a way to explore these themes in a deeper, more nuanced way, and will be invaluable when we plan further public engagement around embryo models. By understanding public hopes, concerns and sensitivities better, we can design engagement that addresses these views more directly, that asks the right questions and that listens to the answers more closely."

#### **Commissioner Blog**

• Lessons have also been shared via a <u>Policy Workshop Case Study</u> prepared for the Centre for Science and Policy (CsaP) about their own policy workshops which contributed to the development of the Code. The Cambridge Reproduction project manager was then invited to share lessons on the process (including the public dialogue) at two CSaP professional development workshops organised for the Cambridge Stem Cell Institute and the Gurdon Institute respectively: in both cases the importance of dialogue and lessons learnt from the process were shared.



#### **Creating momentum to sign up to the Code**

- The Code has received very positive coverage in academic circles so far, mainly from institutions hosting individuals who participated in drafting the Code, but also from the wider UK and international stakeholders consulted during the drafting process.
- G-SCBEM's working group chair has committed his institution to applying the Code in future work: "I hope that the field will welcome the recommendations we will be introducing them into our programmes going forward." Hull York Medical School. The plan is to now get key research institutions and labs to make similar commitments.
- In the medium term the aim is for the Code to become an essential part of credible science, providing increased transparency and accountability for embryo model research. G-SCBEM now intends to disseminate the Code more widely and encourage UK researchers, funders, research organisations, professional societies and publishers to sign up to it.
- In early 2025 the team intends to submit a funding application to UKRI Medical Research Council (MRC) in order to put key building blocks for governance in place including an Oversight Committee with lay members, a website and public register of projects.

#### 2.4.3 Gaining wider support for the Code of Practice

G-SCBEM has also followed up opportunities to work with other organisations who are starting to think about embryo model research and governance to help set the context for those conversations and encourage them to support the Code to give it greater weight (see *Box 2.2)*.

#### Box 2.2: Other policy processes where the Code can help frame the conversation

- HFEA will be deciding on its future policy advice to government. There are no immediate plans
  for them to recommend extending the current Human Fertilisation and Embryology (HFE) Act
  to include embryo models, but their position may partly be informed by a major review on
  SCBEM's being undertaken by Nuffield Council on Bioethics (NCoB).
- The NCoB's team were involved with the public dialogue via the Oversight group: they heard
  participants' support for the recommended Code, but also concerns that some types of models
  might need to be included in a different sort of regulatory framework, depending how the
  science develops in the future.
- G-SCBEM have also had direct opportunities to feed into NCoB's process: Professors Niakan
  and Sturmey participated as expert witnesses; while Christina Rozeik (Cambridge Reproduction)
  and Sandy Starr (PET) shared their reflections on the Code and the dialogue at stakeholder
  workshops.
- The NCoB review leader has acknowledged the dialogue's role in their own process: "This [dialogue] report will help to inform our rapid review project to assess and advise on the ethical and regulatory issues raised by research in this area." NCoB LinkedIn
- The Chair of the NCoB working group endorsed this view: "We will consider this guidance and the proposals for oversight mechanisms in our review and hope to contribute independent and ethically robust recommendations to inform the wider governance of this research." Science Media centre expert reaction to the Code.
- The HFEA has also welcomed the Code approach. G-SCBEM hope that if HFEA endorse the Code this will increase its credibility and the extent to which UK researchers and funders follow the Code.



The messages from the dialogue are also expected to reach wider audiences including

- parliamentarians via the <u>Parliamentary Office of Science and Technology</u> report (see section 2.2.2); and
- **the wider public via events** such as those being organised by Naomi Moris (Francis Crick), Emily Jackson (London School of Economics) and creative consultancy The Liminal Space. These events are using wider public engagement techniques to showcase the latest research into embryo models and asking visitors what they think about the potential uses for this research and how it should be regulated. One such event was an exhibition on <a href="Embryo models: how stem cells reveal the mysteries of development">Embryo models: how stem cells reveal the mysteries of development</a> at the Royal Society <a href="Summer Science Exhibition">Summer Science Exhibition</a>, (July 2024). Other events are planned in the coming months.

#### 2.4.4 Influencing international approaches of governance of SCBEMs

- The <u>ISSCR</u> is also intending to expand on its <u>guidance</u> for the use of stem cells and embryo model research which it first developed in 2021. At its international conference in July 2024, Sandy Starr of PET presented at a session on <u>Identifying the ethical complexities and governance implications for embryo model research which covered the Code and the dialogue which informed it (see *Table 2.1*). The Code principles were well received by a mix of more than 60 international scientists and ethicists.</u>
- ISSCR has now set up its own <a href="Embryo Models Working Group">Embryo Models Working Group</a> comprising 12 international leaders with expertise in stem cell science, clinical applications, ethics, and regulatory affairs. The group is tasked with developing a White Paper on the governance of SCBEMs. Alongside US, Japanese, Chinese and European specialists, the group includes Peter Rugg-Gunn and Sarah Franklin who have both been involved in this or the previous HDBI dialogue.
- Elsewhere, most leading research countries have yet to undertake their own in-depth public engagement on the governance of embryo models. The exception is the Netherlands where <u>public opinions</u> are being sought on reform of the 14-day rule and the status of embryo models through less structured forms of public engagement such as public meetings and events. However, an ethicist involved in the Dutch process has taken back her reflections on being part of the G-SCBEM dialogue process. Reportedly she was impressed by depth of the deliberation and is interested to find opportunities for similar types of qualitative research in the Netherlands.

#### 2.4.5 Encouraging further public interest and support for embryo model research

- All of the public dialogue participants reported really enjoyed the workshops and high levels of satisfaction with having been part of the process. After the final workshop participants shared their feelings and how much they had valued being part of groundbreaking discussions in such a fast moving area of science. Their feelings are summarised in the word cloud below (Figure 2.2 and in Annex C).
- Many commented on what a privilege it had been to take part, and to be offered the chance to influence how embryo model research would be regulated in future. Typical views were how they had valued:

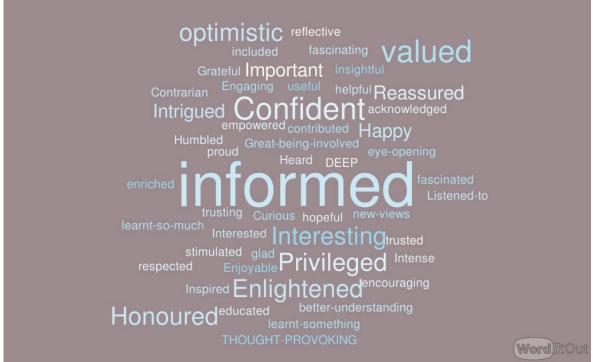
"Having the opportunity to learn about and discuss such a complex topic. Having the opportunity to contribute to development of a code of conduct for important research."



"The sense of how committed everyone is to doing the right thing, engaging the public and still progressing science."

• Most participants also relished the opportunity to continue being involved in a topic that they had come to find interesting and thought-provoking. By the end of the process the overwhelming majority of participants (32 out of 35 respondents) were keen to be kept updated and all received the final report: nearly two thirds (19) also hoped to be involved in any further stages of engagement. This pool of informed participants is a potential resource that G-SCBEM could reconvene in the future, for instance as a sounding board as the Code is rolled out, or as it comes up for review.







## 3. How the dialogue has met is objectives and lessons on contributing factors

#### 3.1 Overview

This section describes how the dialogue met its objectives and lessons on key success factors (described in more detail in Annex B). The commissioners took the opportunity to work with a team and set of participants who had been through a previous related dialogue. This allowed the dialogue to be delivered to a tight timescale and within a more limited budget than would otherwise be needed for a dialogue with nearly 40 participants. Despite these constraints the objectives were fully met, as summarised in Table 3.1. The key factors which contributed to success were: the accumulated experience in the core project management and delivery team; reconvening a group of participants with prior knowledge of how dialogue works and some familiarity with the topic; and working with a small but diverse group of specialists who were able to provide information across a broad range of scientific, ethical and legal perspectives in an engaging way. These factors allowed field work to be completed within an intense two-week period and for participants to grasp the wider societal issues and come up with clear recommendations about how they hoped to see embryo models governed (how stringently, which aspects and who should be involved) in the near future and longer term.

