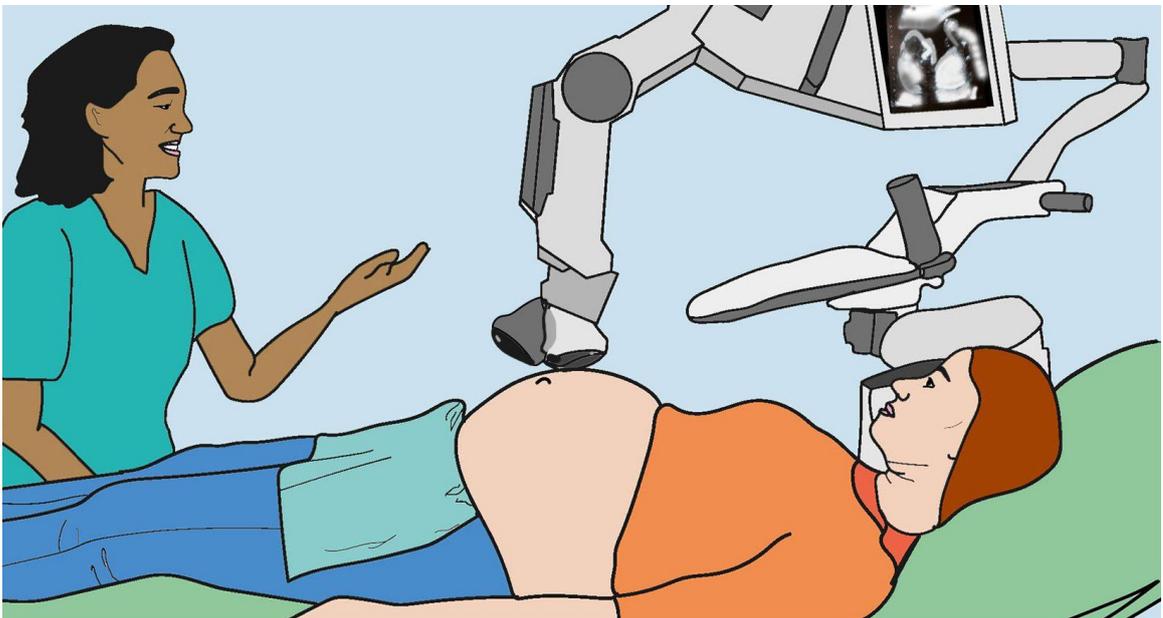


Report to Wellcome/EPSRC Centre for Medical Engineering (CME)
Public Engagement team (PE)

Evaluation of public dialogue on Scanning and Surgical Innovations in Pregnancy

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Quality Management

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1. Introduction

This report has been prepared by URSUS Consulting on behalf of the Wellcome/EPSRC Centre for Medical Engineering (CME) Public Engagement (PE) team to present the findings of an independent evaluation of the Centre's **public dialogue on scanning and surgical innovations in pregnancy**.

1.1 Background and context

Researchers in the Centre are developing a number of technologies that could help improve the diagnosis and treatment of conditions that some babies develop while in the womb through two ongoing Wellcome-funded projects:

- [iFIND](#) uses advanced medical imaging to improve screening and diagnosis of fetal conditions in the womb.
- [GIFTSurg](#) is developing surgical interventions to treat specific fetal conditions such as spina bifida and twin to twin syndrome in the womb.

These technologies have the potential to improve outcomes across England, but how they are used could also impact the experience of families from the 20-week scan onwards, and lead to a change in the way they are cared for. The Centre wanted to talk to members of the public to understand their thoughts on these developments.

In February 2019 the PE team commissioned a workshop to explore the range of available public engagement methods and deepen the team's understanding of how they could be used. The workshop was attended by 19 participants including members of both research projects including researchers, clinicians, and support staff. The participants agreed that an externally facilitated public dialogue was the preferred option. This would be more resource intensive than the Centre's usual public engagement approaches but would give time to inform public participants about the planned innovations and allow them access to researchers to answer their questions in order to explore what the public might be concerned about or want to know more about in terms of scanning and surgical innovations in pregnancy.

The project team considered, and discounted, participants who were currently pregnant (as talking about unexpected findings and potential challenges in pregnancy could cause unnecessary worry) and the 'general public' without experience of pregnancy (as it was considered important that participants should have a benchmark experience to compare potential changes to). The decision was therefore made to focus specifically on parents that had experienced a pregnancy where a condition developed in the womb, as well as those who had experienced a pregnancy without a condition.

1.2 Dialogue objectives

The overall aim of the dialogue was to understand participants' views in order to help influence future research and innovations in scanning and surgery during pregnancy and to help improve the outcomes for expectant parents and their babies in the future. During September 2020 the PE team commissioned and co-designed a public dialogue with the following objectives:

Core objectives

- Understanding different aspects of public acceptability regarding the iFIND and GIFTSurg projects including ultrasound screening, diagnosis including imaging technologies, post-diagnostic support, surgery and support, associated data gathering and future usage, language, and presentation.
- Identifying questions and issues to inform future research applications.

Secondary objectives:

- Building engagement capacity and familiarity amongst the core group of researchers.
- Utilising a multi-stakeholder advisory group as a means to ensure balance and ownership of the dialogue materials and outputs.
- Providing a clear report for the extensive project team, but also for wider readership within the health sector.

When first proposed in 2019 the public dialogue was expected to take place face-to-face, but by the time it was commissioned in Autumn 2020 the COVID pandemic and social distancing restrictions meant that all aspects had to be designed for delivery online. Initially the process was expected to take six months, with each participant attending three half day (3 hour) sessions on Saturdays, with a few weeks between sessions to allow for reflection.

However, uncertainties about when a second national lockdown would be lifted led to slippage of several months. One of the three planned sets of workshops fell on Saturday 17th April 2021 during a national period of mourning for HRH the Duke of Edinburgh. King's College London decided to cancel all external events until after the funeral which meant the workshop could not go ahead and had to be cancelled. The decision was made to condense the remaining dialogue sessions into one three-hour workshop for each group of participants.

2. Methodology and process for the Public Dialogue

2.1 Governance and project management

Project Management

The Centre's PE team commissioned independent specialists in public dialogue, 3KQ, to co-design and deliver the public dialogue process. Roles were shared so that the PE team was responsible for selecting and convening a Steering Advisory Group (StAG), coordinating researcher inputs, and working with its six charity partners¹ on the recruitment process and running a wellbeing room. 3KQ was responsible for the overall design, developing materials (videos, PowerPoints, and 'scenarios' and 'situations') to stimulate discussions. They were also responsible for recruitment of participants (via a recruitment agency and selecting participants volunteering via charities), independent facilitation, and tech support before and during the dialogue workshops as well as report writing and preparing a vox pop video of the process afterwards.

Overall, the division of responsibilities worked well. 3KQ carried out a handful of stakeholder interviews with specialists and quickly got to grips with the technical content and the issues that mattered to researchers. Good working relationships and communication resulted in *"a good open collaborative relationship, more like a partnership or co-production than working with external consultants"* and a team that was *"easy to communicate with, open to suggestions and quick to make changes"*. However, the PE team also reported spending more time on tasks such as reviewing materials and liaising with charities than they had expected.

Governance arrangements

The PE team decided to set up a standalone StAG in recognition of the size and importance of this public dialogue. The StAG consisted of 13 people drawn from the Centre's researchers (four each from the iFIND and GIFTSurg teams), two charities (Antenatal Results & Choices (ARC), and Bliss), an ethicist, an NHS representative, and a communications consultant in Artificial Intelligence. The StAG met online three times and was tasked with steering the overall framing of the dialogue, helping to develop and review stimulus materials, contributing expertise as specialists at workshops, and reviewing the final outputs. StAG members had opportunities to attend briefings, a training workshop led by ARC and a dissemination workshop. They were also invited to take part in the public dialogue workshops as observers or specialists.

Budget

Delivering an online public dialogue was a learning process for the whole team and required adaptative design throughout. The final budget was £113K (including VAT) which covered independent design and facilitation of workshops, preparing four short 'stimulus' videos for use during the workshops and a vox pop video afterwards and a thankyou payment to participants (£160/each) as well as the independent evaluation. It also included contributions for the charity involvement in running a wellbeing room, a relaxation exercise and delivering sensitivity and language training for researchers. Partly due to a misunderstanding that VAT had not been included in the original quote this represented a 25% increase on the originally envisaged budget. The variation also reflected additional costs from designing the dialogue for online delivery. Savings in travel and venue expenses for face-to-face meetings were more than offset by the need for more pre-planning and materials development time,

¹ Antenatal Results & Choices (ARC), ECHO, Twins Trust, CDH-UK, Shine and Bliss

provision for tech support for participants and recruiting additional independent facilitators to allow for smaller discussion groups.

