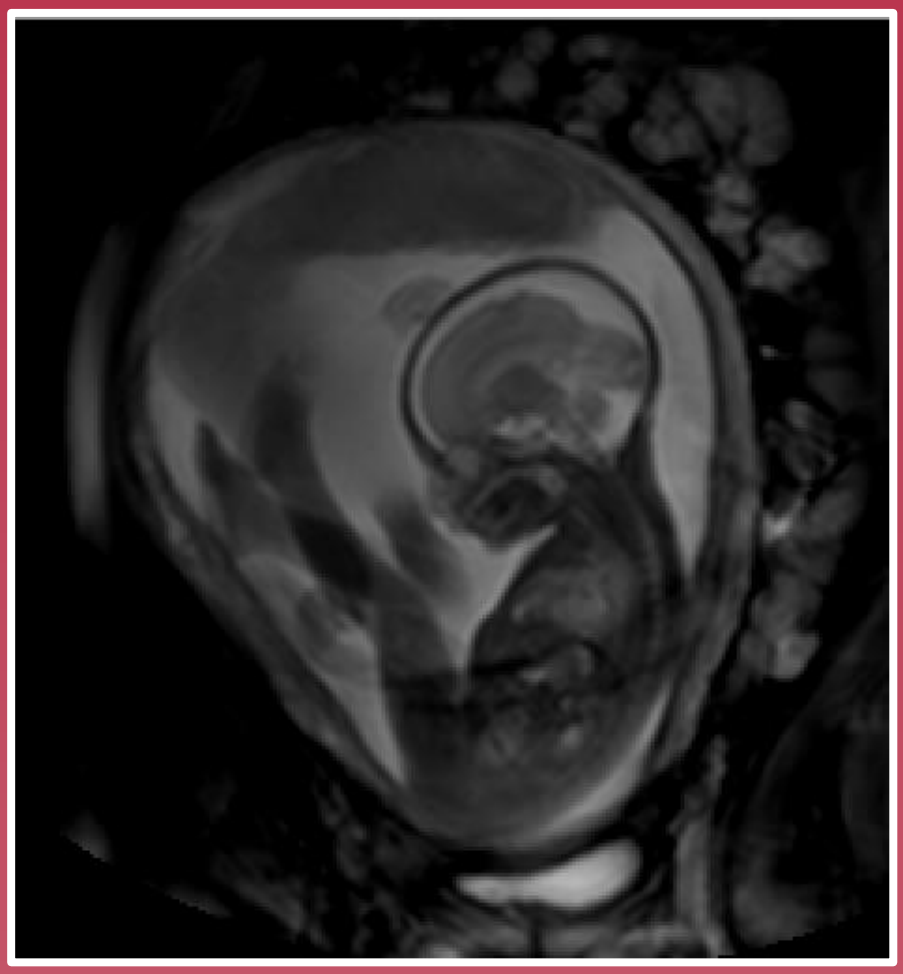
Public Dialogue on Scanning and Surgical Innovations in Pregnancy

Report of dialogue workshops with members of the public



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KING'S College LONDON

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3KQ

Table of contents

1. Introduction 3

1.1 Project background 3

1.1 Context 4

1.2 Objectives 4

2. Methodology 5

2.1 Dialogue process overview 5

2.1.1 Workshop design 6

2.1.2 Participation 9

2.1.3 Sensitive handling and support 13

2.1.4 Terminology 15

2.1.5 Development of the materials and stakeholder advisory group 15

2.1.6 First workshop stimulus material content - videos 16

2.1.7 Second workshop stimulus materials – scene setting 17

3 Summary of the participants' feedback 18

3.1 Innovations in screening – the 20-week scan 18

3.1.1 Key themes 18

3.1.2 Initial response to an automated 20-week scan 20

3.1.3 Two 20-week scan scenarios 25

3.1.4 Accountability 31

3.1.5 Final thoughts 33

3.2 Advanced diagnostic tools 34

3.2.1 Key themes 34

3.2.2 Response to developments in advanced diagnostic tools 35

3.2.3 Incidental findings: knowing during pregnancy vs. not knowing 38

3.3 Interventions on the baby during pregnancy 42

3.3.1 Key themes 42

3.3.2 Response to interventions on the baby while still in the womb. 43

3.4 Future research priorities 47

4 Appendices 51

4.1 Stakeholder Advisory Group (StAG) membership 51

4.2 Stimulus videos 52

4.3 Glossary of terms 52

4.4 Demographic data 53

4.6 For more information 54

1. Introduction

1.1 Project background

Two significant Wellcome Trust funded research projects, Intelligent Fetal Imaging and Diagnosis (iFIND) and Guided Instrumentation for Fetal Therapy and Surgery (GIFT-Surg), co-located within the School of Biomedical Engineering & Imaging Sciences (BMEIS), King's College London, have been exploring ways in which new technologies can improve the detection, diagnosis and treatment of congenital conditions. GIFT-Surg is a collaboration between King's College London, University College London and Katholieke Universiteit Leuven, as well as clinical partners Great Ormond Street Hospital, University College London Hospital NHS Foundation Trust and UZ Leuven.

This online public dialogue project was designed to explore how members of the public feel about some key innovations from these two research projects and their views about potential changes to scanning and surgery during pregnancy healthcare provision.

The project was funded and managed by the Wellcome/EPSRC Centre for Medical Engineering, aligned with the School. Independent facilitators, 3KQ, were appointed to deliver the public dialogue in partnership with the Centre's public engagement team. Independent evaluation company, URSUS Consulting, was appointed to review the design and the delivery of the dialogue process. We partnered with a number of relevant charities to help support the project (ARC, Bliss, ECHO, Twins Trust, Shine and CDH-UK).

The project took place between September 2020 and July 2021; this was during the coronavirus pandemic and was therefore carried out entirely online.

The organising team is extremely grateful to all those who gave their time to support the project and would like to thank the researchers, partnered charities, members of the stakeholder advisory group and participants who all contributed to the success of this project.

1.1 Context

For the context of this dialogue it is important to be aware of the difference between screening, diagnosis and intervention.

- The 20-week ultrasound scan is a routine **screening** test which is offered to all pregnant women in the UK: it aims to detect anomalies which may need further investigation.
- If an anomaly is identified the families will be referred to a fetal medicine specialist who will usually perform a more detailed ultrasound scan and discuss options for further tests such as MRI or genetic testing. This process aims to **diagnose** whether the baby has a condition.
- For a small number of families who have a specific condition diagnosed (such as spina bifida or twin-to-twin transfusion syndrome) and meet certain criteria they have the option of interventions, including operating on the baby while still in the womb (fetal **surgery**).

1.2 Objectives

The key objective of this public dialogue was to understand **different aspects of public acceptability** of new technologies being developed and to enable future research to be influenced by engagement, relating to:

- machine learning and automation in ultrasound scanning
- advanced diagnostic imaging, including MRI
- robotic tools for scanning and intervention
- keyhole surgery on babies in the womb

Supplementary objectives and outputs were as follows:

- Identify questions and issues to inform future research applications
- Build engagement capacity and familiarity of a core group of researchers from these large research projects
- Utilise a multi-stakeholder advisory group as a means to ensure balance and ownership of the dialogue materials and outputs
- Provide a clear report for the extensive project team, but also for wider readership within the antenatal healthcare sector

> *POST EVENT REFLECTIONS*
>
> ***"We are definitely at a point now that it is a crucial time to do more public engagement. Two worlds collide – the naturalistic parent concept of pregnancy world and medicalisation of scanning. It is crucial to have input from parents and those who will be using the services."***
>
> **—Researcher**
>
> ***"If technology can help in a better patient experience that is a positive step forward."***
>
> **—Participant**

2. Methodology

2.1 Dialogue process overview

The dialogue required a lengthy and thorough planning phase, reflecting the complexity of the subject matter and the need for robust process design online to ensure a safe and supportive space for participants to discuss sensitive issues around pregnancy.

> *POST EVENT REFLECTIONS*
>
> ***"Real strength in having moderators – the whole infrastructure in putting something like this together was intensive but there was real value in being so thorough."***
>
> **—Researcher**

Project process

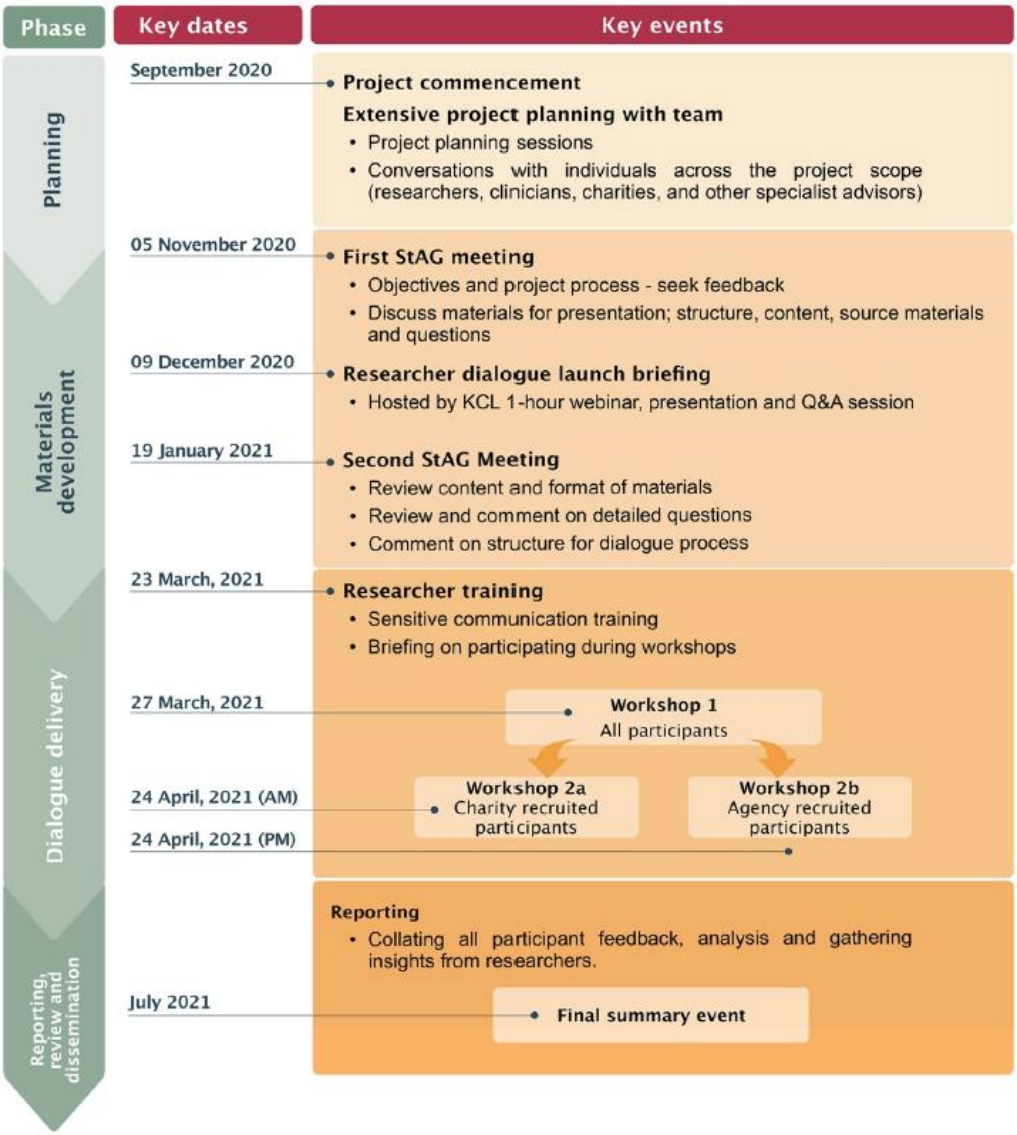


Figure 3: *11-month project process plan for the public dialogue including project phases, timeline and key-related events.*

The process began with project planning, establishing a stakeholder advisory group (StAG) and the development of stimulus materials to enable participant discussion during the workshops.

Two online StAG meetings enabled researchers, medical doctors, antenatal healthcare staff (sonographers and midwives), NHS Commissioners, relevant charity representatives, an external artificial intelligence communication consultant, and an ethicist, to steer and advise on the content development of the stimulus materials.

Recruitment of public participants

Two cohorts of 24 target participants were recruited. The first group were people who had experienced a pregnancy where a condition from birth (congenital) was identified; this group was recruited via a range of charities who support parents. The second group were people who had experienced a recent pregnancy where no condition was identified; this group was recruited via a recruitment agency. See section 2.3.3 for more detail.

> *POST EVENT REFLECTIONS*
>
> ***"Important that the public hear: I think it's useful to gauge opinion, but everyone will have different concerns based on personal experience."***
>
> **—Participant**

Researcher involvement

It is important for research scientists to be involved in public dialogues to hear first hand how members of the public respond to the ideas being developed through their research. During this project various opportunities were provided for researchers to participate, including:

- **February 2019**: An engagement workshop, which brought research teams together and explore the level of interest in pursuing a public dialogue
- **December 2020**: A webinar for researchers and clinicians working on iFIND and GIFT-Surg projects provided an overview of the dialogue process and opportunities for involvement.
- **March 2021**: Language-sensitivity training was delivered by the charity Antenatal Results & Choices (ARC). The session was designed to develop researchers' confidence and competence for engaging on sensitive issues relating to antenatal care and pregnancy.

