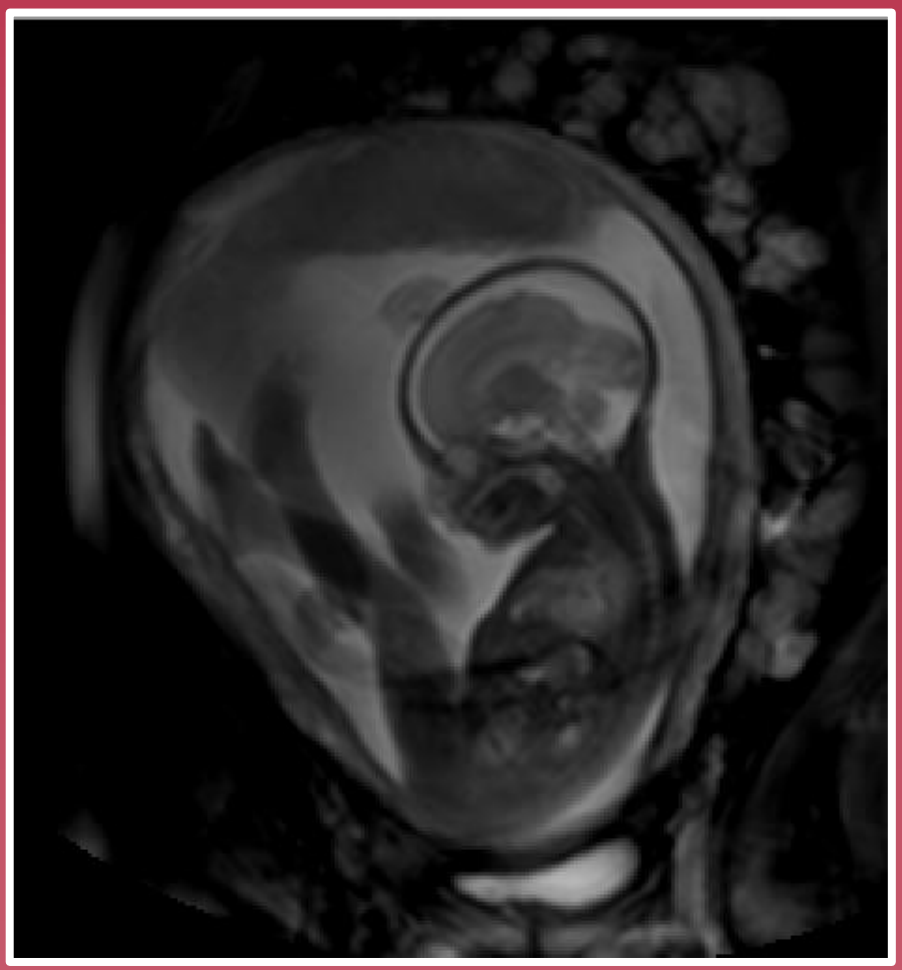
Public Dialogue on Scanning and Surgical Innovations in Pregnancy