Initially the contractors had assumed that some of the PE team or researchers might be trained to facilitate small group discussions, but it soon became apparent that, given the sensitivity of the topics, it would be more appropriate to allocate additional resources for experienced independent facilitators for the first workshop. The decision to condense workshops 2 and 3 freed up some resources which were allocated to a final vox pop video about the process and findings. In lieu of attending a third workshop, participants were asked to spend the time on a homework task reviewing materials and discussing them with family and friends. This added value to the deliberations by bringing in wider opinions than the 43 participants who attended the workshops. The PE team also secured an additional 5K to commission a design company to produce an animated summary of the process based on the final dissemination workshop.

2.2 Framing, design and recruitment of participants

Framing of the dialogue

The workshop process and outputs are summarised in *Figure 1*. Each participant attended two 3-hour workshops. The workshop design was iterative with workshop 1 focusing on informing participants and identifying the issues they wanted to discuss and workshop 2 was designed to explore those issues in more detail. StAG members contributed to and reviewed the stimulus materials.

Workshop 1 provided an overview of the current antenatal journey and highlighted the difference in regional rates of detection of key conditions during the 20-week scan. Sessions then covered the full range of proposed innovations. Information was provided through four short videos (6-9 minutes each), with contributions by three members of the StAG, explaining how innovations in scanning and advanced diagnostics such as MRI could be used if scans picked up anomalies, and how new and emerging surgical techniques could be carried out for certain conditions while babies are still in the womb. Treatments discussed included laser surgery for twin-to-twin transfusion syndrome and open or keyhole surgery for spina bifida myelomeningocele. Videos were shared in plenary and then discussed in small, facilitated breakout groups (7-8 participants each) which identified questions for specialists and issues which participants wanted to discuss in subsequent sessions.

Workshop 2 was then designed to pick up topics identified by participants during workshop 1 and in their evaluation feedback. Within the compressed time available the team agreed to focus more on scanning and MRI innovations (iFIND) – which will impact on many expectant parents – and slightly less on GIFTSurg innovations, which will only ever be applicable to a small handful of families each year.

The first round of discussions focused on the 20-week scan and were framed around two 'scenarios' - designed to be futuristic but plausible - for how the proposed innovations might be rolled out during the antenatal journey. One lower-tech (based in a GPs surgery) and one high-tech scenario (based at a hospital) were designed to explore what aspects really mattered to patients in terms of the location, who is involved, the underlying technology, the speed and format of results, detection rates and need for re-testing. Descriptions of the scenarios and prompt questions were shared with participants before workshop 2 giving them a chance to review the detail and talk through the issues with friends and family.

The second discussions explored 'situations' based on the expectation that the innovations during scanning and diagnosis would lead to an increased rate of discovery of conditions of all sorts (from serious which nothing can be done about, through serious but where surgery can be planned for at birth or in utero, to less serious which would have been discovered and treated at birth to conditions which pose no health risks) and potential treatment pathways. Small group discussions focused on what information participants would want to be given and what support they would want if a serious condition (spina bifida, twin to twin syndrome etc.) was diagnosed that would be suitable for an intervention before birth.

A final set of discussions explored participants' recommendations for the future focus of research.

Figure 1: The public dialogue process and outputs



Recruitment of participants

A total of 43 public participants broadly reflective of the age, gender, ethnicity, and education levels of recent parents in England (see Annex A) were recruited as two distinct groups:

- **Group A- Parents who had experienced a diagnosis of a variety of conditions which developed in the womb.** Following a 20-week scan, individuals within this group may have gone on to have children living with conditions, had medical interventions before or after birth, or their baby may have died during pregnancy or after birth, including those who had a termination for medical reasons. The PE and 3KQ team worked with existing partner charities via their support groups and social media to recruit parents with a variety of experiences. A final selection of 25 participants was made from more than 75 interested respondents. A second round of targeted invitations was sent to groups representing parents from Black and minority ethnic backgrounds and non-childbearing parents to try and fill some gaps. 21 participants attended workshop 1 and 19 also attended workshop 2.
- **Group B - Parents who had experienced an 'as expected' pregnancy journey within the last three years** including having antenatal scans and support through to the birth of a healthy baby. This group were recruited via an agency, to reflect the national profile for age, ethnicity, and educational levels of child-bearing parents or their partners. The aim was to recruit 30% non-childbearing partners. Recruitment was slightly skewed to over-represent those from Black and minority ethnic backgrounds to compensate for

gaps in Group A. Of the 24 recruited, 22 attended workshop 1 and 21 also attended workshop 2.

Recruited participants were sent links to an online whiteboard (Conceptboard) with joining instructions and background information including support links to charities and a wellbeing room. After workshop 1 all participants who responded (41) agreed that the recruitment process (both via a charity or the recruitment agency) worked well and was not too intrusive (34 strongly agreed, 7 tended to agree).

2.3 Evaluation methodology

The evaluator was recruited shortly before the first StAG meeting and observed all team and StAG meetings, trainings, and dialogue workshops. Formative evaluation input was shared during the design process and evaluation feedback collected via online surveys from participants (41 for workshop 1 and 39 for workshop 2), researchers (6) and charities (4) was shared after events. Participant feedback is presented in Annex A. Anonymous quotes from participants, researchers and charities are included throughout the report in blue italic font.

3. Evaluation findings: design and delivery

This section summarises evaluation findings on the design and delivery of the public dialogues with a focus on how the following key challenges were addressed:

- **To recruit and retain a good mix of participants**, reflective (but not statistically representative of) the English population who have experienced recent births, including parents who have experienced diagnosis of a condition which developed during the womb. The latter group is typically harder to reach but of particular interest to the Centre's researchers.
- **To meet a duty of care to all participants, especially those who had experienced difficult pregnancies**, by providing an environment where they would feel respected, valued, and safe to share their experiences and opinions, with further support available if they needed it.
- **To provide participants with sufficient, accessible, balanced information and time to discuss it** across a broad range of medical, engineering and AI areas so that they could contribute informed opinions without overwhelming them with detail.

Evaluation findings on how well these challenges were addressed and any lessons emerging are described in the following paragraphs.

3.1 Engaging a good mix of participants throughout the process

A reflective sample overall

The process of working through the Centre's partner charities and the recruitment agency resulted in a good mix of participants across most criteria (age, location, education levels and pregnancy experiences). However, a preponderance of white middle-class women volunteers through the charities meant that people from Black and minority ethnic backgrounds and men and non-childbearing parents were under-represented in Group A. The PE team made concerted efforts to fill these gaps in the weeks before the workshops via targeted marketing to antenatal and postnatal support groups for Black mothers² and through charity websites to invite more non-childbearing partners to take part. Despite these efforts there were still some gaps in Group A (only 2 of 21 participants were from minority ethnic backgrounds and only 2 men) which were offset in the overall cohort by over-sampling in the agency-recruited Group B to arrive at 20% of the overall cohort recruited from Black and minority ethnic backgrounds.

This highlighted for both the core team and StAG members (researchers and charities) the wider challenges: both that Black and minority ethnic individuals are under-represented on charity subscriber lists and that it is often difficult to recruit them for medical research, particularly if they have had a difficult experience. As one StAG member pointed out, there would have been value in hearing from more individuals from Black and minority ethnic backgrounds in the groups who had experienced conditions which developed in the womb, and this may have affected some of the insights which emerged: "*it potentially skews the feedback for the first group, and also suggests that more work is needed (not by this group but in general for public engagement in healthcare) to engage minority or marginalised groups in accessing support.*" **I StAG member**. Participating charities recognised the need to resolve these gaps in their current audiences and one charity (Bliss) now intends to work on this with Centre researchers.

² @Dopeblackmums, @prosperitys, @MotherhoodGroup and @fivexmore

One of the researchers would also have liked to see more fathers (who only made up 10% of the charity-recruited group). *“In general, in research it is difficult to get access to the whole population with over-representation of highly educated white females >36.”* **I CME researcher**

Participants remained fully engaged through the process

The relevance of the topic and participant-led design helped to keep all participants fully engaged. There was a high retention rate (over 95%) between sessions; the two participants unable to attend the second workshop had entirely understandable reasons that their babies were very sick and one took the trouble, while in hospital with her baby, to share how much she had enjoyed the process and her thoughts on the homework task. Participants appeared fully engaged during the discussions with their screens turned on and actively contributing during small group sessions. The technical support provided by the 3KQ project manager before and during the sessions helped to ensure that people were able to get online. There were no signs that any participants felt digitally excluded and almost all reported after the first workshop that there had been no impediments to them fully participating. Observers were impressed how engaged participants had been, one noting: *“I was pleasantly surprised at the recruitment and retention between sessions – I had thought that 3-hour sessions on Saturdays was asking a lot of the participants, but it seemed to be fine.”* **I StAG member**

3.2 Fulfilling a duty of care to participants

Recognising the sensitivity of the topic and how the process could be triggering for some participants, the PE and 3KQ teams paid a great deal of attention to ensuring that participants felt comfortable, supported and that their voices were heard. The team’s duty of care to participants was well met through the design, the way small groups were run and the additional support provided for those that needed it.

