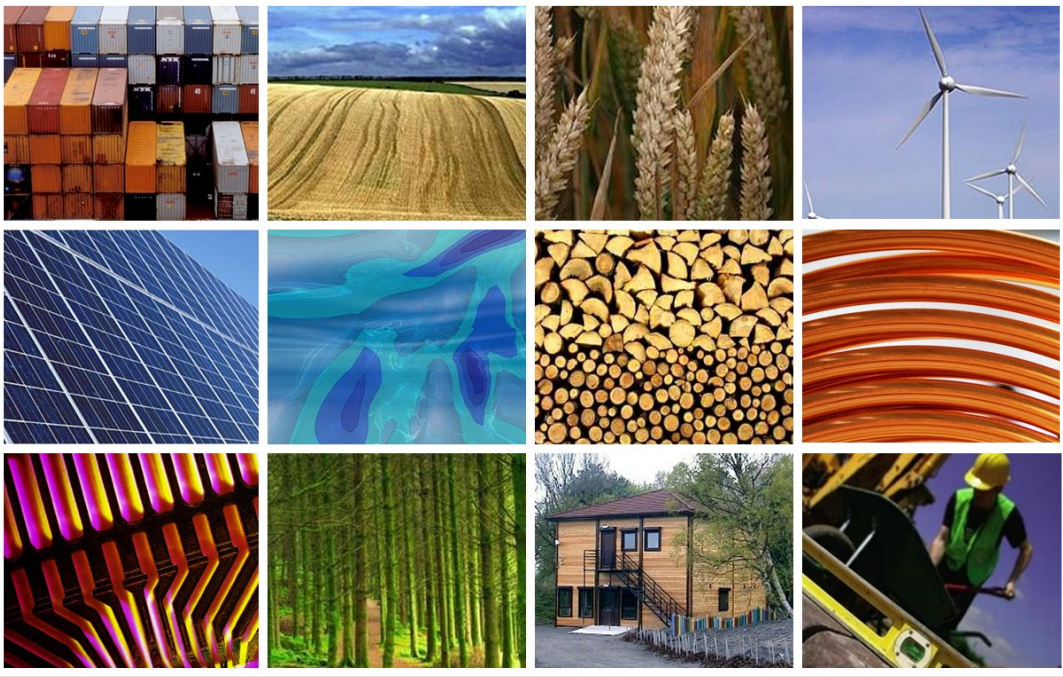


HDBI and UKRI Sciencewise

Evaluation of a Public Dialogue on Early Human Embryo Development in research

Impact report

May 2024



Quality Management

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Acronyms

BBSRC	Biotechnology and Biological Sciences Research Council
CERI	Communities experiencing racial inequality
CoP	Code of Practice
DHSC	Department of Health and Social Care
EHD	Early human development
EHE	Early human embryo
ESC	Embryonic Stem Cell
HFE Act	Human Fertilisation and Embryology Act 2008
HFEA	Human Fertilisation and Embryology Authority
HDBI	Human Developmental Biology Initiative
IG	Insight Group
ISSCR	International Society of Stem Cell Research
iPSC	Induced pluripotent stem cell
IVF	In vitro fertilisation
NCCPE	National Coordinating Centre for Public Engagement
NCoB	Nuffield Council on Bioethics
PET	The Progress Educational Trust
REC	Research Ethics Committee
SCBEM	Stem cell based embryo model
SMC	Science Media Centre

Executive summary

This draft impact report has been prepared by URSUS Consulting Ltd. It presents the findings of an independent evaluation of a public dialogue on Early Human Embryo (EHE) research commissioned by the Human Developmental Biology Initiative (HDBI) and supported by UKRI Sciencewise.

Context

- The HDBI programme funds research carried out on early human embryos which have been donated from fertility treatments that will no longer be used for family building and from embryos created from donated sperms and eggs which will only be used for research. Research is regulated by the [Human Fertilisation and Embryology Act 2008 \(HFE Act\)](#) and licensed by the [Human Fertilisation and Embryology Authority \(HFEA\)](#).
- The HFE Act reflected the work of the Warnock Committee and was shaped by the understanding of the scientific possibilities and societal views at that time. It bans the cultivation of embryos beyond 14-days of development or before the formation of the primitive streak. The 14-day rule is intended to balance potential medical benefits with the diversity of views on the special status of a human embryo.
- Since it was introduced in the UK (and then adopted in many other countries) scientific advances mean it may be possible to cultivate an embryo for longer than 14-days, with potential benefits in extending knowledge into the so-called 'black box period' of 14-28 days about which relatively little is known.
- International scientists have proposed via the International Society of Stem Cell Research (ISSCR) that where the legislation allows and public opinion supports it, the 14-day restriction should be removed.
- In the UK, the Department of Health and Social Care (DHSC) has tasked HFEA with reviewing the HFE Act and recommending whether it is still fit for purpose. HFEA undertook a stakeholder consultation exercise in 2023, but relatively little was still known then about the public's views on EHE and the 14-day rule.

Dialogue objectives

As part of its overall commitment to public engagement, HDBI commissioned the public dialogue in order to:

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

Secondary objectives of the dialogue were to help inform future policy development (e.g. around the 14-day rule) and to help share HDBI's research priorities and encourage future public engagement.

Dialogue approach

- 70 participants (including 9 in a pilot, 21 with lived experience and 42 reflecting the general public) from across the UK met in a mix of online and face-to-face workshops (Newcastle and London). The group was diverse, reflecting demographic characteristics and a mix of religions and views on EHE research and knowledge about the relevant legislation.

- Over the course of a webinar and 3 workshops the participants heard from several dozen specialists including scientists, IVF practitioners, ethicists/philosophers, regulators and patients with lived experience.
- Participants deliberated in small groups of 7 both online (webinar and first workshop) and then face-to-face (workshops 2 and 3) about their hopes and concerns for existing and future research and their reflections on any red lines and how the research should be governed in the UK and internationally.
- The process was overseen by a large and diverse Oversight Group (OG) co-chaired by two academics from scientific and ethical perspectives respectively. The OG included people with wider legal, history, patient or governance backgrounds. The OG as a whole helped to shape a robust process and ensure that the findings were credible.
- The project was designed and delivered by experienced contractors, Hopkins Van Mils (HVM) and managed by a small core team including the HDBI public engagement team and Sciencewise.

Meeting the dialogue objectives

- Although this was a complex and contentious area, a realistic timeframe and budget, an experienced delivery team and design that made the most of a blended delivery approach ensured that all three primary objectives have been met.
- OG members and HDBI researchers considered the process and findings so useful that they seized the opportunity to secure a small BBSRC grant and Sciencewise contract extension to commission a mini follow-on dialogue on a related subject (Stem Cell Based Embryo Research) which had been lightly touched on during this dialogue.

Policy impacts

- Since the report was published it has generated a lot of interest and discussions with stakeholders across the sector. A carefully coordinated dissemination plan - starting with a webinar hosted by the Science Media Centre (SMC) and supported by a press release and social media campaign the following day - saw the report findings receiving wide press coverage and downloads by hundreds of researchers.
- The findings have also been shared with the HFEA, via their representation on the OG, a presentation to wider HFEA staff, and through discussions between HDBI, Sciencewise and the HFEA chief executive. Whilst no immediate direct impact is expected on UK policy, the findings have already contributed to a wider UK and international discussion about the 14-day rule and been lodged in the government library so will be available to policy makers as and when the HFE Act is revisited. The findings and lessons on the process also have the potential to demonstrate what robust public engagement can look like to ISSRC members (via the OG Co-Chair who leads relevant working groups) and via links made by the members of the OG with policy processes in other countries such as Netherlands and Australia.
- The findings have also started to feed into planning and delivery of future research within the HDBI network. Most immediately the Babraham Institute intends to publish regular reports on their research and its outcomes designed for the general public, as recommended by dialogue participants. Researchers who have been involved in the process are enthusiastic to see more two-way public engagement in the future. The public engagement team are also looking for other opportunities to continue working with this informed set of participants.

Key factors which contributed to meeting objectives and impacts

- The governance and project management arrangements which helped with a broad framing, balanced and accurate materials, and a well-coordinated strategy for disseminating the final report and its findings.
- A blended approach – online and face-to-face – which added real value by involving more participants (than if it had just been face-to-face) while also benefitting from the different nature of conversations online and ‘in the room.’
- A diverse mix of participants were well supported and remained engaged throughout with very little drop-out. Prior lessons from running dialogues on similarly emotive topics was evident in the design team’s attention to ensuring that participants felt comfortable and valued. This included running a separate group for those with lived experience of IVF, miscarriage and conditions that develop during early embryo development), continuity in a small, experienced facilitation team across each location, ensuring language was sensitive, and that emotional support was available to those who found the topics upsetting.
- Sufficient, fair, accurate and well-presented information engaged participants, while contributions from specialists gave them the breadth of perspectives they were hoping to hear. Video interviews proved particularly helpful in bringing the topic alive and helped participants gain the knowledge they needed without overwhelming them.
- The enthusiasm and time invested by the HDBI team – from principal investigators to early career-stage researchers - in being filmed in their labs to contribute information for participants about their research and motivation, attending online and face-to-face workshops as specialists or observers and answering participants’ questions (during and between sessions) helped engender a strong sense of trust in both the science and the process.
- Robust data capture and time spent on analysis contributed to a high quality report that put the participants’ voices front and centre.
- By the end of the process, all participants felt that they had been able to make meaningful suggestions on future research priorities, red lines and future governance of EHE research, including the 14-day rule. By the end of the process the majority of participants were cautiously in favour of revisiting the 14-day rule, albeit with a number of caveats. Participants enjoyed being part of this dialogue so much that almost all volunteered to be a part of the follow-on 35-person process.

Recommendations:

For Sciencewise and commissioners

- Allow a realistic timeframe – enough time for scoping, field work, analysis and sharing findings with the OG help ensure a streamlined reporting and launch process.
- Weigh the costs and benefits of a blended online and face-to-face approach compared to a wholly online process. In this case the face-to-face elements involved additional direct costs (participant, facilitator and specialist travel and subsistence, venue hire) with some participants travelling from afar; however, online processes are not necessarily less costly as they often involve additional staff costs for technical support and for facilitators to work with smaller groups.
- Encourage the commissioner team to be as involved as possible. Both participants and your organisation will benefit from hearing directly from each other. A steady commissioner presence can help build participant trust that their contributions will be listened to.

- Look for opportunities for follow-on dialogues if opportunities arise: using the same participants (subject to permissions to recontact being in place), contractor and evaluator can make for a very cost-efficient follow-on dialogue in related areas.
- A large Oversight Group can really help shape the dialogue but requires plenty of secretariat support (preparing agendas, briefing chairs, sharing documents, collating feedback) to make it work effectively.
- Plan a comms and dissemination strategy early and use formal and OG networks for sharing messages, particularly where the intention is to inform a national conversation rather than directly influence policy.

For delivery contractors

- Vary the format of workshop sessions to suit the nature of the topic, stage of the process and number, location and type of participants. Face-to-face elements at some stage of the process can add real value and not necessarily be more costly than online.
- Consider the pros and cons of running a dedicated online share space alongside the workshops (to share materials, collect individual reflections, answer questions). In this case the site was well used by almost all participants in parallel with the workshops.
- Consider different formats for stimulus materials including videos, infographics, live presentations, panel discussions etc. In this case filming in the lab really helped bring the research topics alive for participants.
- Wherever possible build in an online pilot stage with members of the public to test timings, materials, and identify questions which will need to be answered.
- If the topic is contentious enough to attract public protest, ensure mitigation measures are in place to manage the risks.
- Consider pre-filming some specialist inputs in order to allow participants in different groups/locations to hear the same information and to bring in different perspectives that they want to hear but could prove too emotional or uncomfortable in the room/Zoom.
- Ideally consider a lead facilitator for each cohort to help create a welcoming environment, forge a group identity and actively manage specialist inputs and final plenary sessions. Aim for continuity in the facilitation team for all workshops in a specific location.
- Consider whether the topic might be emotionally upsetting to participants and, if so, build in support options (such as opportunities for time out, talking to an empathetic listener or a trained counsellor) which will be comforting to participants, even if they are not needed.
- Use a mix of techniques during online meetings to capture participant views as a group (e.g. visible note taking on interactive whiteboards) or individually (e.g. chat box and eVoting).
- Allow plenty of time for analysis and report drafting: time spent on coding, agreeing a structure and the overall narrative can help streamline the drafting and sign-off process.
- Allocate resources for a final video to capture reflections from participants and commissioners which can be shared at the report launch or on social media. In this case both the final video and stimulus videos have been shared on YouTube and will be a useful resource for other dialogues on related topics.
- Consider whether the findings on substance or process can be shared more widely with academic audiences: if so, encourage the commissioners or OG members to author an academic article for a peer-reviewed journal.

1 Introduction

1.1 Introduction

URSUS Consulting Ltd has prepared this impact report of a public dialogue on early human embryo (EHE) research commissioned by the [Human Developmental Biology Initiative \(HDBI\)](#), a Wellcome-funded research consortium. Co-funding and support has been provided by the UK Research and Innovation (UKRI) Sciencewise programme.¹ The public dialogue was designed and delivered by experienced contractors specialists Hopkins Van Mil (HVM).

This report draws on evaluation observations, qualitative and quantitative feedback from public participants, specialist contributors, members of the Oversight Group (OG) and from insights from a wash-up meeting with the core project management team and from desk research on how the dialogue findings are being disseminated and used. The report focuses on the outcomes and potential impacts of the dialogue (*Section 2*), lessons about how good practice enabled the dialogue to meet its objectives (*Section 3*) and emerging conclusions and recommendations for future dialogues (*Section 4*). Supporting evidence is shown in a series of annexes.

1.2 Background and context

- The HDBI consortium is a five year, £10 million pound research initiative based across multiple research institutions in the UK² and two in Europe. HDBI members undertake research on early human embryos (EHE) amongst other topics. For EHE research they work with tissues donated from fertility treatments that will no longer be used for family building, and from embryos created from donated sperms and eggs which will only be used for research.
- Research is regulated by the [Human Fertilisation and Embryology Act 2008 \(HFE Act\)](#)³ and licensed by the [Human Fertilisation and Embryology Authority \(HFEA\)](#). The original HFE Act (1990) reflected the work of the Warnock Committee⁴ and was shaped by the understanding of the scientific possibilities and societal views at that time. The HFE Act bans the cultivation of embryos beyond 14-days of development or the appearance of the primitive streak (which sets up the body’s axis and the point at which the embryo can no longer split into identical twins), whichever is first. The 14-day rule was proposed as a balance between the potential medical benefits of research and views on the special status of the human embryo. The Act does not cover stem cell based embryo models

¹ Sciencewise helps to ensure policy is informed by the views and aspirations of the public. The programme is led and funded by UKRI with support from the Department for Business and Trade (DBT). [Involve](#), the UK’s leading public participation charity, provides expert advice, assurance and support to the programme.

² University of Cambridge (including Babraham, Gurdon and Cambridge Stem Cell Institutes), UCL, King’s College London, the Francis Crick Institute, University of Oxford, the University of Dundee and the University of Newcastle.

³ Human Fertilisation and Embryology Act 2008, <https://www.legislation.gov.uk/ukpga/2008/22/contents> regulates the use and storage of human embryos and gametes, as well as the provision of fertility treatments and research involving human embryos.

⁴ Mary Warnock and the Committee of Inquiry into Human Fertilisation and Embryology. The report of the Committee of inquiry into human fertilisation and Embryology. 1984 <https://wellcomecollection.org/works/pxgeeqnf/items>

(SCBEMs)⁵, but scientists in the UK tend to apply the same limits as for human embryos. Since 1990, the so-called 14-day rule has been widely adopted around the world.