Table 3.1: How the d	lialogue has met its objectives
Objective	Factors that contributed to success
To understand public views on the value and potential risks of, research using embryo models	<ul> <li>All participants heard the same background information about the science and how it could be used via a mix of formats and were able to review before and after in their own time.</li> <li>Despite the complexity of the science the way information was presented was mainly pitched about right (in terms of quantity and detail) and was accessible (particularly the images of embryo models).</li> <li>Almost all felt well enough informed about the differences in types of models to identify the benefits and societal risks in some depth. A final session also helped generate some useful ideas on terminology for communicating concepts more widely. Almost all participants felt their prior experience on the HDBI dialogue helped them get up to speed quickly.</li> </ul>
To understand whether and/or how public participants expect embryo models to be regulated in future, including legal and governance structures	<ul> <li>Legal specialists and ethicists provided a very detailed grounding on current regulations and future options from voluntary to mandatory approaches. This gave them a sound basis for discussing the pros and cons of different approaches.</li> <li>ePolling during workshops (Menti) provided a snapshot of where the whole group stood on a spectrum of preferred approaches and confirmed a share desire for some regulation.</li> <li>An infographic summary of an early version of the Code shared in the final workshop gave participants something concrete to discuss. Most were supportive of the voluntary approach but many favoured a stepped approach culminating in statutory legislation if embryo models become too similar to human embryos and start to have recognisable features or the ability to experience pain. They were mindful of the HFE Act 14-day rule which they had discussed at length in the previous dialogue.</li> </ul>
Help make sure that public views are reflected in the Code of Practice being developed by Cambridge Reproduction for research using stem cell based embryo models	<ul> <li>Five key recommendations on governance emerged from the dialogue including: recognising the need for regular review; including some types of models in legislation in the future if necessary; involving the public in governance, increasing awareness of the science including what it is trying to achieve and its benefits; and having some type of time limits were all reflected in the final version of the Code (See <i>Figure 2.1</i>).</li> <li>As noted in Section 2.3.2 these points were largely recognised in the Code. The factors which enabled this to happen were: <ul> <li>The careful timetabling to allow each process to inform the other.</li> <li>Timely decisions made by a small but multi-disciplinary Oversight Group.</li> <li>The time commitments made by the commissioner project managers who were also contributing authors for the Code.</li> <li>The involvement of wider G-SCBEM group members as specialists at workshops so that they were able to take what they heard from participants back into the drafting process.</li> </ul> </li> </ul>



#### 3.2. Key factors which contributed to meeting the objectives

#### 3.2.1 Efficient and effective governance arrangements

- A small but representative oversight group (OG)- who included research scientists, legal, ethical, science history and policy perspectives as well as most having experience of deliberative processes. The OG was chaired by the Sciencewise DES: this was an unusual role for a Sciencewise-funded project where the DES is usually an independent advisor, but in this case worked very well. The DES was well acquainted with the issues (as a result of her work on the previous dialogue) but was able to take an objective position. The main benefit was that the group could be convened at short notice and make their inputs at the most useful points in the process. As a result the OG members were closely involved in framing the discussions, the design flow and generating ideas for stimulus materials. The OG were an important factor in being able to delivery a high quality process so rapidly.
- Use of an interactive mapping tool (Miro) for co-design sessions helped both OG and core group members to get a dynamic view of the overall design, how topics and issues should be threaded through the workshops and where the gaps were. The OG was able to suggest where more time was needed (e.g. to describe different types of models) which helped participants come to more nuanced views about the difference and similarity with classic human embryos and from other types of human tissues.
- **Deliberate overlaps between teams** including the roles of the Cambridge Reproduction and PET project managers who were also contributing authors, and individuals who had either sat on the previous dialogue Oversight Group or on G-SCBEM's working group. This provided continuity and provided a clear route for the participant's views to feed into the Code drafting (*see 2.3.1*).

#### 3.2.2 A diverse and inclusive mix of participants

All of the 36 participants had some prior knowledge of dialogue processes and familiarity with the embryo model topic which helped them get straight into the substance of the dialogue.

- The satisfaction participants had taken from the previous dialogue meant that 70 including those with strong religious views who were opposed to human embryo research wanted to be involved. Re-recruiting from the previous sample resulted in a group of 36-38 participants who together reflected national demographics<sup>2</sup> and a mix of relevant lived experiences including IVF, miscarriage, conditions that develop at the earliest stages of embryo development and attitudes to early human development research. Had the recruitment needed to start from scratch it would have been more time-consuming costly to get such a diverse and inclusive mix. As one participant noted: "The variety of age, gender and geographical range seemed to be very well selected for such an important subject to be discussed fairly."
- Participants' prior experience of the HDBI dialogue also had benefits in getting them up to speed much more quickly than would otherwise have been possible.

<sup>&</sup>lt;sup>2</sup> 19 Male, 18 Female, 1 non-binary; 6 Black British, 9 Asian British, 21 White British and 2 mixed ethnicity; and roughly equal numbers from age groups 18-29, 30s, 40s, 50s, with 4 from 60-70+.



Their familiarity with the process and online technologies (Zoom, Recollective and Menti) reduced the time needed for onboarding. They were also able to get comfortable in small groups and start working together more quickly, so reducing the need for introductory warm up sessions. Participants were also able to get up to speed and feel confident with the subject matter (see below). Participants reported that their prior experience helped in both process and content terms. As one put it: "I fully agree that being involved in the previous dialogue helped me deal with issues, questions that I had, and generally having the experience was helpful."

This view was also shared by the commissioners:

"Participants had already had occasion to reflect in depth on the science and ethics of research involving human embryos. This left them well-placed to consider whether, and in what respects, research involving SCBEMs should be regarded differently." **PET website**.

## 3.2.3 Efforts to ensure all participants felt comfortable and supported in a wholly online process paid off

- The design team built on lessons from the previous dialogue to ensure that participants felt comfortable. Because they had worked together before online most participants were happy for the dialogue to be wholly online, although a few also reported that they would have preferred to have met at least once face-to-face.
- The team built in proven emotional support options for those who found the
  topics upsetting. Provisions included taking time out, talking to an empathetic
  listener or contacting support organisations listed in the participant pack. It was
  possible to make cost savings for this dialogue based on lessons from the previous
  dialogue that a dedicated therapist on standby would not be needed by participants.
- All participants said they valued knowing support was there, even if they did not
  need it themselves. Perhaps because many of the emotional issues had already been
  surfaced, fewer seemed to find the topic upsetting this time. Indeed, two thirds of
  participants reported that they did not need any support. A typical view was that:
  "I didn't use it, but only because I felt I didn't need to. It was lovely to know that
  these [support measures] were in place though."
  - For the minority who needed support they reported that taking time out or talking to a member of the facilitation team was really helpful.
- Mixing small groups part way half-way helped achieve a balance between getting participants settled in and exposing them to a stimulating range of perspectives. Keeping in small groups where they recognised some faces for the first two weeks and then mixing up small groups for the later workshops worked well. Almost all participant reported that they felt comfortable and enjoyed hearing from a mix of people with different backgrounds and perspectives. Mixing the groups also helped to manage a few individuals who tended to dominate despite the best efforts of the facilitators. All but two participants enjoyed the mixing of groups. For most participants hearing a variety of other voices was a highlight of the process. A typical view was that "it was useful to get other points of view and have a different facilitator" and "It was also great that we all already felt more confident expressing our thoughts at that point."
- As a result all participants felt they had been treated equally and with respect.

  There was unanimous agreement amongst participants including those that had



strong religious views that they recognised were different from others in their group – that they had been treated respectfully and been able to make their voices heard. "I felt mine and other opinions, thoughts and suggestions were really valued."

#### 3.2.4 Prior experience of the HDBI dialogue helped inform the design and materials

The delivery team's experience of running a similar dialogue allowed them to design the process and develop appropriate stimulus materials quicker than would otherwise be possible. This was important since the timeline did not allow for piloting.

- The design team were able to transfer lessons about the amount and simplicity of information participants would need, and the formats and terminology which would make it accessible without overwhelming them. Materials on SCBEMs from the previous dialogue were shared as a primer, together with a jargon buster to explain unavoidable jargon before the first session. More detailed information was then shared by specialists in the workshops. Infographics (characterising the different types of models) and images (e.g. of embryo models researchers were working on) helped participants engage with the complexity and brought the topic alive. Most participants quickly grasped the important differences and similarities between embryo models and classic human embryos. Almost all participants found the information they heard covered the range of perspectives they wanted to hear: "The information was great considering there is so much to take in, grasp and then understand."
- A well designed and easily navigable share site (Recollective) proved invaluable in such a fast paced dialogue. Many participants highlighted how being able to review specialist presentations before or after workshops helped them feel confident about the material discussed in the workshops. For instance, an infographic of an early draft of the Code shared before the final workshop enabled participants to have much more concrete and detailed discussions on what they liked, disliked or felt was missing during their small group deliberations. Mostly participants found time spent on Recollective helped them feel well prepared for the next discussions.

"It was handy to revise on our previous discussions, there was always a lot of new information to reflect on."

"Some information I found hard to understand but being able to watch the videos back and have a document with jargon helped."

- Unsurprisingly given the intensity of the workshops schedule not all found it possible to keep abreast of new material shared between mid-week sessions: "Sometimes it was difficult to keep up with the tasks with the workshops being so close together and work commitments."
- Many participants highlighted how helpful it was to have some previous understanding of embryos and EHE research as they navigated the new topic.
   Mostly, participants felt sufficiently well informed without feeling overwhelmed.
   However, a few stressed that they would not have been able to keep up with such a fast-paced dialogue without some prior knowledge.
- "A really complex topic but I think the previous dialogue gave me a good foundation to build on my understanding for this one."



