Written evidence from Centre for Cancer Screening, Prevention and Early Diagnosis Wolfson Institute of Population Health, Queen Mary University of London (PMA0110)

This submission is drawn from our expertise and experiences as senior academics in QMUL's Centre for Cancer Screening, Prevention and Early Diagnosis.

We have some concerns about the framing of the questions (e.g. 'What needs to be done in order to encourage uptake of personalised medicine in the NHS and provide a service that puts patient needs first?') as these have implicit assumptions about patient needs and values, but clearly not all health professionals or patients would consider AI, genomics or personalised medicine to be top healthcare priorities. Therefore, we emphasise the crucial importance of understanding patient and provider perspectives.

We have focused on three key topics: Moving towards preventative medicine, Health Data Infrastructure, and Deployment in Practice.

1. Moving towards preventative medicine

We fully support this strategy and are conducting a wide range of studies around cancer prevention, screening and early diagnosis.

1.1 ***To maximise precision prevention, a new mechanism and model to deliver genomics at scale is needed.*** We are building such a model: an end-to-end digital scalable strategy and model for large scale genetic testing upon cancer diagnosis and in unselected unaffected population for personalised cancer risk prediction based on moderate- to high-penetrance genes along with other risk factors and polygenic risk scores for breast and ovarian cancer. This is direct to patient (at home), uses end-to-end digital technology, is saliva-based, and feeds into the NHS infrastructure/system but is parallel to it so as not to overload an already busy system (see DETECT-2[1] and PROTECT-C[2] studies). Existing validated tools such as CanRisk and Tyrer-Cuzick can be used in such a personalised risk prediction strategy. Ongoing research is further developing this approach for other cancers e.g. endometrial and colorectal.

[1] https://www.detect-2.co.uk/
[2] https://www.protect-c.co.uk/

1.2 ***It takes too long for evidence to change NHS practice due to systemic barriers***. The time taken from generating the evidence base including the economic analysis (demonstrating cost-effectiveness) to implementing policy change and then changing NHS practice is too long. The barriers faced include: resistance to change from entrenched stakeholders who are stuck in 'Business As Usual' frameworks; lack of NHS/health-system mechanisms to enable this; lack of NHS and Integrated Care Board (ICB) funding; lack of provider (NHS trust) support; lack of NHS implementation even after NICE recommendation.

1.3 ***Example 1: NHS Jewish BRCA programme***[3]. It took 10 years to publish research outcomes and another 8 years to get to programme implementation negotiating several barriers. A sustainable funding mechanism is still a work in progress. The NHS Genomic Test Directory have still not changed their criteria despite NICE recommendation.

1.4 ***Example 2: New NICE Guideline NG241***[4] ***'Ovarian cancer: identifying and managing familial and genetic risk'***. NHS implementation barriers exist for personalised prevention, which our team have shown is cost-effective. The NICE guideline recommends genetic testing in high prevalence populations and considering ovarian cancer surveillance in BRCA/high risk populations using the ROCA or AI algorithm (based on UK ovarian cancer screening trials[5]). However, there remains resistance from NHS Trusts to implement. Furthermore, NICE recommends lowering genetic testing thresholds to first degree relatives of ovarian cancer patients, but this has not been implemented due to barriers to change in genetics/genomic test directory and lack of funding to support.

1.5 ***Example 3: Lack of dedicated NHS funding***. Prevention delivers long term outcomes and benefit, but providers get no credit or incentivisation to support prevention. For example, there is no NHS reference cost code for most prevention and genomics-enabled early diagnosis and prevention.

1.6 ***Funding needs to flow beyond genetic services.*** NHS funding is currently focussed on genetics services alone, but it needs to flow across care delivery pathways, stakeholders and all

[3] https://jewishbrca.org/
[4] https://www.nice.org.uk/guidance/ng241
[5] https://www.thelancet.com/article/S0140-6736(21)00731-5/fulltext

NHS health professional caregivers outside the genetics services. For example, cancer clinicians and generalists delivering preventive oncology interventions (surveillance, medical and surgical prevention) and those managing long-term health consequences (e.g. menopause) also need to also be involved in agenda setting, policy formulation and receive funding for these services.

1.7 ***Inequalities.*** We are concerned that the issues outlined above may lead to widening health inequalities and likely postcode lottery in prevention medicine. Research is recommended to ensure careful implementation to reduce this likelihood.

1.8 ***Precision Prevention hubs.*** We recommend the setting up of Precision Prevention hubs for delivering high quality precision prevention across the NHS; these should include multidisciplinary and multiple diseases/phenotypes. These would need new infrastructural resource and capacity. They would also need more cost-efficient genetic testing lab infrastructure at scale.

