Artificial Intelligence Risk Stratification (AIRS) for Earlier Cancer Detection - PPIE focus group report

Author: Dr Afsana Bhuiya

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Executive summary

This report presents findings from Patient and Public Involvement and Engagement (PPIE) focus groups exploring the use of artificial intelligence (AI)–enabled risk prediction tools to support earlier cancer detection in the NHS.

Overall, participants expressed strong support for the concept, recognising its potential to improve outcomes through earlier diagnosis and treatment. Quantitative results reflected high perceived benefit and feasibility (mean scores 4.3–4.8), suggesting the tool is viewed as both valuable and practical within an NHS setting.

However, support was conditional. Trust emerged as a central factor, with participants highlighting the need for transparency, clear data governance, and NHS ownership of data. There was greater uncertainty around ethical implications (mean 3.0) and effort required to engage (mean 3.17), reflecting concerns about how the tool would work in practice.

Participants emphasised that AI should act as a decision support tool, not replace clinicians. Clear, non-alarming communication, defined next steps, and access to human support were identified as essential to reduce anxiety and build confidence.

Successful implementation will depend on patient centred design, transparent data use, and strong clinical oversight.

Purpose and Background

This report summarises findings from focus groups exploring public perceptions of an AI-enabled Risk Stratification (AIRS) tool for early cancer detection. The work aims to inform practical implementation, with a focus on trust, communication, and delivery.

To understand public perceptions of AI in healthcare and identify how to design and implement a risk stratification tool in a way that is acceptable, trusted, and effective.

Methodology

NCLCA wanted to ask a diverse group of people from North Central London (NCL) to join them in these focus group discussions. With support from the Patient Partnership and Experience of Care Manager at NCLCA, an advert (see supplementary item 1) for the event was posted on NHS public groups and participants asked to complete an online questionnaire (which included demographic questions and questions about digital confidence - see supplementary item 2) to register for the event. Of the 70 people who registered – a final 10 were selected. Selection criteria included North Central London residency declaration and diversity of demographic characteristics (e.g. ethnicity, age etc) and digital confidence.

Two virtual focus groups were conducted – on the 24 March 2026 and 28 April 2026 – with the aim to have the same group of participants in both groups. The first focus group aimed to explore definitions an understanding terms in this topic (see supplementary item 3). The second focus group was then building on this preparatory work so theme around care pathways, communication and user implementation outcomes could be explored. The implementation outcomes were captured using validated questionnaires that asked about – acceptability, appropriateness and feasibility (see supplementary item S7 – Implementation questions).

The focus groups were run using facilitated discussion (AB and FM), scenario-based exploration, and supported by Mentimeter polling for completing questionnaires. Sessions were recorded so they could be analysed easily.

The qualitative findings were analysed using thematic analysis. Transcripts and note were read, and themes were drawn inductively till saturation was reached.

The quantitative data from the Mentimeter surveys were analysed using basic descriptive statistics.

Sessions and participants

Demographic summary:

Total participants: 8. Groups: Group 1 (2 participants), Both sessions (6 participants)

Geographic coverage: Barnet, Camden, Enfield, Haringey (North Central London)

Ethnically diverse group (Asian, White, Black, Mixed backgrounds), with a mix of working, retired, and other life situations. 2 participants identified as having a disability.

Age group	Number
25–34	4
35–44	2
55–64	2
Ethnic group	**Number**
Asian or Asian British	2
White	2
Black / Black British / Caribbean / African	2
Mixed / Multiple ethnic groups	2
Gender	**Number**
Woman	3
Man	4
Non-binary	1
Status	**Number**
Working	5
Retired	1
Unable to work	1
Looking after home/family	1

For more detailed demographics see supplementary item S5.

Digital confidence, AI understanding and NHS data use:

A diverse and digitally confident group, with varying understanding of AI and NHS data use — providing valuable, realistic public perspectives on AI-based risk prediction tools. For a detailed breakdown please see supplementary item S6.

The questions

The full deck of questions can be found in supplementary items S3, S4 and S7.

The following are some examples of key questions that were asked:

Where do you think this tool should be used? (e.g. at your GP practice? In hospitals?)
Who should run the tool?
How should the NHS be contacting these people?
How should follow-up be handled so it does not cause unnecessary anxiety?
How comfortable did you feel about this early cancer detection tool?
Tool seems suitable.
Tool seems implementable.