Sensitivity and language training was provided by ARC for the core team in December 2020 and for 19 researchers in March 2021. The PE and 3KQ teams also took part in an informal drop-in session run by ARC to see appropriate language and empathetic listening in practice. The learning from these sessions helped inform the wording of recruitment materials (invitations, questionnaires) and design stimulus materials and discussion prompts. The key learnings were reinforced in pre-briefing sessions run by 3KQ for specialists and observers. The training and briefings helped both facilitators and specialists to avoid using over-medicalised language and largely resulted in answers to participant questions that they found comforting rather than worrying.

Ground rules set expectations for participants making it clear that there were no silly questions, that everyone’s opinion was equally valid and that participants comments would be captured and used, but anonymously. Participant’s evaluation feedback after workshops 1 and 2 highlighted how they had felt heard and how valued this had made them feel.

Highly experienced facilitators created a warm and welcoming atmosphere. The pool of experienced and well-briefed facilitators allowed for small groups (7-8 for workshop 1 and 6-7 for workshops 2) and a core group of three facilitators provided continuity between workshops for the most vulnerable groups (such as those who had experienced a termination for medical reasons). The groups quickly gelled and participants unanimously agreed after workshops 2 that the environment created by the hosts was warm and supportive. *“All the hosts where very helpful and friendly and if you didn’t understand something they were straight on it to make sure you did.”* Participants also unanimously strongly agreed that all participants were treated with respect, irrespective of their background or experience. One praised *“A very welcoming team. It felt very friendly and open. Very helpful and very professional.”*

Participants' contributions were visibly captured. Workshop participants' thoughts, questions and recommendations were captured by the facilitators using a combination of notetaking on Conceptboard, recordings that were transcribed for reporting and Zoom polls during plenary sessions. The Zoom polls were used to give the participants' immediate feedback on the sentiment in the room, for instance by creating a word cloud based on three words that participants used to describe how they were feeling about the technologies being discussed. Participants could also have added their own notes on Conceptboard, but this proved too complicated during the live sessions. However, some facilitators shared their screens so that participants could review and correct the post-it notes during the sessions or in their own time. This was appreciated by the participants: "*[our facilitator] was excellent at facilitating our group, ensuring she had captured our views correctly, being empathetic and allowing everyone to voice their opinions and experiences.*"

Conceptboard also proved a useful way for the 3KQ coordinator to summarise the similarities and differences in what was being said across all groups and to report back to plenary. This proved an efficient way of reporting back to plenary and mirroring back points in participant's own words helped them feel some ownership of the messages emerging.

Small groups were carefully curated according to their antenatal experiences. The questionnaire sent to charity-recruited volunteers generated information which allowed the 3KQ coordinator to cluster those with similar pregnancy experiences and to brief facilitators. This meant that in almost all cases participants reported feeling comfortable and most chose to share their own experiences with the group (and many clearly found this a therapeutic experience). For instance, those who had experienced a termination for medical reasons were in one group, and male participants (2 in Group A and 4 in Group B) were with at least one other non-childbearing parent to minimise any sense of not feeling entitled to share their opinions.

After workshops 2 almost all participants agreed that they had been interested to hear from others in their groups with similar experiences during pregnancy (of 39 respondents 32 strongly agreed while 4 tended to agree). Comments shown in Annex A are clear evidence that the groups who had experienced conditions which developed during pregnancy really appreciated being able to talk with others with similar experiences. Indeed, many said that they would have liked a little more time in the early sessions to describe their past experiences before getting into discussing the innovations. Only one participant reported feeling uncomfortable during small group discussions: she would have preferred if others had been asked not to nurse their babies during the sessions as she had found this a very painful reminder of the loss of her baby. She was, nevertheless, pleased to have been able to contribute.

Additional emotional or practical support was available to those who needed it. The design included a virtual "well-being room" run as a breakout room on Zoom staffed by a volunteer from one of the charities where anyone feeling overwhelmed by the discussions could take time out and talk to an empathetic listener before re-joining the session. All participants knew that this space was available to them and, although only one person actually felt the need to take it up, all evaluation respondents unanimously agreed it was a comfort to know it was there. "*I was able to use the break room at the moment I needed to. Thank you for that.*" **1 participant, Group A.**

The team also commissioned a pre-recorded mindfulness practice which was available on YouTube after both workshops so that participants could spend ten minutes relaxing after

the discussions if they wanted. Likewise, the take up was quite limited but participants appreciated the amount of thought and care that had gone in to providing this option. Pre-workshop materials shared on Conceptboard also provided links to organisations including the NHS and specialist charities for issues raised by the discussions. The charities responding to the evaluation really valued the care taken in providing this support and several reported that they will draw on this experience in work with their own members/users.

3.3 Providing participants with sufficient, accessible, and balanced information and space to enable balanced dialogue

During workshop 1 participants gained a broad overview of the current process and sweep of proposed innovations via the short films made by 3KQ. Participants were also able to ask specialists clarifying questions in small groups and plenary sessions. The films worked well to convey information in an engaging and succinct way, using plenty of images of the technologies in use alongside the specialists talking about the issues they would address. As the films went through several iterations the emphasis shifted from explaining how the technologies worked to how they would affect the patient's journey.

Using pre-recorded films had a number of advantages, allowing the team to ensure specialist inputs used accessible language, kept to planned timings and provided a contingency in case one of the specialists was not able to participate or had poor Wi-Fi connection on the day. Had there been more available time (if all three workshops had been able to go ahead) there may have been opportunities to increase the return on the time and effort put into producing the films by showing parts of them again or asking participants to review them between sessions.

StAG members agreed that the films gave a balanced view of the proposed innovations and helped to address the potential issues which might arise as they were rolled out. Participants also found the content and presentation well-pitched: by the end of workshop 1 participants unanimously agreed that the filmed presentations had provided information on the research and dialogue process in a way that was clear and easy to understand (36 strongly agreed, 5 tended to agree). They also unanimously agreed that the information provided felt relevant to the topic they discussed (40 strongly agreed, 1 tended to agree).

After workshop 1 many participants in both Groups A and B mentioned how much they had valued finding out about scientific and technological advances which would affect the future of scanning and treatment. Typical views were that "*it was interesting to know how advanced technology is becoming.*" And helpful "*being able to talk to professionals*". A few participants commented that they would have liked to receive a little more information in advance. One noted after workshop 1 that "*Seeing materials/videos ahead of the session is helpful to consider thoughts and opinions. And also, a good way to ask friends and so that way, you get more feedback/views in the workshop.*"

During workshop 2 participants were not given much new information on the technologies, instead focusing on scenarios for how technologies might be rolled out or what it might mean in terms of future diagnosis or treatment. The low and high tech 20-week scanning scenarios were pretty detailed but participants appeared able to grasp the issues since they had reviewed them in advance as their homework task. Although the StAG had contributed to or

reviewed the scenarios a slight inaccuracy³ which might have affected participants' enthusiasm for the high-tech scenario did not come to light until after the discussions.

All the 38 respondents after workshop 2 reported finding the scenarios helpful in thinking about the wider issues (34, 89.5% strongly agreed and 4, 10.5% tended to agree). One participant commented that they: "*helped to provide some context which shaped thought processes a bit better*" and another that "*I thought the scenarios were very good for opening your mind to different options for you throughout pregnancies.*" Based on observations during the workshops the scenarios also proved a very effective way of bringing in a wider set of opinions beyond the participants in the room. Almost all participants appeared to have done the required homework and had explored the scenarios with at least one other friend or family member: a handful had canvassed wider opinions (via phone calls and emails and in one case via a WhatsApp antenatal and childbirth group). Several individuals actively sought out opinions that might be different from their own (either from those who had not yet experienced a pregnancy or who had had the opposite experience to their own in terms of diagnosis of a condition during pregnancy). The homework task therefore helped to amplify the number of opinions heard and some participants reported it had helped to shape their own opinions.