2.1.1 Workshop design

Fully online project

The project took place during the coronavirus pandemic. As a result the process was designed to take place completely online, with all project planning meetings, stakeholder meetings and the dialogue workshops themselves taking place online, via video conferencing platform Zoom. Although prior to the pandemic these types of meetings would have been

held face-to-face there were a number of discernible benefits of this online approach which suited the target group.

Firstly, it enabled parents of young children to participate where childcare may have been an issue attending a face-to-face meeting; secondly it allowed people from all over England to meet together without prohibitive travel times and costs, enabling a wider range of views to be heard.

For project planning, materials development and facilitating the workshops an online whiteboard tool (Conceptboard) was used to house all materials in one place. Participants were invited to view Conceptboard before, during and after the meetings; where they could access details for the meeting, view the stimulus materials in their own time, and see the outputs of the discussions that took place in other breakout rooms and the previous workshop to ensure the process was open and transparent. During the small group discussions the facilitators captured the discussions directly onto the Conceptboard so that all participants could see how their comments had been captured and view discussions from the other small groups.

Figure 4: *The Conceptboard: an online tool used to house all materials for the discussion.*

Participant-led dialogue

The process was designed to be a participant-led virtual dialogue. This involved presenting the information to them (in the form of the stimulus videos) during the first workshop and then hearing from them what questions and issues it raised. Subsequent workshops were then designed to respond to the issues raised by participants. Although the organising team considered in advance the types of issues participants might be interested in, these were not prompted.

> *POST EVENT REFLECTIONS*
>
> ***"Everything was led by participants in the groups within the broad outline of the sessions – not so 'managed' as we would normally try and be and therefore the conversation was much richer and varied because they were talking about the issues that mattered to them."***
>
> **—Researcher**

Schedule of dialogue meetings

The workshops all took place on Saturdays, to maximise the chances of participants being able to commit time around work arrangements and to arrange potential childcare, if required. The workshops with participants took place on the following dates:

- **Workshop 1** - Saturday 27th March 2021 – a three hour meeting (10:00 - 13:00) with all participants.
- **Workshops 2a and 2b** – Saturday 24th April 2021 – two three hour workshops, one in the morning (10:00 - 13:00) with the charity recruited participants, and one in the afternoon (14:00 - 17:00) with agency recruited participants.

An additional two workshops were planned for the morning and afternoon of Saturday 17th April 2021. This coincided with the funeral of HRH Duke of Edinburgh and a period of national mourning; which led to instruction from King's College London to cancel all external events during this time.

As the first workshop had been extremely productive, the project team took the decision not to rearrange the cancelled meeting, instead asking participants to do a 'homework task' and condensing the remaining discussion sessions into the final workshops on 24th April.

Participants received £160 as a thank-you payment in recognition of their time and contributions; including attending the first workshop, completing the homework task, and attending the second workshop.

2.1.2 Participation

Target participants

The new and emerging technologies from the King's College London research have the potential to change the way the 20-week screening scan is carried out during pregnancy and potentially lead to a change in the way families are cared for if a congenital condition is detected, therefore it was important to talk to participants who have recent or significant experiences of the 20-week scan.

Two groups of participants were recruited, within the following parameters:

CHARITY RECRUITED GROUP *People who have had a pregnancy of a baby with a congenital condition*	AGENCY RECRUITED GROUP *People who have had a recent pregnancy without a congenital condition*
◊ The pregnancy of the baby with the condition was within the last 12 years - the rationale being that the 20-week ultrasound has changed little in the last 12 years so their experience will be relevant to current practice. ◊ Any congenital condition, identified either during pregnancy or after birth. ◊ Recruited via charity partners. An advert was developed, along with a survey to capture details. The advert was shared on social media via charity partners. ◊ Participants were selected based on a spread of geography, ethnicity, age, education level and pregnancy experience. ◊ Offered a £160 thank you payment for their time and contributions including both workshops and a homework task in between.	◊ The pregnancy was within the last three years - the rationale being that those who had expected antenatal journeys would have better recall of the 20-week scan if recent. ◊ Recruited via a specialist market research agency to enable selection on key demographic factors - including geography, ethnicity, age, parental role and education level. ◊ Offered a £160 thank you payment for their time and contributions including both workshops and a homework task in between.

All participants were located in England only and received their antenatal care through the NHS.

- Both child-bearing and non-childbearing parents / partners were invited to join.

The project team considered, and discounted the following options:

- Engaging with participants who are currently pregnant; it was felt that talking about conditions, unexpected news and potential problems in pregnancy could cause unnecessary worry to a person who is currently pregnant.
- Engaging the 'general public' without experience of pregnancy / the 20-week scan, as it is important that participants have a benchmark experience to compare potential changes with the current service.

Participant selection and turnout

Charity recruited group: the initial call for participants was extremely popular and 78 responses were received within two weeks. A group of 26 participants were selected, with the aim of maximising diversity of geographic location, ethnicity, parental role (i.e. childbearing mother or father/partner/non-childbearing mother), educational level and the pregnancy experience. A diversity of experiences were selected to ensure there was a spread of participants with the following experiences:

- Parents who have experienced termination of pregnancy / termination for medical reasons after a diagnosis following 20-week scan screening or later in pregnancy
- Parents who experienced a pregnancy where a congenital condition was detected via antenatal scans
- Parents for whom the condition was detected once their baby had been born / not picked up during pregnancy
- Participants who had been offered or had undergone interventions / fetal surgery during pregnancy
- A range of different conditions diagnosed, including congenital heart disease, brain and spine conditions, genetic conditions, twin to twin transfusion syndrome, and abdominal conditions affecting the kidneys, diaphragm and digestive system.

26 participants were recruited for this group. A total of 21 participants attended the first workshop, and 19 attended the second workshop. There was a slightly higher dropout rate than anticipated just before both workshops, the majority due to their children being ill, including a number of hospital admissions.

> *POST EVENT REFLECTIONS*
>
> ***"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."***
>
> **—Participant**

Agency recruited group: 28 participants were recruited from this group. A total of 22 attended workshop 1 and 21 attended workshop 2. It is important to note that even though the participants of this group were selected because they or their partner had experienced a pregnancy where no congenital condition was identified, this does not mean that their pregnancy proceeded without issue. Many described illness or other issues with either the pregnancy or birth that were not related to a congenital condition, and this group required the same sensitive approach to engagement as the charity-recruited group.

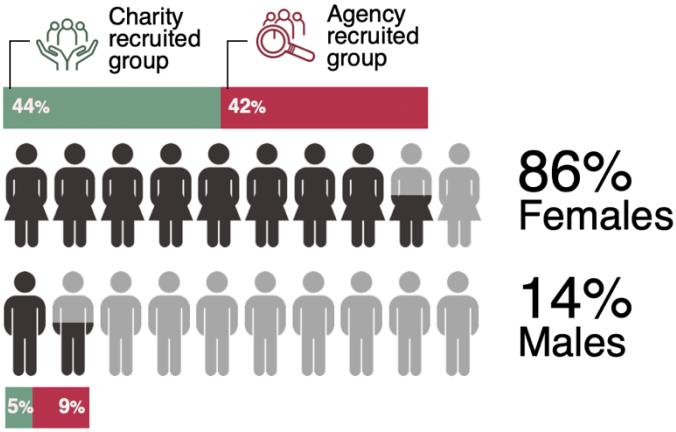
> *POST EVENT REFLECTIONS*
>
> ***"It was really refreshing to go through these discussions with a new group of people – a reminder of the need to seek out new opinions all through our research"***
>
> **—Researcher**

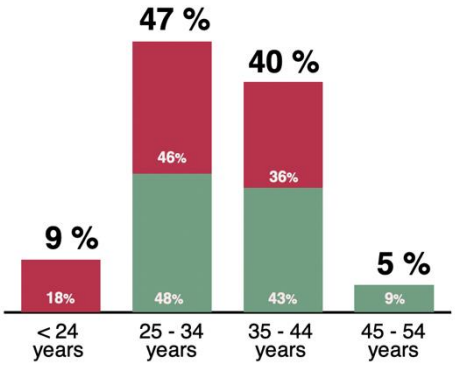
Participant demographics

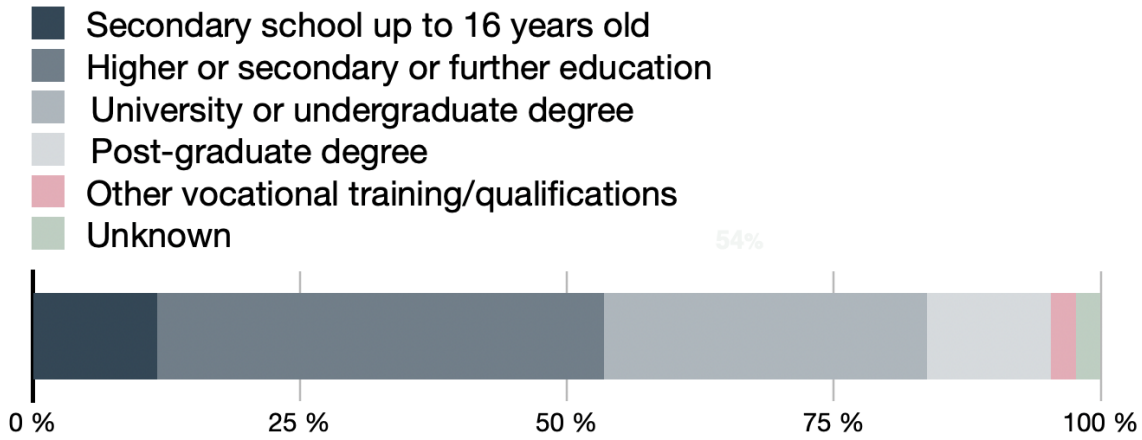
A concerted effort was made to try to recruit as diverse a group of participants as possible.

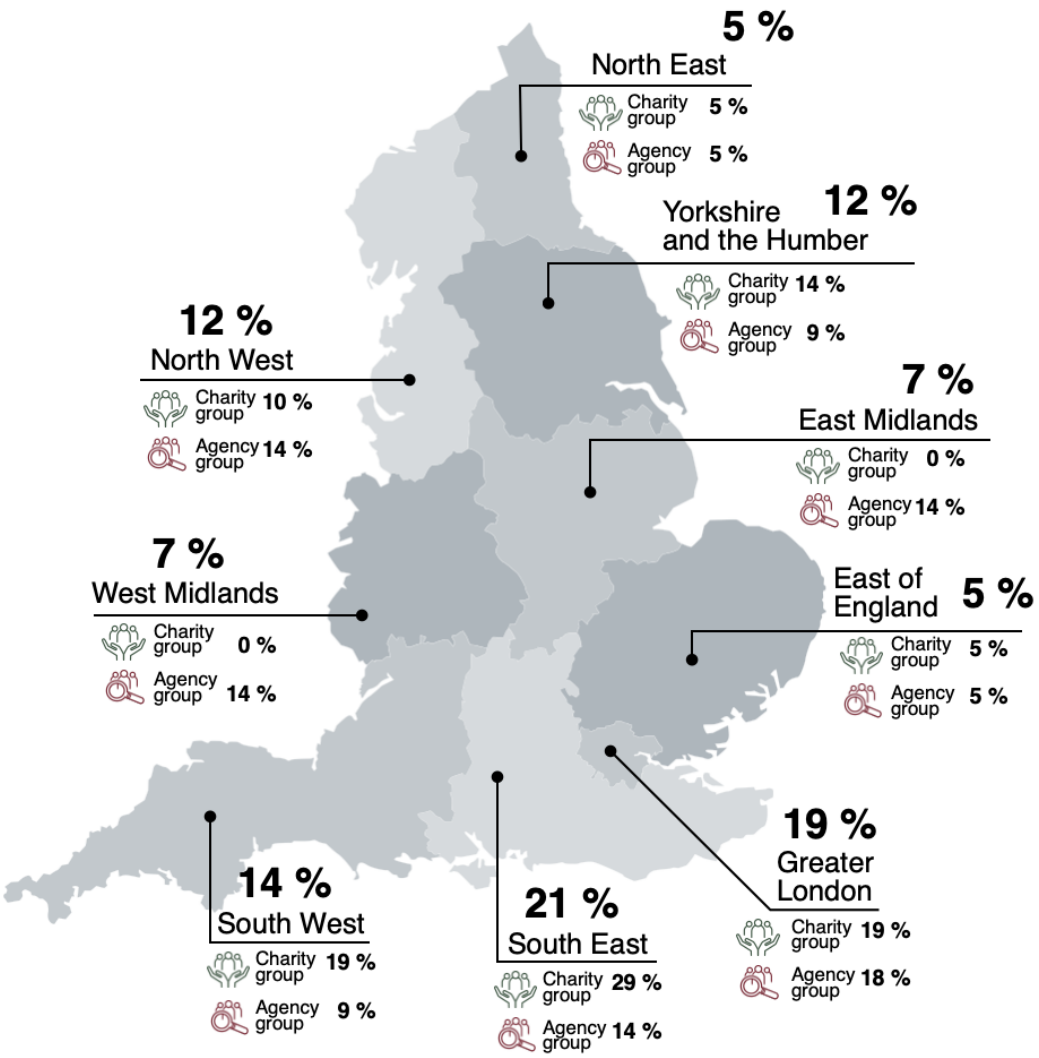
The group who experienced “as expected” pregnancies were recruited via a specialist agency and therefore quotas for ethnicity, gender, location and educational attainment were easily met; including enhanced diversity for this group to compensate for lower levels in the charity group.

