



A focused discussion looking at a new Artificial Intelligence (AI) tool to support breast cancer diagnosis in the NHS

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Background

Aim of the workshop

To understand the views of men who have received a breast cancer diagnosis on:

- Their experience of the pathway of care surrounding their diagnosis
- The utility, design and delivery of the Ibex Galen Breast product

Participants

We sought to have five to eight attendees for the workshop, as well as two ‘hosts/facilitators’ from Health Innovation Oxford and Thames Valley (HIOTV). We felt it was important for one of the hosts to be a male colleague from HIOTV to help male participants feel comfortable. It was also agreed that it wouldn’t be suitable for the study’s expert by experience or public partner to attend, as they are both female. No one from Ibex was in attendance.

We asked people to express an interest in attending the workshop through:

- The Men’s Virtual Meet Up (VMU)
- National charities: Breast Cancer Now voices network, Male Breast Cancer Global Alliance

Format

Attendees were sent a short briefing paper in advance of the workshop which provided some background about Galen Breast and the research study. It also included an overview of the workshop and some things for attendees to consider in advance of the event. We intentionally limited the number of participants to ensure sensitivity was given to the personal nature of the discussions. The psychological safety of attendees was a key concern. Throughout communications we made this clear to attendees and offered a pre-event phone call to answer any questions or worries. It was also made clear that people could drop out of the workshop at any time, temporarily or permanently.

The workshop was broken down into three sessions, with clear questions or conversation topics and a scheduled break. One of the sessions involved making notes of our discussions on a virtual whiteboard for attendees to view, comment and collaborate on.

Attendees were sent a follow-up thank you email after the workshop, with details on how they could claim reimbursement for participating.

Workshop outputs

The workshop was attended by five men who very openly, and generously, shared their experiences. Below is a summary of the key discussion points and themes that were raised during the workshop.

Experiences of care

During the first session of the workshop, the discussions centred around attendee's experience of care – particularly receiving their diagnosis.

All but one of the attendees felt their diagnosis was handled correctly, with care, dignity and speed.

“It was a very slick process”

Half of the attendees were unaware that men could get diagnosed with breast cancer, and it was widely agreed among the group that there is a huge issue regarding awareness and education on men's breast cancer.

When first presenting to the doctor with their concerns, one attendee said their GP dismissed them and said “it is probably just a cyst” and asked them to return if the lump is still there in a few weeks. The lack of urgency with this initial interaction was noted as concerning, as men often struggle with presenting to the doctors in the first instance, so this triggered a feeling of ‘everything is OK’ and there isn't anything wrong or to be concerned about.

As a man going through the diagnosis process and care pathway, there were times attendees felt embarrassed and uncomfortable, especially when going for a mammogram. One attendee felt that he was a ‘novelty’ to the clinicians treating him, as they were so used to treating women. It was highlighted one of the biggest issues facing men receiving a diagnosis is the lack of male focused information. Ensuring there are patient information leaflets specifically designed for men was noted as a big need in the current care pathway. One attendee also flagged they tried very hard to find a men's support group he could turn to, as he wanted to ask questions about the issues he was having with his treatment of tamoxifen, but really struggled to find the support he needed.

We asked attendees how much they knew/were told about the process of getting their diagnosis i.e. what would be tested, how and by who. Generally, attendees agreed they knew very little. This wasn't considered a huge concern however, as they felt they could put their trust in health professionals to ‘get the job done’. As discussions progressed throughout the workshop, a couple of attendees reflected back to this question and said if they had known more about this process it could have impacted the confidence they had in their diagnosis.

When questioned how much research everyone did regarding the process of their diagnosis, answers varied. This highlights the fact that each individual approaches their care differently – for some, having more knowledge felt like having more power and control over their care. One attendee said they did very little of their own research and chose to trust and be led by the healthcare professionals in front of them. This is key to consider when working on communications and public facing documents. More was discussed on the notion of communication in the third session.

Views on Artificial Intelligence (AI) in cancer diagnostics

The second session of the workshop focused on gathering attendees views on AI being used in the diagnostic pathway.

The overarching view of all attendees was that this was a positive thing. It was commented that anything which could improve outcomes and speed up diagnosis should be explored and adopted as soon as possible.

“Anything that improves outcomes is important to take on board and move forward”

It was clear that the personal experience of living or having lived with cancer, impacted the views expressed – attendees were extremely keen and passionate towards opportunities that could improve outcomes and better themselves, and others, in the future.

The issue of fairness to access, and continuity of care was noted. One attendee said they would want the technology to be available to all as best practice, rather than being a ‘postcode lottery’ as to whether your care would be benefitted by the use of AI.