- Recent advances in scientific techniques now make research beyond 14-days a technical possibility and many scientists point to potential benefits in allowing research during the 'black box' period (14-28 days) about which relatively little is known. Beyond 28 days, researchers have easier access to research material via embryos donated from terminations or via early scans.
- Many scientists now believe there is a case to revisit the 14-day rule. The [International Society for Stem Cell Research](#) (ISSCR) publishes guidelines which set an international standard for ethical behaviour, diligence and transparency in stem cell research. They updated their [guidelines](#) in 2021 to reflect technical progress made in cultivating embryos and models and their potential for health and care benefits.⁶ The new ISSCR guidelines propose replacing the 14-day limit with a strict case-by-case oversight of proposed research that could run longer, provided the rationale is well justified, is allowed for by legislation and is supported by extensive public engagement.
- However, relatively little is known about public attitudes on either the research or its governance. In 2016, the Nuffield Council on Bioethics (NCoB) [ran a workshop](#) on the issue and concluded there was insufficient political or public support for a review at that time. More recently the Progress Educational Trust (PET) conducted [a large online survey](#)⁷ (2,233 nationally representative UK adults in 2022) which found general support for research on embryos and some support for extending the 14-day rule, but was unable to probe the underlying values and reasoning for respondents' views or their views on governance.
- HFEA has been tasked by the Department of Health and Social Care (DHSC) to review the HFE Act and as part of this process carried out a [public consultation](#)⁸ in early 2023. The audience was mainly expected to be informed stakeholders, but also attracted hundreds of responses from individuals via a campaign by organised by religious groups, which made it difficult to gauge whether this was representative of wider public views.
- HDBI is committed to engaging with the public about its research and its ethical, social and legal implications. This dialogue was conceived as foundational research to better understand public aspirations and concerns based on current perspectives and near-future scientific developments. The findings are expected to help HDBI identify what types of research are considered appropriate, and what conditions should be in place to ensure it can be used to its fullest in the future within a framework of public trust.

⁵ Three-dimensional embryo-like aggregates formed in suspension from embryonic stem cells (ESC) or induced pluripotent stem cells (iPSC).

⁶ E.g. improved medical interventions for conditions such as recurrent miscarriages, improved techniques for performing in vitro fertilisation, better understanding of biomarkers of healthy pregnancies, the use of genetically edited embryos for reproductive purposes, the use of lab-created sperm and eggs for reproductive purposes and improved use of stem cells for regenerative medicine.

⁷ Progress Educational Trust (PET) [Fertility, Genomics and Embryo Research: Public Attitudes and Understanding, June 2022](#). Section 3 on public attitudes to embryo research found widespread support for embryo research for medical purposes, such as developing treatments for genetic diseases but less support for non-medical purposes with some concerns about the ethical and societal dimensions. The findings suggested opinions on EHE research were shaped by factors such as religious beliefs, political affiliation, and personal experience with infertility.

⁸ HFEA, Overview of HFEA public consultation on law reform, 2023. <https://www.hfea.gov.uk/about-us/modernising-the-regulation-of-fertility-treatment-and-research-involving-human-embryos/overview-of-hfea-public-consultation-on-law-reform-2023/>

- Beyond this, the research is also expected to have potential to inform HFEA, DHSC and ISSRC's reviews of governance over the use of early human embryos in research, but not within the short term.

1.3 Public dialogue objectives

The primary dialogue objectives were:

- To develop a holistic understanding of participants' views of the societal and ethical issues around human developmental biology research;
- To identify participants' views of the research questions and outcomes of human developmental biology research (*widened from an initial focus on HDBI research only*) that reflect societal priorities; and
- To enable scientists and public participants to engage in a constructive dialogue to hear, reflect, consider and respond to issues around the research.

Additional objectives relate to potential impacts on HDBI's work:

- To improve the quality of scientific research in this area by ensuring it is in greater alignment with participants' priorities, specifically:
 - To shape research directions in future grant applications;
 - To inform research strategies; and
 - To embed a culture of engagement and improve future engagement tools and activities.

And on wider policy processes:

- To use this initial evidence base of public views to inform future public engagement, policy decisions and reviews such as around the 14-day rule in laboratory embryo culturing (for instance the HFEA's advice on HFE Act by highlighting areas of regulation needing reform to meet public expectations).

1.4 Dialogue framing

- The Oversight Group (OG) suggested two timeframes for the research:
 - short-term, application-based research with the potential to deliver direct medical benefits in reducing miscarriage, improving in vitro fertilisation (IVF) success rates or understanding conditions that develop in the first 14 days of development; and
 - longer term, fundamental, 'blue skies' research which will contribute to a better understanding of early human development but is unlikely to result in immediate health benefits.
- The OG recommended to include examples both of research applications that would currently be allowed within the law (i.e. up to 14-days) and 'edge cases' in the window beyond this (the so-called 'black box' from 14-28 days during which the neural tube closes), if it were permitted under a future law change.
- Case studies on SCBEMs were included since a number of HDBI labs are using them in their research up to 14-days. Recent scientific advances and lack of regulation mean that some international labs are already going beyond 14-days with SCBEMs and this was a topic generating significant media coverage at the time of the dialogues (summer 2023).

- Experience from previous public engagement on the topic and HDBI's own experience of working with a small Insight Group⁹ (IG) of individuals with lived experience of relevant conditions also helped shape the sample of public participants to be recruited to include:
 - A group of 19 individuals with lived experience (of IVF, miscarriage and conditions relevant to the research) who were purposefully recruited via charities and met in a separate online group. This was intended to make them feel comfortable, give them space to talk about their own experiences, and make it easier to analyse their views for similarities and differences from those of the general participant groups.
 - Individuals with strong religious convictions since the Warner review, the PET survey and HFEA consultations suggested this was a key factor shaping people's attitudes to EHE. Of the 42 participants in the general groups, 25 described themselves as practising a religion (including Catholics, Protestants, Jews, Muslims, Hindus and Buddhists) while 17 described themselves as atheists, agnostics or preferred not to say. Timings on a Friday evening and Saturday may have made it difficult for those from orthodox backgrounds to participate.

1.3 Dialogue approach

- The process was managed by a core team made up of a two-person HDBI public engagement team, a UKRI Sciencewise dialogue and engagement specialist (DES), the delivery contractors (HVM director and project manager) and the independent evaluator.
- A total of 70 participants from across the UK took part: 9 via an online pilot process; 19 with lived experience (of IVF, miscarriage and relevant conditions); and 42 broadly reflective of the demographics of the UK population recruited through free-find methods or charities. They received a thank you payment of £400 for taking part in all activities.
- Most participants took part in 15 hours of deliberation made up of 13 hours spent in workshops and at least two hours reviewing and responding to material on the online space (Recollective). The general public groups met twice online and then face-to-face on a Friday evening/Saturday in Newcastle (northern group) or London (southern group).
- The process was overseen by a 20 -person Oversight Group (OG) co-chaired by Professors Robin Lovell-Badge (Francis Crick Institute) and Bobby Farsides (Clinical and Biomedical Ethics at the Brighton and Sussex Medical School). The OG brought together a rich mix of backgrounds including scientists, policy and legal specialists, ethicists, science historians and patient representatives (see *Annex A* for a list of members). The group met four times online to help frame the dialogue, refine the recruitment brief, agree information to share with participants and specialist roles.
- Participants heard from 24 specialists including 8 OG members who contributed via pre-filmed videos or in person during online and face-to-face workshops.
- The final dialogue report was published at the [HDBI, Sciencewise](#) and [HVM](#) websites on October 25th 2023. A short film in which the participants and researchers share their journey was published at the [Babraham Institute YouTube](#) channel on 10th January 2024. Supporting materials developed during the dialogue are available at HDBI and Sciencewise websites and on YouTube.

⁹ PERSPECTIVE| 15 September 2022: Exploring the challenges and opportunities of public engagement with fundamental biology, Naomi Clements-Brod, Leah Holmes, Emma L. Rawlins
<https://journals.biologists.com/dev/article/149/18/dev201170/276538/Exploring-the-challenges-and-opportunities-of>

2 Potential for impact

2.1 Overview

Since the report was published, it has generated a lot of interest and discussions with stakeholders across the sector. A carefully coordinated press and communications campaign - starting with a webinar hosted by the Science Media Centre (SMC) followed by a coordinated press release and social media campaign - saw the report findings receiving wide press coverage and viewed by hundreds of researchers (see [Tables 2.1](#) and [2.2](#)).

The findings also have the potential to inform the wider conversation around EHE research policy review. Findings have been shared with officers and the director of HFEA. Whilst there is unlikely to be a directly traceable impact on UK policy before the general election, the findings are already contributing to a wider conversation around EHE generally with interest from academic, think tanks and patient organisations (see below) and much wider press coverage around the 14-day rule (see [Table 2.1](#)) suggesting broader interest from the general public. The report has been entered into the government library and will be available for review as and when the HFE Act is revisited. Lessons on what makes a robust and credible public engagement on this topic have the potential to feed into ISSCR sub-committees and via links made by OG members with policy processes in other countries such as Netherlands and Australia.

The findings are also feeding into planning and delivery of future research bids by HDBI, to strengthen support for public engagement (with a mini dialogue commissioned on the back of this one) and to inform approaches to communication on EHE research more widely.

2.2 Dissemination and media coverage

Launch, press and social media campaign

- A well-thought through and executed communications strategy led by the HDBI public engagement team and involving the OG members resulted in a great deal of press coverage and social media interest in the public dialogue.
- The report was officially launched at a 1-hour online press briefing hosted by the Science Media Centre (24th October 2023) at which Peter Rugg Gunn and Robin Lovell-Badge introduced the underlying science and HVM described the dialogue process and findings. Some 16 science writers from broadcast and print media (BBC, BBC News, CNN, Telegraph, Guardian and The Economist) and more specialist science outlets (Science, Nature, Francis Crick Institute, Progress Educational Trust) attended. Journalists asked questions about how best to report public opinion (in view of the relatively low numbers involved) and about the wider policy/regulation implications of the findings.
- The resulting press coverage from the BBC, CNN and print media ([Table 2.1](#)) in the week following the launch and findings shared through coordinated blogs, tweets and LinkedIn articles ([Table 2.2](#)) created a first wave of interest.
- A later in-depth article in the Guardian at the end of December (including quotes from senior HDBI researchers and Sarah Norcross, an OG member) did not mention the dialogue directly but focused on opinions about the 14-day rule: this generated a second

wave of interest with the article picked up in specialist science and international press (such as the International Business Times).

- A slight delay in completing the public dialogue videos worked to the project’s advantage in creating a third wave of social media interest when it was launched on [YouTube](#) on 10th January 2024, to coincide with a very widely read [blog on the Babraham Institute website](#) by PhD researcher Amy Wilkinson. The video has since been used to engage participants in a mini follow-on dialogue on SCBEMs (see below).

Table 2.1 Media coverage of the public dialogue and its key messages

Outlet	Link and coverage
BBC News article	<ul style="list-style-type: none"> • Michelle Roberts, 25th Oct https://www.bbc.co.uk/news/health-67204553 <i>Scientists: Allow forbidden 28-day embryo experiments</i>. Describes the fieldwork, including a link to the report, the findings in relation to the 14-day rule and SCBEMs and this research as a first step if the law were to be changed. Balances quotes from HDBI with a quote from Right To Life UK spokesperson, Catherine Robinson, opposed to EHE research.
Today programme (Radio 4)	<ul style="list-style-type: none"> • https://www.bbc.co.uk/programmes/m001rq34 Robin Lovell Badge interviewed for final minutes of the programme and talked about the dialogue, the potential benefits of extending the 14-day rule, participants’ views on doing so and the next steps if the law were to be changed.
BBC Science Focus article	<ul style="list-style-type: none"> • https://www.sciencefocus.com/news/public-supports-14-day-embryo-research-limit-extension Focuses on the 14 day rule, cites the report and balances quotes from Robin Lovell-Badge and Peter Rugg-Gunn from the Babraham Institute press release e.g. “Other countries will be looking to the UK to see how we deal with the 14-day rule; we are not there yet with any mandate to make a change, but this does give a strong pointer”, balanced with link to an article in the Journal of Medical Ethics (2021) making the case for not extending.
BBC tweet	<ul style="list-style-type: none"> • 25th Oct Sophia McCully on X - <i>UK scientists are calling for the current 14-day limit on embryo research to be doubled to 28-days, so they can study the unexplored secrets of early human development</i>. Followed by an article in the British Medical Journal arguing for extension to 28-days.
CNN	<ul style="list-style-type: none"> • 26th Oct, Katie Hunt, Breakthroughs in race to create lab models of human embryos raise hopes and concerns, 10 min read – refers to the SRC briefing and cites Peter Rugg-Gunn, Robin Lovell-Badge, Naomi Moris and Bobby Farsides and SCBEM researcher from the Weizmann lab (Israel), but does mention the public dialogue explicitly.
Science Magazine	<ul style="list-style-type: none"> • 25th Oct, Public support for extending the 14-day rule on human embryo research indicated by foundational dialogue project based on Babraham blog.
Laboratory Equipment	<ul style="list-style-type: none"> • 27th October UK Survey Reveals Support for Extending 14-day Embryo Research Rule includes quotes from Robin Lovell-Badge and Mike Norman about the public’s interest in being involved in decisions about legislation and science.
The Lancet	<ul style="list-style-type: none"> • Editorial Vol 402 November 4, 2023, Human embryo research: re-forming societal agreement includes discussion of findings and implications of the dialogue and a link to the report.
Nature magazine	<ul style="list-style-type: none"> • 6th December ‘<i>Ceci n’est pas un embryon?</i>’ <i>The ethics of human embryo model research</i> https://www.nature.com/articles/s41592-023-02066-9
Guardian article	<ul style="list-style-type: none"> • 30th December Hannah Devlin Science correspondent: in-depth piece based on an interview with Peter Rugg-Gunn, Kathy Naikan and Sarah Norcross (OG member): https://www.theguardian.com/science/2023/dec/30/leading-scientists-call-for-review-of-14-day-rule-on-embryo-research-miscarriage.
Centre for Genetics and Society	<ul style="list-style-type: none"> • Blog on website: Scientists call for review of UK’s 14-day rule on embryo research picking up and commenting on Guardian article

International Business Times	<ul style="list-style-type: none"> 1st Feb 2024 https://www.ibtimes.co.uk/uk-scientists-advocate-comprehensive-review-14-day-rule-embryo-research-1722487 (does not mention the dialogue but quotes from previous interviews with Professors Rugg-Gunn and Naikan).
Daily Hawker UK	<ul style="list-style-type: none"> https://www.dailyhawker.co.uk/exploring-the-potential-of-embryo-experiments-extending-the-14-day-limit/

Dissemination of the findings to wider audiences

The HDBI team has also shared the findings with the following wider audiences:

- **Progress Education Trust Annual Conference** (6th Dec 2023) - Peter Rugg Gunn spoke on a panel and highlighted the dialogue; other members of the OG also took part (Sarah Norcross, Kathy Naikan, Bobby Farsides and Sarah Chan).
- **HDBI researchers at the consortium meeting** (23rd Jan 2024) – Mike Norman presented on the dialogue process and its findings to a group of 50 HDBI researchers from most of the consortium members and a range of PhD students, post docs, and group leads (including the 4 HDBI research theme lead researchers) who showed great interest in both the findings and the process (see *section 2.4*).
- **National Coordinating Centre for Public Engagement Engage Live conference** (May 2024) – Mike Norman presented about the public dialogue to public engagement professionals and UKRI public engagement representatives which generated significant interest from science, social science and humanities researchers interested in using PD as a methodology and in the support available via the Sciencewise programme.

In the next few months the Babraham public engagement leads will look at future dissemination opportunities including:

- **Academic articles** - Peter Rugg-Gunn and Mike Norman plan to write two articles for different audiences: one with a human biology focus (e.g. for Cell Stem Cell where ISSCR often publishes for the field); and the other with public engagement interests (e.g. via Research For All - the journal of the National Coordinating Centre for Public Engagement (NCCPE)).