- "I was lost on a couple of occasions. However, I had a good foundation of understanding from previous talks to grasp. The small group sessions also helped to clarify."
- Occasionally their previous knowledge coloured participants' discussions in less helpful ways. The evaluator and some participants noted that many participants brought their previous thoughts on the 14-day rule to the SCBEM discussions: this sometimes proved a red herring since embryo models do not follow the exact timeframes, or necessarily involve the same steps or morphological markers as classic human embryos. While scientists emphasised that this made the 14-day rule less relevant, images shared of embryo models which appeared to show heart-beat like pulsing or a primitive streak, almost certainly contributed to discussions about the need for fixed term limits.

## 3.2.5 The team made minor adjustments during the process to ensure enough time for small group deliberations

- The timetable and budget for this project did not allow for piloting to test flow and timing but the team was able to adapt designs as timing issues became apparent after the first workshop. These included technical issues and specialist presentations over-running. Technical issues included poor Wi-Fi and glitches in moving participants into breakout rooms and short deadlines meant there was no time to review specialist presentations in advance so they tended to over-run.
- After workshop one practical contingencies were put in place in case of Wi-Fi problems (other facilitators briefed to step in as lead facilitator, to share stimulus materials or to move participants around, if needed) and to allow more time for deliberations. For instance, agendas for later workshops were fine-tuned by consolidating two comfort breaks into one, shortening specialist presentations/using panel discussions (which were easier for the lead facilitator to control) and extending the final workshop by 15 minutes. In the end the balance of time spent between sharing information and small group deliberations felt about right for the majority of participants: but a sizeable minority 10 out of 35 respondents still felt that they would have liked more discussion time. A typical comment was that "with such thought-provoking topics I felt I would have liked more time to speak and also for others to tell me and the group their thoughts."

## 3.2.6 The involvement of specialists including G-SCBEM working group members created a sense of trust in the process

• The timing of workshops immediately after Christmas only allowed a very narrow window for identifying, recruiting and briefing specialists. A whole-team effort resulted in a good mix of nine scientists, legal specialists and ethicists covering all the perspectives that the OG had identified as necessary. The deliberate overlap between the OG and wider G-SCBEM group which included all these perspectives made recruitment somewhat easier. However, as noted above, there was insufficient time to review specialist presentations: in one case this meant the presentation was too complicated and repeated some ground which had already been covered, perhaps confusing some participants.



- A novel approach of running an independently moderated expert panel sessions helped avoid overreliance on PowerPoint presentations. An eminent science journalist skilfully chaired a three-person panel made up of a scientist, an ethicist and a legal specialist. Carefully chosen questions worked really well to highlight different perspectives on key issues. Participants particularly enjoyed this format as a different and interesting way of hearing specialist views: "Really good blend of experts legal, ethicists and scientists loved the debate." Had there been a little more time, the session could easily have run for longer. Participants said that they would have welcomed hearing more in this format: "The panel discussion was really interesting and I think would have been more beneficial if longer and earlier on."
- Specialists also answered questions at short Q+A sessions in plenary and in small groups in a way that participants found helpful. Initially the plan had been for small groups to work together to frame priority questions to be asked in plenary. In the event most presentations overran and this element had to be cut. However as a reflection of how comfortable and confident they felt most participants were happy to ask questions via the chat function or in person. This allowed the lead facilitator to get a good number and range of questions answered: any that went unanswered were then addressed by specialists in small groups or picked up by the core team to be answered between sessions. By the end of the process almost all participants felt their questions had been answered. Many expressed their appreciation of how open specialists had been. This was an important element in building trust and may have contributed to largely positive attitudes to using embryo models in research. It was also gratifying for researchers to hear how interested participants were in their work (see Section 2.4.2).
  - "They all did a very great job and a big thank you to them! Especially answering all those questions that they had fired at them!"
  - "All my questions were answered and helped me understand and built trust that way."
- The Cambridge Reproduction team's close involvement through all the workshops and in sharing the Code helped demonstrate how committed they were to hearing from the public and using the findings. The coordinator's presentation on why the dialogue had been commissioned and how the team planned to use the findings contributed to a strong sense that the process was trustworthy. Participants appreciated the infographic summary of the draft Code and the resulting discussions elicited useful recommendations on what should and should not be permitted, and suggestions for who should be involved in research oversight committees. The visibility of the members of G-SCBEM also helped ensure that participants felt they were being listened to and resulted in a high level of confidence that their suggestions would be reflected in the final draft of the Code.

3.2.7 An experienced team of facilitators provided a sense of continuity and were able to capture participant's thoughts in ways that enriched the report

 An experienced small team (a lead facilitator and one table facilitator to each seven participants) was able to leverage its experience from the HDBI dialogue to get the most out of a wholly online process. The continuity in the team across both dialogues and between individual workshops was really important in allowing them to understand the complexity of the topic and to ask questions which got beneath the surface of what people said.



- The facilitation team created a warm and welcoming environment that helped overcome the early technical glitches. We observed that participants were more patient with technical issues than if they had been new to the process, and were confident enough to initiate conversations. Participants appeared very engaged and there was very little drop out between sessions. In one case participants initiated their own round of introductions and reflections when a facilitator was unexpectedly delayed.
- Small group discussions mostly felt natural so that those with different views felt comfortable expressing them. Participants were mostly confident to leave their cameras on during small group discussions. The visible notes that facilitators took on an interactive whiteboard (Jam Board) provided visual prompts to help participants build on each other's points and feel that their own points were being captured accurately. Several participants reported that they felt they have been able to raise different perspectives than those held by others in the group or raise points that others had not thought of.
- Participants unanimously reported back that they felt heard. Many commented in written feedback how much they felt valued, and that their opinions really mattered, even where they did not agree with others:
  - "As someone who isn't necessarily in favour of the research, I felt happy that I was being listened to and my thoughts were being written down."
- A variety of online tools were used to good effect to capture participant views in ways which added rich layers of data for analysis. In addition to transcripts of recorded group discussions and Jam Board, an online survey tool (Menti) was used to add variety to the ways in which participant views were captured. Menti proved popular with participants and was able to chart participant journeys and the mood of the room at key points in the process (e.g. providing a visual representation on where people sat on a spectrum from no regulation to stringent legislation).
- Exercises on Recollective also offered participants opportunities for individual reflection and to provide more structured thoughts in their own time. Many took this opportunity although about a third said they either did not have time or had nothing more to add.
- Sufficient time was allocated for coding and analysis of all these data sources
  and to allow the drafting team to stand back and develop a clear narrative for
  the whole report. The different layers of evidence added depth and nuance and
  contributed to a well-written report that put the participants' voices front and centre,
  while providing clear guidance to G-SCBEM's working group.



#### 4. Conclusions and Recommendations

#### 4.1 Conclusions

This was a successful fast-paced dialogue designed to feed directly into a policy drafting process being run by a large working group of academics. The success of the project within a tight timeline and budget was largely a result of the opportunity to re-convene the team and participants who had been involved in a previous related dialogue.

A wholly online process worked well to bring a mix of participants from across the country together over a fortnight. Time between meetings allowed them to reflect on what they had heard between meetings and for the delivery team to make minor adjustments to the process. Any potential downsides of an online process - such as needing extra time for the participants to get familiar with the technology, each other and speaking naturally in small groups - were mitigated by the participant's familiarity and comfort with the process, topics and the others involved. Working closely with a multi-disciplinary Oversight Group and policy drafting group enabled a faster than normal turn-around on workshop designs, materials and recruitment of specialists.

Publishing the dialogue report several months before the final version of the Code allowed key insights to feed in alongside comments from other stakeholders. Although the dialogue report itself did not attract much wider attention, the key messages are very much embedded in the Code, which has attracted both national and specialist press and social media coverage. The Code has been well received by academics in the UK and has the potential to have an impact as research institutes, funders and publishers are encouraged to sign up. In the next year G-SCBEM hope to move forwards with setting up governance arrangements and these will reflect some of the participant's recommendations on sharing information with the public and involving them in research decisions. There is also longer term potential to impact on international research practices and UK thinking on regulating embryo models as the science develops in the future.

#### 4.2 Recommendations for Sciencewise and commissioners

- Commissioning a follow-on process picking up on a topic partly covered in a larger dialogue can be a cost effective and efficient way of informing a policy process where time and resources are limited.
- A very intense online timetable can run the risk of high drop-out rates or participants feeling overwhelmed by the amount of information they are expected to take on. In this case their prior knowledge of the research area, their appreciation of the opportunity to inform policy, and familiarity with the delivery team and other participants helped to keep them engaged in the process. In normal circumstances it is preferable to spread online events over a longer elapsed time to allow participants more time to get to grips with such a complex topic.
- Where a process is focused on a specific policy drafting process, encourage those
  involved to participate in workshops as specialists or observers so that they can directly
  feed what they hear into the process and build trust in the process. Ensure they are well
  briefed and only make inputs at the invitation of the facilitators (where they can help
  clarify points or answer questions) in order to maintain the independence of the process.