Executive summary report of dialogue workshops with members of the public



KING'S College LONDON

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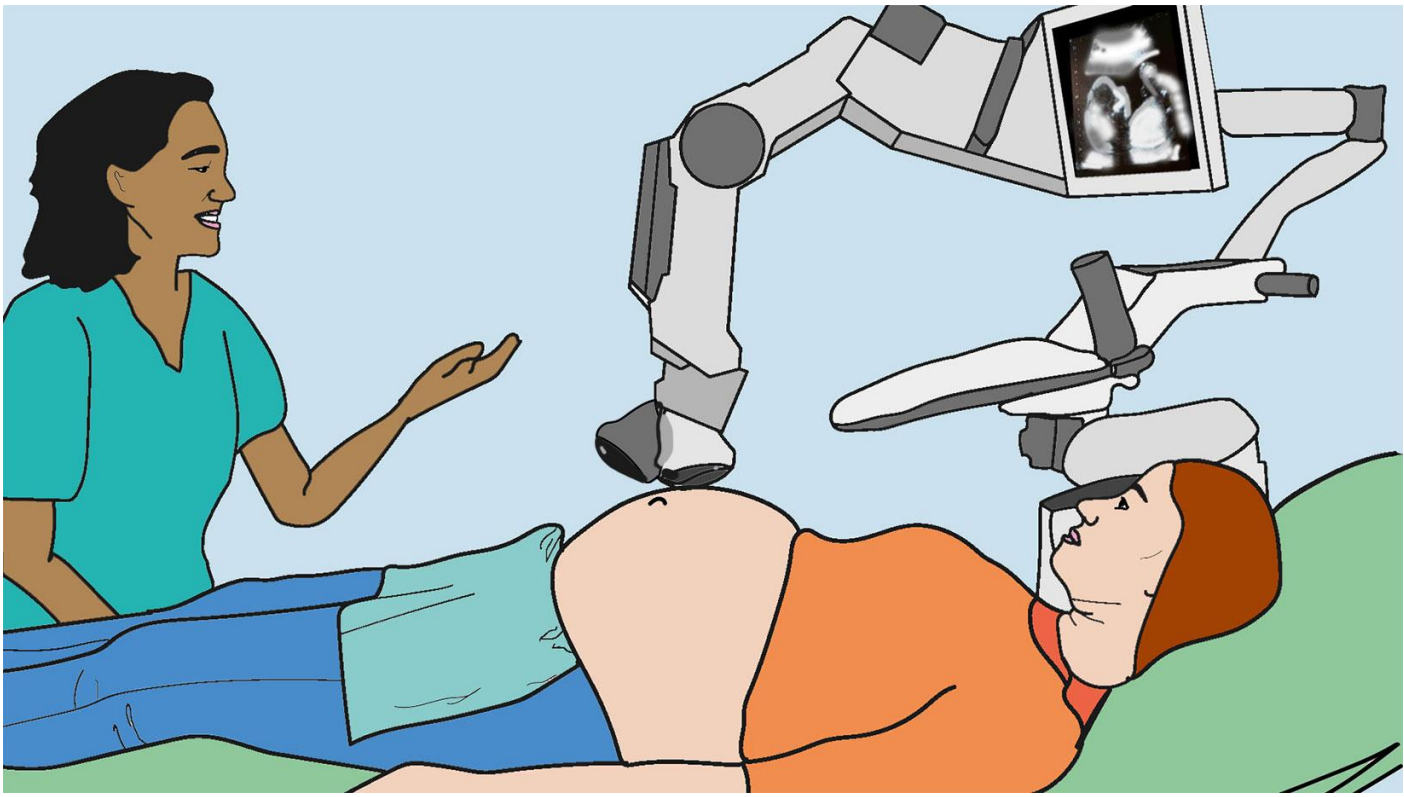
Executive summary

Introduction

Researchers in the Wellcome/EPSRC Centre for Medical Engineering, King's College London, have been exploring ways in which new technologies can improve the detection, diagnosis and treatment of conditions that some babies develop while in the womb. These technologies have the potential to improve outcomes for babies with conditions, but could also impact the experience of families and lead to a change in the way care is provided.

An online public dialogue project was designed to explore members of the public's hopes and concerns on how this research may impact antenatal care. 43 participants from across England took part in a series of online workshops during March and April 2021. All participants had experienced antenatal care within the NHS in England; half having experienced a pregnancy of a baby who had a condition and half having a recent pregnancy where no condition was identified. Participants were carefully selected to ensure a wide range of past experiences and demographics were represented.



During the workshops, participants heard about innovations in the following key areas:

- The use of machine learning technology to increase detection rates during the 20-week scan, by automatically measuring the baby and detecting anomalies.
- The use of robotic arms with multiple ultrasound probes to improve the quality of images collected during ultrasound scans.

- Innovations in additional imaging tools such as MRI to assist the diagnosis of conditions while the baby is still in the womb, and how these advanced techniques can benefit families.
- Advancements in fetal surgery, using technologies such as laser and keyhole surgery to operate on babies while still in the womb.

Context

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**).

Key findings

1. The real-time expertise and reassurance provided by sonographers is more important than detection rates or convenience

Participants supported the aim to improve detection rates, with a strong caveat that any technological developments should support, not replace, the role of the specialist operator (the sonographer).