Table 2.2: Social media and website dissemination of the findings

Organisation	Planned dissemination activities
HDBI/ Babraham Institute	<p>HDBI website and share site</p> <ul style="list-style-type: none"> • Google site for the public participants to register their interest – 57 registered some interest. The page will be revised so they can sign up to hear more from the project and receive invitations to future • Babraham Institute web page News Blog. • The webpage has been visited 4,500 times since the report was published and as of mid Feb with 3,850 link clicks / downloads of the dialogue report • Press release: Public support for extending the 14-day rule on human embryo research indicated by foundational dialogue project • Report lodged with the Parliamentary library and will be available to download by parliamentarians <p>Babraham Institute</p> <ul style="list-style-type: none"> • LinkedIn blog • Link to videos on Babraham YouTube channel (300 views by end April 2024 for 13 videos on introduction, regulation, personal reflections and specialist presentations) • BI Tweets on X

	<ul style="list-style-type: none"> • Amy Wilkinson, 10th Jan link on X to blog on Babraham Institute website (nearly 5K views) • Rugg-Gunn Lab, 10th Jan link on X to videos on YouTube link • Rugg-Gunn Lab, 25th Oct X link to report (over 10K views) • Rugg-Gunn Lab, 28th Oct X Public support for extending the 14-day rule (600+ views) • Emma Rawlins lab 25th Oct X (2500+ views) • Gurdon Institute, 26th Oct X link to report and blog at website (1.1K views), highlights finding that the public is interested in the science and wants to engage more with scientists
Tweets by other institutes/labs	<ul style="list-style-type: none"> • James Briscoe, Francis Crick Institute, 27th Oct X link to report (1.1K views) • Cambridge Reproduction, 25th Oct blog at website by T Smythe • Bioengineering 27th Oct on X link to report • Boroviak Lab 27th Oct X link to the report • Dr Zoe Bolton, Lancaster University, 15th Nov blog at website: Is it time to revisit the 14-day rule? explores the origins of the 14-day rule in the UK and considers the arguments for and against extending the current limit quoting the dialogue findings in detail with a link to the report • Katrien Devolder (Oxford University Uehiro Institute of Ethics), 8th Nov tweet on X and blog 8th Nov on Practical Ethics at the Uehiro Institute, 8th Nov blog New report shows public support for extending the 14-day rule on human embryo research There are good reasons for extending the 14-day rule (we could learn more about why miscarriage occurs, for example) but it is important that scientists clearly communicate to lay audiences about their work, and how and why they're doing it
Sciencewise	<ul style="list-style-type: none"> • Tweets on X – 25th Oct to report (65 views) and on 10th Jan link to videos on YouTube (911 views)
Involve	<ul style="list-style-type: none"> • Issuu 25th Oct full report on website
Progress Education Trust (PET)	<ul style="list-style-type: none"> • 7th Aug 2023, HDBI public engagement team shared reflections on the public process in a piece in BioNews 1201 and in Comment • 30th Oct 23, Public open to doubling of 14-day limit on embryo research published in News, BioNews 1213 and on LinkedIn • PET Annual Conference 2023 6th Dec 2023 – included sessions on the 14-day rule, stem cell-based models and what scientists want from a review of the law with Peter Rugg-Gunn mentioning the dialogue
Other public engagement	<ul style="list-style-type: none"> • OG member Emily Jackson and dialogue specialist, Naomi Moris (Crick) are working with Liminal Space to carry out a public awareness raising and engagement campaign on SCBEMs

2.3 Potential for policy impact

A secondary, impact-related objective for the dialogue was to use the foundational evidence on public attitudes to EHE and expectations of regulation to help inform policy. It is too early to detect any direct impacts but there is already evidence that the dialogue is helping to shape the conversation around governance of both classic embryos and embryo models used in research.

Opportunities to inform the HFE Act

HFEA was involved in this dialogue both as a member of the OG and via presentations on the regulatory context made by senior HFEA staff (see *Annex A*). HFEA has completed its review of whether the HFE Act is fit for purpose and made recommendations to DHSC reflecting the outcomes of its online consultation (about 1,200 responses) and stakeholder discussions.

Box 2.1: HFEA review of EHE research within the HFE Act

- The HFEA consultation included specific questions around EHEs in research, the moral status of the embryo and discussion of the 14-day rule and sought feedback from stakeholders on whether a new mechanism should be put into law to allow for parliamentary consideration of the 14-day rule in the future, outside of reopening the HFE Act. The text made it clear that any proposed changes would need to be carefully considered in light of ethical concerns and public attitudes and values.
- The consultation generated very polarised views with many respondents arguing that the 14-day rule should be extended or removed to allow more research on EHE development and potential therapies for infertility and genetic diseases: in contrast a large number of individuals - many coordinated via a few religious groups – argued for maintaining the 14-day rule as a valuable compromise that balances the respect for human dignity and the advancement of scientific knowledge.
- In November 2023, the HFEA announced its [proposals to change the law](#):¹⁰ the section on research highlights debate around the merits of the 14-day rule and on “*embryo like entities*” (SCBEMS) as ‘...*most pressing; the research is advancing quickly on both*’.
- The proposals do not cite the public dialogue, but do chime with the dialogue participants’ views. Specifically Section 4 notes that:
- “*On the 14-day rule it is clear that science would be able to move beyond this limit, with potentially significant benefits to our understanding of early embryo development. However, given the importance of putting some limit on embryo research a consensus on any new limit would need to be reached and we need a mechanism for doing that. It is important that any possible amendment of the Act would continue to have a clear time limit for embryo research.*”
- The DHSC has said it will “*carefully consider*” HFEA’s review and its recommendations and “*work closely*” with the HFEA to “*ensure the UK remains at the forefront of safe and ethical fertility treatment and research*” (HFEA website).
- There is no agreed timeframe for new legislation, with no plans to move further before a general election. Beyond that no political party has yet made any official statement on revising the HFE Act or revisiting the 14-day rule (although individual politicians from all three major parties in health or science posts have expressed views in favour or against review).¹¹

- HFEA has had access to the findings of the HDBI dialogue via various routes. The report was shared via its representative on the OG and via a meeting between HDBI, Sciencewise and the HFEA chief executive to discuss the findings and scope for further public engagement. The possibility of HFEA building on this foundational dialogue to commission a larger one on fertility and research to inform any major changes in legislation was raised.
- The findings have also been shared more broadly with wider audiences within HFEA via an online webinar in early February 2024. The HDBI public engagement manager and HVM presented the rationale, process and findings from the public dialogue. About 30 staff attended, including three individuals who had been closely involved as OG members, specialists or stakeholders. The participants said they appreciated the overall richness of the findings and asked detailed questions on attitudes to SCBEMs vs. human embryos, views of UK vs. overseas research and asked for advice on how public dialogue opinions were best presented to the media (in terms of numbers and representativeness).

¹⁰ <https://www.hfea.gov.uk/about-us/modernising-the-regulation-of-fertility-treatment-and-research-involving-human-embryos/modernising-fertility-law/>

¹¹ E.g. Conservative MP George Freeman (2016, in favour of review); Labour MP Heidi Alexander (2017, not convinced of the need for change; Liberal Democrat MP Norman Lamb (2019, in favour of review).

Helping inform governance of research using Stem Cell Based Embryo Models

The success of this dialogue and its foundational, but light-touch, insights into public views on SCBEMs encouraged members of the OG (Kathy Naikan, Peter Rugg-Gunn, Bobby Farsides and Emily Jackson) to consider repeating the public dialogue methodology to inform the G-SCBEM initiative being led by Cambridge Reproduction.¹² A task group is developing a Code of Practice (CoP) to address the current grey area in how embryo models are regulated. The CoP is expected to be published in May 2024 and any public dialogue needed to be carried out very rapidly to be able to feed in meaningfully.

Cambridge Reproduction successfully bid for additional funding from the Biotechnology and Biological Sciences Research Council (BBSRC) and UKRI Sciencewise for a small dialogue which reconvened 35 participants from the HDBI dialogue. The commissioner has been able to capitalise on the accumulated experience and enthusiasm generated by the HDBI dialogue to work with an informed cohort of participants, the contractors (HVM and URSUS) and some members of the OG to deliver an intensive online dialogue during January 2024. This approach proved successful in generating rich insights which have helped informed the final CoP.

Helping inform international policy on the 14-day rule

- As noted above (*section 1*), the ISSCR recommends that EHE research could take place beyond 14-days if there is broad public support within the jurisdiction (demonstrated through public engagement), and where appropriate governance is in place. In most countries or US states, this would include a change in regulations to remove or extend the 14-day limit and ensuring that specialised scientific and ethical oversight processes are in place for assessing the justification for such research.
- OG co-chair Robin Lovell-Badge was a lead author for ISSCR's guidance and is now chairing a working group tasked with helping define what appropriate public engagement might look like. In press releases associated with this dialogue he has described the finding as likely to be of interest to other countries: "*Other countries will be looking to the UK to see how we deal with the 14-day rule; we are not there yet with any mandate to make a change, but this does give a strong pointer*" and is expecting to share both the findings and lessons learnt on the process with relevant committees. Findings both on classic and model embryos (see above) are likely to be of interest to wider ISSCR audiences at their annual conference in July 2024.
- Reportedly, the findings and their implications for policy in the UK are being watched with interest in Israel, Australia and New York State. However, it will be important that the scientists do not simply transfer the findings from this dialogue to their own context, but rather learn lessons about how to carry out similarly robust research in their own jurisdictions. This is already starting to happen. For instance, during a recent evaluation of the Dutch Embryo Act, the [Health Council of the Netherlands](#) (Nov 23)¹³ recommended

¹² A working group has been convened by Cambridge Reproduction including scientists, legal scholars and bioethics experts, as well as representatives from major funders and regulators to explore governance of these models which are not currently covered by the HFE Act. The group is committed to reflecting public alongside stakeholder views.

¹³ The 14-day rule in the Dutch Embryo Act Report to the Minister of Health, Welfare and Sport No. 2023/16e, The Hague, October 31, 2023, file:///C:/Users/annam/Dropbox/PC/Downloads/16e_The-14-day-rule-in-the-Dutch-Embryo-Act_advisory-report-1.pdf

doubling the limit for classic human embryo research to 28 days and also extending it to cover embryo-like structures (SCBEMs). A public dialogue is now being carried out to gauge public views on these proposals: a member of the team involved (Nienke de Graeff) also contributed to the SCBEM mini dialogue (see above). She shared her appreciation of the robust approach to selection of participants and to exposing them to wider range of information and perspectives, and signalled her intention to share lessons learnt with those running the Dutch public dialogue process.

2.4 Potential to influence research priorities and public engagement

Another secondary objective was for the dialogue to have an impact on HDBI's research to reflect a greater alignment with participants' priorities and strengthening commitment and tools for public engagement.

Shaping research directions in future grant applications and informing research strategies

- It is too early to identify impacts on specific HDBI institutions' research strategies, but evaluation feedback from almost a dozen researchers (via an online evaluation survey and informal discussions) suggests they got a good deal out of the process, including a better understanding of the public's priorities.
- Researchers who were involved as specialists and observers in the workshops reported that they had really valued being part of the process (See *Box 2.1*). Principal investigators and early-career post-graduates alike found the discussions helpful in putting their work in a wider societal context and hearing directly from the public about their priorities and red lines.

"I really valued the robust discussions during the public dialogue. This enriched my understanding of the potential and risks of this sensitive area of research and the priorities of the public. It will be important to keep the incredibly helpful points raised at the forefront of future discussions" [Professor Kathy Niakan](#), PET BioNews.

"The opportunity to hear such a broad range of views about my area of research, which made me think about how my work fits in with the wider context of society." (post-graduate researcher via online survey).

- Many researchers taking part in the workshops were surprised, but pleased, to realise that the public is keen to hear more about their work and generally trusts the UK scientists involved. One highlighted the *"desire for the public to be involved once their interest is sparked"* and another the widely shared preference for health outcome-led research: *"Generally very supportive of scientific research in EHE, as long as it is responsible and there are outcomes that benefit human health."*
- The more limited interest in fundamental research also resonated: *"Less support for EHE for blue skies research."* However, one specialist noted that this may partially have reflected the difficulties in explaining the aims and outcomes of such work: *"details of some of the longer term research were shockingly vague – as a scientist even I had some difficulty figuring out what some of the scientists were suggesting."* We noted that participants found this topic more difficult to engage with until it was linked to an applied research outcome which could only be explored if the 14 day rule was extended (e.g. the case of studying the closing of the neural tube during the black box window which could have an impact on spina bifida research).

- Several specialists surveyed were surprised to learn that participants were generally less concerned about **how** embryos were used in the research, than **who** was doing it and why in terms of potential outcomes on society. One example that participants had frequently mentioned was concern about trying to eliminate liveable conditions such as Down's Syndrome. As one specialist noted: "*Most people didn't seem to have concerns about EHE [in the lab]rather concerns over commercial use and 'bad motivations' seem more significant than 'moral status of the embryo' (although still present to some extent).*" For many of the scientists involved this reinforced the need for more transparency and two-way communication to build trust in the science.

Embedding a culture of engagement, improving future engagement tools and activities

- The HDBI webpage describes this dialogue as: "*A foundational piece of work [that] was an initial step towards wider UK public engagement on this topic and provides direction to future public consultations and research.*" In evaluation feedback a few HDBI researchers noted the value of two way communication of this type rather than more conventional public engagement with self-selecting audiences or via reports published at websites. It was a revelation to learn that although most participants knew very little about EHE research at the outset, this was not due a lack of interest, but rather to the need for different types of communication. One noted that: "*Lack of/limited awareness of [current] research communication to the public – I thought it was lack of public interest.*" Taking part in the process therefore helped researchers realise that there was an appetite for more transparent and engaging communication. The PowerPoints created for this dialogue are seen by the HDBI public engagement team as a useful output in their own right, providing a template they intend to reuse as examples for future public engagements.
- This also emerged as a strong suggestion from the northern workshops. Participants suggested regular, easy-read updates on the research (rationale, expected outcomes and actual benefits) in a format designed for the wider public. This message resonated with the Babraham Head of Public Engagement (Peter Rugg-Gunn) who immediately committed his institute to producing regular reports explaining the research and its outcomes.
- The HDBI scientific data outputs manager has now taken the lead and shared the first such [research output summary](#) in early February 2024. A series is planned for a new '[Featured Outputs](#)' section which will continue to grow over the remainder of the HDBI programme with public audiences in mind. The HDBI team also intend to encourage research councils and funders to do likewise.
- Specialists – both researchers and ethicists - also noted how interested participants were in who decides what research takes place (i.e. governance), and specifically who is represented on research ethics committees (RECs). "Many participants are more concerned about how/who is making decisions, than that research is happening" and "*I had never really questioned what factors went into deciding the make-up of the RECs: this is something I have gone on to find out more about since the dialogue.*"
- The HDBI programme lead and public engagement team are keen to continue working with those participants who express an interest in continuing to be involved. As noted above this has already involved reconvening half of the participants for the embryo

model mini dialogue. The website is also being updated so that participants can sign up to be kept up to date on the research or involved in other opportunities which might arise such as being part of HDBI’s Insight Group (see Section 1), being a participant in future dialogues on related topics or even being considered as a lay member of a REC: 57 participants have signed up so far.

- At the HDBI conference in late January 2024, discussions on the success of the dialogue fed into discussions about how public engagement should best be built into the follow-on grant application (HDBI2). The HDBI team are keen to continue using public dialogue as a methodology and lots of questions about how dialogue approaches compare to more survey-based ones. There are no immediate plans for further dialogues, but the public dialogue report identifies other topic areas of potential interest which could be of interest during HDBI2, if it goes ahead.

Box 2.2: What researchers got from taking part in the dialogue

"This is different from other forms of public engagement because it goes beyond just informing people about the science; it also aims to get back the public’s perspectives on the scienceseeing how interested the participants were to hear what we had to say, as well as the deep respect they had for every single person’s views, gave me more confidence." Amy Wilkinson, [Babraham Institute Blog](#).