- Commissioner presentations should always be counterbalanced with specialists able to provide a different perspective.
- For a pacy process, such as this, consider the benefits of keeping the oversight group small but diverse. The time savings in convening a group quickly, and getting their active engagement can outweigh the benefits of a larger group that represents all possible stakeholder viewpoints. In this case all key perspectives were covered by a carefully chosen small group. Any wider perspectives can be reflected in the process in other ways such as through specialist inputs and participant's lived experience.
- Consider whether the dialogue findings deserve to be shared more widely. If so, encourage all OG members to disseminate reports and findings through their networks.

#### 4.3 Recommendations for delivery contractors

- Build in opportunities for participants to experience the diversity of experiences and views within the group (e.g.by mixing up small groups between sessions, feedback in plenary, ePolling etc). This is particularly important for an online process where there are not the opportunities for informal social interactions offered by face-to-face workshops.
- Consider running a dedicated online share space alongside the workshops as a repository for workshop materials. Such a space could allow those who are interested and have time to contribute individual reflections to enrich the evidence for analysis.
- Consider varying the length of workshop sessions to suit the stage of the process. In this
  case starting with a shorter information giving sessions (an online webinar) and building
  up to longer workshops for deliberative and reflective stages worked really effectively.
   Since participants already had some knowledge of the research context less time was
  needed for warm-up introductions and top-of-the-head reflections.
- Consider the pros and cons of running a dedicated online share space alongside the workshops. In this case a share site proved valuable to participants for reviewing materials and feeling confident that they were keeping up. Those that had time also appreciated sharing individual views which added a further layer of evidence.
- Even where time is tight for developing stimulus materials, consider a mix of formats to keep participants engaged. In this case PowerPoints presentations were supplemented with unscripted reflections and an expertly moderated panel discussion. The latter worked particularly well to juxtapose the perspectives of a scientist, ethicist and legal specialist and was welcomed by participants as a novel and interesting way of hearing different perspectives.
- Aim for continuity in the facilitation team so that the team are as informed as the participants and are able to probe beneath the surface of what people say. However, consider mixing up groups during later workshop to add variety for participants.
- If the topic is likely to be emotionally upsetting, provide for emotional support options (such as opportunities for time out, talking to an empathetic listener or links to external support organisations) for those that need them.
- Use a mix of techniques during online meetings to capture participant views as a group (e.g. transcriptions, visible note taking on interactive whiteboards) or individually (e.g. chat box and eVoting).
  - Allow a realistic timeframe for analysis and report drafting: time spent getting the narrative and structure right at the outset can help streamline the process and avoid the frustration of multiple drafts.



## **Annex A: Oversight Group Members**

Name	Organisation
Suzannah Lansdell	Sciencewise, Chair
Subhadra Das	Historian and writer
Mina Mincheva	Science writer, European Society of Human
	Reproduction and Embryology
Nick Hopwood	Deputy Chair, Cambridge Reproduction
Roger Sturmey	Professor of Reproductive Medicine at the Hull York
	Medical
Steve Wilkinson	Professor of Bioethics, Lancaster University
Julian Hitchcock	Legal expert, independent/ Biolawgy (Life Science Law
	and Regulatory Consultancy)
Naomi Moris	Head of team, Francis Crick Institute
Anna Middleton	Genetic Counsellor, University of Cambridge
Ranveig Svenning Berg	Nuffield Council for Bioethics
Dina Halai	Head of science policy, HFEA
Sandy Starr	Progress Educational Trust
Christina Rozeik	Cambridge Reproduction

Specialist contributors to the dialogue via film or in person

Speakers:	Institution	Role in dialogue/ contribution
Peter Rugg- Gunn	Group Leader, Babraham Institute	Science of SCBEMs
Naomi Moris	Group Leader, Francis Crick Institute	Science of SCBEMs
Roger Sturmey	Professor of Reproductive Medicine, Hull York Medical School	Science of SCBEMs
Stephen Wilkinson	Professor of Bioethics, Lancaster University	Bioethics
Christina Rozeik	Coordinator of Cambridge Reproduction	Introduction to the dialogue and the Code of Conduct
Philip Ball	Science writer and previously editor at the journal Nature	Hosted a panel of specialist
Rosamund Scott	Professor of Medical Law and Ethics, Kings College London	Legal specialist
Kathy Liddell	Professor of Law, Cambridge University	Legal specialist
Nienke De Graeff	Asst Professor, Dept of Ethics & Law, Leiden University Medical Centre, Netherlands	Bioethics



Annex B: Summary of evaluation findings in relation to Sciencewise best practice principles

Best practice principles	How addressed in design and delivery	
Learning from practice throughout	Process design benefitted from experience of the team gained through the HDBI dialogue	<ul> <li>The contractor and half of the Advisory Group (AG) were able to draw on their previous experience from delivering the HDBI EHE dialogue: this allowed for the process design and materials to be developed to a tight timescale and budget. Members of the core team (Cambridge Reproduction and Progress Educational Trust) and AG were able to take a hands-on role in reviewing stimulus materials.</li> <li>A combination of the continuity of the delivery/Sciencewise/evaluation team, familiarity with some of the scientists, advance sharing of the sections of the HDBI report on what participants had said about embryo models and sharing of the short process video (that many of the participants featured in) all helped to create a sense of confidence and excitement in taking part.</li> <li>Participants unanimously agreed that having been involved in the previous dialogue had made it easier for them to discuss the issues around SCBEMs (28 strongly agreed, 7 tended to agree). However, a few pointed out that previous discussions may also have slightly muddied the waters by making them focus on the 14-day rule when this was much less relevant to embryo models.</li> </ul>
The purpose of the project was clearly explained	Explained in the webinar and reiterated in each of the workshops	<ul> <li>After the webinar the majority (32 out of 37 respondents strongly or tended to agree, 5 were neutral) felt they understood the objectives and why G-SCBEM working group was interested in their inputs and similar numbers (33 out of 37, 4 were neutral) felt confident that G-SCBEM group would take the findings in to account in the drafts of the Code of Practice. By the end of the third workshop confidence had grown marginally (32 out of 35 felt confident and 4 were neutral) and many commented that they really hoped to see their views taken into account.</li> <li>The visible presence of the Cambridge Reproduction team at all workshops, clear presentations, open reflections on what they had heard and how it might be used all helped to build high levels of trust and confidence in the process.</li> <li>One participant remarked that the enthusiasm of the G-SCBEM project manager made it highly likely that their views would be reflected in the Code. Only one participant felt sceptical, not about the regulation, but rather about the momentum behind the research: "Not really [confident how results will be used] - but I think there's always a part of bias in cases like this where a certain institute funds something, if the whole group was completely against the research, would the institute stop studying?</li> </ul>
Information shared with participants was pitched at the right level, covered a range	Participant packs sent out several weeks in advance described the objectives, context, and arrangements	<ul> <li>After the webinar almost all (31 out of 37) reported they had found it helpful in preparing them for the workshops - 5 were neutral and just one tended to disagree.</li> <li>Information about the underlying science built gradually from the participant pack (recapping on what had been discussed in the previous dialogue), and built from the webinar and through workshops 1 and 2 to explore different types of models, how they were made and how they might be used. Information on governance was initially introduced via the Code of Practice (webinar), with more detail on different types of governance approach and what they could deliver during workshop 2 and detailed discussion on the proposed Code of Practice in Workshop 3.</li> </ul>
of perspectives and gave them a shared understanding without overwhelming them	A dedicated share site (Recollective) enabled participants to preview some materials and review others (recorded presentations) before and after workshops.	<ul> <li>All participants reported finding the Recollective site useful for reviewing materials and preparing for the next session (of 35 respondents, 27 strongly and 8 tended to agree). Over the course of the workshops participants were expected to complete 14 activities (including evaluation) and despite the intense programme with little time between mid-week workshops almost all completed all tasks.</li> <li>Many participants particularly highlighted the usefulness of being able to review specialist presentations so that they felt confident they had grasped the complex science and governance issues: this helped them feel well prepared for the next discussions: scarcely anyone said they felt out of their depth or overwhelmed. Almost all also found it provided a useful space to continue conversations between the workshops (21 actually used it, about one third would have liked to but did not because they did not have time (5), or didn't feel they had a lot to add (8), just one was unsure.</li> </ul>