Participation and validity considerations

Participation levels varied significantly, with a small number of individuals contributing most of the discussion. Some participants spoke minimally or not at all. There were also indications that at least one contribution may have been AI-generated. These factors introduce limitations regarding representativeness and authenticity.

Results

Qualitative results

	Theme	Findings
1	Strong Support for Earlier Cancer Detection	Participant linked early detection to better outcomes and saw this as both symptom recognition and preventative approaches. *Participant SS: 'And for me, early detection really means early intervention, which means longer survival or fulfilling survival.'*
2	AI Seen as a Support Tool, not a Replacement	AI should assist decision making, not replace it. The human roles are important to ensure context, judgement and empathy. *Participant JS: 'I don't see AI replacing people… there's still judgement, context and empathy.'* *Participant LG: '. While the final decision should actually come from a real person, because I wouldn't want AI making final decisions for me, because at some point it might be wrong.'*
3	Conditional Trust in AI	Trust in AI tools was conditional, not automatic, and depended on governance (regulation), transparency (how is risk calculated), and human involvement. *Participant SS: 'If there are no checks put in… information may not be 100% accurate.'*
4	Communication of Risk is Central	Risk communication is a key part of the acceptability of this service. Preferences included initial contact via SMS/NHS App (seen more trustworthy and less anxiety provoking than phone call). Follow up – human interaction is essential. Communication that explained why they were flagged and what happens next was key. - with the phrase 'at risk' preferred to high risk/increased risk. *Participant KH: 'yes, it should be recommended that you speak to somebody first. Or if you want to speak to somebody, then there is going to definitely going to be somebody available for you to speak to. So a person to speak to should also be recommended maybe when you are being notified.'*
5	Importance of Clear and Clinician led pathways	Participants preferred models where AI outputs were embedded into trusted clinical pathways such as hospital or GP settings. They wanted clear next step from the tool identifying them and wanted things to be straight forward. *Participant LG: 'Then I would also want the actual explanation. It should be from a real person, like my GP. Hearing it directly from a doctor would make me feel like more reassured and able to ask questions instead of like trying to understand everything from a message or later.'*
6	Digital confidence and AI understanding were not the same	While participants were digitally confident – their understanding of AI varied. Some were highly familiar and others needed more explanation. *Participant KS: 'AI is a digital tool that helps with automation and helps to execute algorithms faster and more efficiently.'*
7	Equity and Inclusion Concerns	Participants were concerned about fairness and inclusivity in AI implementation. *Participant JS: 'the data and systems behind it. If not used carefully, it can miss people or worse, reinforce inequalities. So it's just a powerful assistance and it should be used carefully.'*

Quantitative results

Domain	Question	Scoring 1=Lowest 5=Highest	N	Mean
Acceptability	How comfortable did you feel about this early cancer detection tool?	1-5	6	4.33
Acceptability	How much effort do you think it will take to engage with this tool?	1-5	6	3.17
Acceptability	There are moral or ethical consequences for people engaging with this tool	1-5	6	3
Acceptability	The tool COULD improve outcomes for people (i.e. pick cancer up early and earlier treatment)	1-5	6	4.33
Acceptability	It is clear to me how the tool will help improve my detection of cancer earlier	1-5	6	4.17
Appropriateness	Tool seems fitting.	1-5	6	3.67
Appropriateness	Tool seems suitable.	1-5	6	4
Appropriateness	Tool seems applicable.	1-5	6	4.17
Appropriateness	Tool seems like a good match.	1-5	6	4.17
Feasibility	Tool seems implementable.	1-5	6	4.5
Feasibility	Tool seems possible.	1-5	6	4.33
Feasibility	Tool seems doable.	1-5	6	4.33
Feasibility	Tool seems easy to use.	1-5	6	4.83

Scoring was high across all 3 implementation outcomes. Acceptability showed highest scores in comfort and improvement of outcomes, with mixed views on effort. Appropriateness showed highest scores for suitability and applicability. Feasibility was high across all measures. - with ease of use of tool at the highest end.

Discussion

Overall

The project explored public perspective on the use of AIRS tools to support earlier detection of cancer in the NHS. It combined qualitative and quantitative insights. Overall, the participants were supportive of this concept, but it was conditional on how the tool is governed and implemented with specific attention to communication and pathway management.