"This public dialogue is an important first step and as a scientist I am reassured by the findings, but there is still a long way to go to fully understand this complex issue." Professor Peter Rugg-Gunn, [Babraham Institute blog](#)

Specialist contributors via evaluation survey particularly valued:

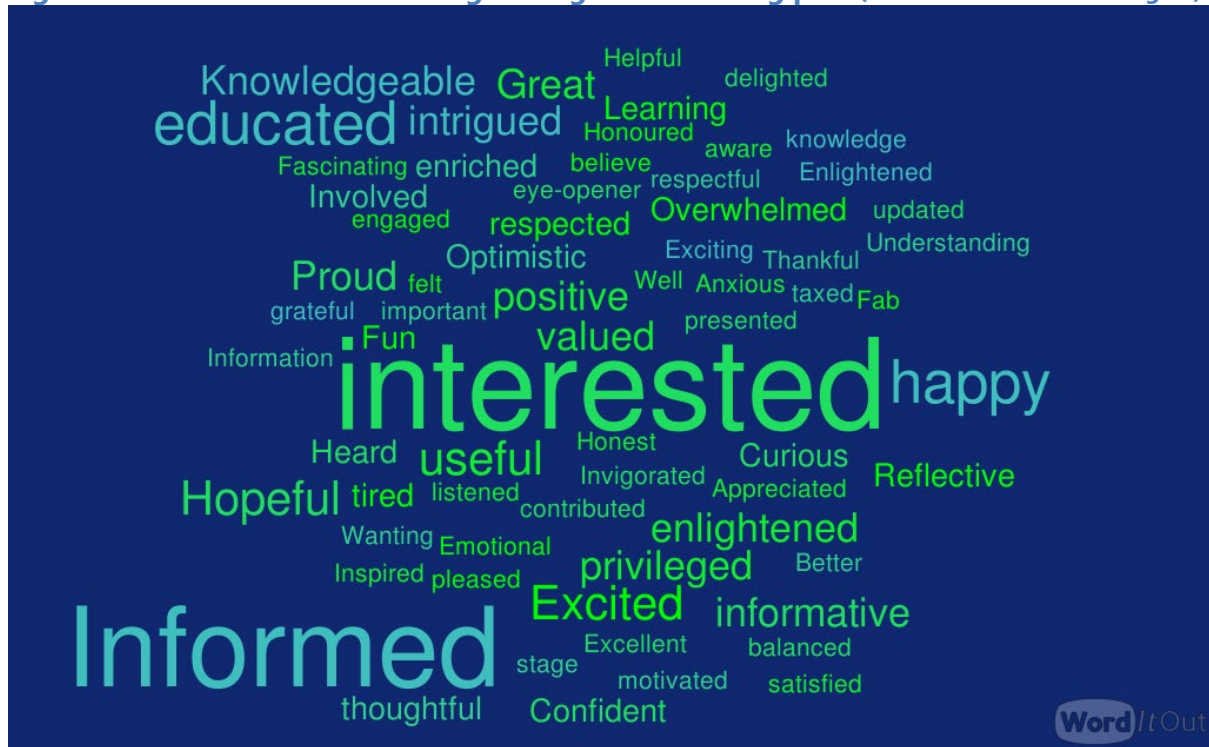
- *"[participant’s] level of insight and reflection and ability to make very good inferences about what implications research might have."*
- *"Glimpse into how our research may be perceived by a larger audience."*
- *"Awareness of wider public views on EHE – being able to explain the type of work I do to non-specialists."*
- *"Listening to discussions as they are happening and understand the thinking process and how views evolved."*
- *"To see the desire of the public to participate in this sort of consultation."*
- *"And their desire to be informed."*

2.5 Increased public interest in being involved in this topic

- Almost all participants were enthusiastic about their role in informing HDBI research and future governance. As highlighted in the short video, word cloud below and feedback comments in *Annex C*, participants took their role very seriously.
- Everyone enjoyed the experience and learning about a topic that most previously knew very little about but that seemed so important to them.
- Many participants found the journey emotional – particularly those who had lived experience or had family and friends who had experienced miscarriage, IVF or serious birth conditions – but few found it overwhelming. Only a handful needed to take advantage of the emotional support on offer (see *Section 3*).
- Those that had concerns about EHE research felt comfortable enough to express them, even where these were not the majority view. These individuals felt that other participants were listening: *"it felt like a proper conversation"* and *"they really seemed to want to hear our opinions"* and that that HDBI were also *"really listening."* The constant presence of scientists from the HDBI team helped participants see them as approachable, well-intentioned and created very high levels of confidence that their suggestions would be listened to.

A participant from the southern group was quoted in the Babraham Institute blog and [Science Magazine](#) advocating for this public dialogue as the start of a wider conversation: *"I do think that an extension of this public dialogue, and educating wider society has a benefit in itself. This is really complex and sensitive and the wider you talk about it before decisions are made, the better."*

Figure 2.1: Three words describing feelings about taking part (most common shown largest)



2.6 Comparing the dialogue costs with potential economic benefits

Dialogue costs

- The total financial cost of the dialogue was £162,699 (excl. VAT) which covered the design, recruitment and thank you payments to participants (£350 for online and £400 for the general public workshops for attending all sessions), venues, catering and travel costs for face-to-face workshops, and analysis, reporting and the independent evaluation.
- The budget included resources for a professional filmmaker to make a short video of the process to be shared on YouTube. This budget was also used to develop some high quality short videos as stimulus materials.
- UKRI Sciencewise contributed £93,974.50 (excl. VAT and including all the filming costs) while HDBI contributed £68,724.50 (excl. VAT) plus in-kind costs of £18,000 in staff costs (including the time of the public engagement team and research scientists).
- The blended delivery approach with some elements delivered face-to-face and shorter sessions online helped get the most out of the available budget: it would have been difficult to get the mix of participants with specific lived conditions from all over the country together in one space so the online worked very well for this element, and likewise for the pilot session. Splitting the time for the north and south groups between

face-to-face and online enabled a larger number of participants from across the UK (including Northern Ireland and Scotland) to be involved than would otherwise have been the case.

- We estimate that, taken together, non-HDBI OG members and specialists contributed at least 24-30 additional days being filmed, attending meetings, preparing stimulus materials, attending workshops and reviewing documents. Valuing this time at an opportunity cost of £500/day suggests an additional in-kind contribution of about 10% (£12-15K) on top of the financial budget.

Potential economic benefits

It is too early for the dialogue to have had any direct economic impacts. However, if HFEA and DHSC were to take the overall dialogue finding that most participants support EHE research and would be cautiously supportive of revisiting the 14-day rule (with caveats), that could help to support a case for reviewing the legislation with a view to "*ensure the UK remains at the forefront of safe and ethical fertility treatment and research*" as DHSC has signalled it intends to do (HFEA website).

EHE research already delivers potential economic benefits in the areas where it is currently focused. This includes helping to increase IVF success rates (currently 33% for patients aged 18-34 and only 4% for patients aged 43-50 in 2021)¹⁴ and helping to reduce the rates of miscarriage (estimated at a 25% probability at four weeks).¹⁵ Many participants in the workshops expressed strong hopes that extending EHE research could improve these outcomes. In improving IVF success rates they also hoped that treatments would become cheaper and more widely available on the NHS (without the current restrictions based on postcodes, age and family situation). As well as benefitting families who cannot currently afford to pay for IVF privately, they expected to see savings for the NHS.

In the longer term the participants had high hopes that EHE could lead to breakthroughs in understanding the causes of serious birth conditions which develop at the earliest stages of human development (currently one baby for every 45 births¹⁶ is diagnosed with a congenital anomaly). Again their hopes were for early identification, treatment or prevention of congenital cardiac anomalies and neural tube defects like spina bifida. They felt better patient outcomes would also have direct economic benefits for the NHS.

¹⁴<https://www.hfea.gov.uk/about-us/publications/research-and-data/fertility-treatment-2021-preliminary-trends-and-figures/>

¹⁵<https://www.nct.org.uk/pregnancy/miscarriage/miscarriage-your-questions-answered>

¹⁶<https://digital.nhs.uk/data-and-information/publications/statistical/ncardrs-congenital-anomaly-statistics-annual-data/ncardrs-congenital-anomaly-statistics-report-2020>

3. Lessons on factors which allowed objectives to be met

3.1 Overview




- The dialogue has successfully met all three of its primary objectives (see *Table 3.1*).
- Key factors which helped deliver a high-quality process were: a large, diverse and very engaged OG; the efficiency and experience of the core management team; the time commitment and topic expertise contributed by HDBI related scientists and other specialists; and the blended delivery design which balanced reach (70 diverse participants with a range of relevant lived experience and attitudes) with depth of deliberation in settings suited to such a sensitive topic.
- The overall design, interest in the topic, welcoming environment created by the facilitation team and staged thank you payments all helped achieve extremely high retention rates in all groups. The final workshops - held in person with an overnight stay in Newcastle or London – helped participants and specialists feel at ease with each other. All enjoyed finally meeting face-to-face and we noted the effect this had in energising discussions around this complex and emotive subject, while challenging each other respectfully.

3.2 Lessons on good practice principles

A large and diverse OG (about 20 members) brought together expertise from EHE science, social science, governance, patient representatives and think tanks to ensure a balanced framing with all perspectives represented

- The novel approach of appointing two co-chairs (a research scientist and an ethicist) worked well in several ways: it allowed more flexibility in scheduling meetings at the most appropriate point in the process; ensured that ethical and societal concerns balanced out more pro-science perspectives; and added extra capacity to follow up with the quieter members of the group to make sure they were getting heard. Time invested by the secretariat in planning the agendas and briefing the co-chairs helped ensure that the large online meetings were useful and all viewpoints were heard. At the first meeting the group identified the need for an historical perspective and recruited accordingly.
- The OG’s insights were invaluable in shaping the overall framing, the recruitment sample and advising how to bring in more challenging voices (e.g. strong religious views) without having a forceful presence in the room which might disrupt the workshops. In this case they advised pre-filming a presentation with a representative of a Christian think tank so that participants heard the perspective but did not feel obliged to agree with it.
- Two thirds of the OG members also contributed directly to the public dialogue workshops as specialists sharing information or their own reflections via short, pre-recorded video, PowerPoint presentations or answering questions online or in the room.
- The delivery team and commissioners really appreciated the active role and time the OG invested, while their up-close view of the workshops and what the participants said helped them appreciate the nuance and richness of the findings. Overall, the OG members interviewed felt it had been a robust process, their time invested had been commensurate with what they got out of it, and that the final report would add real value to the field. They felt that policy makers and researchers could treat the findings with confidence.

Table 3.1: How the dialogue met its objectives

Objective	How it has been met	
Develop a holistic understanding of participants' views of the societal and ethical issues around human developmental biology research	 Fully met	<p>The scope of discussions was broadly framed to cover short and long term applications (which proved more challenging), classic embryos and SCBEMs and potential benefits and risks. Filmed segments with individual researchers helped participants understand what they hoped could be achieved through their research.</p> <p>As the design built from a webinar through workshops 1 and 2, all participants heard the same information from specialists and were able to acquire enough knowledge to feel informed to discuss the societal and ethical issues associated with the research. Participants appreciated being able to review the scientific presentations and videos between workshops at the Recollective site.</p> <p>We noted that, despite the complexity of the topic, they developed nuanced views relatively quickly, and ethicists were able to highlight other ethical/societal issues for participants to consider. They quickly took them on board and terms such as ensoulment and slippery slope became common parlance.</p>
Identify participants' views of the research questions¹⁷ and outcomes of human developmental biology research that reflect societal priorities	 Fully met	<p>The long list of research questions (see footnote) was skilfully woven into the design of individual sessions with some topics introduced through formal presentations or case studies and others raised by specialists during plenary sessions and reflections.</p> <p>Time spent developing and refining stimulus materials and testing the design flow and prompt questions (at the pilot) helped ensure that all topics were covered.</p> <p>Harms, benefits, implications for future research directions (including red lines) were discussed in workshops 2 and 3 while regulation and the 14-day rule was discussed in depth in the final 2 workshops.</p> <p>Prioritising research with immediate health care benefits (IVF, miscarriage, conditions that emerge in early childhood) surfaced as widely shared priorities: however, many had serious concerns about the implications that successful research might have in eliminating liveable conditions (such as Downs). Most participants were cautiously in favour of revisiting the 14-day rule, albeit with caveats and suggestions for future governance.</p>
Enable scientists and public participants to engage in a constructive dialogue to hear, reflect, consider and respond to issues around the research.	 Fully met	<p>Purposive recruitment resulted in a good mix of 70 participants both reflective of UK demographics and of different viewpoints including religious beliefs and attitudes to EHE research. They heard from some 26 specialists (14 scientists, 6 social scientists, 3 patients, 3 regulators/Governance experts) and the face-to-face workshops afforded lots of opportunities for them to meet and interact in person.</p> <p>The facilitation style, attention to pre-briefing on the use of sensitive language, consideration of the best way for specialists to contribute (via video, online or in person) all helped create a comfortable atmosphere where participants felt confident to challenge each other and ask questions of specialists. The public were delighted to hear about the specialists' research and realise that they had the public good at heart as opposed to 'rogue scientists' they had read about in the media.</p> <p>10 HDBI researchers played a really active role (making 14 appearances over 7 workshops): in evaluation feedback and in their comments in press releases and on social media almost all reported how much they valued the chance for constructive two way dialogue: "<i>Most important is having a conversation (i.e. not just speaking at the public, but it is just as important, if not more, to listen).</i>" (HDBI Researcher, BI blog) and "<i>True two-way discussion and insight</i>" (HDBI Researcher, online survey).</p>

¹⁷ What do participants perceive to be societal implications of research with early human embryos? What ethical questions do participants raise around research with early human embryos? What implications / applications of research with early human embryos are most important to participants? Where should scientists be focusing in this area? What should the future of embryo research in the UK look like? What do participants think about the trade-offs for possible medical/healthcare implications of this research and where do the red lines exist? How does the 14-day rule factor into their thinking about possible outcomes? How do emerging alternative research models in this field affect their views?

A comfortable timeline allowed plenty of time for stakeholder consultation, piloting and materials development without last minute rushes (e.g. in recruiting participants and specialists, or signing off designs or materials).

- **Stakeholder interviews during the scoping stage, use of a shared whiteboard for planning out the design and an efficient HDBI team helped to identify the types of expertise needed well in advance.** This made it possible to involve dozens of specialists from very different perspectives in sharing information with participants over the course of the online and face-to-face workshops. As noted below participants mainly found their inputs very helpful and did not seem overwhelmed by the number they met.
- **The design overall benefitted from an early meeting with HDBI's Insight Group** (a small group of patients and those with lived experience). This provided useful pointers towards the types of questions participants were likely to need answers to and avoided insensitive language (such as 'birth defects' rather than 'conditions'). We observed – and participants agreed - that the materials and presentations struck the right tone and avoided causing upset.
- **Recruiting in good time allowed some presentations to be reviewed in advance** to ensure they were pitched at the right level, used sensitive language, avoided jargon and didn't overrun.
- **Time and budget allocated to a small pilot (9 participants from mixed background across the country) helped ensure that timings, the framing of questions and flow were tested in advance:** the online workshops with lived experience participants gave a second chance for final amendments (e.g. in making a presentation on SCBEMs less complicated) before the general public groups. In this case the pilot sessions also generated interesting findings that were incorporated into the final analysis.
- **The timeline allowed almost all the stimulus materials to be thoroughly reviewed by the OG for balance and accuracy.** In the one case where there was not enough time, a few errors on different regulatory approaches around the world slipped through but specialists were able to pick this up and correct the error in the room.
- **A dedicated share site (Recollective) served several purposes** – as a repository for all the information shared with participants, and as an opportunity for individuals to share further reflections, beyond what they said in small groups. The site enabled those that wanted to review what they had heard and to digest other pieces of information (such as audio clips of interviews and answers to questions asked in previous sessions) in their own time. Generally participants found the site useful and had the time and enthusiasm to complete short homework tasks. This added to the overall richness of the data and analysis.
- **The timeline allowed enough time for coding and analysis of the huge volume of evidence collected from online and face-to-face meetings.** The team had time to share the emerging findings and a proposed structure with the core team and then take the time needed for further analysis. The result was a high quality first draft of the report and a very smooth process of editing and final sign-off.
- **Time and budget for preparing stimulus materials** – including a filmmaker embedded in the team – allowed information to be shared in many formats without overwhelming participants. The resulting mix of videos, infographics, wall poster, PowerPoints helped participants gain the knowledge they needed, kept them interested and prevented most from feeling overwhelmed.