	Specialists (scientists, legal experts and ethicists) shared info via video, PowerPoint presentations and reflections (individually or as a panel). Participants mainly asked questions via chat box and they were answered in plenary.	<ul> <li>Almost all participants reported that specialists had shared information in a way that they found accessible (out of 35, 25 strongly agreed, 9 tended to agree) and hearing directly about groundbreaking science was often quoted as something they particularly valued about the process. Many enjoyed the videos and a graphic explaining the different stages/make-up and uses of different types of model.</li> <li>Participants mostly (32 out of 35) felt that they had managed to get their questions answered during plenary and panel Q+A sessions and overall felt satisfied with this. The plenary panel approach helped ensure that everyone heard the same answers before breaking into their small groups. A few participants highlighted this as an area where they would have appreciated a little more time for specialists to answer questions in small groups and/or a mechanism for sharing answers on Recollective.</li> <li>Most participants (31 out of 35 respondents) found the information shared with them covered the range of perspectives they wanted to hear - including science, ethics and legal perspectives and diverse views from the other participants. A few participants pointed out that although it was really interesting to hear about the science in detail, they did not necessarily need this volume of information in order to contribute on the governance arrangements.</li> </ul>
There was enough time overall for deliberative discussions	The design gradually built from mainly sharing new info in the webinar, to mainly small group deliberations by workshop 3.	<ul> <li>About two thirds (21 out of 35 respondents) felt the balance between hearing from specialists and time spent deliberating in their small groups was about right, but a sizeable minority (10 out of 35) felt discussion time was too short (particularly for workshops 1 and 2): only 1 felt it was too long.</li> <li>Participants had a number of constructive suggestions for how this could be addressed for similarly dense and complex topics, ranging from more time overall (several reported feeling the longer workshop (3) was better paced), to more reflection time between sessions, to a shift in balance from time spent learning new information from specialists in favour of more time spent discussing it in small groups.</li> <li>Recollective proved really important in such a pacy dialogue – participants found it invaluable for previewing/reviewing materials and for more considered individual deliberation between sessions</li> </ul>
Independent, professional, effective facilitation	A small team of a lead facilitator and 4 additional table facilitators provided complete continuity between sessions. All brought prior experience in early human research from the HDBI dialogue. Small groups stayed together for the first two workshops and were mixed up for the final session.	<ul> <li>Participants unanimously agreed (mostly strongly agreed) that the facilitation team was professional and effective. The lead facilitator created a warm, friendly and welcoming atmosphere as participants joined while checking their audio and cameras worked.</li> <li>We observed that all facilitators were well briefed and understood the topic well enough to probe what underlay participant's views, without being tempted to try and answer technical questions.</li> <li>Participants reported that they felt they had been heard and many commented in written feedback how much they felt valued, and that their opinions really mattered.</li> <li>The decision to mix up small groups for the final workshop paid-off: almost all participants reported that they had enjoyed hearing different voices and opinions (31 out of 35 agreed). Two individuals reported that they had felt more at ease in their original groups because of some strong characters who tried to dominate discussions.</li> </ul>
Inclusive process, all voices heard and participants felt valued and supported	The team had made provisions to support any participants that might find the topics emotionally upsetting.	<ul> <li>Good mix from all four groups in the previous dialogue (north, south, lived experience and pilot) and participants enjoyed reconnecting with familiar faces and also meeting those from diverse backgrounds. A handful commented on the diversity and mix as a particular strength of the design.</li> <li>Almost all (31 out of 35) appreciated knowing that there was support available if they found the topics discussed were emotionally upsetting and while most did not need to use it some did: 13 took a breather, 5 talked to the facilitation team and 2 contacted organisations listed in the participant pack.</li> <li>As a result of the participants prior experience (see above), a well-crafted design, supportive environment and space created to share their views almost all participants felt they had been able to make a useful contribution to the discussions about future governance of SCBEMS (33 out of 35 positive, 2 neutral).</li> <li>Several told us that despite the complexity of the science they still felt they had been able to make useful inputs on the draft Code of Practice, even if they did not understand all the niceties of the different models.</li> </ul>



<b>Participants</b>
views captured
and shared with
them

A mix of approaches to capturing participants' views including recorded transcripts, visible note taking (e.g. Jam board), online survey tool (Menti) and Recollective.

- The richness of the discussions was captured from recordings and facilitator note-taking on Jam board so that participants could check how their points were recorded and build on each other's. Jam board notes were the basis for sharing initial findings with the OG: coded manuscripts (using NVivo) and data collected on Recollective were used for the detailed analysis.
- Menti.com was used to good effect throughout the workshops to break the ice, demonstrate where participants were joining
  from, and give a shared view of the range of views in the room.
- The team took a flexible approach to questions asked: the initial idea of repeating a questions on preferred approaches to governance mid-way through and at the end of the process to evidence the participants' journeys was dropped as it became apparent that views had become more nuanced with many now talking about a stepped approach from voluntary guidance (the Code) to statutory legislation if embryo models become too similar to human embryos.



### **Annex C: Feedback from participants after workshops 1 and 3**

1	I understand why the Stem Cell based embryo	Strongly agree	Tend to	Neither	Tend to disagree	Strongly	disagree
	model governance (G-SCBEM) is carrying out this	24	agree	5	0		
	dialogue	21 56.8%	11 29.7%	5 13.5%	U	0	
2	I feel confident that the findings will be used to	Strongly agree	Tend to	Neither	Tend to disagree	Strongly d	isagree
	inform the SCBEM Code of Conduct	22	agree 11	4	0	0	
		59.5%	29.7%	10.8%	U	0	
3	I found the participant pack helpful in preparing me for the workshops	Strongly agree	Tend to agree	Neither	Tend to disagree	Strongly d	isagree
	me for the workshops	23	8	5	0	0	
	11 2 25	63.9%	22.2%	13.8%			
	orkshop 3 – 35 responses via SurveyMonkey	Strongly agree	Tend to agree	Neither	Tend to disagree	Strongly disagree	Don't kno
1	I found the Recollective site a useful way of reviewing what we had heard and preparing for	27	8	0	0	0	0
	the next session.	77.1%	22.8%				
	<ul> <li>It was handy to revise on our previous discussions,</li> <li>It was really useful for refreshing my memory before</li> <li>It was easy to access and use</li> <li>Timelines were a bit short to fit in.</li> <li>Excellent opportunity to voice my views and also list</li> </ul>	e new sessions.					
	<ul> <li>It was really useful for refreshing my memory before</li> <li>It was easy to access and use</li> <li>Timelines were a bit short to fit in.</li> <li>Excellent opportunity to voice my views and also lis</li> <li>It was generally excellent as it has everything it was would preferred the link to be available from recolle</li> <li>Good to get some understanding before the session</li> <li>Sometimes it was difficult to keep up with the tasks</li> </ul>	e new sessions.  ten to others as well in one place but some re ective n with the workshops be	a a nice, controlled enviro eason I couldn't access vi	nment deos/documents once l	had submitted the tas	k which was frustr	ating. Also
	<ul> <li>It was really useful for refreshing my memory before It was easy to access and use</li> <li>Timelines were a bit short to fit in.</li> <li>Excellent opportunity to voice my views and also lise It was generally excellent as it has everything it was would preferred the link to be available from recolled.</li> <li>Good to get some understanding before the session.</li> <li>Sometimes it was difficult to keep up with the tasks.</li> <li>Yes, very helpful and you could do it at your own performance.</li> </ul>	e new sessions.  ten to others as well in one place but some rective n with the workshops becace.	e a nice, controlled enviro eason I couldn't access vi eing so close together ar	nment deos/documents once l ad work commitments			ating. Also
2	<ul> <li>It was really useful for refreshing my memory before It was easy to access and use</li> <li>Timelines were a bit short to fit in.</li> <li>Excellent opportunity to voice my views and also lise It was generally excellent as it has everything it was would preferred the link to be available from recolled.</li> <li>Good to get some understanding before the session.</li> <li>Sometimes it was difficult to keep up with the tasks.</li> <li>Yes, very helpful and you could do it at your own pass.</li> <li>Absolutely, it helps extremely as the sessions are very service.</li> </ul>	e new sessions.  ten to others as well in one place but some rective n with the workshops becace.	e a nice, controlled enviro eason I couldn't access vi eing so close together ar	nment deos/documents once l ad work commitments			J
2	<ul> <li>It was really useful for refreshing my memory before It was easy to access and use</li> <li>Timelines were a bit short to fit in.</li> <li>Excellent opportunity to voice my views and also lise It was generally excellent as it has everything it was would preferred the link to be available from recolled.</li> <li>Good to get some understanding before the session.</li> <li>Sometimes it was difficult to keep up with the tasks.</li> <li>Yes, very helpful and you could do it at your own performance.</li> </ul>	e new sessions.  ten to others as well in one place but some rective n with the workshops be ace.  ery long, it gives you cl	a a nice, controlled enviro eason I couldn't access vi eing so close together ar hance to comeback with	nment deos/documents once l od work commitments clearer head and think a	ngain in different persp	ective	Don't kno



- I found all the presentations really interesting and accessible the format/slides were helpful and I could quite easily sit and watch some of the presentations again.
- They did a great job, but more time for each of them for Q&A would have helped clarify things quickly.
- Fantastic and very interesting.
- Very clear and precise and made it obvious where the information was.
- Really good blend of experts legal, ethicists and scientists loved the debate
- [yes but] I was lost on a couple of occasions. However, had a good foundation of understanding from previous talks to grasp. The small group sessions also helped to clarify.
- Yes they were all great, but especially the lady from Holland, but I can't remember her name {Nienke}.
- One kinda went round in circle I found, not answering certain questions in a very straightforward way and seemed biased.
- They all did a very great job and a big thank you to them! Especially answering all those questions that they had fired at them!