The second set of discussions on diagnosis of different types of conditions through improved scanning accuracy and MRI also worked well to explore whether parents preferred to have more or less information to inform their choices and what they felt that clinicians should do with any additional knowledge (i.e., consent and sharing of findings). A third question explored what support participants would want in place if a serious condition (such as spina bifida or twin to twin syndrome etc.) which would be suitable for an intervention before birth was diagnosed. Most participants were able to respond to these questions but a few commented that this session was more difficult and for some it felt a bit rushed. "*Some of the questions were a bit ambiguous and difficult to respond to.*"

The final session drew on the information from prior discussions and participants' own experiences to identify their priorities for future research. The facilitators' prompts did not specifically mention technologies and so some of the suggestions were broadly related to the antenatal journey but not necessarily in areas of relevance to the CME researchers. One participant commented "*I found the last question a little confusing regarding areas of research.*"

Most of the participants felt the overall pace of the workshops and time available felt about right; only one mentioned the cancelled workshop and would have liked to see it rearranged rather than cancelled. However, a handful of Group A participants said they would have appreciated more time to get to know each other and describe their own experiences in their small groups. For future dialogue with groups with similar lived experiences, it would be useful to allow an additional 30 minutes for a warm-up session so each that person had a chance to share their stories if they wanted to before getting into the dialogue questions.

³ under the high-tech scenario (which most participants had preferred) it would not be possible to view scan results on the screen.

4. Outcomes and impacts

4.1 Participants enjoyed the process and felt they had made a valuable contribution

Participants really enjoyed and valued the opportunity to take part. By the end of the process all participants agreed that the dialogue had allowed them to think through the issues and contribute informed opinions about how the proposed innovations should be developed in the future. All were happy to take part in a Zoom group photo and, in a ringing endorsement of the experience, all 39 participants after workshop 2 said they were happy to be recontacted by King's College London for further research. A handful were also happy to be filmed after the workshops, to describe the process and what they had got out of it. These contributions were included in the vox pop video.

Participants' many positive comments are shown in *Annex A* and a few are summarised in the box below. Many commented on how grateful they were and privileged to have taken part and how pleased they were that their opinions had been valued. When asked if they would have liked anything to have been done differently, most responded that everything had worked well and - other than more time to talk to each other - they saw little scope for improvement. A typical view was that *"So much [worked well] ...it was really interesting to hear everyone's perspective, the challenges faced by health professionals, I really enjoyed taking part"*.

By the end of workshop 2 respondents unanimously agreed (33, 86.8% strongly agreed and 5, 13.1% tended to agree) that the dialogue had allowed them to think through the issues and contribute informed opinions about how these innovations should be developed in the future. They also agreed that it is important that the public hear about and help shape how this type of research will be used in future (36, 92.3% strongly agreed, 2, 5.1% tended to agree, only 1 participant neither agreed nor disagreed). All respondents reported feeling confident or hopeful that their inputs will help to ensure that these innovations are as beneficial as possible to new and expectant parents in the future. (32, 82% strongly agreed, and 7, 18% tended to agree). This feeling was particularly strong amongst those who had experienced a condition that developed during pregnancy: *"Knowing that we are helping to make a difference to future medical technology."* A few described some trepidation initially, or that the process was emotional but, overall, they reported having had very positive experiences. *"The fact that it was on Zoom and in front of a screen for a long period of time was a bit draining but on the whole, it was a great experience to be part of."* And *"Amazing research, I am very glad to have taken part. I hope we can see some results in the future."*

Many also shared heartfelt messages about how empowering it had been to have the chance to give something back to the health care sector in the hope that something good would come out of their own difficult experiences. Several expressed their appreciation at being listened to. *"Whilst my pregnancy ended, I hope I can find opportunities like this where I can contribute to the future care of other people so some good can come of my experience."* While another stressed the value of *"Being able to share our experiences in the hope that changes in technology and clinical practice can help others in future."*

Participant reflections on taking part in the dialogue

Participants who had experienced a condition which developed in the womb

- *"I feel honoured to have had the opportunity to be a part of this workshop. I am so grateful to know that my experiences and thoughts may help in some way to improve outcomes for both parents and their babies in the future. It has been a therapeutic experience for me - that in*

contributing to this, somehow my baby might 'live on' in those babies that will benefit from this new research and technology is a huge comfort to me. I am so glad to have been able to do something practical to help others possibly have a better experience and to know the ways in which outcomes may improve across the country."

- *"Everyone was so wonderful. It is exciting to see what new developments will arise and to have helped future babies and parents in some little way has been a huge comfort."*
- *"I was apprehensive at first, I joined as a way to give back for all the amazing help offered to myself and my son. So, thank you."*
- *"I feel proud that I've been able to have an input and hopefully something good will come out of [my] very difficult experience."*
- *"Giving views about something that as someone who has been through the topic of the research, I was not given the chance to before."*
- *"I am really pleased I was able to take part. I feel really empowered and rewarded for sharing my views and opinions on these matters."*
- *"Thankful for having been given the opportunity to contribute my thoughts and past experiences."*

Those who had had an "as expected" pregnancy

- *"I am very happy that I took part, and I didn't realise how much of an interest I have in this field."*
- *"I feel positive to have been able to give my opinion to help develop and improve technologies and experiences."*
- *"I am so happy to be involved and I would be more than happy to get involved again in the future."*

4.2 Core objectives were achieved

Understanding different aspects of public acceptability regarding the iFIND and GIFT-Surg projects

The dialogue fully achieved this objective providing rich material and some 30 key insights (with some overlap) about public acceptability of innovations being developed by almost all the iFIND and GIFT-Surg innovations. These were summarised as six key findings in the executive summary. Responses to the evaluation found that on average (on a scale of 1 to 100 where 1 is mostly concerned and 100 is mostly unconcerned) most participants tended to be optimistic about the innovations being discussed (79/100), but those who had experienced a diagnosis during pregnancy tended to be most positive (83/100), while those without this experience were more hesitant.

Researchers interviewed reported that the dialogue had come at a useful point in the overall research cycle at a time when it was easier to visually convey how the innovations might be used. The finding that people wanted equality in geographic outcomes and experience was seen as a strong validation of the whole purpose behind the iFIND focus on technologies which would improve the accuracy of scanning outcomes across the country.

Researchers reported that the messages they heard from participants resonated with what they had heard through other forms of engagement: *"It adds to my understanding of what the public considers important."* And was a good reminder of the need to talk the public: *"Really refreshing to talk through innovations with a new group of people – a reminder of the need to seek out new opinions all through our research."*

Several researchers were encouraged by the generally positive attitudes to the technologies and interested in their general preferences for scanning in hospitals, involving sonographers and indeed the importance of the relationship between parents and a human specialist, whatever the technology being used. However, as noted above (*Section 3.3*) if they had

access to additional information, it may have slightly tempered their enthusiasm for the hi-tech scenario. One researcher reported that she would use these insights in her current research and discussions with colleagues. *“The findings that people are very receptive to changes in technology but that they want to know how it will benefit them, their baby and their experience was very useful. I will use these findings in my research on parent experience of scans in pregnancy and impact on parent/fetal bonding.”*

With a third round of workshops) more time could have been devoted to talking about the surgical interventions but, overall, the researchers were happy with the balance of the discussions. Several researchers noted that parents who had experienced a condition that developed in the womb had both a greater appetite for the most intrusive technologies, but also more capacity to talk about them. Indeed, several GIFT-Surg researchers wondered whether the participants in Group B (those who had experienced as expected pregnancies) would have struggled to discuss surgical interventions in greater depth. One StAG member noted that, given the level of enthusiasm for innovation expressed by participants, it will be a challenge to manage public expectations of how widely in utero interventions will be available *“not because it is brand new but because there are very few suitable cases.”* Several researchers found the dialogues to be a useful reminder about the need for accessible language and to focus on the patient journey rather than the underlying technical/engineering detail, especially with first time parents.

Views of researchers on the overall findings

- *“One of the key insights was that the group was quite positive about the scanning innovations regardless of their experience but much more circumspect for the more intrusive technologies unless they had had a difficult pregnancy already.”*
- *“Marked differences between those with normal and difficult pregnancies – those with high-risk pregnancies were happy to have everything [technology] thrown in – those without this experience were more hesitant.”*
- *“I was in with a group who had had uncomplicated pregnancies and the discussions on GIFTsurg complex surgeries for spina bifida and twin to twin surgery in utero seemed too steep a learning curve for this group. Quite difficult to get to that level or thinking about these very specialised interventions for conditions that are very rare.”*
- *“The findings are very much in line with what we have seen from other public engagement – we have a tendency to try and protect parents against excessive medicalisation of pregnancy but there is such a huge spectrum of experiences and we need to take this into account in how we present the research.”*
- *“What I took away from the dialogue was meeting people who were new to the technologies and discussing it afresh.... That was really valuable to me to remind myself what people outside the research group know about and to find new research questions.”*

Identifying questions and issues to inform future research applications

Interviews with a handful of researchers confirmed that the public dialogue has generated insights that will help inform their current and future research and thinking about how innovations should be rolled out in future. During workshops and an online survey, they gave examples of questions the dialogue had raised and some of the issues which will feed into their individual research applications. One research midwife gave the example of how she will build on the learning from the process that those who have experienced difficult pregnancies are willing and welcome the opportunity to be involved in research. She now plans further research on scanning and diagnosis with this group. *“Pregnant women are*

often treated as a vulnerable group so it has been really useful to be able to take findings from the public dialogue to say that, even those who have had difficult experiences can find it really useful to take part and feel empowered by sharing their experiences.”