This was more challenging for the charity recruited group as it was a self-selecting group. A collaborative effort was made to recruit from ethnic minority groups and information was shared with five dedicated charities operating in this field but interest levels remained low. This was a problem recognised by the partnered charities who also struggle to achieve diversity in their engagement activities. All eligible participants who were from an ethnic minority group or a non-child-bearing parent were selected.









A full breakdown of the demographic data collected is shown in appendix 4.4.

POST EVENT REFLECTIONS

> ***"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."***
>
> **—Researcher [reflecting on the need for increased diversity in research]**

2.1.3 Measures to ensure the issues were handled sensitively and participants were supported

The project team recognised early on that this is an extremely sensitive subject matter, and discussions would inevitably lead participants to reflect on past difficult experiences. The diagram below shows the measures that were implemented to ensure participants felt supported and protected.

Extended planning phase	Thorough advance briefing
◊ Ensuring all potential sensitivities had been considered and there was enough time to develop sensitive materials ◊ Enough time to communicate with participants in a respectful manner (i.e. personal emails, direct line of contact to project manner, adequate advance notice of events).	◊ Briefing document shared with participants prior to volunteering themselves. ◊ This covered what would be discussed at each event, what types of images would be shown (e.g. ultrasound images), who the other participants would be and how the meetings would be facilitated.

Carefully curated breakout room groups	Consultations with charities who specialise in supporting people who have experienced a diagnosis during pregnancy or after birth
◊ Ensuring that those who had experienced baby loss for example had others in their room who had experienced similar.	◊ Consultations with charities who specialise in supporting people who have experienced a diagnosis during pregnancy or after birth ◊ Antenatal Results and Choices (ARC), Bliss and ECHO. ◊ Gathered their input on the approach to engagement at an early stage and implemented their recommendations.

Ensuring sensitive language used	Provided a 'wellbeing room' during each workshop
◊ Reviewed research papers on language for sonographers, with respect to delivering unexpected news. ◊ Sought input on the terminology from specialists in inclusion ◊ Sensitive language training delivered by ARC for the core project team in December 2020 and for 19 facilitators and clinicians / researchers in March 2021.	◊ A separate Zoom meeting, hosted by a charity partner, which was open throughout each of the workshops and participants were encouraged to leave the main meeting and enter the wellbeing room if at any time they needed time-out.

Provided a relaxation session for the end of each workshop	Ensuring participants comfortable participating online
◊ An optional recorded mindfulness practice was made available for participants after each workshop.	◊ Three 'tech check' sessions in advance of the first workshop open for any participant to practice using Zoom and Conceptboard. ◊ One to one support available to any participant needing it.

POST EVENT REFLECTIONS

"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."

—Participant [reflecting on the wellbeing room]

"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 yours .....so to be able to have 5 minutes to yourself if needed was a brilliant idea."

—Participant [reflecting on the wellbeing room]

2.1.4 Terminology

For ease we used certain terms consistently within the dialogue, recognising these terms are often interchangeable within wider usage:

- **20-week scan** – also known as the mid-pregnancy scan or the anomaly scan, which takes place between 18 and 21-weeks' gestation.
- **Parents:** mother or childbearing parent and father / non-childbearing parent
- **Termination of pregnancy** – also known as TFMR or termination for medical reasons.
- **Unexpected news / findings** - also known as anomaly, abnormality, defect, or a 'problem' with the baby.

Please note that participants were invited to use whichever terminology they felt comfortable with, while being mindful of potential sensitivities to others.

2.1.5 Development of the materials and stakeholder advisory group

Initially the content for discussion was wide ranging and undefined, with multiple research projects working on a range of innovations within both iFIND and GIFT-Surg. A stakeholder advisory group (StAG) was established to help guide the project team and advise on which aspects of emerging technology would be most useful to focus on and discuss with members of the public. The StAG included a wide range of specialisms including fetal surgery, fetal cardiology, sonography and imaging, nursing and midwifery, ethics, robotics, artificial intelligence and NHS procurement; the full list of members is shown in Appendix 1.

The group met online twice, with additional conversations on specialist areas with individual members outside of the meetings. The process of developing stimulus materials is summarised below:

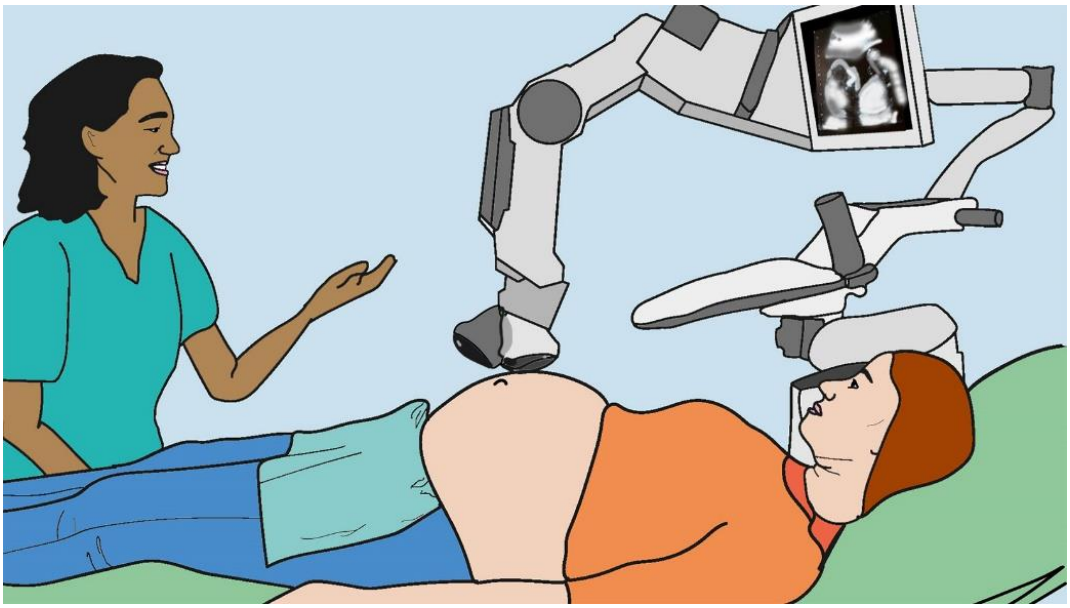
- **Stage 1: Initial call for content and resources**
  - Researchers and clinicians shared images, papers, articles and other resources relating to their research
  - Project team developed draft outline of content for dialogue
- **Stage 2: 1st StAG meeting**
  - StAG members discussed what would be most useful for them to hear from the dialogue
  - Discussed draft outline of content in detail
  - Agreed to use video format for online meeting and for the visual nature of some of the research (scan images etc)
- **Stage 3: 2nd StAG meeting**
  - Honed and refined the content, ensuring the messages are accurate and accessible
  - Discussed potential key themes for discussion
- **Stage 4: Video development**
  - Interviews with key clinicians / researchers / medical professionals
  - Finalised the videos

2.1.6 First workshop stimulus material content - videos

Five bespoke videos were shown to participants during the first workshop to give an overview of **screening for congenital conditions** in pregnancy, and how the patient pathway progresses if an anomaly is detected at the 20-week scan. Links to these videos are shown in Appendix 2.

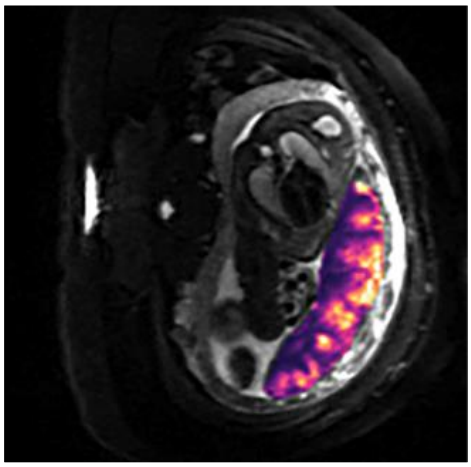
Innovations in screening tests

Three short videos outlined the fetal anomaly **screening** programme currently delivered by the NHS via the 20-week scan, and described the antenatal journey if an anomaly is detected or suspected at this scan. Interviews with Dr David Lloyd (Consultant Fetal Cardiologist) and Jackie Matthew (Sonographer and Researcher) at St Thomas' Hospital/King's College London, described some of the challenges of effectively detecting congenital conditions at the 20-week scan and how the detection rates of certain conditions vary widely depending on where you live in the UK. Participants heard how the iFIND research is seeking to address some of these challenges through automation; firstly using a robotic arm to allow multiple ultrasound probes to be used by a single operator thereby improving the field of view, and secondly using machine learning computer software to automatically detect and measure fetal anatomy.



Advanced diagnostic tools

Dr David Lloyd and Professor Anna David (Consultant Obstetrics and Maternal Fetal Medicine, University College London Hospital/UCL EGA Institute for Women's Health) explained how if an anomaly is suspected at the 20-week scan, parents can meet with a fetal medicine specialist who will usually perform a more detailed ultrasound scan and discuss options for further tests. These may include new imaging techniques designed to help specialists get more detailed information and **make a diagnosis**, particularly using MRI. These additional scans could help to generate a much more accurate understanding of the diagnosis and how it could affect the baby, before and after birth. This could then help to reduce much of the uncertainty around a diagnosis, both for the mother and the medical teams looking after them and their baby.



New ways of treating conditions by operating on the baby while still in the womb

Professor Anna David outlined new and emerging techniques for carrying out **surgery** on babies with certain conditions while they are still in the womb, to improve their chances of survival and reduce the long-term impacts of these conditions. Treatments discussed include key-hole laser surgery for twin-to-twin transfusion syndrome and open or keyhole surgery for open spina bifida / myelomeningocele.

2.1.7 Second workshop stimulus materials – scene setting

Following the first workshop, where a significant amount of feedback was gathered from the participants, a sub-group of specialists from the StAG was utilised to develop a number of scenarios to stimulate further discussion. These scenarios were designed to be futuristic although plausible, suitably different to the *status quo* in order to explore how much change participants were comfortable with. It is important to note that these scenarios do not reflect the aspirational outcomes of the research projects, they are hypothetical scenarios to prompt meaningful discussion.

More detail of the scenarios is available in section 3.1.3.

3 Summary of the participants' feedback

3.1 Innovations in screening – the 20-week scan

During the first workshop participants were asked to consider what questions they had, or what issues came to mind on hearing about the research via the stimulus videos. During the second workshop participants were presented with two potential scenarios of how the **screening** technologies could be used in the future. The outputs from the discussions at both workshops are summarised within this section.

3.1.1 Key themes

The key themes that emerged in relation to new technologies for screening and the 20-week scan from both workshops were as follows:

- Participants generally **supported technological development** in this area, particularly to address geographic inequalities (the "postcode lottery") and increase overall detection rates of conditions.
- There was an overwhelming sense that any technological developments, particularly those that rely on artificial intelligence or machine learning, **should support, not replace, the role of the trained sonographer** or other specialist human operator.
- It was seen as critical for a specialist human to be on hand during scans to provide real-time support and explain what is being seen.
- Participants who did not experience a diagnosis of a condition, often see the **20-week scan as an important milestone**; a half-way point of pregnancy, a chance to see and **bond with their baby** and an opportunity to find out the sex.
- The **charity recruited group** who had experienced a pregnancy of a baby with a condition (many of whom had been through an intensive medical journey with additional investigations and interventions) **were more comfortable** with the additional technology, while the **agency recruited group**, who generally had 'as expected' antenatal journeys were **more cautious or sceptical**.
- Any changes in the way the 20-week scan is carried out needs to be e**xplained in a clear and accessible way** to expectant parents, and any scan results should be delivered by a professional trained in sensitive language.
- **The actions and words of the sonographer** when delivering news of any unexpected findings largely **determines the parents' experiences** and it was common to hear parents feel like blunt, uncaring language had sometimes been used with them, and this had negatively affected their experience, regardless of the medical diagnosis.
- The detection of an anomaly at the 20-week scan can be a significant shock and it is critical that **clear information, sensitive emotional support and signposting** to key charities is provided in a consistent way across the country.