- **The decision to allocate budget for an experienced filmmaker meant that much of the stimulus material could be pre-filmed.** The resulting high-quality videos allowed specialists to share information (their hopes and concerns for the science, their reflections on ethical issues and regulation) in the way deemed most appropriate for the participants.
- **This allowed views that were likely to be very emotive (such as those of patients with experience of IVF and miscarriage) or strong religious views to be heard without participants feeling under pressure** to empathise and agree with their viewpoints' simply because they were in the room. This has produced legacy materials which could be repurposed after the dialogue for further HDBI engagement (see *section 2*).
- **Having videos ready in advance also had benefits in ensuring that participants all heard the same information,** could review it before or after each session, while ensuring that presentations didn't overrun and encroach on small group discussion time.

Sensitive facilitation and duty of care to participants

- **Each cohort benefitted from a lead facilitator and a small team of experienced facilitators** (1:7 participants) able to provide complete continuity over all four workshops. Groups visibly felt comfortable in the warm atmosphere the team created and gelled quickly both online and face-to-face.
- **Facilitators benefited from a good understanding of the topic and where each individual was coming from** (in terms of starting attitudes to EHE research and religious convictions) so that they were able to probe sensitively into the meaning behind what individuals said and bring conversations back on track when needed.
- **All participants found facilitators professional, independent and empathetic** and unanimously agreed that they had been treated with respect: almost all felt they had been able to make their voices heard. Specialists also praised the productive and inclusive environment that the facilitators created.
- **We observed a good mix of people including those with strong religious convictions and a mix of starting views on EHE Research.** As noted in section 1 the recruitment brief purposively recruited more than half of general group on the basis that they were practising Christians, Muslims, Jews, Hindus or Buddhists. A wall chart summarised how different world religions viewed EHE and ensoulment: in talking around this topic many participants were comfortable to share their own religious views (including in the final vox pop video).
- The group also included a mix of starting attitudes to EHE research (half supportive and a quarter each opposed or neutral) and Menti polling tracked how these views changed over the course of the process. A few specialists reported that they had expected to hear stronger opposing voices in the final workshops. However, we noted that many of those who started out strongly opposed to EHE research shifted their position as they heard more and negotiated with each other. A few were staunchly opposed throughout but were mainly comfortable in expressing their views, even where they were different from most others in the room. In just one case, where facilitators noted an individual feeling uncomfortable in their group they responded by mixing up the groups so that the individual would feel more at ease sharing their opinions.

- **Many specialists noted the respect participants showed to each other** and this was highlighted by one OG member when interviewed for a press article: *"I commend the participants for the care and mutual respect they have shown throughout. Their engagement and commitment to a subject few of them had previously considered allowed for a wide range of views to be expressed and considered"* (OG member quoted in Science Magazine article).
- **The attention paid to ensuring that support was in place for anyone who found the subject emotionally distressing was deeply appreciated by participants.** All participants strongly agreed that different options for getting support (including taking a breather during the workshops or talking to the lead facilitator, one of the support organisations listed in the participant pack or to the independent counsellor they had met at the initial webinar) was comforting. About a fifth took time out at some point and some talked to their facilitator but other options were not needed (see *Annex C*).

The enthusiasm and time invested by the HDBI team really enriched the process

- **A very efficient project management team supported a large group of HDBI researchers (10 across all career stages from principal investigators to postgraduates) who committed significant time to the process.** Filmed in their labs, they shared information on their research, their motivation and positions on the 14-day rule, and attended both online and face-to-face workshops. Both those attending as specialists and observers answered participants' questions during online and face-to-face sessions. The core team invested a lot of time in providing written answers to be shared on Recollective (in retrospect this could probably have been streamlined as some groups asked the same questions repeatedly).
- **The energy that the HDBI team put into the process produced real benefits in helping to understand the research in its lab and wider societal context.** Being able to visualise the research appeared to contribute to many participants being ultimately more concerned about the societal outcomes of the research than how it was undertaken (see *Section 2*).
- **Many participants said the chance to meet scientists and talk with them on an equal footing was a highlight of the process.** Contributions from younger/early career scientists who might not normally have been involved worked particularly well: participants enjoyed hearing about their passion and hopes for the work and found them approachable. And as noted in *Section 2*, they found it really encouraging to here that the public was interested in their work.
- **In general participants were fascinated to hear about the groundbreaking research and heartened to realise that the scientists were normal people with the best intentions** (in contrast to some of the rogue international scientists being covered in the media). *"Really helped to address perceptions of unfriendly scientists – could see that they are not 'playing God' but real people."* Indeed, hearing how seriously HDBI researchers thought about ethics may have been a key factor in the overall shift towards cautious support for extending the 14-day rule.
- **A few scientists wondered whether participants had been given enough basic science grounding,** but we observed that in fact participants had more than enough information to cut through to the implications and started to ask salient questions from the very first sessions.

- **By the end almost all participants felt they had heard a full range of perspectives,** including from those most likely to benefit or with the greatest concerns about the research. Specialists agreed that "*it was important to show broad perspectives - both extreme for and against views – as well as more nuanced views in between.*"
- **A small minority of participants felt it would also have been interesting to have more representatives of different religions or scientists opposed to extending the 14-day rule in the room.** Despite the core team's best efforts, it proved difficult to find individuals happy to present these views but most participants and specialists found that the ethicists/philosophers in the room were able to bring these perspectives to the discussions. In recognition that they wanted to hear from scientists too, the HVM team adapted the final day design to allow all the specialists in the room to share where they personally stood on the 14-day rule and why.

Within a modest budget, the blended delivery approach achieved a good balance between breadth of numbers, diversity and depth of discussions

- **Recruitment methods (free find and a specialist recruitment agency working with charities) worked well to deliver a challenging brief.** This included a balance of ages, genders, socio-economic backgrounds, individuals from communities which experience racial inequalities (CERI), experience of relevant health issues, religious beliefs and attitudes towards science and knowledge of the relevant regulations. The achieved sample reflected this complex mix. Specialists interviewed told the evaluators that they appreciated the opportunity to talk to people from such broad backgrounds: they largely felt the groups represented the diversity they had hoped to see. As one specialist remarked "*it was particularly good to have that mix of participants – rather than those with prior interest or self-selected that we usually see in scientific engagement with the public.*"
- **The decision to run the lived experience group as effectively a parallel mini dialogue paid off:** it allowed the participants more space to discuss their own experience without making the general participants feel uncomfortable. The approach also made it easier to analyse findings to understand whether those with direct lived experience of IVF, miscarriage and as patients/carers of those with relevant conditions held similar or different views to the general public groups (as suggested by PET's quantitative survey). In the event their attitudes were more similar than had been expected.
- **Some online participants found the final session (6 hours online on a Saturday) over-long** and found that questions that worked well in person appeared a bit repetitive online. Several specialists also noted that "*some [open] questions were asked many different ways and some participants got a little tired of it.*" In retrospect this session could probably have been reduced to half a day.
- **Participants, specialists and facilitators appreciated the more lively and informal nature of the face-to-face workshops.** The weekend sessions allowed space for a variety of techniques for capturing participant feedback (carousels, pairs, panels, participants feeding back) and more informal discussions which created an energy that both participants and specialists enjoyed. Participants also noted: "*Having scientists and specialists milling around in the room really made it feel like a dialogue.*" Specialists also enjoyed their role in the room and took the chance to talk to participants informally (although a few would have appreciated a clearer role: "*being able to pull up a chair to*

small groups rather than “hovering on the outside”). Junior researchers particularly appreciated hearing how interested the public were in their work.

- **The core team were alert to the risks that a public meeting on such a contentious subject could have attracted organised protest and planned accordingly.** Plans included the choice of low-key venues outside city centres; details only shared directly with participants; and nominating a team member with an agreed approach to how they would engage constructively with any protesters. On this occasion the events did not attract any attention, but it was important to have risk mitigation plans in place. The first venue in Newcastle (Friday night) proved less than ideal in terms of acoustics, catering and location, and this was one of the few areas where participants suggested things might have been done differently (see *Annex C*). Fortunately, the team was able to find a more central and comfortable venue for the final workshop. The same point was made by participants in London, but was less of a problem and did not need a change of venue.
- **The facilitation team used a variety of effective techniques for capturing participants’ views during both online and in the face-to-face sessions** so that the participants could check what was being said, build on each other’s thoughts and understand what others in the room were thinking. A mix of visible notes taken on shared screens/flipcharts or interactive whiteboards, and exercises to capture individual thoughts (post-it notes, chat function and homework tasks) and eVoting were used to good effect. Participants enjoyed the process of eVoting (Mentimeter) which helped lead facilitators to sum up the sentiment in the room at the beginning and end of sessions: the tool worked equally well on Zoom and in the room.

4. Conclusions and recommendations

4.1 Conclusions

This foundational dialogue was well-designed and efficiently delivered over a short time scale in order to provide insights about the participants' hopes, concerns and suggestions for future regulation of EHE research. The findings add depth and nuance to previous qualitative and quantitative research in this area.

- The dialogue benefitted from the experience and empathetic style of the design and facilitation team, engagement of the OG and effectiveness of the core project management team.
- The blended delivery approach achieved was effective and created the conditions to recruit a larger number of more diverse participants and share information and discuss sensitive topics in the most suitable setting.
- The careful design, intensive involvement of specialists, pleasing mix of stimulus materials, ample time for small group deliberation both online and in person, and effective use of online tools (Zoom, Recollective, Menti polls) contributed to the primary objectives being fully met.
- A well-thought through and coordinated dissemination and communication strategy has also enabled the public dialogue report and its findings to reach a wide audience through HDBI researchers, OG members and national and international press.
- In due course, the dialogue has the potential to inform the wider policy debate around whether the HFE Act - and specifically the 14-day rule - is fit for purpose, and how EHE research should be regulated for the public good in the UK and internationally. The coverage that it has attracted in the press suggests that this first dialogue on the topic is already contributing to a wider conversation.

4.2 Recommendations for future dialogues

For commissioners

Procurement, timetabling and sign-off

- Allow a realistic timeframe for all stages. In this case time spent in scoping, staggered field work and ample time for analysis meant that the sign off process was very smooth.
- Look for opportunities for cost-effective follow-on dialogues if opportunities arise. In this case, Sciencewise was able to respond quickly to secure a small contract extension with the same delivery contractor, evaluator and group of participants.

Governance arrangements

- Plan for the time required to convene a large Oversight Group and consider whether face-to-face or online meetings will work best according to the nature of the topic, the number of times people are meeting, the length of time for meetings and where people are located.
- If it is important to involve participants with different religious views in a dialogue, ensure that the meetings are scheduled at times that will be appropriate for them. In this case a Friday evening/Saturday schedule allowed those from all major religions to take part but may have prevented those from more orthodox backgrounds being involved

and a larger national dialogue (e.g. to inform changes to the HFE Act) may need to organise some sessions at different times or different formats to include all views.

Maximising policy and research impact

- Having commissioners in the room throughout the workshops increases trust in the process and confidence that the key messages will be taken into account. In this case some 10 HDBI researchers were actively involved and found hearing directly from the public very beneficial to their work.
- Make the most of the budget for filming a final video to capture reflections from the commissioners as well as participants. This is likely to be a useful resource for the sharing messages from the dialogue and for sharing at any dissemination or future engagement activities (e.g. with funders, policy makers or press). In this case the video was not ready to share at the press launch but generated a second opportunity for social media comms several months later.
- Consider sharing the dialogue report through other formal routes (e.g. in this case via the Parliament library) so that the findings are available to inform a national conversation rather than influence a policy process directly.
- Consider whether the findings on substance or process can be shared more widely with academic audiences and, if so, encourage suitable OG members or specialists to author articles for a peer-reviewed journal.

For delivery contractors

- Think carefully about whether a mix of face-to-face and online elements can work together to get the best out of both delivery formats. Consider which format works best for the topic, group size and locations. In this case an initial online webinar worked well for information sharing and ending with in person sessions suited the remaining tasks and topics to be discussed and gave a sense of closure. In other cases an opportunity to meet in person, might create value in establishing a rapport and sense of group identity that will last throughout a process.
- Consider the pros and cons of running a dedicated online share space alongside the workshops (to share materials, collect individual reflections, answer questions).
- Consider different formats for stimulus materials including videos, infographics, live presentations, panel discussions etc. In this case filming in the lab really helped bring the research topics alive for participants.
- Wherever possible build in an online pilot stage with members of the public to test timings, materials, flow and identify questions which will need to be answered.
- If the topic is contentious enough to attract public protest, think about what mitigation measures will need to be in place to manage the risks.
- Consider pre-filming some specialist inputs as one approach to allowing participants in different groups/locations to hear the same information and to bring in perspectives that might make participants feel uncomfortable in the room/Zoom.
- Ideally consider a lead facilitator for each cohort to help create a welcoming environment, forge a group identity and active management of specialist inputs and final plenary sessions. Aim for continuity in the facilitation team for all workshops in a specific location.

- Consider whether the topic might be emotionally upsetting to participants and, if so, build in support options (such as opportunities for time out, talking to an empathetic listener or a trained counsellor) which will be comforting to participants, even if they are not needed.
- Use a mix of techniques during online meetings to capture participant views as a group (e.g. visible note taking on interactive whiteboards) or individually (e.g. chat box and eVoting).
- Allow plenty of time for analysis and report drafting: time spent on coding, agreeing a structure and the overall narrative can help streamline the drafting and sign-off process.