3	Being involved in the previous dialogue has made it	Strongly agree	Tend to agree	Neither	Tend to disagree	Strongly disagree	Don't know
	easier for me to discuss the issues around SCBEMs	28	7	0	0	0	0
		80%	20%				

#### Comments:

- Having the context and intentions for the research helped me to understand the whey and what for.
- I have an understanding of the significance of both studies now.
- More confident than I was previously, but I still find it a very difficult topic to understand.
- I feel a lot of the information I learned previously was good to know to discuss embryo models and have a better understanding.
- Really complex topic but I think the previous dialogue gave me a good foundation to build on my understanding for this one.
- It was crucial to have participated in the previous group. It helped me a lot to see things more clearly. Looking at all from a more scientific perspective, that is the most important for advances in many areas.
- Definitely, would've been hard to start from zero, even finding the motivation to research online would've been nigh-on impossible without the previous dialogue.
- I can certainly now understand the difference on a subject I knew nothing of before. Very interesting.
- I fully agree that being involved in the previous dialogue helped me deal with issues, questions that I had and generally having the experience was helpful.
- I think it might have confused some people as they were comparing both sessions, it might have been helpful to clarify at the beginning of second round that it had nothing to do with the fourteen day rule.
- 100% as the embryo itself topic is very heavy and not easy; without previous knowledge I would have had different thoughts to this.

4	The information shared with us covered the range	Strongly agree	Tend to agree	Neither	Tend to disagree	Strongly disagree	Don't know
	of perspectives I wanted to hear.	23	8	3	1	0	0
	or perspectives a manneal to means	65.7%	22.8%	8.5%	2.9%		

#### **Comments:**

- I never felt misguided at any point, and all my questions were answered.
- Not quite sure how I would have liked it different.
- Personally, I would like to see/know more about other areas of research. Not only/mainly about IVFs.
- We didn't really touch very much on the nature of consciousness (although that is a hard topic!)
- Interested to hear what the future could provide.
- Yes again the information was great considering there is so much to take in, grasp and then understand.
- Missing psychologist viewpoint and it felt like everyone was in favour of the project rather than a balanced panel.



Specialists were able to answer our questions	Strongly agree	Tend to agree	Neither	Tend to disagree	Strongly disagree	Don't k					
satisfactorily (e.g. via panels, Q+A sessions and	24	8	2	0	1						
small groups)	68.5%	22.8%	5.7%		2.9%						
Comments:											
May have helped if Specialists had spoken up more in the [small] groups.											
They knew their field so gave answers that supported their work.											
I think they did a great job; I think there was j	ust too many questions	to be answered so still so	much to hear about.								
I feel there was a lot to answer and sometime	s questions got missed.										
Everyone gave helpful and considered answer	s and were very patient	as we all improved our u	nderstanding of the topic.								
It would be great if we could have a final doc	ument with many of the	questions that were imp	ossible to answer in the sess	sions. Many of those q	uestions were recu	rrent di					
the workshops.											
Yes, but there wasn't enough time though. I was a second to the second time though.	ould have loved more t	ime and opportunity on	this.								
Absolutely brilliant especially Peter!											
Not all questions were answered in the chat of	lue to time.										
Very well presented.											
All my questions were answered and helped me understand and built trust that way.											
The panel discussion with Philip hosting was a			re beneficial if longer and e	earlier on.							
Of course there was a time limit but I believe											
The amount of time available for discussions i	n About right	Too short	Too long	Not sure							
small groups vs hearing from specialists felt	23	10	1	1							
small groups vs hearing from specialists felt	23										
small groups vs hearing from specialists felt	65.7%	28.5%	2.9%	2.9%							
Comments:	65.7%	28.5%	-	2.9%							
Comments:  • The last small group discussion seemed that	65.7% the questions were very	28.5%	-	2.9%							
Comments:  • The last small group discussion seemed that • Initially it was too short but the last couple of	65.7%  the questions were very f workshops were fine.	28.5% similar and so was too lo	ong.	2.9%							
Comments:  • The last small group discussion seemed that • Initially it was too short but the last couple of • Very complex issues and lots of points trying	the questions were very f workshops were fine. to be covered – not end	28.5%  similar and so was too loo	ong. ssions								
Comments:  The last small group discussion seemed that Initially it was too short but the last couple of Very complex issues and lots of points trying I did feel I had some points to raise but some	the questions were very f workshops were fine. to be covered – not end etimes there wasn't enough	28.5%  similar and so was too loog time given to discurd time for the moderate	ong. ssions		answers lol.						
Comments:  • The last small group discussion seemed that • Initially it was too short but the last couple of • Very complex issues and lots of points trying	the questions were very f workshops were fine. to be covered – not end etimes there wasn't enough	28.5%  similar and so was too loog time given to discurd time for the moderate	ong. ssions		answers lol.						
Comments:  The last small group discussion seemed that Initially it was too short but the last couple of Very complex issues and lots of points trying I did feel I had some points to raise but some	the questions were very f workshops were fine. to be covered – not end etimes there wasn't enough to would often run out of	28.5%  similar and so was too looping time given to discurred time for the moderate fitime.	ong. ssions or to go round the group, s	some people had long		s for lor					
Comments:  • The last small group discussion seemed that • Initially it was too short but the last couple of • Very complex issues and lots of points trying • I did feel I had some points to raise but som • The small group time felt too short, my group • Only because I think it can be difficult for every quite easily.	the questions were very f workshops were fine. to be covered – not end etimes there wasn't enough to would often run out of	28.5%  similar and so was too looping time given to discurred time for the moderate fitime.	ong. ssions or to go round the group, s	some people had long		s for lo					
Comments:  • The last small group discussion seemed that • Initially it was too short but the last couple of • Very complex issues and lots of points trying • I did feel I had some points to raise but som • The small group time felt too short, my grou • Only because I think it can be difficult for every quite easily. • For the small groups. Short for Q&A with the	the questions were very f workshops were fine. to be covered – not end of the times there wasn't enough would often run out or enyone to get an opported specialists.	28.5%  similar and so was too loogh time given to discurd time for the moderate firme.  unity to say something of	ong. ssions or to go round the group, s	some people had long		s for loi					
Comments:  The last small group discussion seemed that Initially it was too short but the last couple of Very complex issues and lots of points trying I did feel I had some points to raise but some The small group time felt too short, my groud Only because I think it can be difficult for every quite easily.  For the small groups. Short for Q&A with the	the questions were very f workshops were fine. to be covered – not end of the times there wasn't enough would often run out or enyone to get an opportunity specialists.	28.5%  similar and so was too loogh time given to discurd time for the moderate of time.  unity to say something of 1:1 sessions.	ong. ssions or to go round the group, s n each topic and also becau	some people had long use I could talk about s		s for lo					
Comments:  The last small group discussion seemed that Initially it was too short but the last couple of Very complex issues and lots of points trying I did feel I had some points to raise but some The small group time felt too short, my groud Only because I think it can be difficult for every quite easily.  For the small groups. Short for Q&A with the Think more small groups But moreover the With such thought provoking topics I felt I we	the questions were very f workshops were fine. to be covered – not end of the times there wasn't enough would often run out or enyone to get an opported specialists.	similar and so was too loo ough time given to discu- ugh time for the moderate of time. unity to say something of 1:1 sessions. the to speak and also for	ong. ssions or to go round the group, s n each topic and also becau	some people had long use I could talk about s		s for loi					
Comments:  The last small group discussion seemed that Initially it was too short but the last couple of Very complex issues and lots of points trying I did feel I had some points to raise but some The small group time felt too short, my groud Only because I think it can be difficult for every quite easily.  For the small groups. Short for Q&A with the Think more small groups But moreover the With such thought provoking topics I felt I was	the questions were very f workshops were fine. to be covered – not end of the times there wasn't enough would often run out or enyone to get an opported specialists. The should ve been some tould have liked more time out and we ran out of the times.	similar and so was too leading time given to discurrently time for the moderate fitime.  Inity to say something of the sessions.  The to speak and also for the moderate for the moderate fitime.	ong. ssions or to go round the group, s n each topic and also becau others to tell me and the gr	some people had long use I could talk about s oup their thoughts.	ome of the subject						
Comments:  The last small group discussion seemed that Initially it was too short but the last couple of Very complex issues and lots of points trying I did feel I had some points to raise but some The small group time felt too short, my groud Only because I think it can be difficult for every quite easily.  For the small groups. Short for Q&A with the Think more small groups But moreover the With such thought provoking topics I felt I we I felt the small groups discussion were too si	the questions were very f workshops were fine. to be covered – not end extimes there wasn't enough would often run out on anyone to get an opported specialists. The should ve been some could have liked more time ort and we ran out of time to get my head around the special speci	similar and so was too leading time given to discurd time for the moderate of time.  Inity to say something of the to speak and also for the amount of information of the amount of information in the similar to see the speak and also for the speak amount of information in the similar to see the speak and also for the see the speak amount of information in the see the speak amount of information in the see the see that	ong. ssions or to go round the group, s n each topic and also becau others to tell me and the gr	some people had long use I could talk about s oup their thoughts.	ome of the subject						