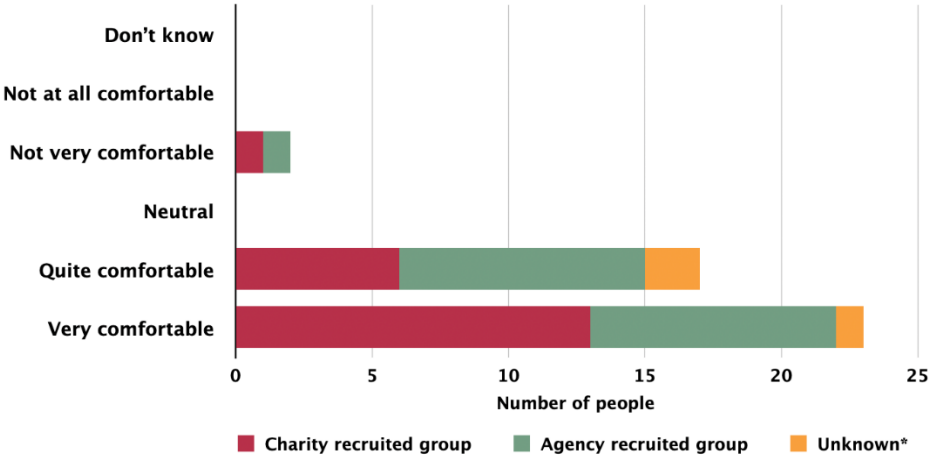
- Seeing a sonographer in **a hospital setting is reassuring**, and the travel time to reach hospital was not seen as a concern. Participants were not tempted by the potential to have an ultrasound scan in a local GP surgery.
- Participants did not pick up on shortening the scan appointment length as a concern.
- There was a strong sense across participants that **waiting any length of time for scan results during pregnancy is stressful and should be avoided**, if possible. Participants generally felt that introducing any delay for results, when they were used to receiving immediate test results, was a compromise they would not be willing to make.
- Enthusiasm was expressed for the **wider possibilities these technologies could bring**, particularly the detection of conditions earlier in pregnancy (before 20 weeks), improving estimation of fetal weight, reducing rescan rates or even machine-learning assisted mobile scans during midwife appointments.
- Of the **very small minority that were uncomfortable** with technological developments in the 20-week scan, the concerns were based on whether multiple ultrasound probes would be safe, a concern about robotic/mechanical ultrasound arms potentially being less gentle than a human, or a general mistrust of technological development. However, these concerns were restricted to only a small handful of comments.

> *POST EVENT REFLECTIONS*
>
> ***"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."***
>
> — **Researcher [reflecting on the value of public dialogue]**

3.1.2 Initial response to an automated 20-week scan

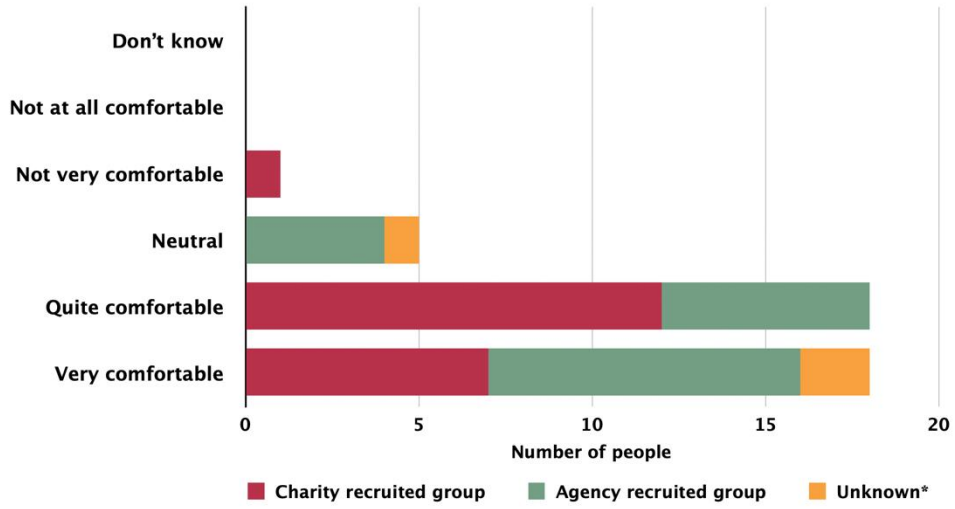
After the relevant stimulus videos, participants were asked to rate how they felt on what they had heard, via live Zoom polls. Results were not shared in real time so as not to bias the conversations that followed.

> ***Q: Given what you've just heard, how comfortable do you feel about the direction of the research regarding the initial 20-week ultrasound scan?***



**Unknown where participants accessed the Zoom meeting as 'guest' and the software does not record their name.*

> ***Q: Given what you've just heard, how comfortable do you feel about potential changes in the way the 20-week ultrasound scan is carried out?***



**Unknown where participants accessed the Zoom meeting as 'guest' and the software does not record their name.*

Participants then moved from the main discussion into small breakout groups (consisting of five participants plus a trained facilitator and member of the research/clinical team), and discussed their initial response to what they had heard and what questions or issues it provoked for them.

> *POST EVENT REFLECTIONS*
>
> ***"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."***
>
> **—Participant**

Participants raised the following main areas of questioning or concern:

Reducing geographic variation

Participants across both groups were surprised and concerned to hear that there is a strong geographic variation of detection rates across the UK, and agreed with the research aims that this is an important problem to eliminate.

There was support for more tools to standardise care and achieve consistent detection rates across the country, especially from those who had experienced antenatal care in more than one place.

There were discussions among the agency recruited group questioning whether the NHS could or would make this technology available to all, bearing in mind the disparity of care and *"postcode lotteries"* that currently exist.

> *POST EVENT REFLECTIONS*
>
> ***"The finding that people wanted equality in geographic outcomes and experience very much validates our whole purpose behind the research – to address the shocking divergence in outcomes geographically in screening."***
>
> **—Researcher**

Machines, with a human operator

There were many positive views expressed on the new technology as a tool to support clinicians. There was support for the potential of technology to be more accurate, reduce bias, produce clearer images and reduce human error. Participants from the charity recruited group were enthusiastic about how the new tools may 'free-up' sonographers to focus on the parents and provide emotional support during the scan.

> *"You go into it thinking you have to keep really quiet and not ask questions because the person needs to concentrate - particularly if you are having a scan where you already know that there is an issue, they can be the most difficult and emotional times."*
>
> — **Charity recruited participant**

However, both groups wanted reassurance that the human factor would not be lost. They wanted reassurance that a medical specialist would be operating, programming and quality assuring the technology. There was a concern that the benefits of human instinct could be lost.

> *"Can a robot have a hunch?"*
>
> — **Agency recruited participant**

Participants from the agency recruited group were nervous of creating an over-reliance on computers, questioning whether there would be a loss of skills and whether sonographers may lose their jobs. They also raised the concern of potential IT failures and data breaches. Data protection was raised by a very small number of participants.

The idea of a robot or robotic arm caused some trepidation from both groups, being described as potentially "*daunting*, *less personal* and *less gentle"*. Some participants felt that they would need to be persuaded to accept robotic technology and how they would feel "*protective of the bump"* (charity recruited participant) and that *"feeling a hand on my belly is reassuring"* (agency recruited group). They wanted assurance that 'multiple probes' would be safe for them and their baby. Others felt more accepting of a robotic arm and that it could even be more comfortable.

> *"There will probably be less probing about and trying to push the baby about with the new technology."*
>
> — **Agency recruited participant**

Waiting for results

There was a lot of discussion around the potential for expectant parents to have to wait any period of time before receiving the results of their scan. Of those that expressed a view, participants in both groups felt that at the very least, an initial assessment should be made available to expectant parents at the end of their scan. Although there was a positive acknowledgement that it would be *"good to properly review the results"* and to relieve pressure on sonographers in real time, they felt that not getting reassurance immediately would lead to worry and anxiety. The tolerance of the length of wait was discussed, with most feeling that waiting days rather than hours would be a challenge.

> *"Sometimes you can even see the problem on the screen yourself – then a wait would be difficult."*
>
> — **Charity recruited participant**

There was a concern expressed that leaving the hospital without results may lead to them getting *"lost in the system"* and having to chase up with the hospital for their results, however, one participant highlighted the potential benefits of not receiving results in real-time:

> *"Having a small delay between scan and results could be a good thing. So much emotion involved - a bit of time to prepare for conversation might be a good thing."*
>
> — **Charity recruited participant**

Excited about the possibilities

Both groups were excited about the possibilities of new technologies in screening pregnancy care, including the potential for:

- New technology to reduce re-scan rates, particularly charity recruited participants who described instances where the need for multiple re-scans and the waiting in between had caused extra stress.
- Conditions to be detected earlier in pregnancy, giving families more time to prepare or make choices. Charity recruited groups described how 20-weeks feels late in a pregnancy to be screened for conditions.
- Automated technology to improve the accuracy of other scans- either the 12-week scan or growth scans later in pregnancy.
- Improved scanning for twins and higher order multiple births.
- Improved scanning for different body shapes.
- Larger images of the baby could be constructed, *"from head to toe"*.
- Detecting more conditions than the 11 currently screened for at 20-weeks. Some participants in the charity recruited group talked of how conditions affecting soft tissues are usually not detected, and how better image quality could mean these types of conditions could also be detected during pregnancy.
- Allowing more joined-up care, and centres to be able to share data better. Charity recruited participants described significant disparity between hospitals and how scans were repeated upon referral to a specialist centre. They suggested that having the scan available on file could help multidisciplinary teams to review the scans, and could even avoid parents having to travel to a specialist centre altogether.
- Better assessment of growth and fetal weight. Agency recruited participants described a number of instances where the calculation of fetal weight had been inaccurate which had led to an impact on their antenatal care.

One charity-recruited participant highlighted how the new technology could have benefited their experience in multiple ways:

> *"I went through three different hospitals and it was a nightmare… At the first scan they couldn't get the measurements so I was sent away and not scanned until two weeks later, when I was put in a room with one person and got a very blunt identification of a problem. I then had to go elsewhere for further diagnosis. These newer techniques could have really helped my experience."*
>
> — **Charity recruited participant**

Length of appointment

During the video it was suggested that a future 20-week scan appointment may be shorter than it is currently - this was mostly not picked up on as an area of concern and only a small number mentioned it. One charity recruited participant stated that it is *"reassuring that scans are long"* and an agency recruited participant wanted to ensure they wouldn't *"feel rushed"*.

One participant from the agency recruited group queried whether shorter scans may improve waiting times.

> *"I had to wait for three hours for my scan in the summer heat, it was really uncomfortable".*
>
> — **Agency recruited participant**

Communication and support

Participants from the charity recruited group were positive about a new approach, as long as any changes are communicated to expectant parents so they know what to anticipate; through communications materials and demonstrations. They mentioned the need for a specialist to talk through the results of any report, plus proper support and after-care for parents for whom an anomaly is detected. Initiatives suggested here included support, counselling, peer-to-peer support and signposting to charities for impartial advice. Similarly participants from the agency recruited group queried how a machine would potentially deliver unexpected news. Note that participants were not explicitly told that the machine itself would not deliver the scan result. This was an incorrect assumption a few participants formed themselves. This can be seen as an interesting finding in itself: that people make their own assumptions about what technology will or won't do unless instructed very clearly and proactively about the boundaries of roles.

> *"How would anomalies be relayed to the patient if done by the computer/robotic arm? How would this be worded if generated by a robot? Would it still be a person that shares unexpected news?"*
>
> — **Agency recruited participant**

One charity recruited participant suggested that it would be useful if a simplified leaflet was available for parents who have had an anomaly detected, to explain what happens next (e.g., rescan, referral to specialist centre etc) to address some of the uncertainty they face in that moment. Another suggested that there could be a greater role for midwives in preparing people for the 20-week scan and its importance.

> *"Currently no discussion [with midwife] at all apart from 'have you got the date'."*
>
> — **Charity recruited participant**

> ***"The 20-week scan is seen by most people as the gender scan and not really anything about detecting for anomalies. I don't know how many people go in really prepared for what the outcome might be."***
>
> **—Charity recruited participant**

Implementation

There was a reservation expressed from one member of the charity recruited group, about the potential for the automated technology to increase false positives and the stress this would lead to. They also queried the impact of detecting many more abnormalities at screening, both on the health service and families.