Annex A: Oversight Group Members

Name	Role(s)	Organisation(s)	Expertise
Bobbie Farsides	Professor of Clinical and Biomedical Ethics	Brighton and Sussex Medical School	Bioethics
Robin Lovell-Badge	Group leader	Crick Institute	HDBI related Research
Ros Williams	Lecturer in Digital Media Society	University of Sheffield	Sci Tech and Medicine in Society
Georgie Ariaratnam	Public Engagement Expert	Crick Institute	Public Engagement
Nick Hopwood	Professor History of Science and Medicine	University of Cambridge	History of Science, in particular, History of Embryology
Emily Jackson	Professor of Law	LSE	Law
Sarah Norcross	Director/Deputy Director	Progress Educational Trust	Policy
Sarah Franklin	Professor of Sociology and Director	University of Cambridge	Sociology
Kathy Naikan	HDBI, Group leader	Crick Institute	HDBI Research
Marcin Smietana	Senior Research Associate	Cambridge Reproduction	Queer Studies
Alessia Costa	Post Doc Social Scientist	Wellcome Connecting Science	Bioethics
Clare Ettinghausen	Director of Strategy and Corporate Affairs	HFEA	Policy
Angharad Thomas	Head of communications		
Subhadra Das	Researcher and storyteller	Independent	History of Science
Peter Rugg-Gunn	HDBI Science Lead, Head of Public Engagement and Group Lead	Babraham Institute	HDBI Research
Danielle Hamm Ranveig Berg Rebecca Mussell (Peter Mills for OG1)	Director Research and Policy Manager Associate Director	Nuffield Council on Bioethics	Bioethics
Haidee Bell	Public Participation Lead	Wellcome	Funders
Sarah Dickson	Head of MRC Regulatory Support Centre	MRC	Funders
Catherine Hill Sharon Martin	Interim Chief Executive Business Development Manager	Fertility Network UK	patient group
Felicity Boardman	Deputy head of the unit Social Science and Systems in Health.	University of Warwick	Disability Studies
Sarah Milosevic	HDBI Public Insights Group	Independent	Person with lived experience

Specialist contributors to the dialogue via film or in person

Speakers: name and institution	Topic
Amy Wilkinson, Babraham Institute	Regulation Panel Discussion: Researcher perspectives day to day research
Bobbie Farsides, Brighton & Sussex Medical School	Speaker panel: regulation and ethical reflections on Q&A
Claire Ettinghausen, HFEA	Present on current regulatory system, role of HFEA & respond to questions in the zoom chat

David Jones, Anscombe Bioethics Centre	Regulation Panel Discussion: Catholic Bioethics perspectives
Desislava Staneva, Cambridge University	Regulation Panel Discussion: Researcher perspectives: setting up a project
Emma Rawlins, Gurdon Institute, Cambridge University	Reminder of types of research & how the research is done
Elizabeth Robertson, Oxford University	Contributor to video on personal reflections on EHE research
Emily Jackson, LSE Law School	Contributor to video reflecting on regulation of EHE
Felicity Boardman, University of Warwick	Regulation Panel Discussion: Ethical/societal considerations
Katarina Harasimov, Cambridge University	Present on Embryo Part 1: Size, vs foetus etc. and responded to questions in the chat
Kathy Niakan, Cambridge University	Researchers: Q&A resource/observing
Katrien Devolder, Oxford University	Regulation Panel Discussion: philosopher and bioethical considerations
Mag Aushev, Newcastle University	Present on Embryo Part 1: Size, vs foetus etc. and respond to questions in the chat
Mateo Mole, Babraham Institute	Contributor to video on motivations for carrying out EHE research
Natalie Silverman, the Fertility Podcast	Contributor to videos on personal reflections on EHE and its regulation
Naomi Clements-Brod	Introduction to HDBI and the purpose of the dialogue
Naomi Morris, Crick Institute	Embryo part 2: alternatives & how used e.g. Stembrzyoids.
Peter Rugg-Gunn, Babraham Institute	Present on What is human developmental biology and case studies of different types of research.
Peter Thompson, HFEA	Present on current regulatory system, role of HFEA & respond to questions in the zoom chat
Robin Lovell-Badge, Crick Institute	Reminder of types of research & how the research is done and regulation panel discussion
Sarah Chan, University of Edinburgh	Speaker panel: bioethics prompts and reflections
Sarah Milosevic, HDBI Public Insights Group	Contributor to video on public reflections on EHE research
Seeta Salva, Fertility patient	Contributor to video on personal reflections on EHE research
Stephanie Ellis, chair of Cambridge Central Research Ethics Committee	Contributor to video about governance arrangements for EHE and SCBEM research
Venessa Smith, Guys & St Thomas'	Regulation Panel Discussion: Perspective of consenting process for embryo research

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

How design and delivery has helped to deliver the dialogue objectives	
Key elements of design and delivery	Reflections on what worked well, what less so and lessons learnt
<p>Project management and governance arrangements helped with a broad framing reflecting the fast changing context, but also focused on meeting the dialogue objectives</p>	<ul style="list-style-type: none"> Project management team and Oversight Group agreed a framing which would provide a broad background understanding of early human development, how embryos are currently used (in both research with short term potential to affect health outcomes and longer term blue skies research to increase knowledge). Agreed to also devote some space to discussing stem cell based embryo models (SCBEM) which were being widely reported in the media. Amendments suggested by the OG (after OG2) and in piloting (with 7 members of the public at 3 x 2 hour online workshops) were taken into account so that the overall structure and design enabled participants to gradually build their understanding of the science and explore their aspirations and concerns for future use of EHE research. Discussions around blue skies research proved more challenging for participants until they were given examples of how extending beyond the 14 day rule into the black box period (14-28 days) might benefit conditions such as spina bifida.
<p>A good mix of stakeholders involved throughout the process</p>	<p>The design used a number of devices to bring in a range of perspectives including exposing participants to perspectives of those with very strongly held concerns or aspirations for EHE research, without putting them under undue emotional pressure to emphasise with any particular view.</p> <ul style="list-style-type: none"> A large and diverse OG actively involved in framing, reviewing materials. At least 8 were also involved in sharing information and perspectives with participants. Interviews with stakeholders including research scientists, clinicians, ethicists, those involved in regulation and patients who have experienced IVF and miscarriage. A number of OG members were included. Different perspectives embedded in information shared with participants <ul style="list-style-type: none"> pre-recorded videos of patients with lived experience (of IVF, miscarriage, deciding whether or not to donate embryos) helped participants understand their hopes and concerns without putting them under any emotional pressure to support EHE research as they might have felt if they had been in the room. presenting the range of religious perspectives on EHE and when life begins in an infographic (on Recollective and as a wallchart) allowed for objective discussion about different views a pre-recorded video with David Jones of Anscombe Centre allowed him to present his beliefs without dominating or derailing discussions. Only one participant said that they would have liked to hear these views presented in the room. Participants mostly felt they heard the range of perspectives they wanted to and specialists felt <i>"It was important to show broad perspectives - both extreme for and against views - as well as more nuanced views in between"</i> but some participants would have liked to hear from more religious representatives and scientists who did not believe in EHE but they proved difficult to identify or recruit within the timeframe. Purposive recruitment included sampling questions on knowledge of HFEA and the HFE Act and attitudes towards early human embryo research. This also included recruitment of one cohort of participants with lived experience (of IVF, miscarriage, caring for

	<p>or having serious health conditions) and a proportion across all cohorts who held strong religious beliefs. This helped to ensure that a range of underlying values were present in the room and throughout the small group discussions. We noted that individuals were confident to share their religious views while respecting those of others.</p>
<p>A hybrid process added real value in both involving larger numbers of participants while also benefitting from the different nature of conversations in the room</p>	<p>The blended delivery approach allowed relatively high numbers and geographic spread for the overall size of the budget, while allowing all participants to hear the same background information and most to also benefit from meeting each other and specialists in person.</p> <p>The length and timing of workshops was convenient for most (>90%) participants</p> <ul style="list-style-type: none"> • online session timings and length (weekday evenings) and spread over several weeks so that participants would not be overwhelmed worked well for all (one specialist presenter found the evening sessions difficult in terms of childcare). • A number of the lived experience group found the Saturday session (6-hours online) over long and the wording of some questions which worked OK in person rather repetitive online. A few – particularly those that had travelled far – found the Friday evening sessions finished too late. • Participants had time – and almost all used opportunities -for individual deliberation on the Recollective site between sessions. <p>The design of final workshops allowed plenty of time for deliberation, but some sessions felt a little repetitive</p> <ul style="list-style-type: none"> • The F2F weekend sessions allowed space for variety (carousels, pairs, panels, participants feeding back) and more informal discussions which created an energy that both participants and specialists enjoyed: <i>“having scientists and specialists milling around in the room really made it feel like a dialogue”</i> <i>“really helped to address perceptions of unfriendly scientists – could see that they are not ‘playing God’ but real people.”</i> • All specialists responding to the survey felt there was enough time to discuss the issues properly and most participants agreed • A number of the lived experience participants found the final workshop session a bit repetitive and a few specialists also felt that <i>“final day of deliberations seemed to be a bit repetitive in nature”</i> with several noting <i>“some [open] questions were asked many different ways and some participants got a little tired of it.”</i> and another wondering if the prompt questions (particularly around expectations) could have been more directed and less open. • We observed that both participants and specialists really valued the opportunity to talk more informally to each other in the room and this helped the small groups work together to identify priorities. Meeting scientists over breaks and as they wandered around the room really helped to cement the trust that most participants said they felt in scientists by the end of the process. <p>Effective use of technology</p> <ul style="list-style-type: none"> • Zoom meetings were very well managed with the Lead Facilitator welcoming participants in and checking their audio and camera and a dedicated tech support member of the team on hand to ensure everything worked smoothly. • Online tools such as Mentimeter (for in workshop polling) and Recollective (shared micro site) were used to good effect during both online and F2F elements. <p>Some additional organisational challenges involved in meeting face to face</p> <ul style="list-style-type: none"> • The potential that a public meeting would attract picketing/ protest by religious groups required was well anticipated and addressed through: careful choice of venues; invites only shared with participants; and nominating a team member with an agreed

	<p>approach to engaging with protesters if necessary. On this occasion the event did not attract attention but it was important to have planned for it.</p> <ul style="list-style-type: none"> • However, the low profile community venue selected in Newcastle was not ideal (double-booking for the Saturday, location which made some participants nervous, catering and acoustics) but issues were quickly addressed (finding a more central location, laying on taxis etc.) but inevitably some participants share negative comments on accommodation and refreshments in their evaluation feedback.
<p>Involving a diverse and inclusive mix of participants who were satisfied with having taken part</p>	<ul style="list-style-type: none"> • Free find methods used to recruit the two main groups to be reflective of the general UK population. This also included recruitment of one cohort of participants with lived experience (of IVF, miscarriage, caring for or having serious health conditions) and a proportion across all cohorts who held strong religious beliefs. A specialist recruiter working alongside charities proved effective for recruiting a smaller cohort (19) with lived experience (of IVF, miscarriage, serious birth conditions). • Additional sampling questions ensured a range of starting knowledge and attitudes about EHE and its regulation. The majority had heard of the HFE Act (58%, 41 had heard of it, 41%, 29 had not) and the 14-day rule (75%, 52 had not heard of it). About equal half were opposed to or neutral and half supportive of EHE use in research (15 strongly opposed or opposed; 17 neutral and 38 supportive or strongly supportive of it). The general population sample also included a majority of participants with some religious conviction (1 Buddhist, 12 Christians, 5 Hindus, 3 Muslims and 4 Jews) and 17 with no affiliation or who did not want to specify. The lived experience also included a small number (3) of participants who opposed EHE on religious grounds. • The resulting mix of 70 individuals (including the pilot) appeared reflective of UK demographics including gender, age, geographic locations, and communities experiencing racial inequalities (CERI). • The overall design, interest of the topic, environment created by the facilitation team and staged thankyou payments (£350 for online and £400 for the general public workshops) contributed to extremely high retention rates in all groups. • Scientists and other specialists appreciated the opportunity to talk with such a broad public: <i>"particularly good to have that mix of participants – rather than those with prior interest or self-selected that we usually see in scientific engagement with the public"</i> • Specialists who took part almost all found diversity as they expected (although 1 expected to see more directly opposed to EHE research). They all felt that participants seemed to understand how the findings would be used, certainly by the final workshops.
<p>Inclusive with relevant support provided for all those who needed it</p>	<ul style="list-style-type: none"> • Incentive payments plus travel expenses and subsistence for those travelling to Newcastle and London – and a full description of additional support available at the recruitment stage – was designed to ensure that no one was excluded on the basis of income or caring responsibilities (and informal discussions with the Northern group showed that this allowed a number of individuals caring for disabled family members to attend). • Online delivery of the lived experience group probably made it more convenient for participants with disabilities or small children to participate. • Digital onboarding was provided via an initial tech check-in and support provided to those who needed it. • A great deal of thought went into ensuring that support was available to those who found the topic emotionally triggering including: taking time out, talking to the lead facilitator, links to external support organisations, access to an independent counsellor (who attended the first workshops and was available during and after all workshops). All participants appreciated the forethought put into providing emotional support – even if few felt the need to use it.

<p>Diversity of views respected</p>	<ul style="list-style-type: none"> • Lead and small group facilitators created a very warm and positive atmosphere both online and in person and acknowledged the challenges of the topic and encouraged all participants to take part. <i>"All set an open and friendly tone with the feeling that people were being treated on an equal footing."</i> (Commissioner). • Participants unanimously agreed and so did most specialists that everyone was treated equally and with respect, and almost all felt that they had been able to make their voices heard. <i>"I got the feeling that the facilitators made the participants feel like they were really being listened to."</i> • Rules of Engagement/Ground rules presented in the intro sessions stressed there were no wrong questions, acknowledged people would have different views, and that everyone should be treated with respect. Facilitators were quick to remix one small group where an individual felt picked on because other group members perceived them to not be fully participating. • Documents prepared by HVM were easy read and in plain English and shared in advance at the Recollective site. • Time was also built in for review of scientists' presentations to ensure they were accessible, not too dense, avoided scientific jargon wherever possible and were conscious of language sensitivities (e.g. disease vs. conditions, 'throwing away' embryos, gender specific roles etc.). Preparing presentations in advance may have been a strain for many specialists but the HDBI public engagement team considered the resulting set of templates/exemplar presentations showing how to present to the general public is of real added value for future public engagement.
<p>Enough, fair, accurate and engaging information shared with participants.</p>	<p>Participants all had the chance to hear the same information from a similar mix of specialists. They found the Recollective site a useful space to preview and review information and for individual deliberation</p> <ul style="list-style-type: none"> • Advance documents were available on Recollective before the webinar and added to throughout the dialogue with materials for participants to review and discuss including short films, news articles, presentations, answers to questions raised during the dialogue and summaries of small groups discussions. The HDBI project management team put a great deal of effort in responding to unanswered questions between sessions and posting answers to the Recollective site. <p>Information was pitched at the right level so that participants felt informed without feeling overwhelmed</p> <ul style="list-style-type: none"> • High quality videos proved effective as stimulus online, offline and in the room. A number of talking head videos provided background information on the science and a variety of lived experience and other perspectives. Almost all specialists agreed that all the key issues seemed to have been covered in an appropriate way <i>"range of views presented well."</i> • High production values (filming with scientists in the lab) probably used more of the film maker's time than originally budgeted for, but the resulting videos were engaging for participants who found the lab footage powerful. • Specialists almost all agreed that participants seemed to understand and be able to use the information they heard: <i>"from the questions they asked it was clear participants understood most things"</i> and <i>"I think it was effective that they got their questions answered between sessions."</i> another that the Qs could have been better filtered, and that HDBI observers were a resource which could have been drawn on more to answer some questions in small groups. • Almost all specialists understood that the public does not need to have a full understanding of the underlying science in order to appreciate the wider societal and ethical issues involved: just one scientist told us they felt that the science was <i>"covered very quickly or distilled down to the extent that it left them with gaps in understanding – more time for real background (what EHE research does not just its applications) would have been helpful."</i> <p>Participants appreciated the considerable efforts put into helping participants get their questions answered</p>

	<ul style="list-style-type: none"> • Scientists were able to answer many questions in plenary or in small groups but there were fewer representatives on the regulatory side and many questions were raised on regulation and the donor consent process which could not be answered in the room • The HDBI team invested quite a lot of time and effort in getting all questions answered between sessions and posting answers on Recollective. Participants generally appreciated the effort but this did not stop some small groups repeatedly asking questions which had already been answered.
<p>Shared by a large pool of specialists representing different perspectives</p>	<p>A large number of specialists (28), including many from the HDBI team (10), were involved in sharing information in person or via video or audio clips.</p> <ul style="list-style-type: none"> • The project management team worked closely in identifying gaps/ perspectives/skills and backgrounds needed and drawing up a long list of potential contributors. The lead facilitator provided a verbal briefing and all presentations were reviewed by the HVM team. A few scientists reported finding the briefing on their role a bit vague compared to what they are used to – and preparing presentations in advance for review challenging! • Information shared by specialists at 34 different slots: 17 contributed live and 11 via pre-recorded video segments. Independent specialists included academics (research scientists, ethicists, philosophers, social researchers and IVF practitioners), those with experience of IVF and/or embryo donation, and those involved in regulation (HFEA, legal specialist and a Research Committee member). • The process created many opportunities for HDBI team members to have a two way discussion with the public about their work: 8 EHE scientists and 2 public engagement team - 14 sessions (live online and in person or via pre-recorded videos). • Scientists and regulators presented in person (recorded for review on Recollective): ethicists reflected on what they had heard and prompted discussions in small groups by introducing ideas that they might not have thought of. • A few specialists would have welcomed a clearer role at the face to face sessions: several would have welcomed <i>"more of a seat at the table in SG discussions so that they can hear and answer questions etc without feeling awkward or like eavesdropping."</i> <p>Some specialists felt that ethical and legal issues could have been presented more formally and given more explicit time in the discussions.</p> <ul style="list-style-type: none"> • Ethical views were shared in different ways including an audio clip (Insoo Hyun), talking head videos (Felicity Boardman, Stephanie Ellis, lived experience specialists) and by either an ethicist or philosopher present in the final workshops to sum up what they heard and suggest other issues or ways of looking at things that participants might find useful to consider. • We observed that this worked well in the room, and that participants liked the provocations and analogies shared (particularly in London) and we heard these points reflected in later conversations. However, during the online session participants may have found the feedback unstructured or hard to follow. • A few specialists had anticipated something more formal: <i>"perhaps I'd expected some presentations on a variety of ethical views"</i> and for explicit sessions rather than ethics permeating all discussions: <i>"I felt there was not so much time to discuss ethical issues."</i> While another would have liked to see more time given to topics such as when an embryo becomes human. • One observer suggested that more structured exercises could have helped tease out the issues (such as a gamifying scenario to stimulate discussions about the future and where the slippery slope might lead). • Time could have been saved and participants might have felt more satisfied if the 'blocker' questions were dealt with in plenary with the LF or HDBI observers sharing the answers, checking whether they were satisfactory, and if not what more was needed.