7	It was useful to be able to continue our	Agree and used it	Agree but didn't use it because I was too busy	Agree but didn't use it because I had nothing to add	Disagree	Not sure								
	conversations on Recollective between workshops	21	5	8	0	1								
		60%	14.3%	22.9%		2.9%								
	Comments:			•										
	Gave me more time to collect my thoughts from the sessions, before giving feedback and questions.													
	I did put some points in this part.													
	• I think it is useful, but it's not my preference for discussing topics like this - I prefer live discussion													
	Didn't really have time to fully.													
	Allowed time to read and understand in slow time.													
	Yes because as a question came into your head, you	could get your thoug	ghts down right away.											
	Keeping it fresh and pushing us to dig deeper into w.		, , ,											
	<ul> <li>Reeping it tresh and pushing us to dig deeper into what we thought.</li> <li>I didn't use recollective in such a way as I have managed to ask and put an input in live sessions but it has really helped to find out more and gain more ideas.</li> </ul>													
8	The facilitation has been professional and	Strongly agree	Tend to agree	Neither	Tend to disagree	Strongly disagree	Don't know							
	effective.	32	2											
		94.1%	5.9%											
	Comments:													
	<ul> <li>Very professional and supportive.</li> </ul>													
	<ul> <li>Overall it was extremely well organised.</li> </ul>													
	<ul> <li>Very smoothly done.</li> </ul>													
	<ul> <li>Very professional in all ways possible.</li> </ul>													
	Definitely.													
l .	Excellent all around.													
1														
		des.			I would like to thank the professional way the whole process was run.									
	Very good presentation and knowledge from all side													
	<ul> <li>Very good presentation and knowledge from all side</li> <li>I would like to thank the professional way the whole</li> </ul>													
	<ul> <li>Very good presentation and knowledge from all side</li> <li>I would like to thank the professional way the whole</li> </ul>													
	<ul> <li>Very good presentation and knowledge from all side.</li> <li>I would like to thank the professional way the whole.</li> <li>Really good.</li> <li>They have been all excellent Thank you to them!</li> </ul>		Tend to agree	Neither	Tend to disagree	Strongly disagree	Don't know							
9	<ul> <li>Very good presentation and knowledge from all side</li> <li>I would like to thank the professional way the whole</li> <li>Really good.</li> </ul>	e process was run.	Tend to agree 8	Neither 0	Tend to disagree 0	Strongly disagree	Don't know							
9	<ul> <li>Very good presentation and knowledge from all side.</li> <li>I would like to thank the professional way the whole.</li> <li>Really good.</li> <li>They have been all excellent Thank you to them!</li> </ul>	e process was run.  Strongly agree												
9	<ul> <li>Very good presentation and knowledge from all side.</li> <li>I would like to thank the professional way the whole.</li> <li>Really good.</li> <li>They have been all excellent Thank you to them!</li> </ul>	Strongly agree 27	8											
9	<ul> <li>Very good presentation and knowledge from all side.</li> <li>I would like to thank the professional way the whole.</li> <li>Really good.</li> <li>They have been all excellent Thank you to them!</li> </ul> I felt I was able to make my voice heard	Strongly agree 27	8											
9	<ul> <li>Very good presentation and knowledge from all side.</li> <li>I would like to thank the professional way the whole.</li> <li>Really good.</li> <li>They have been all excellent Thank you to them!</li> <li>I felt I was able to make my voice heard</li> </ul> Comments:	Strongly agree 27	8											
9	<ul> <li>Very good presentation and knowledge from all side.</li> <li>I would like to thank the professional way the whole.</li> <li>Really good.</li> <li>They have been all excellent Thank you to them!</li> <li>I felt I was able to make my voice heard</li> <li>Comments:</li> <li>The facilitators were very encouraging.</li> </ul>	Strongly agree 27 77.1%	8											
9	<ul> <li>Very good presentation and knowledge from all side.</li> <li>I would like to thank the professional way the whole.</li> <li>Really good.</li> <li>They have been all excellent Thank you to them!</li> <li>I felt I was able to make my voice heard</li> <li>Comments:         <ul> <li>The facilitators were very encouraging.</li> <li>Perhaps I pushed in too much!</li> </ul> </li> </ul>	Strongly agree 27 77.1%	8 22.9%											
9	<ul> <li>Very good presentation and knowledge from all side.</li> <li>I would like to thank the professional way the whole.</li> <li>Really good.</li> <li>They have been all excellent Thank you to them!</li> <li>I felt I was able to make my voice heard</li> <li>Comments:         <ul> <li>The facilitators were very encouraging.</li> <li>Perhaps I pushed in too much!</li> <li>Sometimes there was too many people trying to tall Big group and not sure anyone would want to heal</li> </ul> </li> </ul>	Strongly agree 27 77.1%	8 22.9%											
9	<ul> <li>Very good presentation and knowledge from all side.</li> <li>I would like to thank the professional way the whole.</li> <li>Really good.</li> <li>They have been all excellent Thank you to them!</li> <li>I felt I was able to make my voice heard</li> <li>Comments:         <ul> <li>The facilitators were very encouraging.</li> <li>Perhaps I pushed in too much!</li> <li>Sometimes there was too many people trying to tall big group and not sure anyone would want to hear</li> </ul> </li> </ul>	Strongly agree 27 77.1%	8 22.9% views in any case :)											



10	I found it helpful to know that support was	Strongly agree	Tend to agree	Neither	Tend to disagree	Strongly disagree	Don't kno			
	available if I found the topics we discussed	26	5	4						
	emotionally upsetting	74.3%	14.3%	11.4%						
	Comments:						•			
	<ul> <li>Yes that was reassuring.</li> </ul>									
	I didn't find the topic emotionally upsetting.									
	Good to have the support available but the topic di	id not impact on me e	motionally in any negat	tive wav.						
	<ul> <li>Not needed by me.</li> <li>100% but it was not needed.</li> </ul>									
	I didn't feel at all uncomfortable during the session.  This is a session.	5.								
	I didn't feel any need to use these extra options.									
	I didn't use, but only because I felt I didn't need to.	it was lovely to know	that these were in place	e though.						
		Taking a breather	Talking to one of the	Contacting an organisation	None of the above					
11	I made use of the following (NB may sum to more		facilitation team	listed in the participant pack						
11	I made use of the following (NB may sum to more than 100 because some may have used more than	during the sessions	idelitation team							
11	than 100 because some may have used more than	13	5	2	21					
1		13 37.4%	5 14.3%	2 5.7%	60%					
	than 100 because some may have used more than	13 37.4% Strongly agree	5	2 5.7% Neither	= -	Strongly disagree	Don't knov			
11	than 100 because some may have used more than 1 form of support)	13 37.4%	5 14.3%		60%	Strongly disagree  1 2.9%	Don't kno			

#### Most that commented really appreciated hearing different views when small groups were mixed:

- Please do this more.
- VERY HELPFUL TO HEAR DIFFERENT VIEWS
- It was easier to chat in smaller groups, more different points of view could be discussed.
- I was with a lot of the same people
- I was surprised that the majority of views so in line with each other I would have expected more stark differences in opinion. For example, the majority agreed this research is needed, no one objected on moral/religious grounds.
- Agree. It was also great that we all already felt more confident expressing our thoughts at that point.
- Great to hear opinions that I definitely didn't agree with!
- It was useful to get other points of view and have a different facilitator.
- This was valuable to hear other than rolled opinions and thoughts. Things that hadn't necessarily thought of before.
- I agree working in small groups helped me focus to the job in hand.
- It switches some lights I didn't know were there and helped me view things differently.
- It was a lovely debate in the last group which was absolutely great.

#### Two would have liked to stay with their original groups, one explained why:

I didn't like the group change and felt I could voice my opinions more in my initial group. I found things got heated and one member of the group had strong conspiracy theories and tried to manipulate the rest of the group with non-factual information.