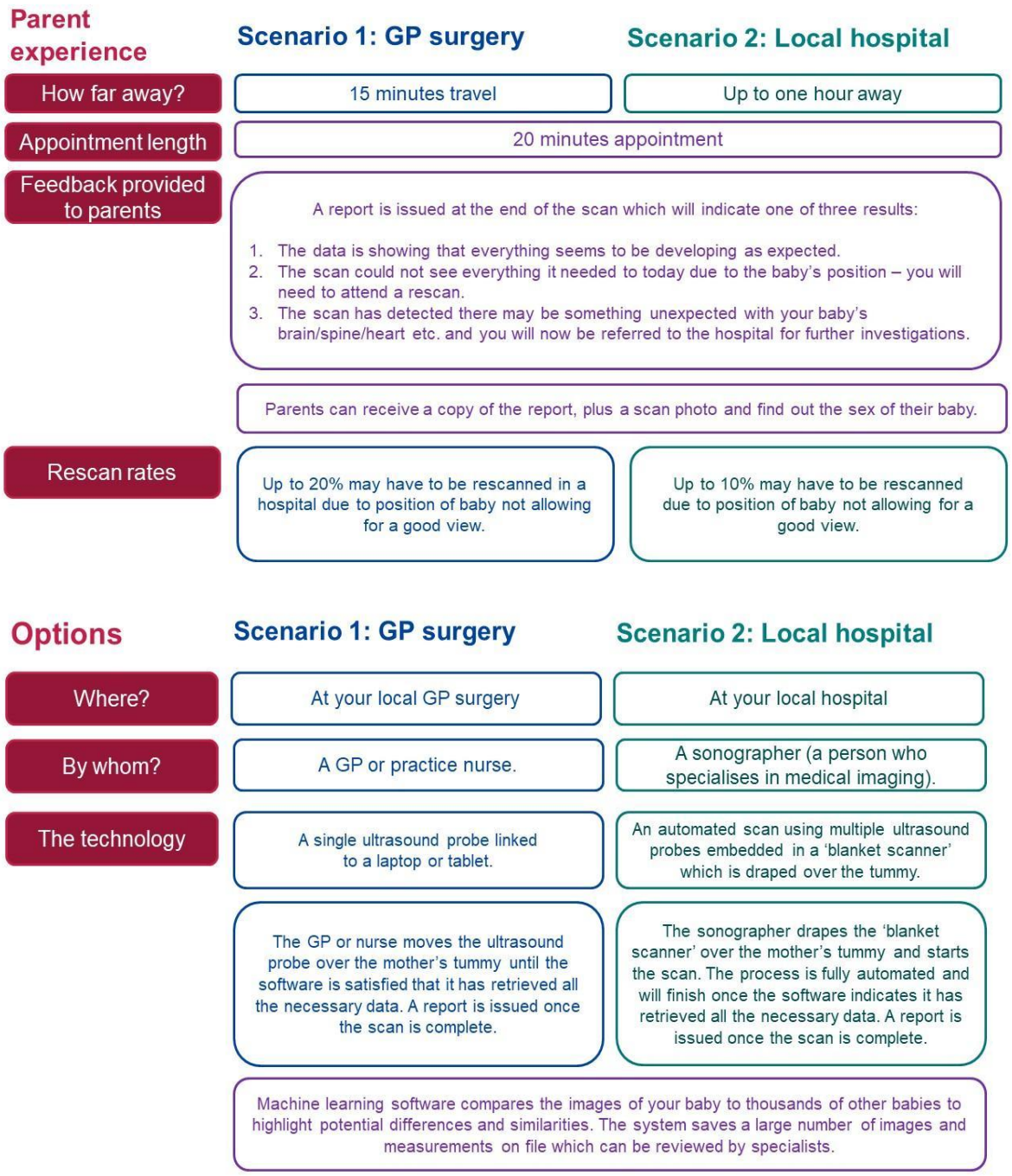
3.1.3 Two 20-week scan scenarios

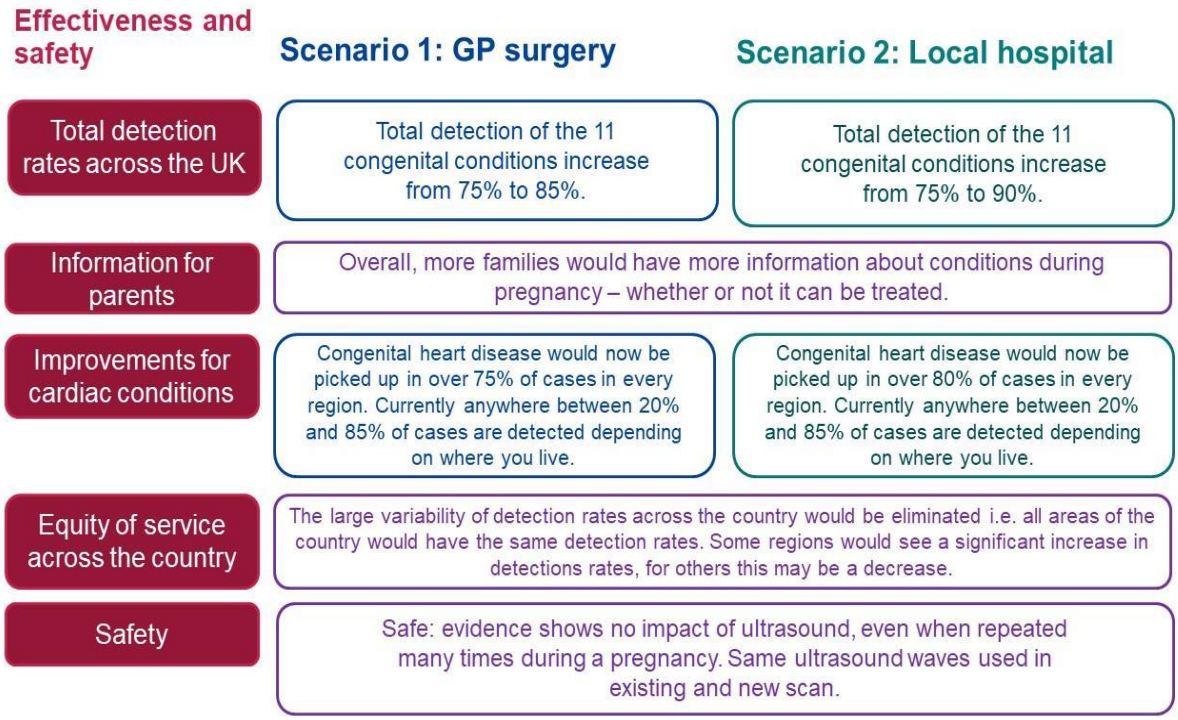
The participants were asked to consider two scenarios, which tested the notion of whether in the future screening ultrasound tests could be delivered by a general healthcare professional (i.e. not a sonographer), without expertise in medical imaging. Participants were sent these in advance of the second workshops (by email and on Conceptboard) and encouraged to speak to friends or family about these options.

The scenarios

The two scenarios presented two different options of applied technology for the 20-week scan.

The 20 week scan scenario


Parent experience
Scenario 1: GP surgery
Scenario 2: Local hospital
How far away?
15 minutes travel
Up to one hour away
Appointment length
20 minutes appointment
Feedback provided to parents
A report is issued at the end of the scan which will indicate one of three results:
1. The data is showing that everything seems to be developing as expected.
2. The scan could not see everything it needed to today due to the baby's position – you will need to attend a rescan.
3. The scan has detected there may be something unexpected with your baby's brain/spine/heart etc. and you will now be referred to the hospital for further investigations.
Parents can receive a copy of the report, plus a scan photo and find out the sex of their baby.
Rescan rates
Up to 20% may have to be rescanned in a hospital due to position of baby not allowing for a good view.
Up to 10% may have to be rescanned due to position of baby not allowing for a good view.
Options
Scenario 1: GP surgery
Scenario 2: Local hospital
Where?
At your local GP surgery
At your local hospital
By whom?
A GP or practice nurse.
A sonographer (a person who specialises in medical imaging).
The technology
A single ultrasound probe linked to a laptop or tablet.
An automated scan using multiple ultrasound probes embedded in a 'blanket scanner' which is draped over the tummy.
The GP or nurse moves the ultrasound probe over the mother's tummy until the software is satisfied that it has retrieved all the necessary data. A report is issued once the scan is complete.
The sonographer drapes the 'blanket scanner' over the mother's tummy and starts the scan. The process is fully automated and will finish once the software indicates it has retrieved all the necessary data. A report is issued once the scan is complete.
Machine learning software compares the images of your baby to thousands of other babies to highlight potential differences and similarities. The system saves a large number of images and measurements on file which can be reviewed by specialists.



POST EVENT REFLECTIONS

"The scenarios helped to provide some context which shaped thought processes a bit better."

—Participant

The feedback from discussions

Feedback received in response to the two 20-week scan scenarios is summarised in the following table. Rows in green show where the opinion was expressed similarly across both groups, rows in white show comments that were unique to each group. **Emboldened statements** show where there was a strength of opinion (i.e., multiple comments making the same point).

Charity recruited group	Agency recruited group
GP Surgery scenario positives	
◊ **GP surgeries are local, familiar and bring the benefit of personal relationships.** ◊ **Cost of travel and accessibility,** particularly if someone was very young and not used to hospital settings or did not have the resources to travel. Free parking at the GP. Easier to attend appointments if you have dependents. ◊ **Convenience factor,** accessible to more parents "don't have to take a day off work."	
◊ Machine learning would be reassuring. Comfortable with the probe. ◊ Reducing pressure on hospitals and sonographers, saving time.	◊ Good for those who do not like medicalised birth plans, e.g. those who prefer holistic / home births.
GP surgery scenario negatives	
◊ GPs are by their nature, generalists and are not specialists in fetal imaging. A concern about **how unexpected results would be delivered**, and whether **the right support would be provided**. "Sonographers have a more supportive nature." ◊ GP surgeries, GPs and practice nurses are **already time pressured** and it can be difficult to get appointments. A concern that appointments might be **rushed** to meet appointment time targets. ◊ The **notion of family doctors and familiar relationships no longer exists** for many, "don't really have family doctors anymore, that personal interaction isn't there." There is a **lack of trust** in GPs from some, with a sometimes poor relationship.	
◊ Concern that the fast-track referral pathways would not work well from a GP surgery. **No specialists on hand** to take another look.	◊ The **GP/nurse would lack experience** to encourage the baby to change position / may struggle with the technology. ◊ Attending hospital for antenatal scans allows for familiarisation before delivery.

<table>
<tr><th>Charity recruited group</th><th>Agency recruited group</th></tr>
<tr><td colspan="2">Hospital scenario positives</td></tr>
<tr><td colspan="2">◊ This option provides the reassurance of both the improved pick up rates provided by the automated technology, but also the comforting, knowledgeable presence of a sonographer / specialist in imaging. A sonographer is trained not only in medical imaging, but also engaging with expectant parents and delivering unexpected news. “Even if the software is really good, I still want that specialist human.”
◊ There are specialists on-hand within a hospital setting who can be called on to investigate further, if something is detected at the scan.
◊ Travel time is not a concern. “It's not like any other scan as it's about your baby, not you. Don't mind how far I have to travel.”</td></tr>
<tr><td>◊ Sonographers are experienced enough to be able to spot something a machine might miss.
◊ The potential for the blanket scanner to reduce rescan rates.
◊ Potential to improve scans for multiple births.
◊ The technology matters less than the sonographer, who ultimately determines your experience.</td><td>◊ Higher pick-up rates.
◊ The blanket scanner sounds quite comfortable compared with the probe.
◊ These scans are reassurance for parents, as well as checking the baby. The presence of the sonographer, talking through what you see on the screen is a bonding experience. May be more likely to attend private scans if this hospital experience is changed too much.</td></tr>
<tr><td colspan="2">Hospital scenario negatives</td></tr>
<tr><td colspan="2">None.</td></tr>
<tr><td>◊ The blanket scanner may feel too automated or futuristic for some people.</td><td>◊ Some people don’t like going to the hospital, there is a greater risk of catching covid.
◊ Are multiple ultrasound probes safe?</td></tr>
</table>

In summary there was an overwhelming (although not universal) preference for the hospital based scenario from participants in both groups. Participants placed huge importance on the expertise and bedside manner of sonographers either to handle unexpected news sensitively (strong sentiment from the charity recruited group) or to talk the parents through what they are seeing and provide a bonding experience (discussed by the agency recruited group). There was a recognition from many in the charity recruited group that their experience had shaped the strength of preference towards the hospital option.

"For my first pregnancy [the GP option] would have been fine, I wouldn't have known any better. But all of us here have experienced difficult pregnancies and would want the experience of the hospital."

— **Charity recruited participant**

"I spoke to my friends in a spina bifida support group and they would all prefer to be in a hospital for the reassurance."

— **Charity recruited participant**

Being scanned in a hospital setting was also seen as reassuring, as referrals may be quicker and there are often other specialists on hand to provide input on any arising issues. The increased detection rates of conditions and lower rescan rates were important factors, but not as significant as the need for a human eye and reassurance from a specialist.

"As wonderful as the technology is, it doesn't have the gut instinct that a person has, from personal experience it was that gut instinct that formed part of our diagnosis."

— **Charity recruited participant**

"Technology is almost a moot point, its the face that's important"

— **Charity recruited participant**

Participants in the agency recruited group described how for them the 20-week scan is a milestone during pregnancy, and for many is an opportunity to see and bond with their baby. They described experiences of accessing private ultrasound scans, and how if the NHS 20-week scan became less personal they would be more likely to access private bonding scans.

"These are screening scans and it's important to check the baby. But it's also exciting, the 12 week is the first time you see your baby, then 20 weeks you can see their hands etc."

— **Agency recruited participant**

"If the technology was like this I would go for the private scans in addition."

— **Agency recruited participant**

Some benefits of the localised GP surgery based scenario were seen, particularly that it is an accessible and convenient location; but the scenario was not popular with most participants due to the concern about a specialist scan being delivered by a generalist clinician. Although a small number liked this scenario because of a good relationship with their GP, considerably more felt a lack of trust in their GP either due the fact that GP surgeries are already overstretched or because of a previous negative experience.

"Might be better to have a trained midwife or sonographer doing scans at GP surgeries."

— **Agency recruited participant**

"Appointment time and effort to get to hospital is irrelevant. Most important to get the best care from the best person."

— **Charity recruited participant**

[NB: It is important to highlight the fact that these scenarios were not designed to be 'one or the other' futures, and that given the range of views, one could potentially foresee different people choosing different options if both the scenarios were offered, although the dialogue suggests the majority of people would opt for the hospital scans.]

There was however, enthusiasm for the technology from many, including whether mobile handheld ultrasound technology could be applied in other situations. Could a mobile scanner be taken into people's homes, or be used at antenatal appointments?

> *"Could the handheld scanner in the GP surgery scenario be rolled-out to be used in midwife / antenatal appointments?"*
>
> — **Charity recruited participant**

> *"Machine learning should be tested in hospital under supervision of trained sonographers. If it is thought to be reliable enough it could then be rolled out for use by others e.g. GPs, practice nurses."*
>
> — **Charity recruited participant**

3.1.4 Accountability

Participants were asked:

Q. The machine learning will be more accurate than the current technology, although still not 100% accurate. How do you feel about a machine potentially missing a condition, rather than a person missing it?

There was a wide mix of opinion in response to this question, with a similar diversity of opinion expressed across both groups.

Participants from both groups felt it may be less '*personal* ' if a machine, rather than a person, makes a mistake. Several from the charity recruited group described how the actions of a clinician who made a mistake during their antenatal care had led to feelings of resentment.