Comparison with existing literature

Consistent with prior research, participants in these focus groups demonstrated **overall support for the use of AI in healthcare, particularly when framed around clear patient benefit such as earlier cancer detection.** This aligns with findings from a large cross-sectional survey (n = 408), where the majority of respondents supported the use of AI for healthcare research and imaging, provided that privacy, consent, and data governance concerns were addressed (87.4% and 86.4%, respectively) (JMIR, 2021)[i]. In this study, participants also reported high perceived benefit (mean = 4.33), alongside strong qualitative support for earlier detection improving outcomes. Furthermore, an analysis from the Health Foundation (2025, survey n=8000 (public)) found public attitudes AI in healthcare was positive[ii]. Collectively, this reinforces that public support for AI in healthcare is high when its purpose is clear and beneficial, but remains contingent on trust, transparency, and robust governance.

Participants in this study showed a clear **preference for NHS-led data use,** alongside concerns about external or commercial involvement. This closely reflects findings from the JMIR (2021)[iii] study, which demonstrated higher levels of trust in public institutions compared to commercial organisations. These findings highlight the importance of institutional trust and suggest that acceptability is influenced not only by what data are used, but by who is using them. Both this study and existing literature emphasise the need to move beyond passive transparency towards active patient involvement, including consultation, co-design, and meaningful choices such as opt-in or opt-out mechanisms.

Variable understanding of AI was observed, despite generally high digital confidence among participants. AI was commonly described as a “support tool”, but uncertainty remained about how it operates in practice. This mirrors findings from the JMIR (2023)[iv] qualitative study on risk prediction, where patients demonstrated diverse and often limited conceptualisations of AI, alongside a need for simple, non-technical explanations and real-world examples. Together, these findings underscore the importance of accessible communication to support informed engagement with AI-enabled tools.

The role of human oversight emerged as a central concern. Participants consistently emphasised that **AI should not replace clinicians, but rather act as a decision-support** tool, particularly given concerns around accuracy and the risk of missed diagnoses. This is supported by research in breast screening (BMJ Public Health, 2024)[v], which identified similar concerns about errors, the potential for “things being missed,” and the continued importance of human involvement. Across both this study and the literature[vi], acceptability appears to increase when AI is clearly positioned as augmenting, rather than replacing, clinical judgement.

Finally, **communication of risk** and its emotional impact were key considerations. Participants highlighted the importance of using balanced, non-alarming language,

providing clear next steps, and ensuring access to human support. While not always emphasised in quantitative studies, this aligns with broader findings in AI and shared decision-making research (JMIR, 2023)[vii], which demonstrate that understanding and communication directly influence acceptance. These findings suggest that the success of AI tools is not determined solely by their technical performance, but also by how information is communicated and experienced by patients.

Conclusions and recommendations

Participants are broadly supportive of AI-enabled risk prediction for earlier cancer detection, viewing it as beneficial, feasible, and appropriate for NHS use. However, this support is conditional on the tool being implemented in a transparent, clinically supervised, and patient-centred way with detail to communication.

Key tensions identified:

- High perceived benefit vs ethical uncertainty
- High feasibility vs unclear patient pathways
- General trust in NHS vs concerns about data use and AI decision-making

These findings suggest that successful implementation will require:

1. **Clear communication strategies - what the tool does, why someone is flagged, what happens next**
2. **Strong clinical oversight - AI as decision support, not replacement**
3. **Transparent data governance - who uses data, how, and why**
4. **Patient centred pathway - clear next steps, access to human support**
5. **Equity focused design - accessible for all population groups**

SUPPLEMENTARY

Link to supplementary information for the PPIE report

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[i] https://www.jmir.org/2021/8/e26162/
[ii] https://www.health.org.uk/reports-and-analysis/analysis/attitudes-to-technology-and-ai-in-health-care
[iii] https://www.jmir.org/2023/1/e43632/
[iv] https://www.jmir.org/2023/1/e43632/
[v] https://bmjpublichealth.bmj.com/content/2/2/e000892
[vi] https://www.health.org.uk/reports-and-analysis/analysis/attitudes-to-technology-and-ai-in-health-care
[vii] https://www.jmir.org/2023/1/e43632/