The final workshop 2 session attempted to generate a list of future research priorities for the Centre. However, since the session was a little rushed and the questions framed very broadly it was only partially able to achieve this. Nevertheless, it did generate a long list of potential research areas, skewed towards the scanning and imaging processes. Since the prompt questions had been broadly framed, suggested research areas related to when scanning should be (eg before 20 weeks), how the results should be communicated and the need to signpost support available from groups and charities and advocacy for parents faced with difficult choices. Researchers from the iFIND project found this a useful starting place for thinking about future priorities for scanning. One commented that *“It’s useful to have this type of information for a service: more often it’s condition specific.”* Two iFIND researchers now plan to build on the findings to re-engage with some of the participants who have already given their permission to be recontacted: *“Going back to this cohort would definitely be useful. We plan to circulate a survey to finalise/prioritise research questions with them”*. Another said *“I’ll definitely use this experience to build into future research either with a new group or with this cohort who are already primed and have discussed some of these issues. That could be really useful.”*

4.3 Achieving the sub-objectives

Building engagement capacity and familiarity amongst the core group of researchers

This was an important sub-objective which was well achieved through the design of the process. The length of the process – 11 months from commissioning to publication of outputs – also created many opportunities for a core group of researchers to engage. The initial workshop in late 2019 involved 19 researchers ranging from PhD students, post docs and clinicians to academics. Of these, ten expressed an interest in staying engaged in the public dialogue. This core group plus seven other researchers attended a webinar in December 2020 which explained how the public dialogue was being designed. Almost all those taking part took the opportunity to suggest specific questions for the dialogue to address. Half of the group (10 researchers) then went on to play a very active role as participants of the StAG (eight), as specialists (three) or as observers (one as a silent observer in each small group of 6-7 participants) at the public workshops.

The online nature and timing of workshops meant that the demands on senior researchers and clinicians time were more manageable than for full day face-to-face meetings. Several were able to attend more than one session. More researchers would have liked to observe sessions that there were spaces available. Those who participated both as specialists and observers were able to help answer participants’ questions and on occasion contribute prompting questions that added real value to the discussions. It was noticeable that researchers, such as the sonographers and midwives that are used to talking to patients, found the role more comfortable and were able to pitch their contributions just right.

The time taken by the PE and 3KQ team to pre-brief researchers on their roles paid off: in almost all cases they were able to answer questions in ways which were sensitive to participants’ worries and in language that they found accessible. A slight downside of the online process was in limiting the opportunities for researchers to talk informally with participants and deepen their insights over coffee breaks.

Many researchers and the PE team reported that being part of the dialogue had been a very positive and valuable experience. Typical comments were that *“I certainly got a lot out of it –*

and most participants seemed to as well.” Being part of the process helped to reinforce their interest in public engagement in general (see box below) with those interviewed stressing how this has now become an established part of their research role. One noted that public engagement had previously been seen as a specialist activity for those with a particular interest but that *“Everyone now realises it’s a part of our core responsibility and actually a valuable thing that enriches you and allows you to get valuable perspectives.”* They recognised that this has been a conscious decision as a Centre and that setting up the Centre and appointing staff to advise, support and help professionalise engagement has now become a core part of the research team structure.

Several stressed effective two-way public dialogue needs to come at the point in the research project cycle where it can enable richer conversations. Most felt that this public dialogue had come at a timely juncture. *“We are definitely at a point now that it is a crucial time to do more public engagement ...It is crucial to have input from parents and those who will be using the services.”*

Involving harder to reach groups

When researchers were asked if they felt that as a result of taking part, they had gained anything that might help them to carry out public engagement activities in future projects they gave a number of examples. In addition to recognising the need for more pre-planning and preparing accessible materials and using more specialised skills than the more traditional public engagement they are used to, they also recognised the benefits of taking the time to engage parents who have experienced difficult pregnancies. Hearing from this group was of particular interest to the research team, many of whom expressed surprise at how willing they had been to take part in the dialogue. *“Encouraging that people felt it was nice to come to a shared space and felt empowered to share their experiences and to be listened to, even if they had had a difficult experience.”* Several researchers now plan to undertake their own research with parents with similar experiences.

Several researchers had also noted how, within this group, individuals from Black and minority ethnic backgrounds were harder to engage. One researcher has therefore applied to the King’s Ethics Committee to undertake further research on *“Representation in UK pregnancy research: Priorities and perceptions.”* This research will focus on engaging parents from Black and minority ethnic communities and try to understand why they have so far been less willing to take part in research and how to encourage and support their participation in future.

Benefits of independent facilitation

Most of those interviewed also commented on how independent facilitation skills and enabling participant-led discussion had helped to deepen the value of the insights that emerged. Researchers contrasted this with their normal role of imparting information and recognised the different skills required: *“Often our public engagement turns into projection or presentation of what we are doing – just public education more like a Horizon programme.”* And *“Seeing neutral facilitation in action was really helpful – putting myself in a neutral position to facilitate conversations with the public. Gave me a realistic grasp of what can be achieved.”* At least three individuals from the Centre are now seeking facilitation training as part of their continuing professional development. One has already secured funding: *“I have included provision for facilitation training into the funding for a research fellowship – I was already interested but watching and learning from experience was so interesting.”*

Several researchers also report using some of the skills observed in new research *“We plan to run some focus groups and 1-2-1 interviews and will be focusing on increasing the diversity and representation of local communities in research and to explore the specific*

perceptions that different groups have.” Two researchers have also set up their own stakeholder groups for specific research projects.

Improved capacity to manage future public dialogues

The PE team also considers the experience of managing this process has helped to develop their understanding of the time, resources and what to look for from an effective public dialogue process in the future. The experience has reinforced their confidence in managing similar public engagement with external support. The team also gained experience in the use of online engagement tools such as Conceptboard which they are now applying in other projects. The lessons learnt about how to work with charities to recruit and support participants is also being carried across to other projects. For instance, the PE Manager is rethinking her approach to an ongoing project with teenagers with experience of cancer treatment and placing much greater emphasis on duty of care provision (recognising potential sensitivities, providing a wellbeing room, and signposting to support services etc.).

During the dialogue workshops the PE team members acted as silent observers: in future processes they would now take on more active roles as independent facilitators, note-takers or rapporteurs feeding back to plenary sessions. Learning through close observation of the independent facilitators, one of the team has gone on to chair a meeting in follow up collaboration with 3KQ and to apply her facilitation skills to leading a workshop with one of the participating charities (ARC). Through the CME training budget, she plans to undertake further training to develop these skills. Such training may also be offered to other interested members of the research team.

Researchers’ views on the importance of public engagement

Reinforcing the importance of public engagement in general

- *“Our research is designed for the public good ... we have responsibilities to engage the public.”*
- *“We can get to a point where we are so absorbed that actually we have a really good idea of what we want to do, but that’s not necessarily what the parents need or indeed want, and so it is really important to have that collaborative and partnership approach to be really successful.”*
- *“We often talk about getting the public involved in research but it is difficult to have meaningful engagement early in research it is hard to engage except in the way of informing, but that is still really important.”*
- *“There has been a step change in development of technologies now becoming more accessible and people are interested. It is also, important to make it accessible to people. It’s really important for transparency in research.”*
- *“I think it is important to engage the public. However, theirs is one voice amongst many which has its own set of priorities, knowledge, and blind spots, so this should be considered when considering their opinions.”*

Enthusiasm for how public dialogue can contribute to their research

- *“In our project [iFIND] we have previously engaged in a very classic kind of patient engagement and with professional groups early on This [public dialogue] was very effective and a useful thing to do now that we are at the point where we are not just exploring the technological opportunities but understanding how you would deploy it in a real scenario. This dialogue was very timely from that point of view.”*
- *“Insightful and really eye-opening – the facilitators didn’t steer the conversation. I found it enriching.”*
- *“Sometimes it’s done really badly, and people are not really informed how it will be used, there’s lots of bad practice so it was great to see public engagement run so beautifully.”*
- *“Seeing neutral facilitation in action was really helpful. It gave me a realistic grasp of what can be achieved.”*

- *“Current PPI approaches are often very engineering or technology led and we are used to be the professional leading and steering the conversation. This was much more canvassing opinion, rather than promoting our work.”*
- *“The whole process has reaffirmed that research that involves members of the public must involve them not be done to them to get real insights.”*
- *“It has given me opinions about how I would do something similar and what I would want to get from it in the future.”*

Using a stakeholder advisory group (StAG) as a means to ensure balanced dialogue and ownership of the dialogue materials and outputs

This objective was well met. The relatively large StAG was able to represent all key interests (researchers, clinicians, charities, and an ethicist) with no obvious gaps and a good ratio of women and individuals from Black and ethnic minority backgrounds.