> *"At one of my scans a measurement was missed by the sonographer, and if it hadn't the condition would have been picked up in time to make a difference, there is a personal anger against that person. So I feel quite keen that machines wouldn't make that kind of human error."*
>
> — **Charity recruited participant**

> *"I prefer the idea of a mistake made by a machine, because it doesn't feel so personal, can't blame a machine."*
>
> — **Agency recruited participant**

Others felt that they would be less understanding if a machine makes a mistake.

> *"I think I would be more angry with a machine than a human. The cost of taking away the personalisation of the human doing it would only be worth it if there was a lack of errors due to the machine element."*
>
> — **Agency recruited participant**

Many from both groups reiterated the importance of maintaining a human presence when utilising automated technology. Parents wanted reassurance that there would be a human overseeing the effectiveness of the technology, and that a sensitive person with good *'bedside manner'* was operating the machine.

> *"As long as there is reassurance to the parents that there would always be a human follow up no matter what, would be unnerving to think only rely on the machine."*
>
> — **Charity recruited participant**

> *"I want the human touch and I want the excellent technology."*
>
> — **Agency recruited participant**

There were a number of comments of acceptance that neither machines nor humans can ever be 100% accurate. And one group of charity recruited participants discussed how the rationale of improved detection rates was strong enough to counteract any concerns about the technologies, particularly for those areas where detection rates have been lower in the past.

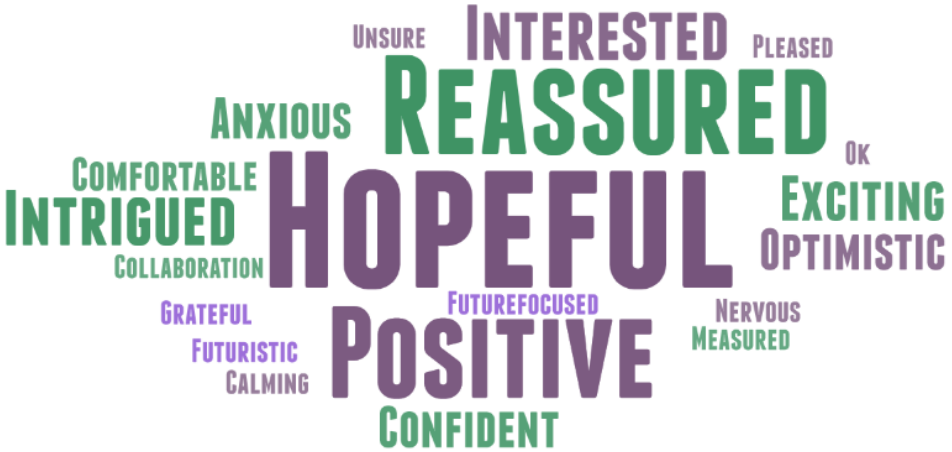
> *"If machine results have the same error rate as a human scan then I feel OK with that. Overall this will improve detection rates so it has got to be a win."*
>
> — **Charity recruited participant**

Specific concerns were expressed about machine learning here, for example hacking and data security, over-reliance on computer programmes leading to significant problems when it fails, and a concern about how many times a machine might make the same error before it is picked up. One participant, who had moved to England during her pregnancy, queried whether these technologies would enable opportunities for international standardisation.

Some participants from both groups felt that accountability was a big issue and it was difficult to express an opinion without further thought, including needing more information on how a machine learns over time.

3.1.5 Final thoughts

At the end of the final discussion on the new technologies for ultrasound, participants were asked which three words best described how they felt about 20-week scans becoming more automated. The word clouds below show the different groups' responses; the bigger the word, the more times it was mentioned.



Word cloud: *Showing the most frequently mentioned words used when participants who had experienced a pregnancy of a baby with a condition (the charity recruited group) were asked to describe how they felt about increased automation in scans.*

Word cloud: *Showing the most frequently mentioned words used when participants who had experienced a recent pregnancy (the agency recruited group) without a condition were asked to describe how they felt about increased automation in scans.*

> *POST EVENT REFLECTIONS*
>
> ***"There were marked differences between those with normal and difficult pregnancies. It highlighted the need to think about how you communicate all this to those having the pregnancy experience for the first time."***
>
> **—Researcher**

3.2 Advanced diagnostic tools

During the first workshop participants were asked to consider what questions they had, or what issues came to mind on hearing about the research via the stimulus video. During the second workshop participants were reminded of the potential outcomes following an anomaly detection at 20-weeks, and were asked to consider some of the implications of more people having more information about the condition of their baby, for example increase in incidental findings (which may pose no health risk) and how these should be managed by medical professionals. The outputs from the discussions relating to diagnostic technologies at both workshops are summarised in this section.

3.2.1 Key themes

The key themes that emerged in relation to **new diagnostic tools in pregnancy** from both workshops were as follows:

- Participants with "as expected" pregnancy journeys were more nervous of new diagnostic tools such as MRI than those who had experienced a diagnosis. They felt that they would **need a lot of reassurance** that these technologies were proven to be safe.
- However there was acknowledgement that this type of investigation is **subjective to the situation** you are in. Many of those who had experienced an MRI in pregnancy and some of those who hadn't, stated how they had or would have taken any investigation that was offered to them.
- Participants who had experienced MRI in pregnancy found the time waiting for these results to be particularly difficult. They described how the **period between 20-24 weeks gestation is critical for making choices** about whether to continue with their pregnancy and waits of 1-2 weeks for test results in this period is very stressful.
- **Different parents wanted different levels of information** about their baby. Some parents only wanted to know about conditions with firm diagnoses that could be acted upon: they actively did not want to know about incidental findings or conditions that they could not act upon. Other parents wanted as much information about their baby as possible, however small or incidental.
- Many participants acknowledged the complex trade-off clinicians face, between giving parents more information about the condition of their baby, and worrying them unnecessarily. The possibility was suggested that **parents could choose how much information** they would like to be given.
- Participants stressed how if more information is given to parents during pregnancy, this needs to be backed up with **reassurance and certainty**, rather than creating stress and worry about an anomaly which turns out to pose no health risk.

- Families who had been faced with decisions relating to advanced diagnostics, described how the **support and information provided to them is critical**. Effective communication of unbiased information including full disclosure of risks was important, along with links to peer support or case studies of real-life examples.
- **Emotional support for families** should include counselling, support for the whole family, and connections to support charities. The groups described how this support should be made available for both those who continue with, and those who terminate their pregnancies.

POST EVENT REFLECTIONS

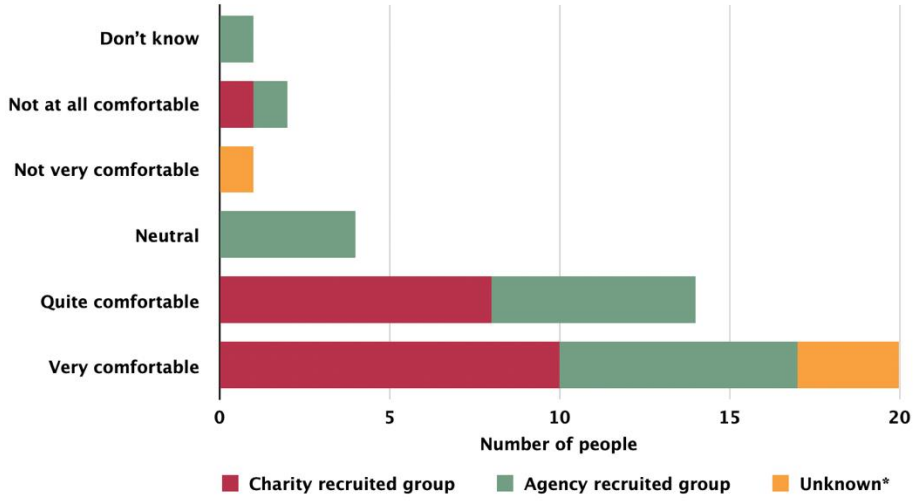
"The group was quite positive about the scanning innovations regardless of their experience but much more circumspect for the more intrusive technologies unless they had had a difficult pregnancy already."

—Researcher

3.2.2 Response to developments in advanced diagnostic tools

After the relevant stimulus videos (see section 2.3.7.), where participants were told about new diagnostic tools for diagnosing conditions in the womb, participants were asked to rate how they felt after what they had heard, via a live Zoom poll. Results were not shared in real time so as not to bias the conversations that followed.

Q. Given what you've just heard, how comfortable do you feel about the direction of the research regarding new diagnostic techniques in pregnancy such as MRI?



**Unknown where participants accessed the Zoom meeting as 'guest' and the software does not record their name.*

Participants then moved into small facilitated breakout groups (as before) and discussed their initial response to what they had heard and what questions or issues it provoked for them. Much of the discussion during the first workshop focused on magnetic resonance imaging (MRI), with participants in both groups sharing their experiences and views on this type of scanning technology.

Participants raised the following main areas of questioning or concern:

Safety

Safety was a strong theme discussed across all participant groups. Participants wanted reassurance that the strong magnetic fields are safe for pregnant women and their babies. Those who had experienced MRI scans in the past described how the machine is claustrophobic, stressful and noisy *"like being next to a massive speaker".* Both groups also talked about how MRI requires long periods lying on your back which is not safe for pregnant women, and questioned why women are asked if they are pregnant when having an MRI on their knee for example?

> *"A lot of the fear comes about because one of the first things they ask of you when you go for imaging is 'are you pregnant?', so you immediately think that there must be a risk to your baby."*
>
> — **Agency recruited participant**

Acceptability

There was an acknowledgement from both groups that this type of investigation is subjective to the situation you are in. Many in the charity recruited group had had an MRI in pregnancy and some of those who hadn't stated that they would have taken it if on offer.

One participant from the charity recruited group described the benefit it had brought to her and her baby.

> *"I had an MRI and it isn't pleasant, but it really did benefit him because the specialist could see where the lesion was… Without the MRI he would have been born without the fetal surgery and therefore would be more disabled."*
>
> — **Charity recruited participant**

Many from the agency recruited group agreed that they would do whatever is needed to reduce uncertainty.

> *"We had an early delivery due to complications with the placenta - so for me personally although there's a risk from all technology, I'm liking the accuracy of what this new technology can give."*
>
> — **Agency recruited participant**

> *"The more severe the potential condition, the more comfortable I would be."*
>
> — **Agency recruited participant**

However, an agency recruited participant expressed uncertainty about MRI and the trade off between that and an alternative choice for care such as early delivery.

> *"When I was expecting my second child, they told me she was underweight.. and they said they may possibly send me for an MRI scan to get the whole picture. I'd been through that prematurity before, so I was OK with having an early delivery rather than going through an MRI as I was a bit freaked out about going for the scan. Personally, I would have preferred to have her a bit early than go through that."*
>
> — **Agency recruited participant**

Some of the charity recruited participants discussed more generally whether it was ethical to give people information during pregnancy that cannot be acted upon or treated. They discussed how terminations for Down's Syndrome have increased since an increase in screening. It was suggested that an ethics committee should be involved in decisions in this area and robust, ethical approach to the kind of information parents are provided with.

> *"Science is racing ahead, but still such an ethical dilemma for parents regarding what to do. No guidance really for parents around that decision making. But such an ethical question about what is the right thing to do."*
>
> — **Charity recruited participant**

Excited about the possibilities

Participants from both groups expressed support for the opportunities for new diagnostic tools to help understand more about the placenta and the types of issues that might be able to be treated with a better understanding of the placenta. A participant in the charity recruited group was hopeful that new technologies could investigate more about conditions which are linked (e.g., heart and brain) and taking a more holistic look at the baby.

Waiting for results

A number of participants from the charity recruited group who had experienced MRI in pregnancy described how they had to wait longer for the results than with ultrasounds; sometimes up to two weeks, which can reduce the time available to make informed choices and cause additional stress. Some stated that there should be limits for wait times, and they would rather travel further than wait longer.

> *"For MRI we had to wait a week for results. We heard nothing, speed feels like a real issue because at this point you know something is wrong and speed may be vital for treatment."*
>
> — **Charity recruited participant**

> *"What is the wait time? The longer it is, the more stressful it is. Even one day is a long time!"*
>
> — **Agency recruited participant**

Communication and support

Both groups described the need for effective communication of unbiased information, full disclosure of risks and emotional support for families faced with these options. However, the charity recruited group specifically described the difficulties parents face when presented with so much information and choice without any preparation. They wanted to see balanced, unbiased information based on lived experience and not encouraging decisions either way.

"The support needs to be there too… as humanely, kindly and compassionately as possible at all stages. There's no preparation for this."

— **Charity recruited participant**

"When you are given the information to make the decision the language is really important because it can have a huge impact in the way you are swayed. The professionals can't offer their personal opinion but the way in which they give the diagnosis needs to have human compassion."

— **Charity recruited participant**

It is helpful to be given details of support organisations when screening reveals issues. e.g., ARC charity, but there was a disparity as to what information is provided depending on your local service.