<p>Independent, professional and effective facilitation</p>	<ul style="list-style-type: none"> • A small group of facilitators (1 lead facilitator and table facilitators for each 7 participants) provided consistency in each location. • All specialists and the core team agreed that the facilitation was professional, independent and effective "<i>the facilitators were amazing! They managed to broadly keep the group on topic while making sure everyone got time to say what they thought.</i>" • The lead facilitators were particularly praised for the way in which they were able to probe into points of interest (so avoiding some of the criticism in other groups that prompt questions sometimes seemed repetitive). • We observed almost all participants became very engaged as they became more confident in the subject matter and expressing their own views. Many changed their minds several times as they negotiated with others and heard more from specialists and came to a nuanced set of views over the course of the dialogue. • We observed almost all participants happy to share their own experiences and views, even when they were different from others in their groups. In a few cases individuals with strong religious convictions were very clear that their views would not change but nevertheless were very engaged in the discussions: in only one case did we see an individual who felt they could not contribute because of an unwavering religious belief that EHE was wrong, but was nonetheless happy to listen. • Specialists were impressed by the level of interest and engagement: <i>"...remarkably engaged in the topic and seemed truly interested to hear more," "lots of discussion"</i> <i>"heard one who originally agreed to take part because of the money but had ended up getting really interested and invested in the topic."</i>
<p>Participants were satisfied with the process and felt that it was important to have taken part</p>	<ul style="list-style-type: none"> • Participants were generally very satisfied about having been part of the process • Most participants started with very little knowledge of the topic but became increasingly engaged • Participants involved and seemed to enjoy feeding back key messages during the F2F workshops on behalf of their small groups. • Individual reflection tasks on Recollective were completed by almost all participants: many welcomed the opportunity to give more considered comments, a number of which are included in the final report. feeling sufficiently well informed for nuanced discussions which marked differences between groups <p>By the end almost all participants felt sufficiently well informed to be able to make a useful contribution</p> <ul style="list-style-type: none"> • They unanimously agreed that it is important for the public to be involved in dialogue on this topic • Almost all were confident in sharing their views and overwhelmingly confident that HDBI was listening and would reflect their views in thinking about future research • Many hoped that they would also help inform HFEA's review of legislation and would be part of a larger national conversation
<p>Robustness of data capture, analysis and quality of reporting</p>	<p>Participant views fully captured and included in the analysis</p> <ul style="list-style-type: none"> • All small group sessions were recorded and transcribed. Facilitators also took their own notes (online) and on flipcharts in the room. Mentimeter was also used to collect unprompted thoughts at the beginning and end of workshops. Participants enjoyed using the app both online and in the room, and the outputs were used in the process to show participants what others in the room were thinking, and to inform recaps in the following sessions. • Transcripts of audio recordings plus facilitator notes were used to identify themes which were discussed with the core project management team to structure the initial coding. • Grounded analysis - reading and rereading to flesh out themes, attitudes and changing views – resulted in an analytical report which also used direct participant quotes to highlight the range of participant's views and the values that underpinned them. <p>Outputs well presented, credible and easily understood</p>

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| | <ul style="list-style-type: none">• Two short film(s) (3 minutes) using interviews with a handful of participants (London) and scientists (Cambridge and Crick) will be completed by late October and will bring the dialogue process and findings to life for wider audiences• Stimulus materials (video and PowerPoint) will be a useful resource for HDBI/Babraham to share with the wider public and to support further public engagement on this topic (e.g. by HFEA, Cambridge Reproduction, other countries). Unfortunately oversights in securing all the necessary permissions to share via YouTube at the outset has made this a more time consuming/costly element than intended and has contributed to a slight delay in the launch.• PowerPoint presentations prepared by scientists and reviewed by HVM are considered (by the HDBI public engagement team) as great exemplars of how to communicate with the general public (right level of detail, language, etc.). |
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Annex C: Participant feedback all workshops

Lived experience (LE) all online: southern (S) and northern (N) online and face to face workshops. Feedback collected via Recollective, SurveyMonkey and questionnaire

After online webinar 1. I understand the objectives for this public dialogue on early human development research								
	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Total		
Lived experience	12	6				18		
Northern and Southern	26	14	1			42		
Total	38	20	1	0	0	60		
Percentage	63.3	33.3	1.7	0.0	0.0	98.3		
2. The quantity of information I was sent before the workshops felt:								
	About right	Too much	Too little	not sure				
Lived experience	16	1			1	18		
northern and southern	33	7	2		0	42		
Total	49	8	2		1	60		
Percentage	81.7	13.3	3.3		1.7	100.0		
3. The information shared today was clear and easy to understand								
	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree			
Lived experience	11	6			1	18		
northern and southern	24	17	0		1	42		
Total	35	23	0		2	60		
Percentage	58.3	38.3	0.0		3.3	100.0		
Most felt that they had about the right amount of information and that it was clear and easy to understand. Only one participant felt overwhelmed "It's a difficult subject and too much information has overwhelmed me." And another that "The HDBI fact sheet was too much and shared too late for me to read it all before the meeting." Another acknowledged that "this is a tricky topic: whilst the core subject seems very straightforward the actuality has many complexities."								
After online workshop 1 4. I felt comfortable and able to make myself heard in my small group								
	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know		
lived experience	15.00	2	1			18		
northern and southern	28	6	1			35		
	43.00	8	2		0	53		
	81.1	15.1	3.8		0.0	100.0		
5. I have been treated with respect								
	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know		
lived experience	16	2				18		
northern and southern	33	2				35		
	49	4	0		0	53		

	92.5	7.5	0.0	0.0	0.0	100.0
6. Was there anything that prevented you from fully participating this evening?						
	Nothing at all		tech or other issues			
lived experience	14	4	Mostly said nothing or that everything was fine e.g. "I was happy, I asked questions and feel I've learnt a lot on this."			
northern and southern	33	2	And "everything ran smoothly and it was a good online space." Half a dozen across all groups had tech issues which were followed up by the HVM Tech support team.			

After the final workshop

1 I understand why HDBI wants to understand public views on early human embryo research and how it is regulated

	Strongly agree	Tend to agree	neither agree nor disagree	Tend to disagree	Strongly disagree	Total
Lived experience	15	4				
Southern	16	4				
Northern	19	2				
All	50	10	0	0	0	60
percentage	83.3	16.7	0.0	0.0	0.0	100.0

Lived experience:

- I think the HDBI has shown it wants to see the publics' views by being part of this dialogue, I have learnt a lot and welcomed the chance to have been involved.
- I think it's very important to hear the views of the public and not only this, but for the public to hear and engage with the scientists etc. as this is a two way street
- I believe HDBI wants to make an informed decision and wants to hear a wide range of different opinions on the matter.
- I wish them success
- So they can make informed decisions
- they want to see and understand how the public see the research and what are the implications of any changes that are going to be proposed.

Southern

- [yes] Due to all the information provided and also discussions
- I have a better understanding of the process

Northern

- it is a difficult topic - but essential
- very well explained
- It's very important to review the 14 day rule and the research regarding the public views is very important

2 The length of the workshop sessions was convenient for me.

	Strongly agree	Tend to agree	neither agree nor disagree	Tend to disagree	Strongly disagree	Total
Lived experience	6	8	1	4		
Southern	13	6	1			
Northern	13	8				
All	32	22	2	4	0	60
percentage	53.3	36.7	3.3	6.7	0.0	100.0

3 The timings of the workshop sessions were convenient for me.

	Strongly agree	Tend to agree	neither agree nor disagree	Tend to disagree	Strongly disagree	Total
Lived experience	9	7	2	1		
Southern	15	4	1			
Northern	12	9				
All	36	20	3	1	0	60
percentage	60.0	33.3	5.0	1.7	0.0	100.0

Weekday evening sessions fine, the full day (6 hour) Saturday session felt too long for many of the online participants: several would have preferred it split over 2 shorter weekday evening sessions. Many would also have liked more, slightly longer breaks.

- 6 hours today was hard, because there is so much to take in and comment about. (LE)
- I would have liked more sessions and would like to take part in future recaps etc. I would have liked more time to discuss my views and listen to others' views. (LE)
- Last session was a bit too long even with breaks, I would prefer the last one to be split into two sessions instead. (LE)
- The last session was felt too long and was often quite repetitive. The other sessions were a more agreeable time. (LE)
- Monday evening sessions worked great for me. Saturday full day has been a bit intense, would have preferred 2 more shorter sessions. (LE)
- The weekday sessions were fine in length, I must admit this Saturday session has been long, I don't know if it would be better to split it into 2 sessions as opposed to 10-4 full day session. (LE)
- I found the workshops and the online task a little long with not enough breaks. It was a struggle to complete all the online tasks due to work commitments.
- I think possibly the last session may be easier over 2 days
- today was long but understand it was valuable time
- bit too long
- very long sessions with very dense information - I would have preferred 4 workshops and a webinar as it felt draining at times
- I think the 3 hour sessions are better.
- The evening sessions were perfect for me. Allowed me to still have time afterwards to reflex so weren't too late etc.
- Length was good could have gone on for much longer. very intricate topics and was done well
- Yes perfect!
- Evening time worked very well, couldn't have been better
- I think it was great to have them post a normal working week (i.e. past 5 and on the weekend), but I will admit I found the weekday ones made it difficult to have dinner at a good time, so perhaps a point to advise if you are happy for people to eat while on camera.
- I feel the Saturday session would be better broken down into 2 sessions.
- Fine - although Saturday 1st July was London pride so it was not a great selection of dates for a representative population of the public!

Those taking part in the hybrid processes mainly found the session timings convenient, but a few (mainly those that had travelled long distances) found the Friday evening session finished too late.

- Was really good. (S)
- Just long enough to put everyone's opinion forward. (S)
- It was time to look at all eventualities. (S)
- Was very interesting and went quickly. (S)
- Took time to learn. (S)
- Perfect timings. (S)
- Friday evening finished a bit too late. (S)
- It was worth all the time. (N)
- Quite lengthy and hinders my focus, but it's been very interesting and I'd love to do something like this again. (N)
- With some pain ... but worth it. (N)
- A length of around one full day in total would be good. (N)
- Friday night workshop a bit late, Saturday fine. (N).

4 The information shared with us covered the range of perspectives I wanted to hear.

	Strongly agree	Tend to agree	neither agree nor disagree	Tend to disagree	Strongly disagree	
Lived experience	13	6				
Southern	13	5	1	1		
Northern	12	7	2			
All	38	18	3	1	0	60
percentage	63.3	30.0	5.0	1.7	0.0	100.0

Balance of perspectives covered

- Yes 100%. (LE)
- Yes, I learned a lot as well and re-evaluated my standing a bit on this issue. (LE)
- It would have been interesting to hear more opposing views for more of a balance
- A lot of wide range opinions that have given me so much to think about and has also given me information I wouldn't have had otherwise. (LE)
- Very scientific and could have framed slightly different. Good overall. (LE)
- Informative and interesting. (LE)
- Extremely informative with different viewpoints and a range of people. (LE)
- Very thorough. (LE)
- Extremely interesting. (LE)
- Any questions were answered in depth from a professional perspective. (LE)
- Had no previous understanding, was unsure what to expect. (N)
- Very interesting and I feel better informed. (N)
- There was no real "joy of science" talk; there should've been. (S)
- Too focused on IVF. (N)

5 I found the Recollective site a useful way of reviewing what we had heard or preparing for the next workshop.

	Strongly agree	Tend to agree	neither agree nor disagree	Tend to disagree	Strongly disagree	
Lived experience	13	4	1	1		
Southern	17	2	1			
Northern	16	5				
All	46	11	2	1	0	60
percentage	76.7	18.3	3.3	1.7	0.0	100.0

Almost unanimous agreement that it was a useful tool for pre- or post- workshop review of materials. Participants appreciated being able to prepare for the workshops and go back to presentations to review points. Also the material that was only available online was mostly read and often referred to in the deliberations (e.g. rogue scientists, views on how it might affect conditions such as Down's syndrome).

- It was useful and helped me to prepare for the next session, having a mix of activities was great as well as materials from previous sessions in form of videos. (LE)
- It was nice to log in on your own time and at your own speed, also very interesting to see when others last logged in and who was also logged at the same time. (LE)
- Easily accessible and notifications were sent promptly to my e-mail which was helpful. (LE)
- I really enjoyed being able to watch and read information ahead of the sessions and doing it in my own time. (LE)
- Especially being able to revisit the various items that were presented. It helped understanding of points made by the speakers. (LE)
- Very well structured. (LE)
- This was great preparation for workshops. (S)
- Great videos, educational. (S)
- Really useful, efficient platform. (S)
- Good to get knowledge beforehand. (N)
- It was good for sharing some of the thoughts and conversations, I prefer face to face. (LE)
- Easy to use. (LE)
- Excellent allowed to go back and study/watch again to educate ourselves. (LE)

Also appreciated as a space for potentially continuing discussions between workshops: two thirds said they did use it in this way; while most others thought it useful but did not use this facility – some saying that was due to the amount of other info which seemed to cover most angles of discussion.

- Discussed with others and answered my questions. (S)
- Good facility. (S)
- I didn't use the section for additional conversation between sessions. (LE)
- Agree but didn't use it! But I did read the comments added by other users. (LE)

- *I do agree, I did feel however we were given so much information and knowledge (which was great) that it was difficult to come up with a discussion point, so this may be why it wasn't used as much. (LE)*
- *Most covered during workshops (N)*
- *Didn't use it for discussions, but I like it. (S)*

6 It was useful to have space on Recollective to continue our conversations between workshops

	Agree and used it	Agree but didn't use it	neither agree nor disagree	Disagree	Strongly disagree
Lived experience	13	4	0	2	
Southern	16	4			
Northern	11	9	1		
All	40	17	1	2	0
percentage	66.7	28.3	1.7	3.3	0.0

7 Specialists (scientists, ethicists, those with lived experience) were able to share information in an accessible way.

	Strongly agree	Tend to agree	neither agree nor disagree	Tend to disagree	Strongly disagree
Lived experience	14	4	0	1	
Southern	17	3			
Northern	18	3			
All	49	10	0	1	0
percentage	81.7	16.7	0.0	1.7	0.0

8 Specialists were able to answer our questions in a balanced way.

	Strongly agree	Tend to agree	neither agree nor disagree	Tend to disagree	Strongly disagree
Lived experience	15	4			
Southern	16	4			
Northern	15	5	1		
All	46	13	1	0	0
percentage	76.7	21.7	1.7	0.0	0.0

Almost unanimous agreement that scientists shared information in a transparent way, that they answered questions in a balanced way. Many felt they reflected a broad range of perspectives. A few would have liked to hear from even more scientists and one felt that religious views of those opposed to EHE research were not strongly enough heard (although were included via video). In their verbal feedback those that attended F2F sessions really appreciated the chance to talk to specialists on a level playing field outside formal Q+A sessions (during breaks, in small groups and at carousels). They also appreciated the considerable effort that went in to answering all questions between sessions.