Almost all members were fully engaged through the 11-month process. The exception was the NHS representative who may have been over-committed during the COVID pandemic. All other members actively contributed to the framing of the dialogue around the antenatal journey (scan, diagnosis, intervention) and during the first StAG meeting researchers and clinicians shared images, papers, articles, and other resources relating to their research. During the second meeting most contributed to identifying the questions that the dialogue should be addressing. Many reviewed stimulus materials to help ensure they were accurate and accessible. Three researchers contributed significant time, being filmed as specialists for the videos and attending the workshops to answer participants’ questions. In total ten of the 13 StAG members attended a workshop session, all having also attended trainings by ARC and/or briefings by the 3KQ team. The majority of StAG members (9) also attended the final dissemination workshop.

Through evaluation activities and the final workshop, StAG members reported that the findings had resonated with them and will inform their future work. Even those that had not been able to observe the workshops felt a sense of ownership of the findings: *“I made inputs via the StAG to framing and reviewing materials but didn’t feel it was most appropriate for me to attend the workshops – I would have been interested to do so but didn’t want to overcrowd”*. **I senior researcher.**

The three charity members who were interviewed also felt they had benefitted from taking part. They gave as examples a strengthening of their partnerships with the PE team and individual researchers and identifying needs for further research.

Views of StAG members on the public dialogue process

- *“King’s engagement team and 3KQ together did an amazing job.”*
- *“Organisationally went really well – very good communication and both CME and 3KQ kept me in the loop – I’ve been really impressed how it all came together.”*
- *“The organisation of this public dialogue has been great and gave real confidence that it would work well. I really enjoyed the workshops.”*
- *“Thanks so much for the opportunity to be involved ...being part of a process that was really well supported was very inspiring.”*
- *“Running something of this scale is not a side hustle. It’s intensive and needs lots of careful planning and resources and budget but there is a real value to be gained from it.”*
- *“I have learned a lot from the project, and am impressed by the organisation, and the team, and the way you adapted to digital methods under difficult circumstances. I have been thinking more about the importance of getting minority and marginalised communities to input into discussions around how technology could help them.”*

Clear reporting for the extensive project team and for a wider readership within the health sector

The process resulted in a range of high-quality outputs designed for different audiences and dissemination approaches. The detailed [Dialogue Report](#) is comprehensive, well-written and designed. It provides a clear description of the dialogue methodology, the journey that participants went through in their deliberations and their recommendations. The report covers each of the stages of the antenatal journey and identifies some 30 findings (with some duplication). The report makes good use of the Conceptboard notes and transcriptions of small group discussions including anonymous quotes from participants to bring the report alive. Word clouds generated during the workshops were also used to good effect to highlight the differences in attitudes between Groups A and B. Including evaluation quotes from both participants and researchers helps add to the report. Overall, the report reflects what the evaluator, researchers and the StAG heard but is quite long and will principally be of interest to the CME research team.

Both the researchers and charities requested shorter and more visual outputs which could be shared via social media and would be more likely to appeal to wider audiences. With this in mind the team also produced:

- A short (5 page), [executive summary](#) of the six key findings suitable for a non-technical audience.
- A one-page [infographic](#) of the process. This presents the findings as short sound bites and can easily be shared via social media.
- A [vox pop video](#) (2'30") on the process presented by the Centre researchers, PE team and participants. Filming during a national lockdown via Zoom interviews necessarily involved some compromise on production quality but the resulting film has a strong narrative that describes the benefits of public dialogue processes, the enthusiasm of participants and researchers and what they took away from the process. The video should be of interest to the participants and a wider audience of public engagement practitioners. The video is available on YouTube (52 views between July and August 2021).

The project has also generated materials which should prove useful for ongoing public engagement about the Centre's research including the [set of the four videos](#) each explaining a different part of the antenatal scanning, diagnosis, and surgical intervention journey. The PE team also has a [database of 39 participants](#) from around the country who are willing to be involved in further research.

Dissemination

All the materials were published at the Centre's website and the findings discussed at a dissemination event on Thursday 15th July 2021. The online workshop was attended by 33 participants including a mix of StAG members, researchers, and public engagement/ impact professionals from outside the project. Four out of the six participating charities reported plans to share the outputs via their websites or social media and to share insights gained from the dialogues with their staff, supporters and funders via newsletters, social media, and relevant events. One charity also intends to share the results as evidence of partnership working with their trustees and funders.

All public participants were sent links to the vox pop video, one page infographic, the final report and executive summary. The PE team will also signpost ways in which they can continue to be involved with the Centre and partner charities, including being involved in

follow on research projects. Two researchers already plan to recontact them for follow on research.

4.4 Other unanticipated benefits

The process has also delivered a number of other unanticipated benefits for the PE team and participating charities.

Strengthening relationships within the Centre and with its partners. The length and depth of the dialogue process has helped to strengthen relationships between the PE team, StAG members and contributing researchers providing all parties with a better understanding of how their work fits together.

Both the PE team and the partner charities have also seen benefits from the time they invested in delivering training to researchers and helping to recruit parents who had experienced conditions which developed in the womb. Charities ARC, ECHO, CDH UK and Twins Trust all described the dialogue process as worthwhile and a positive experience and described their interactions with the PE team as informative, educational, helpful, and friendly, mindful, clear, responsive, and satisfying. This is expected to strengthen the foundations for effective future partnership working. *“Having a direct contact at King’s and building a relationship with the team has made discussions and any challenges easier to raise.”* **1 charity representative.**

The charities reported being especially pleased to see the effort taken to make the experience a positive one for their members/supporters and several reported being delighted that those they helped to recruit had got so much out of the experience and participated so enthusiastically, even if it would not bring them any direct benefit. One charity (CDH UK) plans to apply the lessons learnt about creating a safe and supportive space to their own public engagement work.

As noted, the challenges of recruiting individuals from Black and ethnic minority backgrounds helped highlight the need to do more in this area. One charity (Bliss) now intends to work with a research midwife to involve this group more in research.

Finally, several charities also benefitted from small financial donations for running training and the wellbeing room and from donations from their thankyou payments by four participants (£360).

5. Conclusions and lessons learnt

The online public dialogue fully met both its core and sub-objectives. The dialogue involved a substantially larger budget than the Centre's usual style of public engagement. A core group of half a dozen researchers were engaged in designing and delivering the process which brought together 43 members of the public with recent experience of pregnancy. Half of the group had experienced conditions which developed in the womb: this is a group the researchers were particularly pleased to be able to hear from. The participants were able to learn about Centre innovations, question specialists and deliberate amongst themselves, friends, and family over the course of a month. The resulting discussions generated insights about the public acceptability of technologies and future research needs which will inform the Centre's work. Being part of the process has also reinforced the team's commitment to public engagement and enthusiasm for independently facilitated, participant-led dialogue.

The process also generated useful lessons about undertaking public online dialogues:

- Online meetings enabled a more diverse group of participants than would have been financially or logistically possible face-to-face. Hearing from participants across the country validated an underlying driver for the Centre's research - to improve the accuracy of antenatal scanning and diagnosis results for all parents, regardless of geography.
- The time between meetings gave participants time to deliberate on what they had heard individually and with family and friends. Shorter online meetings allowed parents of very young children to participate, where childcare may otherwise have been an issue.
- Despite savings in venues and travel from delivering the process online, the additional costs for pre-planning and support (developing engaging materials, tech support to participants, a lower facilitator: participant ratio, briefings for researchers, provisions for participants' wellbeing) meant that online delivery was as resource intensive as a face-to-face process would have been.
- Some of the preparatory tasks were more time-consuming than the team had anticipated (e.g., the recruitment process via charities, developing films as stimulus materials, and training/briefing researchers). However, the attention to detailed planning paid off: the process looked effortless and participants were very satisfied with their experience.
- Given the sensitive nature of the topic and distressing pregnancy experiences of half the participants the care spent in making them feel comfortable, respected, and heard was a crucial element in the success of the dialogue. Highly experienced facilitators were able to ask questions, probe, and capture participants thoughts expertly. Participants were comforted to know that a wellbeing room and relaxation exercises were available, even if most did not need to use them. Lessons learnt on how to run these support services are now being incorporated into other public engagement activities by both the PE team and by partner charities.
- Pre-filmed stimulus materials had benefits in helping the team control timings and how information was conveyed and provided as a contingency against last minute unavailability of specialists. In retrospect the same benefits could probably have been achieved with lower production values and less time spent in producing them.
- Centre researchers and clinicians played an important role: time spent in sensitivity and language training and pre-briefing helped ensure they were able to answer participant's questions in a way they found helpful.
- The delivery team, StAG members, researchers and charities recognised the difficulties in recruiting individuals from Black and minority ethnic backgrounds and non-childbearing parents who have experienced difficult pregnancies as a wider challenge for research which needs to be addressed. Several participating researchers and one charity are now planning further work to address this issue.