Implementation

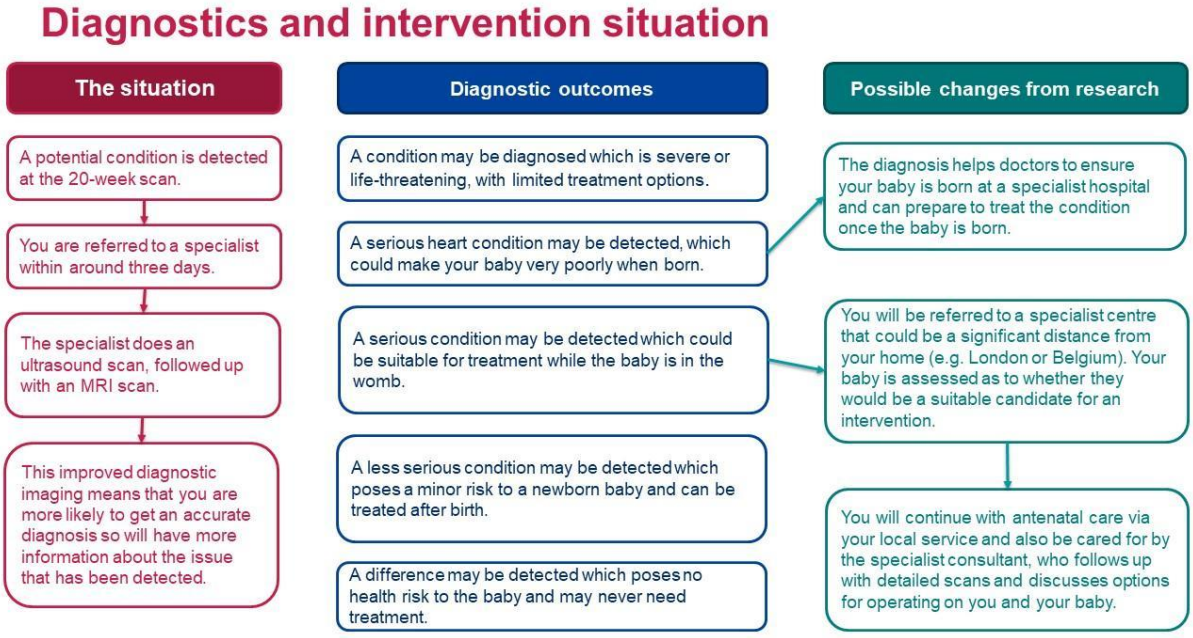
Participants in both groups raised the concern as to whether these advanced diagnostic tools would be available for all who need it, or whether this would be another postcode lottery.

3.2.3 Incidental findings: knowing during pregnancy vs. not knowing

In the second set of workshops participants were given examples of the potential care pathways families can find themselves in if an anomaly is detected at the 20-week scan.

Discussion background

The following slide was shown to explain the journey that happens for *some parents* once a potential condition is detected at the 20-week scan.



This was used as a background for discussion on how clinicians should deal with an increase in anomaly findings and the support and information that should be available to people when faced with a choice regarding interventions.

Discussion questions

Via the following two questions, participants were asked whether it is better to know during pregnancy that your baby has a suspected condition that poses no immediate health risk, or potentially no health risk at all (so called 'incidental findings').

> ***Q. New technology is likely to result in more people receiving information that can't be acted on in pregnancy, poses no immediate health risk to the baby at birth and will be picked up on after birth. Is knowing this in pregnancy better than not knowing? Which would you prefer and why?***

> ***Q. New technology will lead to more diagnosis rates of different issues that pose no health risk, or abnormalities that do not need to be clinically treated. How do you think clinicians / medical specialists should deal with this?***

It was explained that with improved imaging for screening and diagnostics the numbers of these types of cases is likely to increase. Some examples of this were given by specialists during breakout groups, including a very small hole in the heart, a brain cyst which may repair on its own, or an underdeveloped ear.

The discussions in response to these questions are summarised below.

Being able to prepare

Most participants from both groups felt that they would want to know about anything that is detected, no matter how small. They cited the benefits of having more information during pregnancy, describing it as being *"armed"* with knowledge, and allowing them to:

- Prepare mentally and emotionally
- Think about whatever choices may be available, including termination of pregnancy
- Prepare logistically, arrange childcare, get time off work to attend appointments, research the condition, join peer-to-peer support groups and contact charities
- Begin to speak to family and friends about what to expect.

Some participants in both groups would want to know as a matter of principle, in that they wouldn't want anyone else to know more about the condition than they do. One participant felt that even if nothing could be done during pregnancy, it would be useful to begin collecting this information for clinicians and researchers to build understanding of developing fetuses.

Some of the participants from the charity recruited group described their experiences of when a condition is not detected until after birth:

> *"I always think I wish I had known because I had a false sense of security, and when the baby is born it is an awful shock and very stressful. If I had known before I would have been able to prepare."*
>
> — **Charity recruited participant**

Unnecessary worry

Although the majority of participants felt that they wanted all the information that was available, there was a significant minority who did not want to know, and described the benefits of not knowing. They used terms such as *"ignorance is bliss", "really comfortable not knowing", "unnecessarily time consuming"* and *"avoids the what-ifs"* and described how it could cause stress, disruption and unnecessary anxiety. One participant questioned whether the effects of stress during pregnancy had been investigated fully.

> *"Knowing you are having a child with a condition was so worrying, so much tension, pregnancy was not enjoyable at all."*
>
> — **Charity recruited participant**

Sometimes an anomaly can be an indicator of other conditions and one participant in the charity recruited group had experience of this and how it can trigger a lot of uncertainty and further testing.

> *"Not always a case of "this is the condition", it might be more like "this is it, it might be linked to XYZ" and it opens up a lot of uncertainty."*
>
> — **Charity recruited participant**

Complex trade-off

Many in both groups recognised the complexity of this dilemma, and agreed that it is a difficult trade-off between preparedness and unnecessary worry. Some described it as a *"double-edged sword"* and how the benefits of knowing depend on personal circumstances and how significant the findings are.

> *"I think knowing about a condition before a baby is born is a personal journey. Some people like to have the time to get used to it but personally I preferred not to know so I didn't have the stress."*
>
> — **Charity recruited participant**

> *"Being prepared is important but the stress of knowing is too much if there is nothing to be done."*
>
> — **Agency recruited participant**

Information and reassurance

There was a strong emphasis on the need for proper information and support if the identification of incidental findings is going to become more frequently detected in the future. Participants wanted certainty of what the scan had found, backed up by evidence-based research and statistics, with enough time and access to specialists for parents to fully understand what it means. They highlighted the importance of accessible communications backed up by support.

> *"It depends how it's communicated. If the diagnosis is just left on a form and no one explains it to me then that would be difficult."*
>
> — **Agency recruited participant**

Some from the agency recruited group expressed concern that medical professionals can use technical language that people don't understand, or that they don't trust medical professionals when they are trying to be reassuring. It was also questioned whether sonographers have enough time in their appointments to talk parents through these kinds of findings.

Give parents a choice

Participants from both groups discussed whether parents could choose the level of information they would like, and whether they would want to hear about incidental findings that are found.

> *"Could this be offered as a choice e.g. at booking in? Different people have different feelings about what they want to know."*
>
> — **Charity recruited participant**

They identified potential concerns about this approach, either from an ethical perspective (would it be legal or ethical to withhold information?) or procedural (how would clinicians draw the line between a minor or major issue?).

Support needed

In addition to emotional support and signposting, participants in the charity recruited group discussed how more should be available to support wider families. They described how a congenital condition impacts *"everyone in your family"* and how people want to help but they don't know how.

3.3 Interventions on the baby during pregnancy

During the first workshop participants were asked to consider what questions they had, or what issues came to mind on hearing about the research via the videos. During the second workshop participants were reminded of the potential outcomes following an anomaly detection at 20-weeks, and were asked to consider the kind of information and support that should be made available to people faced with a decision about **interventions** during pregnancy. The outputs from the discussions at both workshops are summarised in this section.

3.3.1 Key themes

The key themes that emerged in relation to **interventions during pregnancy** from both workshops were as follows:

- There was support for innovations for operating on babies in the womb (fetal surgery), but **comfort levels were noticeably lower** than for the screening and diagnostic scanning developments. This unease was particularly pronounced for those who had experienced "as expected" pregnancies.
- Once again, participants acknowledged that the acceptability of fetal surgery is completely **subjective to the situation** you are faced with, and many stated that they would do whatever their baby needed if faced with the situation.
- The importance of clear, comprehensive, unbiased information on risks and practicalities was stressed. In this situation **as much information as possible** should be provided, even if it seems an overwhelming amount. Information should be written down, not just verbally given, so that families can read and consider in their own time, after speaking to clinicians.
- **Practical and emotional support** is critical for the intense situations parents are faced with when considering or undergoing fetal surgery. This should include; access to specialists, site visits, case studies, support for relationships and wider families and a recognition of the financial and career impacts.
- **Peer-to-peer support**, the opportunity to speak to parents who have already undergone the treatment, and connections to charities who support families are seen as extremely beneficial.
- **Support should be provided consistently and comprehensively** to all families, no matter where they live in the country. Participants felt that the support provided is patchy currently, and a form of standardised pathway of support that is made available to all families would help to mitigate this.
- Participants who had experienced interventions in pregnancy felt that **care could be better joined up** between local and national specialist services.

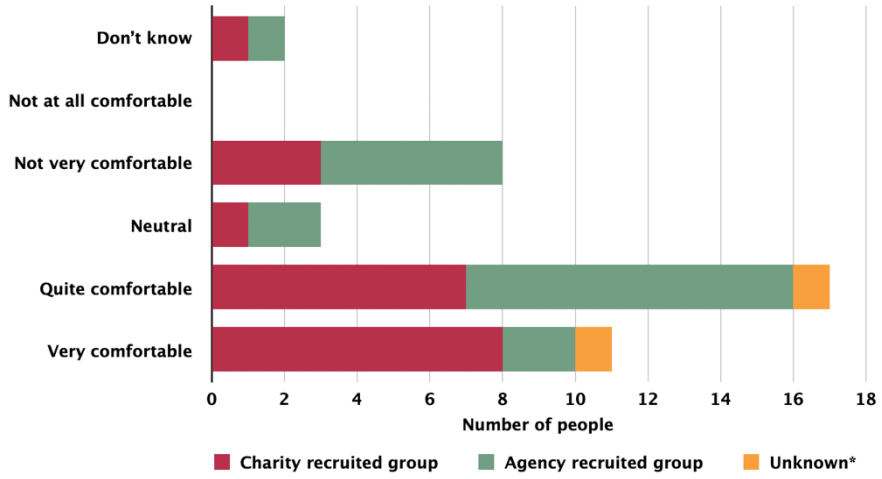
POST EVENT REFLECTIONS

> ***"It's always great as an engineer to have my ideas picked apart because it doesn't matter how good my bit of mathematics is, if it doesn't make any sense – you get a lot of questions about what you're doing and whether it's working. That's really valuable to hear."***
>
> **—Researcher**

3.3.2 Response to interventions on the baby while still in the womb.

In the relevant stimulus videos (see section 2.3.7.), participants were told about the history of fetal surgery and new developments for minimally invasive surgical interventions on the baby while still in the womb. Participants were asked to rate how they felt after what they had heard, via a live Zoom poll. Results were not shared in real time so as not to bias the conversations that followed.

> ***Q. Given what you've just heard, how comfortable do you feel about the direction of the research regarding new intervention options such as keyhole surgery on babies in the womb?***



**Unknown where participants accessed the Zoom meeting as 'guest' and the software does not record their name.*

Participants then moved into small facilitated breakout groups (as before) and discussed their initial response to what they had heard and what questions or issues it provoked for them. In the second workshop they were asked:

> ***Q. If the condition detected is suitable for an intervention before birth, what type of support do you think you would expect to help you and your partner to make a decision about whether to proceed with the intervention?***

As much of the discussion covered similar issues in both workshops it is summarised together in this section.

Excited about the possibilities

Once again participants showed support for the clinicians and researchers developing these technologies and new treatments. There were positive sentiments for the fetoscope technology (the very small telescope and surgical tool used in keyhole surgery) to replace open fetal surgery, and the potential to improve outcomes for babies with congenital conditions and reduce complications for mothers.

> *"Amazing, and slightly terrifying!"*
>
> — **Charity recruited participant**

> *"I think this is brilliant - I understand there are risks but this is something I would do."*
>
> — **Agency recruited participant**

Participants in the charity recruited group queried whether these techniques could be developed to offer more treatments such as internal and digestive conditions, or even preemptive intervention for a condition where the mother was at high risk such as twin-to-twin transfusion syndrome.

Concern about the experimental nature of these treatments

There was, however, a significant level of trepidation for this type of experimental procedure. This uneasiness was much more pronounced in the agency recruited group. Terms such as *"scary"*, *"leap of faith"*, *"guinea pig"* and *"risky"* were used. Participants were keen to ensure the risks and alternatives were fully explained to ensure families gave informed consent. A small number mentioned how religious beliefs could be a factor.

> *"From an Islamic perspective, termination is not allowed, and with more advanced technology more things can be highlighted, but it's a grey area if there is a high risk for the baby."*
>
> — **Agency recruited participant**

Once again, some agency recruited participants acknowledged that it is difficult to form a view on this until you are faced with that situation.

> *"It's such a subjective thing to comment on, but until you've had a baby in that situation… I think if I was told that my baby had a condition that would affect its life I would be likely to have the surgery."*
>
> — **Agency recruited participant**

> *POST EVENT REFLECTIONS*
>
> ***"[The content in this session] was a steep learning curve and a lot to take in, some of these interventions are very ethically and technically challenging. It would have been interesting to have gone back after they had more time to think about it."***
>
> **—Researcher**

Information and support

Participants in the charity recruited group, a number of whom had been offered fetal surgery, talked through their experiences and the support they needed in those moments. Many of these themes were highlighted by the agency recruited group also.