13	I feel I have been able to make a useful	Strongly agree	Tend to agree	Neither	Tend to disagree	Strongly disagree	Don't know					
	contribution to discussions about future	23	10	2	0	0	0					
	governance of SCBEMs	65.7%	28.6%	5.7%								
	Comments:											
	I found it very interesting and wanted to help.											
	<ul> <li>I trust that the views will be taken into considerat</li> </ul>	rion.										
	I contributed, I'm not sure at this point how useful	ıl it will be!										
	I hope so.											
	I feel I have made some points which others hadr	n't thought of.										
	I have found the whole involvement highly interest.	sting and enjoyable										
	As someone who isn't necessarily in favour of the			ened to and my thoughts	were being written down.							
14	I feel confident that the findings will be used to	Strongly agree	Tend to agree	Neither	Tend to disagree	Strongly disagree	Don't know					
	inform the SCBEM Code of Conduct	25	7	2	0	1						
		71.4%	20%	5.7%		2.9%						
	Comments:											
	Would be great to see the results of this.											
	Ihope so.											
	I felt mine and other opinions, thoughts and sugg											
	I was more confident in the end because of all the				_							
	confident with it. SCBEM will need to be as open a		The second secon	-	ral public to be sent to ther	n and support dive	rsity as there					
	is in the general public. They may receive questions from many religions and interested groups.											
		It felt good to know my opinion would make a difference										
	It felt good to know my opinion would make a dia											
			gestions									
	It felt good to know my opinion would make a dia	h my thoughts/ sugg		. I felt more trusting in tl	he end than I did at the beg	inning. I think whe	n you don't					
	<ul><li> It felt good to know my opinion would make a di</li><li> Gaining an understanding and feeling valued with</li></ul>	h my thoughts/ sug have a bearing on v		. I felt more trusting in th	he end than I did at the beg	iinning. I think whe	n you don't					
	<ul> <li>It felt good to know my opinion would make a di</li> <li>Gaining an understanding and feeling valued with</li> <li>Being able to talk about what was proposed and a</li> </ul>	h my thoughts/ sug have a bearing on v irst.	vhere it goes from here	_	he end than I did at the beg	iinning. I think whe	n you don't					
	<ul> <li>It felt good to know my opinion would make a difference of the Gaining an understanding and feeling valued with</li> <li>Being able to talk about what was proposed and understand something you are very sceptical at fit</li> </ul>	h my thoughts/ sugg have a bearing on v irst. ists and used toward	where it goes from here	of practice	he end than I did at the beg	inning. I think whe	n you don't					
	<ul> <li>It felt good to know my opinion would make a difference of Gaining an understanding and feeling valued with</li> <li>Being able to talk about what was proposed and understand something you are very sceptical at fit</li> <li>Knowing that out views will be fed back to scientified</li> </ul>	h my thoughts/ sugg have a bearing on v irst. ists and used toward perspective and able	where it goes from here ads writing of the code co to put my own input i	of practice into very hopeful future.		iinning. I think whe	n you don't					
15	<ul> <li>It felt good to know my opinion would make a different palent</li> <li>Gaining an understanding and feeling valued with</li> <li>Being able to talk about what was proposed and understand something you are very sceptical at file.</li> <li>Knowing that out views will be fed back to scienting.</li> <li>Being able to view this research from a different page.</li> </ul>	h my thoughts/ sugg have a bearing on v irst. ists and used toward perspective and able and discussions wh	there it goes from here  Its writing of the code of  The to put my own input it  The the the contract of the c	of practice into very hopeful future.		inning. I think whe	n you don't					
15	<ul> <li>It felt good to know my opinion would make a difference of the second of</li></ul>	h my thoughts/ sugg have a bearing on v irst. ists and used toward perspective and able and discussions wh	there it goes from here  Its writing of the code of  The to put my own input it  The the the contract of the c	of practice into very hopeful future.		iinning. I think whe	n you don't					
15	<ul> <li>It felt good to know my opinion would make a difference of the second of</li></ul>	h my thoughts/ sugg have a bearing on v irst. ists and used toward perspective and able and discussions wh	there it goes from here  Its writing of the code of  The to put my own input it  The the the contract of the c	of practice into very hopeful future.		vinning. I think whe	n you don't					
15	<ul> <li>It felt good to know my opinion would make a difference of the serior of</li></ul>	h my thoughts/ sugg have a bearing on v irst. ists and used toward perspective and able and discussions wh lic dialogue works	there it goes from here  ds writing of the code of to put my own input i ich makes me feel com hops?	of practice into very hopeful future. fident about the intention	ns behind the dialogue.		n you don't					
15	<ul> <li>It felt good to know my opinion would make a difference of the serior of</li></ul>	h my thoughts/ sugg have a bearing on v irst. ists and used toward perspective and able and discussions wh dic dialogue works	there it goes from here  Its writing of the code of  It to put my own input it  It makes me feel cont  It hops?	of practice into very hopeful future. Sident about the intention interesting and I feel I ha	ns behind the dialogue. ave contributed to a worthy		n you don't					
15	<ul> <li>It felt good to know my opinion would make a difference of the series and the series are series are series and series and series are series and series are series and series are series are series and series are series are series are series are series are series and series are series</li></ul>	h my thoughts/ sugg have a bearing on v irst. ists and used toward perspective and able and discussions wh dic dialogue works entists, lawyers, para we seemed to be ver	there it goes from here  Its writing of the code of  It to put my own input it  It makes me feel cont  It hops?	of practice into very hopeful future. Sident about the intention interesting and I feel I ha	ns behind the dialogue. ave contributed to a worthy		n you don't					
15	<ul> <li>It felt good to know my opinion would make a difference of the serior of</li></ul>	h my thoughts/ sugg have a bearing on v irst. ists and used toward perspective and able and discussions wh polic dialogue works defined in the person of the person of the person of the person of the	there it goes from here  Its writing of the code of  It to put my own input if  It ich makes me feel cont  It hops?  It icipants, it was all very  It well selected for such	of practice into very hopeful future. Sident about the intention interesting and I feel I ha	ns behind the dialogue. ave contributed to a worthy		n you don't					



#### Learning more about such an important topic and the chance to hear from specialists:

- Learning how the research will potentially help in the future treatment of diseases and to improve the success rate of IVF.
- Hearing the professionals opinions and discussing plans for the future
- Hearing from experts, this gave both a scientific perspective and a social, legal perspective
- The most important thing which was discussed during the project to clearly define the difference between human embryo and embryo models.
- Having the opportunity to learn about and discuss such a complex topic. Having the opportunity to contribute potentially to development of a code of conduct for important research
- The knowledge and expertise
- Really, just to get a sense of how committed everyone is to doing the right thing, engaging the public and still progressing science.
- I really enjoyed listing to the presentations and the scientists, I found the topic very interesting and engaging.
- Gaining an understanding and of a subject I previously had no knowledge of
- Learning more about the stem cell embryo models
- BEING ABLE TO HEAR ABOUT THE RESEARCH AND COMMENT ON ITS FRAMEWORK
- Code of practice

#### Diversity of those involved (and that diverse views will be reflected in the Code of Practice):

- the opportunity to hear from people with different perspectives and also directly talk to professionals.
- Gathering, in an orderly way, a spectrum of views from "ordinary" people.
- Education and diversity of participants.
- Being able to comment on and listen to difference in views.
- Getting different views and experts and crystallising our thoughts on the code of conduct.
- Got everyone's different perspectives.
- I think having the groups and showing that there was going to be a high-level of diversity, whilst creating the code of conduct helped to ease thoughts.
- To come together from diverse backgrounds.

#### 16 What, if anything, was missing or might have been done differently?

#### Half respondents said they really felt there was no room for improvement and specifically:

- I can't think how it could have been done any fairer.
- Honestly nothing, I think it was great.
- Can't think of anything.
- Not sure as it felt all views were taken into account.
- Sadly disappointed that I missed the last workshop due to illness. It was done very well

A few constructive suggestions, mainly related to timing – most suggesting a little more time in small groups, perhaps spread over a slightly longer period. Just a few suggesting that the final session could have been face to face, as for the previous dialogue:

- Mix the feedback group up each session.
- It worked really well but perhaps mixing up groups more often and/or doing multiple discourses with smaller participant groups
- I think it was all done in an appropriate way which could help a common person like me to understand about the whole concept of embryo models and how it effects our lives
- More time over a longer period
- Spread the workshops out over 4 weeks maybe



- Have a further workshop to allow more smaller group discussion.
- Longer in small groups.
- Extra time in small groups, maybe an extra webinar to be able to gain more information or have a bit better discussion.
- I had never participated in this type of research. Therefore, I don't have other bases to compare. Overall, I am very happy with how it was carried out.
- 1:1 sessions would've been good!
- Posting the Menti posts on the Recollective.
- More face to face group discussions.
- Would have been good for final one to be in person.
- There was a lot to take in, in such a small time frame, I would have liked a little bit more time to think about what I have learnt, but I understand everything had to be relative.
- Nothing in particular, I think the sessions were well fought out, perhaps another five minute break in between if the session is very long.
- I think clarity from the get-go about what we're talking about I. E. This had nothing to do with previous workshop and maybe longer sessions in smaller group and/or panel discussions rather than presentations. I also feel like the pure science presentations weren't really useful after all, albeit interesting.

## Would you have any interest in continuing to be involved in Cambridge Reproductions work on this topic? Overwhelming majority of respondents (32 out of 35) said yes, with 19 enthusiastically positive:

- Yes. Now that I have managed to digest the information provided I would be interested in being involved as a lay person in the oversight committee.
- Yes because this is something I enjoy learning and sharing my views
- Yes, I think it is very important to keep the public on board with such a delicate field of research study.
- Yes I find this very interesting
- definitely!!
- Yes, if there is anything I can do.
- Yes definitely
- Yes. Do not hesitate to contact me if you have any other opportunities. It was great learning, and I am more than happy to help.
- Yes, if I can be of help!
- Absolutely. I would like to continue with the work as I'm very interested in this and I've enjoyed every part of it. Sorry its ended!
- I would love to be part of any further research on this.
- I would definitely be interested in taking part in the future, I feel that I have learnt so much. I would love to come to the Science Museum as I am member.
- Absolutely, would love to see it to the end.
- Most definitely to see this develop in hopefully full success would be fantastic. To know I played a part WOW.
- yes definitely
- Yes, definitely, I found it very interesting.
- Yes I would be very interested
- Yes I would
- Absolutely, sign me up! I have extremely enjoyed it!