Annex A: Evaluation feedback from participants

Participant responses to evaluation for workshop 1: n=41					
The recruitment process (either via a charity or the recruitment agency or other) worked well and was not too intrusive.	Strongly agree	Tend to agree	Neither	Tend to disagree	Strongly disagree
	34	7			
<ul style="list-style-type: none"> <i>This was something I opted to do after I saw it advertised on the NICU support groups I actively follow. I did not feel pressured into partaking.</i> <i>It was a straightforward and easy process and it did not feel intrusive at all</i> <i>I was able to put myself forward</i> 					
I understand what the objectives of the dialogue are and of today's session.	Strongly agree	Tend to agree	Neither	Tend to disagree	Strongly disagree
	34	7			
<ul style="list-style-type: none"> <i>To help inform future research and use of technology in pregnancy scanning and fetal surgery</i> <i>Really pleased to be able to help and contribute.</i> <i>To gain an understanding of parent's views and opinions on upcoming technologies. To help to clarify these technologies.</i> <i>To obtain the public's perspective and thoughts on advances in technology relating to the screening scan & subsequent surgical treatments in pregnancy</i> <i>To get comments and questions to inform further sessions about new technologies for the 20-week scan and surgery in the womb</i> <i>Discuss potential advances in 20-week anomaly scanning, finding out questions or comments regarding what is proposed / available.</i> <i>Finding out what parents think about diagnostic technology in pregnancy</i> 					
The filmed presentations provided information on the research and dialogue process in a way that was clear and easy to understand.	Strongly agree	Tend to agree	Neither	Tend to disagree	Strongly disagree
	36	5			
<ul style="list-style-type: none"> <i>Really good - can the links be emailed out as would be really keen to watch these again. Sending these in advance might be useful also.</i> <i>Whether or not throughout the application of these methods statistical clarity will be put forward regarding risks.</i> 					
The information provided felt relevant to the topic we discussed.	Strongly agree	Tend to agree	Neither	Tend to disagree	Strongly disagree
	40	1			
The facilitator team captured my questions and respected my input.	Strongly agree	Tend to agree	Neither	Tend to disagree	Strongly disagree
	39	2			
<ul style="list-style-type: none"> <i>Very well captured on the board</i> <i>Lovely facilitator</i> <i>The facilitator (Jenny) was extremely good at reflecting what was said and ensuring everyone had input and being empathic to people's situations</i> <i>Felt very comfortable in our breakout group, will the groups remain the same for each workshop?</i> <i>The team helped me feel very comfortable in sharing my experiences.</i> 					
The pace of the session felt about right.	Strongly agree	Tend to agree	Neither	Tend to disagree	Strongly disagree
	34	7			

Is there anything in particular about the research described that you would like to discuss more in the next workshops?

- Improvements in scanning and detection rates of more conditions.
- I look forward to learning more about scanning and procedures
- Future outcomes
- I think the process of fetal surgery and support out there
- All great
- Fetal surgery developments in spina bifida
- The information about new treatments and how they can't guarantee that they will make a difference/be beneficial.
- It may be useful to ask people if there are any specific areas that they feel merits discussion that hasn't been raised already. In our group the role of the midwife in the 20-week scan was one suggestion
- Statistics and clarity of the risks and whether or not these statistics and risks are going to be made clear to the public and parents.
- Stem cell interventions in utero sounds really interesting!
- Further detail on the keyhole surgery - risks etc
- AI, fetal surgery, availability - how will this be shared throughout the UK
- The support offered to expectant parents.

Was there anything that made you feel that you could not take part fully in today's session? If so, is there any way in which the team can help?

- A lot of the conversation tended to be centred around individuals who were diagnosed with a condition in their pregnancy and what improvements could be made for those conditions. I couldn't really comment on this as this had not happened to me (my baby had a condition but it was not detected or diagnosed until baby was born).
- I was able to use the break room with Jane at the moment I needed to. Thank you for that.
- No, it was an interesting meeting
- No, I felt fully involved and have really enjoyed it.
- No, the concept board was difficult to navigate but didn't stop my participation.
- 5-minute break was quite short in terms of getting a coffee and having a comfort break!
- No, I felt at ease answer and speaking about my experiences

Participant responses to evaluation for workshops 2: n=39 (NB one respondent did not answer all questions)

	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree
I feel I had enough information to enable me to contribute my views today.	35 92.1%	3 7.9%			
• Those experiencing conditions during pregnancy	16	2			
• Those with 'normal' pregnancies	19	1			
<ul style="list-style-type: none"> • There was a lot of information which I found really insightful. • I found the last question a little confusing regarding areas of research. 					
The scenarios were helpful in thinking about the wider issues.	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree
	34 89.5%	4 10.5%			
• Those experiencing conditions during pregnancy	16	2			
• Those with 'normal' pregnancies	18	2			

<ul style="list-style-type: none"> <i>I thought the scenarios were very good for opening your mind to different options for you throughout pregnancies.</i> <i>The scenarios helped to provide some context which shaped thought processes a bit better.</i> <i>I think there could have been more focus on the timing of where you are at in the scan process.</i> <i>There are a lot of avenues to explore, and I find it really interesting.</i> <i>Some of the questions were a bit ambiguous and difficult to respond to.</i> <i>Clear direction on where the individual was at the time of the scans</i> 					
The environment created by the hosts was warm and supportive.	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree
	37 97.4%	1 2.6%			
<ul style="list-style-type: none"> Those experiencing conditions during pregnancy 	18				
<ul style="list-style-type: none"> Those with 'normal' pregnancies 	19	1			
I feel that all participants were treated with respect, irrespective of their background or experience.	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree
	38 100%				
<ul style="list-style-type: none"> Those experiencing conditions during pregnancy 	18				
<ul style="list-style-type: none"> Those with 'normal' pregnancies 	20				
It was a comfort to know that there was a wellbeing room available if I needed it.	Agree - and I did use ¹	Agree – but I didn't use	Disagree- I wouldn't have used	I wasn't aware that it was available	
	6 15.8%	32 84.2%			
<ul style="list-style-type: none"> Those experiencing conditions during pregnancy 	1	17			
<ul style="list-style-type: none"> Those with 'normal' pregnancies 	5	15			
<ul style="list-style-type: none"> <i>Everyone was so lovely, and the breakout rooms/decompress videos were a great idea.</i> <i>I didn't use but thanks to ARC for the support in general.</i> <i>I used the wellbeing room on the first session to have a little cry and pause. This time I did not need to pop out, but I still appreciated that they were there if we needed a chat.</i> <i>I think that was a really great idea to have the wellbeing room as it is a sensitive subject to talk about for some, and also because sometimes hearing peoples' opinions and their difference to yoursso to be able to have 5 minutes to yourself if needed was a brilliant idea.</i> <p>¹Only 1 participant actually used the wellbeing breakout room, others may have been referring to the mindfulness sessions available after each workshop.</p>					
Facilitators were professional, independent, and used appropriate language.	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree
	38 100%				
<ul style="list-style-type: none"> Those experiencing conditions during pregnancy 	18				
<ul style="list-style-type: none"> Those with 'normal' pregnancies 	20				
<ul style="list-style-type: none"> <i>Well, done to the organisation of this research.</i> 					
I was interested hearing from others in my group with similar experiences during pregnancy.	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree
	32 86.5%	4 10.8%	1 2.7%		
<ul style="list-style-type: none"> Those experiencing conditions during pregnancy 	17	1			
<ul style="list-style-type: none"> Those with 'normal' pregnancies 	15	3	1		