Practical and emotional support

- **Logistical support**: somewhere to stay e.g. charity funded accommodation, hotels, travel, particularly for those who have to travel far from home.
- **Financial support**: impact on work and childcare.
- **Support networks** need to be in place: peer support, counselling, access to charities (both ARC and condition-specific support groups), signposting.

> *"I think you should keep contact with people who have had the surgery before so there is a network for parents going into it to turn to and speak to about their experiences. In essence, being able to speak to people who have had the same procedure before you." Agency recruited participant*

- **Emotional support**: coming to terms with the fact that the surgery isn't necessarily a cure for their baby, support through the uncertainty of decision-making, ensure the fathers/non-childbearing parents are considered and made to feel included.

> *"Sensitive, open minded counselling."*
>
> — **Charity recruited participant**

- **Long term support** following diagnosis and birth or loss.

> *"Some years down the line, there could still be a need for counselling etc - very traumatic!!"*
>
> — **Charity recruited participant**

Continuity of care

- Joined-up care: all the way from initial scans through to aftercare from surgery. From community midwives to surgeons.
- An advocate or dedicated nurse/ midwife as a point of contact to help counsel through the process and better knowledge of support groups for specific conditions.

Information

- Written information: families find it difficult to remember what they've been told during consultations, so having written information to refer back to is important.
- Stories, case studies, access to real-life experiences.

> *"I'd want to hear a parent's perspective of having gone through the intervention - how was it? How did it feel? Not just the medical professionals experience but the patient's as well. I'd want to know this before deciding."*
>
> — **Agency recruited participant**

- Unbiased, up-to-date information: on the risks to the mother and the baby, success rates, the potential outcomes of doing / not doing the surgery, the potential impact on future pregnancies, how long recovery and aftercare lasts. Making it clear that it is a choice. As much information as possible to avoid parents having to do their own research or referring to '*Dr Google'*.

> *"As much information as possible, even if it is overwhelming."*
>
> — **Charity recruited participant**

> *"Give parents specific places to go to, for the support they need. Advise them not to google randomly - as this may cause stress and have wrong information."*
>
> — **Charity recruited participant**

- Visiting the facilities and procedure run throughs: who will be in the room, exactly how will the surgery be carried out? What would happen if there was a delay?
- Access to the surgeons: meetings and video calls to answer questions.
- Statistics on the providers: how many procedures are carried out, how experienced are the surgeons, how are the skills developed? Is there a choice of providers?

A standardised pathway of support

- A standardised option throughout the country for a pathway of support to ensure every parent has access to the same information.
- What support is currently available to parents facing these decisions, and how can this be improved; e.g., is there a standard list of information provided?

One charity recruited participant described how there was no decision-making process *per se*, and that it was a critical *"life or death"* moment for their twin pregnancy without any time to consider information or support. Another who had been faced with extremely difficult choices described how they can feel completely overwhelmed in these moments and just want clinicians to tell them "*what would you do in this situation?".*

3.4 Future research priorities

At the final point of the last workshops participants were asked to consider:

> ***Q. Are there other aspects of antenatal care scientists and researchers should be considering?***

Responses ranged from better monitoring in pregnancy, to treatments for specific conditions through to improving the consistency of emotional support provided to all.

Some participants reiterated points made in earlier discussions, that they would like to see new technologies applied to ***detect conditions earlier in pregnancy*** than 20-weeks. Participants from both groups felt that a diagnosis that may lead to a termination of pregnancy would be more manageable earlier in pregnancy.

A number of questions were asked about whether improved imaging could ***increase the range of conditions that could be detected during pregnancy***, for example looking at conditions that affect softer tissues or scanning for indicators of mental health conditions, neurological conditions and autism. Leading on from this, a number of participants asked whether more research could help them to understand ***why conditions develop***, e.g. genetics testing, and the benefit this could have on dealing with the emotional impact of conditions diagnosed in pregnancy.

> *"Why? This is what we want to know. Although it doesn't change anything practically, but it does help us to come to terms with the situation. Did we cause it? Could it have been avoided at all? Was it inevitable?"*
>
> — **Charity recruited participant**

A significant number of participants from both groups talked about a desire for ***more frequent and more accurate monitoring*** during pregnancy, particularly in relation to estimating the baby's size and weight. Participants in the charity recruited group felt that there would be benefit in introducing scans later in pregnancy as standard, to monitor growth and detect conditions that develop after 20-weeks with the aim of reducing stillbirth.

> *"If we had not had a 28 week growth scan we wouldn't have found out. There are circumstances where things happen between 20 weeks and term."*
>
> — **Charity recruited participant**

Participants from both groups suggested specific issues that it may be beneficial to monitor during pregnancy using scanning technologies. Many of these related to ***estimating the growth and weight of the baby***, with many from the agency recruited group citing experience of the inaccuracy of growth estimates and how this impacted negatively on decisions made about their delivery (i.e., induced early unnecessarily, or not induced early enough with a large baby).

> *"It caused me a lot of anxiousness and had additional scans but this wasn't necessary because the percentiles were not accurate and didn't reflect the reality when the baby was born."*
>
> — **Agency recruited participant**

There was a question whether growth monitoring and centile charts could better reflect the height, body weight and other characteristics of the parents. One participant would like to see research carried out on the *"dangerous limits of size",* to better understand the risks of low or high fetal weight, to both the mother and baby.

Some comments were made asking for a ***general improvement in the reliability of scans***, both to ensure conditions are detected accurately and also to reduce the rescan rates. Other suggestions were more specific including improved scanning of the placenta and regular monitoring of blood flow through the umbilical cord.

> *"Can technology make that more accurate and look at amniotic fluid, blood flow through cord, or anything else that can look at things that affect the growth of the baby?"*
>
> — **Charity recruited participant**

Some participants queried whether research could look at ***risk factors to better plan antenatal and obstetric care***, for example:

- Look at risk factors for stillbirth and whether "at risk" cases could be identified
- Understand factors that make caesarean section or assisted delivery more likely
- Monitoring women's health prior to or between pregnancies.

Suggestions for ***research into specific conditions or treatments*** covered treatment of the the mother, babies in the womb and newborn babies:

- hyperemesis gravidarum (severe morning sickness)
- problems with the cervix
- problems with the placenta
- pelvic problems (symphysis pubis dysfunction)
- stem cell transplants at birth
- gentler methods of ventilating babies to prevent long term damage.

Participants from the charity recruited group suggested that more research is carried out to ***support the transition from paediatric to adult care*** within the NHS, as many children born with congenital conditions will require care throughout their lives.

> *"The transition to adult care – it is a paediatric congenital condition – so there isn't necessarily the adult care for these conditions."*
>
> — **Charity recruited participant**

The largest number of comments related to the need to reduce ***variation of care in pregnancy***, both on a geographic basis and the continuity of approach from different healthcare professionals. The majority of these comments were made by the charity recruited group and focused on two key areas:

Firstly ensuring ***all health professionals use consistent appropriate language***, particularly in relation to specific conditions and the implications; ensuring no assumptions are made about whether the parents choose to end or continue with the pregnancy, and being open and honest about the implications of any condition.

> *"Important that the health professions are not to be too blasé about conditions. We didn't get later life information about difficulties they'd face later in life – years down the line there are consequences."*
>
> — **Charity recruited participant**

> *"It (Down's Syndrome) is dealt with in a negative way with an assumption that people don't want to continue with the pregnancy. Maybe a pathway that is standardised and followed in every hospital for continuity in care in every region."*
>
> — **Charity recruited participant**

> *"How people are given information about scans - as I went into my 20 week scan I was nervous and the person who brought me in said 'it will be fine' when in fact it wasn't."*
>
> — **Charity recruited participant**

> *"Training for health professionals like midwives: trusting the scans and listening to the patients about what they want and feel about choices (mums don't always feel listened to!)."*
>
> — **Agency recruited participant**

Secondly ***standardising the information provided to families when an anomaly is detected*** or a diagnosis is given. One participant from the charity recruited group felt strongly that information about the options for termination are not made available, and parents who decide to end their pregnancies are not well-supported.

> *"Ensuring the information on various conditions is up to date and given to relevant hospitals, it's all moving so fast."*
>
> — **Charity recruited participant**

> *"It would be useful to have research about improving communication when people are making a decision about termination for medical reasons. Once we had made the decision about surgical route I felt on my own. As I was going under the anaesthetic, someone asked if we wanted to retain tissue - I didn't even know what they meant and why it might be important."*
>
> — **Charity recruited participant**

Research into the ***emotional impacts and support provided for families who receive a diagnosis*** was another key area of importance for participants (exclusively from the charity recruited group). Specific suggestions included:

- Psychological impacts on parents of receiving a diagnosis
- How stress affects the baby e.g. cortisol hormones

- Impacts on parents' relationship, siblings and wider family
- Assessing the support provided to those who continue with their pregnancy compared with those who opt for termination
- Research into the wider impact on people's lives.

> *"My career was affected. I used to work in paediatrics and found I couldn't work in that area again."*
>
> — **Charity recruited participant**

- Emotional support and advocacy from others who have similar experiences.

> *"Perhaps support for people going through non-standard pregnancy to connect more. Extra scans cause extra stress and it felt hard to connect with people who don't have problems. When I connected with someone who had a non-standard pregnancy I felt less isolated and more 'normal'."*
>
> — **Charity recruited participant**

> *"Importance of having an advocate: my experience was ten years ago. I was young when it happened. A lot of decisions/preferences were pushed in my direction where other things were not explored or explained."*
>
> — **Charity recruited participant**

Other suggestions from the agency recruited group related specifically to ***the experience of routine ultrasound scans***.

- Improving the experience for fathers/partners/non-childbearing parents, making them feel more involved
- Exploring the ethics of collecting more data during scans, including information about the parents
- Finding out why people use private scanning clinics and how this aligns with NHS care
- Developing an app for people to have access to their own data - including ultrasound scan images
- Whether the technology could be developed to enable people to self-scan at home.

4 Appendices

4.1 Stakeholder Advisory Group (StAG) membership

Name	Role	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)
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

Anna MacGillivray	Evaluator	Ursus Consulting
Rhuari Bennet	Dialogue delivery team	3KQ
Pippa Hyam	Dialogue delivery team	3KQ
Hannah Wynne	Dialogue delivery team	3KQ

4.2 Stimulus videos

The videos are available to view on the Wellcome/EPSRC Centre for Medical Engineering project webpage. The videos will be archived at the end of 2022.

4.3 Glossary of terms

Fetal / fetus | A baby inside the womb.

Congenital condition | A health condition that developed while a baby was developing in the womb.

Fetal medicine / maternal fetal medicine | Doctors and nurses who take care of families whose babies have a congenital condition.

Sonographer | A medical professional trained in imaging technologies who typically carries out an ultrasound scan on a pregnant person.

Fetoscope | Very small telescope and surgical tool used in keyhole surgery.

Abnormality / defect / anomaly | These terms are often used interchangeably to describe a difference in a baby that may signify a health problem.

Antenatal: During pregnancy / before birth.

Obstetrician / obstetric medicine / obstetrics | Doctors who specialise in pregnancy and birth / medical care for pregnant women.

Machine learning | An application of artificial intelligence that allows systems to automatically learn and improve from experience without being explicitly programmed. The machine learning being developed for the 20-week scan uses a computer programme to look at past examples of ultrasound scans, finds similarities between the scan images, and then applies these findings to new examples it hasn't seen before. It allows thousands of different ultrasound images to be compared instantly, much faster than a human can.

Artificial intelligence | Artificial intelligent devices and systems are designed to assist human processes and can address problems creatively in a similar way to human behaviour, but often faster or more efficiently (once they have been programmed to do so).

4.4 Demographic data

Answers	Charity recruited group	Agency recruited group
Question: Ethnic group		
White: British	19	12
White: Other	0	2
Black / Black British	0	2
Asian / Asian British	1	3
Mixed or multiple ethnic groups	1	2
Other	0	1
Question: Sex / parental role		
Identify as Female / child bearing mother	19	18
Identify as Male / father	2	4
Identify as female / non child-bearing mother	0	0
Question: Age		
24 and under	0	4
25-34	10	10
35-44	9	8
45-54	2	0
Question: Highest educational level		
No formal qualifications	0	0
Secondary school up to 16 years old (e.g., GCE, O-levels, GCSEs etc.)	0	5
Higher or secondary or further education (e.g., A-levels, BTEC etc.)	8	10

University or undergraduate degree (e.g., BSc, BA, MBBS etc.)	9	4
Post-graduate degree (e.g., PhD, MSc, MA, MD etc.)	3	2
Other vocational training/qualifications	0	1
Unknown	1	0
Question: Region of England		
East Midlands	0	3
East of England	1	1
London	4	4
North East	1	1
North West	2	3
South East	6	3
South West	4	2
West Midlands	0	3
Yorkshire & The Humber	3	2
Question: How did you hear about the project?		
ARC	6	n/a
ECHO	2	n/a
Shine	1	n/a
Twins Trust	2	n/a
Bliss	7	n/a
Word of mouth	1	n/a
Social media	2	n/a

4.6 For more information

Visit the Wellcome/EPSRC Centre for Engineering for more information about our research and public engagement.