The issue of the media’s portrayal of AI was also raised. It was felt that on the whole, the media comment negatively on the use of AI and can scaremonger the public – especially from the perspective of AI taking over the role of humans and replacing them in their jobs. It was felt that educating the public on the technology, and its exact purpose would be crucial.

One attendee who uses AI daily in their job felt there was a commercially driven risk, commenting they felt NICE have big controls on drugs and commercial risk, but who/what body would have the same control over AI technology?

Whilst all attendees felt positive and optimistic about the use of AI, it was identified that as a patient they would want to see very strong evidence that the technology is reliable and can be trusted – this is explored more in the next section. Attendees would want to know the role of humans in the process too, as it was felt the technology doesn’t diminish the need to still have a human involved in the process of a diagnosis.

Trust and design of Galen Breast product

The final stage of our discussion focused on the Ibex Galen Breast product specifically, and what attendees would want/need to know about the product, and their views on communication regarding the product.

A key element to trusting the product was having clear evidence showing its reliability and accuracy. Attendees agreed they would like to know what the error rates of a human were vs the error rates of the AI technology. Whilst they understood that the product works by the technology *supporting* a human (pathologist) – they would find it reassuring to know if the AI produced less errors than a human. One attendee said they would like to know as much detail as how the algorithm for the technology was created.

As our initial discussion in session 1 established, patients don’t always know a lot of detail about the specifics of their diagnosis pathway. When asked if the attendees would want to know if this technology was being used in their care, there was a consensus of yes. It was discussed

that if strong evidence on its reliability could be provided, knowing the technology was being used could provide further confidence that the diagnosis is correct and that nothing has been missed or inaccurately diagnosed. Whilst acknowledging there is always room for a degree of error, knowing that complex, innovative technology had also been used in the process would help alleviate areas of doubt and concern. An interesting question that was raised, was whether patients would ever be informed about what 'colour' their sample was (ref the traffic light system rating that Galen Breast produces as a first-read tool). Attendees wondered whether knowing this information would be beneficial or not, as it might make patients feel that if their sample was rating 'red' and therefore high risk, they might want further testing done and it could cause more anxiety.

When discussing how this could be communicated, and in what format they would like to have the information, the below thoughts were given:

- Keep initial comms simple and not overwhelming.
- Empower the patient to find out more. Ensure there is further information available for people who like to do their own research and know all of the details – signpost to websites or places to find this further info in initial comms.
- Ensure all comms are jargon free – it is a highly emotive time in patients/their families lives, and feeling confused and unsure of what they are being told or are reading, can really add to the feeling of fear, confusion and anxiety.
- Push publicity regarding this study – use local news and radios channels to start getting information out there.
- Make it very clear what the benefits of the technology are to the patient and how it could improve their outcomes.
- Use trusted sources to host the information and help make available.
- Charities are a key source of information for patients and should be utilised to their full potential in communicating information about the technology and this study.

A general theme that came from this discussion was that men quite often find it more comfortable accessing information from third parties, and in their own time. Attendees highlighted the importance of utilising charities more than once. They felt charities are a reliable, credible and non-judgemental source of information. Attendees noted charities are particularly good at spreading news and information quickly too.

A final point that was raised regarding communication was ensuring considerations have been made to mitigate the impact of negative media and news stories. The prominence of social media was also noted as likely to play a part in negative and potentially inaccurate dissemination of information and that this needs to be considered in advance of any news stories breaking.

Key themes and recommendations

Drawing together the outcomes from the group discussions, we have summarised the following three key themes and recommendations:

Positive attitudes

The views expressed by our attendees towards the introduction of AI generally, but specifically the Galen Breast product, was positive. Ultimately patients want to ensure the best patient outcomes are achieved and attendees felt this technology could help towards better outcomes.

Trust

Whilst there is positivity and optimism towards new technology, in order to fully trust it and be comfortable with it being introduced into their, or their loved ones, care pathway, it was trust in the product would be essential. In order to do this, they would like to see facts and figures about accuracy and error rates of the technology, and it clearly demonstrated how the technology assists – and does not replace – pathologists.

Communication

Ultimately, attitudes and trust towards a product are hugely impacted by how information is communicated. It was identified that all communication regarding this technology must be clear, jargon free, and provide clarity to those reading it. Harnessing the platforms and communication channels available and most widely used by breast cancer patients – such as charities – is essential to ensure the information is easily accessible, trusted and widely spread. The language used must also acknowledge that women *and* men get breast cancer.