The 20-week scan is seen as an important pregnancy milestone and bonding experience, and participants are greatly comforted by the presence of a specialist human, to provide real-time support and explain what is being seen.

The reassurance provided by seeing a specialist in a hospital far outweighed any concerns about accessibility or travel time. Nearly all participants were comfortable with machine-learning assisted scans operated by a sonographer, but reacted strongly against the idea of a machine-learning assisted scan delivered in a local setting by a non-specialist healthcare professional.

The language used and support provided by medical professionals has a greater impact on the experience of expectant families than the accuracy or outcome of the scan.

2. Past experience determines the acceptability of new technologies

The participants 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 and positive about new technologies…

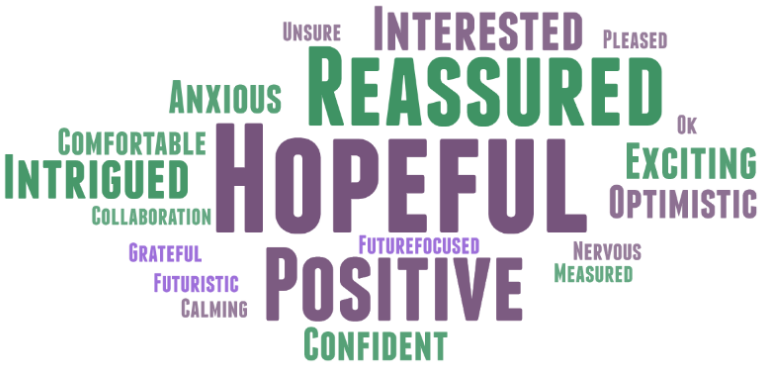


Figure 1: *Word cloud showing the most frequently mentioned words used when participants who had* ***experienced a pregnancy of a baby with a condition*** *were asked to describe how they felt about increased automation in scans.*

... while the group who generally had 'as expected' antenatal journeys were more cautious or sceptical. Reassurance was needed that any new technologies had been proven to be safe.

Figure 2: *Word cloud showing the most frequently mentioned words used when participants who had* ***experienced a recent pregnancy without a condition*** *were asked to describe how they felt about increased automation in scans.*

Participants were supportive but cautious about advanced diagnostic tools such as MRI, but acknowledged that opinions are subjective to the situation you are facing. There was support for innovations in fetal surgery, but comfort levels were noticeably lower than for screening and diagnosis developments i.e., scanning and imaging, particularly for those who had experienced "as expected" pregnancies.

3. Waiting for test results in pregnancy is stressful and should be avoided

The introduction of any additional time to wait between the 20-week screening scan and receiving the results was a compromise participants were unwilling to make, even if accuracy is improved.

The current wait time between a diagnostic MRI scan (if something has been detected at the 20-week scan) and receiving the results was flagged as a significant source of stress. Those who had experienced an MRI scan in pregnancy described difficult waits of 1-2 weeks, mostly occurring between 20-24 weeks gestation, which is a critical time for making decisions about whether to continue with a pregnancy.

4. Support and information for families facing investigations and procedures during pregnancy is critical

Participants with past experience of investigations during pregnancy expressed how valuable the support of relevant charities had been, and how signposting to support organisations should be provided consistently for all families across England.

Support should include counselling for parents and other members of the family, and should continue regardless of the outcome of the pregnancy. It was seen as important that the impact on a family's relationships, careers and finances should also be considered by clinicians.

Participants described how information provided to families should be comprehensive, unbiased, and in written form (in addition to verbal conversations) for families to take away and consider. Full disclosure of risks, as well as case studies of different outcomes should be provided. Families should be offered opportunities to ask questions of clinicians involved as well as other families who have been through procedures.

5. Information given to families should be backed up by a degree of certainty

Participants discussed how improved imaging technology at screening (20-week scan) is likely to increase the number of minor anomalies that pose no/little health risk to a baby, and felt that it was important that information about these anomalies was provided in a way that would reassure families, and not be a cause of unnecessary stress. Although most parents wanted as much information as possible about their baby, others did not, and it was suggested that an element of choice could be given.

6. Further technological research is supported

Participants were enthusiastic about potential applications of new technologies beyond the research, for example estimating fetal weight or detecting conditions earlier in pregnancy.

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