2. Health Data Infrastructure

2.1 Health data are fragmented, delayed, inconsistently coded, and difficult to access. The lack of usable NHS data infrastructure is a major problem. AI may already be able to support personalised medicine through risk prediction and patient stratification when longitudinal electronic health records, screening, imaging, and outcome data are linked. In practice, data are fragmented, delayed, inconsistently coded, and difficult to access. This makes both model development and external validation much harder than they should be.

2.2 **Example:** Currently, results from the NHS colorectal cancer screening programme[6] FIT test may not be available for their GP if a patient then develops symptoms.

2.3 Access to robust, privacy-preserving methods for accessing and analysing free-text data should be prioritised. To maximise the potential of health data for personalised medicine, we need to move beyond reliance on coded, structured data. A substantial

[6] https://www.nhs.uk/tests-and-treatments/bowel-cancer-screening/

proportion of clinically relevant information—often cited as the majority—exists in unstructured free-text records, which remain largely inaccessible for research use in the UK. In contrast, some other countries have developed approaches to enable secure use of such data. Investment in infrastructure should therefore include robust, privacy-preserving methods for accessing and analysing free-text data, including development of de-identification pipelines and secure, federated data environments. This would enable more complete, clinically meaningful datasets for AI development while maintaining public trust and data security.

2.4 Supporting the portability and deployment of AI models is also important. Currently, it can be challenging to move models beyond secure data environments ('safe havens') due to privacy, governance, and information governance constraints. Investment in infrastructure that enables models to be trained, validated, and safely deployed across settings—such as federated learning frameworks and secure model evaluation environments—would support wider translation of research into clinical practice while maintaining data security.

2.5 AI tools need testing within existing NHS clinical systems. More support is needed for real-world validation and implementation of AI tools, rather than the current focus on developing new algorithms. We are clear than Government should focus on enabling testing of AI tools within actual NHS workflows, integrated into existing clinical systems, and monitored after deployment.

2.6 Workforce issues. The NHS and universities rapidly need more people who understand both clinical questions and modern data science. This expertise is frequently lost to commercial companies. Therefore, we need protected funding to grow and retain this expertise, as well as sufficient workforce to facilitate prompt access to approved data requests. For example, timely access to linked cancer screening data remains an issue (see National Cancer Registration and Analysis Service NCRAS[7].

2.7 Clinical academics. We are also concerned about funding for the development and retention of clinical academics with expertise in data science particularly those working with large primary care and linked datasets. For example, academic General Practitioners (GPs) represent a significantly smaller portion of their workforce compared to academic

[7] https://digital.nhs.uk/ndrs/about/ncras

hospital doctors. A 2025 report indicated that academic GPs make up just 0.05% of the total GP workforce (and an even smaller proportion have data skills), while approximately 3% of hospital doctors hold academic roles[8].

3 Deployment in Practice

3.1 A key barrier to the deployment of AI in the NHS is the lack of integration with frontline clinical systems. Many AI tools are developed and validated in research environments but fail to translate into practice because they are not embedded within the electronic health record systems used by clinicians (in UK primary care the key examples are EMIS and TPP). For AI to be adopted at scale it must be seamlessly integrated into clinical workflows, with outputs presented at the point of care in a usable and actionable format. This requires early and sustained engagement with system providers, alongside investment in interoperable infrastructure and clear pathways for deployment within existing clinical systems.

3.2 Recommendations for design and implementation of Clinical Decision Support Systems (CDSS) for early detection in primary care. Our recently published large systematic review makes relevant recommendations for commissioners and policymakers, for design and development teams, and for primary care teams[9]. Key aspects for any innovation for use in the NHS would be those regarding:

- Integration with electronic health records and IT
- Aligning with current practice and complex workflows
- Engaging stakeholders early and throughout developmental process
- Actively address patient and provider concerns
- Specify and deliver a collaborative strategy to incorporate sustainable digital solutions in healthcare systems, including governance and quality control mechanisms
- Provide guidance on use of evidence-based innovations in clinical guidelines to endorse use
- Clarify liability and medicolegal practice prior to implementation (e.g., non-adherence, algorithm and human errors)

[8] https://doi.org/10.3399/BJGP.2025.0089
[9] https://www.candetect.org/wp-content/uploads/2025/08/Recommendations-for-the-Implementation-of-CDSS.pdf

- Provide adequate funding for staff and the development, integration, and maintenance of innovation and functioning IT systems.

We would be happy to expand on any of the above, or to provide additional clarification if requested.

26th April 2026