<ul style="list-style-type: none"> <i>I think everyone has a slightly different journey, but really interesting to hear their views.</i> <i>A chance to tell your experience as the questions were quite general, but not everyone might want to do this. No one had a similar experience in my group which made it even more interesting to hear other's points of view</i> <i>I found it really interesting.</i> <i>Was really interesting, thank you</i> 					
I had enough time and space to make by voice heard.	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree
	33 86.8%	3 7.9%	1 2.6%	1 2.6%	
<ul style="list-style-type: none"> Those experiencing conditions during pregnancy 	16	2			
<ul style="list-style-type: none"> Those with 'normal' pregnancies 	17	1	1	1	
<ul style="list-style-type: none"> <i>I would have maybe liked just a little bit more time or an allocated time slot for each person, I did have times where I didn't give my opinion because time had run out and also because when you're giving your opinion you can sometimes get carried away.</i> <i>Sometimes I wish we had been given a little more time in the focus groups as it felt rushed at times for us all to give our views.</i> <i>I think for those of us who have had complicated pregnancies we are quite keen to share our views and possibly could have used a little more time.</i> <i>I felt as though I was easily able to contribute my opinions and ideas as the smaller breakout rooms were far less intimidating to speak in.</i> 					
This dialogue has allowed me to think through the issues and contribute informed opinions about how these innovations should be developed in the future.	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree
	33 86.8%	5 13.1%			
<ul style="list-style-type: none"> Those experiencing conditions during pregnancy 	16	2			
<ul style="list-style-type: none"> Those with 'normal' pregnancies 	17	3			
<ul style="list-style-type: none"> <i>This was so well organised and thought-out.</i> 					
How do you feel about the research described? (On a scale of 1-10 where 1 = mostly concerned and 10=mostly hopeful)	79/100				
<ul style="list-style-type: none"> Those experiencing conditions during pregnancy 	83				
<ul style="list-style-type: none"> Those with 'normal' pregnancies 	79				
<ul style="list-style-type: none"> <i>Amazing research, I am very glad to be taken part. I hope we can see some results in the future.</i> <i>Great that the NHS is conducting this research.</i> <i>If technology can help in a better patient experience that is a positive step forward</i> 					
I think it is important that the public hear about and help shape how this type of research will be used in future.	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree
	36 92.3%	2 5.1%	1 2.6%		
<ul style="list-style-type: none"> Those experiencing conditions during pregnancy 	16	1	1		
<ul style="list-style-type: none"> Those with 'normal' pregnancies 	20	1			
<ul style="list-style-type: none"> <i>Important that the public hear: I think it's useful to gauge opinion, but everyone will have different concerns based on personal experience. People are often resistant to change.</i> 					

I am confident that our inputs will help to ensure that these innovations are beneficial as possible to new and expectant parents in the future.	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree
	32 82%	7 18%			
• Those experiencing conditions during pregnancy	14	4			
• Those with 'normal' pregnancies	18	3			
Would you be happy for King's College London to contact you about projects related to our future research?	Yes 39 100%	No 0			
• Those experiencing conditions during pregnancy	18				
• Those with 'normal' pregnancies	21				

What, if anything, might have been done differently?

Half of participants in both the morning and afternoon sessions said there wasn't anything they would want to change – saying it was great or perfect or they used the opportunity to stress that it had been well organised:

- *I think it was done very well and wouldn't see the need to change anything.*
- *Nothing, very well organised and conducted.*

A few would have liked a little more info in advance:

- *Seeing materials/videos ahead of the session is helpful to consider thoughts and opinions. Also, good way to ask friends and so that way, you get more feedback/views in the workshop.*
- *Questions ahead of time to allow for preparation.*

Or a little more time so that everyone could speak without running out of time and another would have liked more time for the focus groups. Just one mentioned the second workshop being cancelled and would have liked to see it rearranged rather than cancelled.

One said *"Asking participants not to have babies present who can be seen & heard during the breakout sessions. I became distracted & unable to concentrate properly as someone in our breakout room had a very young baby with them. It's been 7 months since my baby died & although very happy to share my experience & able to participate in these sessions, this was a very unwelcome reminder & distraction"*.

Overall, how do you feel about having taken part in this public dialogue?

Those who had experienced a condition which developed during pregnancy:

- *I feel honoured to have had the opportunity to be a part of this workshop. I am so grateful to know that my experiences and thoughts may help in some way to improve outcomes for both parents and their babies in the future. It has been both a therapeutic experience for me - that in contributing to this, somehow my baby might 'live on' in those babies that will benefit from this new research and technology is a huge comfort to me. I am so glad to have been able to do something practical to help others possibly have a better experience and to know the ways in which outcomes may improve across the country.*
- *Grateful to have had an opportunity to have my voice heard.*
- *Pleased.*
- *A little emotional, but glad to have been involved.*
- *I feel good about it, I have a research background, so I found it super interesting. The fact that it was on Zoom and in front of a screen for a long period of time was a bit draining but on the whole, it was a great experience to be part of.*
- *Like I've made a positive impact.*
- *I was apprehensive at first, I joined as a way to give back for all the amazing help offered to myself and my son. So, thank you.*
- *Pleased that people have a chance to have their say.*

- *Privileged! I Feel lucky to have had the opportunity to contribute. I'm so grateful to our frontline who work in antenatal care and so pleased I can help them too in this small way. I'd love to take part in future research and also to share my experience as I know some good/learnings can be taken from it (TFMR related).*
- *Incredibly privileged, thank you.*
- *I feel proud that I've been able to have an input and hopefully something good will come out of a very difficult experience.*
- *Really interesting and positive experience.*
- *Comfortable.*
- *I am really pleased I was able to take part. I feel really empowered and rewarded for sharing my views and opinions on these matters.*
- *Really pleased and optimistic.*
- *Thankful for having been given the opportunity to contribute my thoughts and past experiences.*

Feedback from the individual who was not able to take part in second workshop

My daughter had open heart surgery yesterday... I feel I couldn't concentrate & give my upmost to today's meeting. I am very interested in everything we have already discussed, & completed the tasks set early this week. Is there any way I could still be involved? Would love the opportunity to watch the meeting back & send you the information I have if that's at all possible?

Those who did not experience a condition which developed during pregnancy

- *I am very happy that I took part, and I didn't realise how much of an interest I have in this field.*
- *I feel happy that I have done it and that I know a little bit of what scans may look like in the near future.*
- *I am so happy to be involved and I would be more than happy to get involved again in the future.*
- *I feel positive to have been able to give my opinion to help develop and improve technologies and experiences.*
- *Excited to have been part of it!!!*
- *Very good*
- *Privileged to take part.*
- *Loved it.*
- *I've thoroughly enjoyed it thank you.*
- *Happy that it could help someone else.*
- *Confident*
- *It was nice to be able to put my feelings and thoughts across to help shape the future.*
- *good*
- *Very happy to have had chance to take part and help shape the future of diagnostic imaging!*
- *Happy*
- *Positive it was very insightful.*
- *Positive*

		Charity recruited group	Agency recruited group	Total
Sex / parental role	Female / mother	19	18	37
	Male / father	2	4	6
Age	24 and under	0	4	4
	25-34	10	10	20
	35-44	9	8	17
	45-54	2	0	2
Ethnic group	White: British	19	12	31
	White: Other	0	2	2
	Black / Black British	0	2	2
	Asian / Asian British	1	3	4
	Mixed or multiple ethnic groups	1	2	3
	Other	0	1	1

Highest educational level	Secondary school up to 16 years old (e.g., GCE, O-levels, GCSEs etc.)	0	5	5
	Higher or secondary or further education (e.g., A-levels, BTEC etc.)	8	10	18
	University or undergraduate degree (e.g., BSc, BA, MBBS etc.)	9	4	13
	Post-graduate degree (e.g., PhD, MSc, MA, MD etc.)	3	2	5
	Other vocational training/qualifications	0	1	1
	Unknown	1	0	1
Region	East Midlands	0	3	3
	East of England	1	1	2
	London	4	4	8
	Northeast	1	1	2
	Northwest	2	3	5
	Southeast	6	3	9
	Southwest	4	2	6
	West Midlands	0	3	3
	Yorkshire & The Humber	3	2	5

Annex B: Steering Advisory Group members

Name	Job title	Organisation
Anna David	Professor and Principal Consultant, Obstetrics and Maternal Fetal Medicine	University College London / University College London Hospital
Andrew Melbourne	Senior Lecturer in Healthcare Technologies	King's College London
Wenfeng Xia	Lecturer in Surgical and Interventional Engineering	King's College London
Neeltje Crombag	Midwife & social scientist	KU Leuven
Jane Fisher	Director	Antenatal Results and Choices (ARC)
Debbie Bezalel	Services Director	Bliss - UK Charity for babies born premature or sick
Jo Hajnal	Professor of Imaging Science	King's College London
David Lloyd	Clinical Lecturer in Child Health and fetal cardiologist	King's College London / Guy's and St Thomas' Hospital
Gavin Wheeler	Research Software Developer	King's College London
Jackie Matthew	Research Sonographer	King's College London
Sophie Bertaud	Paediatric palliative consultant and bioethicist	Great Ormond Street Hospital
Didi Akinluyi	Chief Biomedical Engineer and Head of Clinical Engineering	King's College London / Guy's and St Thomas' Hospital
Tania Duarte	Co-Founder	We and AI (non-profit working to increase the awareness and understanding of artificial intelligence)
Core project team		
Alice Taylor-Gee	Public Engagement Manager	King's College London
Melissa Bovis	Public and Patient Engagement Coordinator	King's College London
Bella Spencer	Public Engagement Officer	King's College London
Rhuari Bennett	Dialogue delivery team	3KQ
Pippa Hyam	Dialogue delivery team	3KQ
Hannah Wynne	Dialogue delivery team	3KQ