- *It is interesting to hear the specialists' views, even if one doesn't necessarily agree with them. (LE)*
- *Again I'd agree. I never felt everyone had the opportunity to say something and people felt at ease speaking. Everyone I saw was very courteous and respectful of others views even if they were different to their own. (LE)*
- *Yes! I found this the most interesting part of the workshops. (LE)*
- *Speaking to specialists on the day of the group [what I valued most]. (N)*
- *Very clear and [well] explained. (N)*
- *This aspect was good, helped to frame discussion, still has its own limitations. (LE)*
- *Scientists etc. very knowledgeable. (S)*

Good range of perspective

- *Excellent, really good perspective (S)*
- *I felt all views were considered (S)*
- *Lots of professional views and personal views. (N)*
- *Great to hear different views from all professionals. (N)*

And answering questions in a balanced way:

- *It was very difficult for them to answer unknown questions on the spot and as some of the questions related to future events they might not and known the answer there and then, nevertheless they all answered in a clear way. (LE)*
- *Yes, In the workshops and followed up on the workspace. (LE)*
- *I think the specialists were brilliant with this, I was drawn in when they were speaking and think they did an amazing job to get the right information across. Love Sarah's views!*
- *The answers weren't too scientific so I was able to understand (N)*
- *Sometimes felt we could have a bit more time. (S)*
- *The panel gave really good insights. (S)*
- *Gave a useful background. (N)*
- *Great talks and very interesting. (N)*
- *I feel much more informed. (N)*

A few noted that:

- *Sometimes it was a bit too scientific and I worried at first I would need to remember it all in order to contribute, it would be great if moderators explained at the start that relevant pieces of information will be later repeated and approached in a step-by-step fashion for reassurance. (LE)*
- *We need to have more views from scientists. (N)*
- *Vanessa Smith's presentation was excellent and she comes across as very trustworthy and honest. Vanessa would be the person you should put forward to the public. Stephanie Ellis comment's about we don't want to move to 140 days so don't worry and said the way scientists explained when things go wonky, bothered her, well, her comments and general presentation bothered me. It also bothered me, that she has been on the research ethics committee for 34 years and talked about the slippery slope of ethics.*

9 I felt sufficiently well informed to make a useful contribution to discussions about how early human embryos should be used in future research.

	Strongly agree	Tend to agree	neither agree nor disagree	Tend to disagree	Strongly disagree
Lived experience	12	6	1		
Southern	17	3			
Northern	15	6			
All	44	15	1	0	0
percentage	73.3	25.0	1.7	0.0	0.0

Almost unanimously felt informed enough to contribute (only 1 unsure) and almost no one reported feeling overwhelmed or that there was too much information or that it was overly scientific.

- *I always found something to make a contribution towards. (LE)*
- *The project encouraged me to look into embryo research with the intention of being able to better understand what we discussed. (LE)*
- *It was great hearing other people's thoughts and opinions, which then triggered thoughts I wouldn't have had otherwise. (LE)*
- *Having been a scientist in a research environment very helpful as I have some understanding of the processes and ethics of it all. (LE)*
- *There are still a few topics I'd love to know more about. (N)*
- *...although there is still the black box area even for the scientists: I feel we were informed as much as possible. (N)*

10 The facilitation has been professional, independent, and effective.

	Strongly agree	Tend to agree	neither agree nor disagree	Tend to disagree	Strongly disagree
Lived experience	15	3			
Southern	19	1			
Northern	18	3			
All	52	7	0	0	0

percentage 88.1 11.9 0.0 0.0 0.0 100.0

Unanimous agreement on the professionalism and independence of the facilitation – with people noting that it was warm, inclusive, maintained focus and that everyone felt free to express themselves, even if their views differed from others.

- *Very professional and made it clear from the outset that no one would have to say anything they felt they didn't want to etc., but likewise you can be free to express yourself to the full in a safe and respectful environment.*
- *Everything was great. (LE)*
- *Mainly agree although I felt in my facilitation group today that it wasn't as controlled as it could have been as I often felt we were going off on big tangents and discussing things not related to the questions. (LE)*
- *Suzannah was brilliant. (LE)*
- *Very professional and easy to access. (LE)*
- *The whole team were brilliant. (LE)*
- *well-structured and facilitated. (LE)*
- *Everyone's views were heard. (LE)*
- *Everyone I saw was very courteous and respectful of others views even if they were different to their own. (LE)*
- *Fully inclusive. (S)*
- *Great workshops and staff. Pleasure to have been a part of. (S)*
- *Thank you, well presented. (S)*
- *Process was very well thought out. (S)*
- *Really well run and facilitated event/project. (N)*
- *Jamie, Kathryn, Suzannah, Valsa all excellent first class people. (N)*
- *The facilitators Jamie and Suzannah were very competent, professional and helpful (N)*
- *Very well done! (N)*
- *Very professional. (N)*
- *Absolutely. (N)*
- *Speakers could do with a mic as some quiet or hard to hear. (N)*

11 I found it helpful to know that support was available if I found the topics we discussed emotionally upsetting

	Strongly agree	Tend to agree	neither agree nor disagree	Tend to disagree	Strongly disagree	
	12	4	2	1		
	16	2			1	
	17	1	3			
All	45	7	5	1	1	59
percentage	76.3	11.9	8.5	1.7	1.7	100.0

Vast majority agreed that it was good to know that duty of care to participants had been fully thought through and provided for: most didn't need to use it – but a dozen took time out from small groups and a handful had discussions with the facilitation team. Just one participant found the process triggering and has taken the opportunity to talk to the counsellor who was on standby during the whole process.

- *I thought it was a very nice gesture to have [support] people on standby if needed. Excellent. (LE)*
- *I know where to turn and who to contact should I need to. (LE)*
- *The start of every session there was a reminder to take time out if needed, all participants were also respectful. (LE)*
- *I didn't need it but great it was available. (LE)*
- *I didn't personally feel the need to take time out, but I understood that others may well have needed to. It was nice to know to that I could have done so at any point without question. (LE)*
- *I didn't feel I needed to. (LE)*
- *Didn't need to. (LE)*
- *I felt I didn't need the support but was glad it was available (N)*
- *Whilst I didn't use any of these options, I think it was hugely important for them to be offered. (S)*
- *[appreciated] but not [used] in particular, and didn't find it upsetting (S)*

12 I took the opportunity to make use of the support available (tick all that apply)

	took out	time talked facilitation team	to followed up with support organisations	talked to the counsellor	none of the above	
Lived experience	3				15	
Southern	7	5			8	
Northern	1	1			19	
All	11	6	0	0	42	59
percentage	18.6	10.2	0.0	0.0	71.2	100.0

13 I think it is important that the public is involved in helping scientists and policy makers understand how different people feel about these issues.

	Strongly agree	Tend to agree	neither agree nor disagree	agree	Tend to disagree	Strongly disagree	
Lived experience	15	4					
Southern	16	3					
Northern	19		1	1			
All	50	7	1	1	0		59
percentage	84.7	11.9	1.7	1.7	0.0		100.0

Almost unanimous agreement that it is important to involve the public in this type of research and policy question. And a high level of confidence that both HDBI and HFEA would listen to the findings of the dialogue

- 100%. I would like to see a public board or committee set up with impartial and varied members of the public go be able to challenge and question scientists on what they either propose to do or indeed are currently doing. It's easy to spend time in likeminded groups and become blinkered to scrutiny so I think this sort of Q&A sessions would benefit everyone. (LE)
- After all, members of the public will be affected by these policy changes for decades to come should they happen. (LE)
- I think it's important the public are informed. But I don't think they need to be in on the decision. (LE)
- It's a necessity as it's for the public so as a standard rule they need to be involved in some way. (LE)
- As it affects the general public. (S)
- Feels great but we're not experts! (S)
- More information should be promoted/campaign. (S)
- Overall, it was very interesting and I feel grateful for being part and giving my views. I loved the Menti. (N)
- Helps both scientists and the public. (N)
- Transparency needed throughout. (N)

One participant tended to disagree: "science needs to be made its own way." (N)

A few participants expressed an interest in continuing to be involved both informally in discussions with the evaluator and on the evaluation feedback form as follows:

- Very interesting, great, feel passionate now about change!!! (N)
- I've enjoyed being part of this dialogue I've found it very interesting and I would be interested in taking part in more to do with this and other things (N)
- Would like to feel we've played a part in change. Await outcome. I will watch with hope for the future of this research. Well done all :). Happy to be involved further even if it's sending emails to answer with thoughts and understanding. (N)
- I would be interested in future events. (N)
- Learnt so much and will follow the topic closely. (N)

14 I feel confident that HDBI and its researchers will take our opinions into account in setting their future research priorities.

Lived experience	77.2	1 0%, several 50s
Southern	80.2	1 less than 50, 1 less than 25
Northern	89.5	1 less than 50

15 I feel confident that what we have discussed will help to inform how research is regulated in the future.

Lived experience	76.4	1 0% a few 50s
Southern	85.6	1 less than 25
Northern	82	4 less than 50

16

What, if anything, was most valuable about the public dialogue workshops?

Participants valued the process itself, learning more about the topic, hearing from specialists and reviewing the contributions before or after, mostly talking to such a diverse group and hearing different perspectives and opinions:

- Lived experience
 - *The process itself*
 - *having it*
 - *Opportunity to really think about these topics*
 - *Learning about the research and issues*
 - *Hearing the work that will be done and also hearing people from different back grounds opinions*
 - *information re the research*
 - *All the information about how an embryo develops and the possibilities of what can be done*
 - *range of views by short videos allowed to be able to review when suited*
 - *hearing from the experts*
 - *The diversity of voices and views that they heard from*
 - *Hearing all the different views and learning about peoples experiences and the science that goes behind it all.*
 - *To not only hear other views, but also being able to express my views. A fellow member actually commented that they hadn't ever thought about a few points I'd raised.*
 - *I felt that my opinion and voice was heard and my contribution respected and appreciated.*
 - *Hearing opinions from other perspectives which made me reflect on and often adjust my own opinions.*
 - *Hearing a cross section of views from people like me*
 - *Getting to talk to people from different backgrounds with a range of perspectives*
 - *listening to a wide range of opinions*
 - *small group discussions then sharing with everyone and professionals*
- Southern
 - *Diversity of perspectives*
 - *The different perspectives and views*
 - *The differences in opinions*
 - *The mix of answers*
 - *Great to hear a range of opinions*
 - *Getting outside your own bubble*
 - *A perfect research*
 - *Interest in learning more about the topic*
 - *I found it was very interesting covering all.*
 - *The process was very informative and interesting and it was great to be part of it and share my views.*
 - *All very interesting*
 - *Sharing education*
 - *Learning much, much more about early human embryo research and meeting such lovely people!!*
 - *To know about embryo research*
 - *The opportunity to be part of a deliberative process*
 - *To participate*
 - *Thank you for letting me be part of this amazing research.*
 - *Thank you for an interesting research.*
 - *Excellent, wishing you good luck for this to be successful.*
 - *Thank you for having me. It was very educative.*
 - *Feel sad that it's ending*
- Northern

Everything: "in person workshop," "all relevant," "Thank you, everything was spot on and extremely interesting", "Brilliant session!" and "great session - thankyou :)."

Hearing from others and being heard:

 - *hearing different views - being able to suggest different opinions*
 - *respectfully listening to others*
 - *it was great that everybody was listened to*
 - *being part of the workshop and giving my valuable opinion*

- *hearing different opinions and meeting others*

Interacting with scientists and specialists

- *being involved in scientist's work and sharing my views*
- *meeting the scientists*
- *listening to the scientists*
- *hearing from speakers and asking them questions*

Opportunity to learn more:

- *hearing more about the subject*
- *all the information we received*
- *scientific information given to the participants*
- *giving me an understanding of a topic I had no knowledge of*
- *Tiring but enjoyable*
- *I feel science was discussed less. Let's not forget we are doing all this to make our lives better. Scientists should have the upper hand. All the best. Looking forward to seeing the final report*
- *very well organised about the dialogue.*

17

All

Lived experience

What, if anything, was missing or might have been done differently/better?

half nothing,

About half commented on the length of the final session or the need for more, longer breaks. Several felt the prompt questions for the final small group sessions could have been clearer and felt a bit repetitive. One felt that the same questions were being asked repeatedly and another that by halfway through the final session participants had shared all their thoughts and were repeating themselves.

Length of sessions and breaks

- *I felt we needed longer sessions or more sessions in quicker succession. Perhaps every evening over 3 or 4 days then the same the following week, it would have allowed points to have been fresher in others' minds*
- *Maybe having the sessions twice a week for 2 hours.*
- *More breaks*
- *slightly longer breaks*
- *more breaks*

Clarity and potentially overlapping nature of questions in final sessions:

- *I felt that the questions in today's (Saturday) session could have been clearer as they felt a bit repetitive to each other*
- *Maybe wording! I felt like the same questions were being asked repeatedly*

Other

- *more info on ref number of reviews undertaken about current law in the 40 years or so and off the prosecutions under the law as wasn't mentioned until final summaries at end*
- *Don't really feel we got into issues deeply enough until the final day. Need longer periods to have the opportunity and time to have productive debates*
- *See answer 14 [comparing 2 presenters one considered excellent, the other less so], chose your presenters carefully.*

Southern

Over half the group said not applicable or reiterated positives and that it was "great the way it was" A few made specific suggestions:

- *More logistical (rather than research!) stuff! 1) In such a large room, and with so many people, I recommend that you use both lapel and hand-held mics for certain parts, as sound was often difficult. 2) Consider conditions for such a long workshop in future, particularly temperature at events held in July. It was roasting all day in the room!*
- *More clinics(?) should have established*
- *Some more diverse groups*
- *Hot lunch please*
- *Please could we have a hot lunch. Thank you.*
- *There was a repetition of some topics. It could have been done in a shorter workshop.*
- *Perhaps more stats from science if they are yes or no.*

Northern

Only thing was venue could have been in hotel and the food was poor.

- *Location of Friday workshop inappropriate and facilities were not good (location sound, echo, floor, venue size etc)*

- *“first venue not ideal”*
- *The location of the Friday evening event wasn't great. Area stayed in also wasn't great hotel in party location very noisy. Food wasn't good for vegetarians - no variety or thought put into it. Not sufficient on Friday night as dinner.*
- *Same venue for both sessions - second one better*
- *Better placed hotel!*
- *food very disappointing at dinner/lunch*
- *general food poor and bland*
- *dinner on first night - this was not given and had tracked from Edinburgh with no meal*
- *I loved how the event was conducted. But it would have been useful to have separate areas for group discussion as it was really noisy in the room we were in and I kept missing parts of the conversation. Also would be useful if the speakers used a mic.*
- *group discussions would have been better in separate rooms. Difficult to hear properly. separate group rooms for quiet.*

18

Please let us know if you'd like to be involved in any of the following ways:

	receiving a full copy of the report	attending a launch event	a continuing follow progress	to Other	
Lived experience	17	11	14	2	
Southern	17	11	14		
Northern	17	15	18		
All	51	37	46	2	60
percentage	85.0	61.7	76.7	3.3	

85% would like report, over three quarters to follow the process and more than 60% to attend any launch (similar across all groups). 2 individuals would like to be involved in any further research or to use their knowledge gained to be part of further research studies.