BCS' Response to the House of Lords Inquiry into Personalised Medicine and AI

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Executive Summary

For this Inquiry: BCS convened a panel of clinicians, digital leaders and senior NHS managers from its Faculty of Health and Care, including individuals actively leading AI adoption. They selected four questions from the consultation – 3, 5,6,8 – that covered areas their expertise.

1) **Health Data Infrastructure and Governance** - The BCS panel identified a significant gap between the ambitions for personalised medicine and AI and the reality of NHS data infrastructure. Progress is hindered by fragmented data repositories, inconsistent standards, opaque access arrangements and under investment in foundational digital systems. Genomic data remains largely siloed within research settings and is difficult to link with routine NHS records at scale. Lengthy, duplicative information governance processes further delay research and innovation, disproportionately disadvantaging smaller organisations and clinicians. The panel concluded that a nationally coherent framework for secure data access, reuse and interoperability is essential. Public trust is weakened less by data use itself than by poor communication and lack of transparency about how data is used and governed.

2) **Translating Innovation into Routine NHS Care** - BCS's evidence highlights that the NHS does not lack innovation, but lacks deployable systems. While AI and personalised medicine technologies are advancing rapidly, their adoption into routine care is slowed by misaligned incentives, fragmented procurement, legacy IT infrastructure and unclear evidence standards for deployment. Innovation is often confined to pilots with no clear route to scale, leading to duplication and wasted effort. Workforce pressures exacerbate these challenges, with limited capacity and incentives for clinicians and academics to focus on implementation rather than discovery. The panel emphasised the need for nationally agreed deployment frameworks, clearer ownership of innovation, and funding models that support implementation at scale rather than isolated pilots.

3) **Regulators' role** - In its response to the recent MHRA consultation, the panel supported a proportionate, lifecycle based regulatory approach that enables earlier patient access while strengthening post deployment oversight. Current regulatory frameworks are seen as overly focused on pre market approval and insufficiently equipped to manage adaptive, data driven technologies once deployed. BCS does not advocate lowering standards, but rather reallocating assurance effort across the technology lifecycle, with robust post market surveillance for safety, bias and performance drift. Stronger alignment between the MHRA, NICE and NHS adoption processes, alongside sustained investment in regulatory capability, is essential to maintain public trust and patient safety while enabling innovation.

4) **National Leadership and Governance of Innovation** - The evidence suggests that ownership and governance of innovation within the NHS are fragmented and unclear. Responsibility is dispersed across multiple national bodies, with no single organisation accountable for translation from research to patient benefit. This fragmentation slows adoption, increases inequalities between trusts and undermines system wide value. Target driven national strategies were viewed as poor tools for sustained innovation, encouraging short term delivery over long term system design. BCS recommends clearer national leadership, defined ownership of translational pathways, sustained investment in Health Innovation Networks, and meaningful patient participation in the design and governance of innovation.

5) Overall conclusion -The UK has world class assets in genomics, AI and health research, but without stronger national leadership, coherent data governance, deployable digital infrastructure and aligned incentives, the benefits of personalised medicine and AI will remain uneven and slow to reach patients

Inquiry Questions:

Q3 Personalised medicine depends on large-scale genomic and health data being accessible and linked together. What further research infrastructure, in terms of data accessibility, compute, etc., is needed to support the development of personalised medicine and AI? Where are the gaps in current provision? How should the Government help ensure that its health data infrastructure is fit to deliver on this promise?

3.i) Access to Data at Scale: Fragmentation and Bureaucratic Friction:

The panel identified a fundamental gap between the ambitions for personalised medicine and AI and the present capabilities of NHS data, infrastructure, and governance. Progress is currently hindered by fragmentation, opacity, underinvestment, and insufficient incentives or accountability across the system.

Personalised medicine and AI rely on population-level, longitudinal datasets that link genomic information with routine health records across primary, secondary and tertiary care.

However, they felt the current access arrangements fell short due to:

1. Genomic data is largely research-centred, with organisations such as Genomics England holding data from specific cohorts. This does not enable seamless access to representative national datasets.
2. The reorganisation into regional Genomic Laboratory Hubs has led to some fragmentation of data, with tests often processed outside local areas and data dispersed across systems, making aggregation difficult.
3. Attempting to link genomic data with routine NHS records requires navigating numerous organisations, inconsistent data standards, and prolonged approval processes, often adding significant time to research or innovation timelines.
4. The system's opacity and bureaucracy hinder innovation. A nationally coherent, joined-up approach to secure data is required.

3.ii) Interoperability: Despite policy focus, interoperability is poorly understood and inadequately addressed in practice.

1. Interoperability is often seen as adopting technical standards, but data must also suit end-user processes and decisions.
2. There is insufficient understanding of workflows, leading to data transfers without clarity about their use or interpretation.
3. System inventories within organisations are incomplete, making it difficult to know what systems exist, how they interact or what data they hold.
4. The NHS struggles to move beyond local integrations to achieve genuine, system-wide interoperability for AI-driven insights and personalised interventions.

3.iii) Digital and IT Infrastructure: The panel felt the NHS's digital infrastructure is a major barrier to the deployment of personalised medicine and AI.

1. NHS IT environments are poorly characterised, with limited central visibility of systems, data flows or dependencies.
2. IT investments often fall short, covering neither basic needs nor advanced analytics or AI.
3. Systems within clinical or research teams are sometimes better managed than central IT, revealing governance and knowledge management weaknesses.
4. AI (artificial intelligence) may help surface and rationalise this complexity, but the panel cautioned that AI cannot compensate for a lack of baseline digital systems (foundational infrastructure), proper documentation of data systems, and high-quality data.

3.iv) Information Governance (IG) emerged as one of the most persistent barriers for researchers and innovators. Information Governance (IG) refers to the policies and processes that ensure data is handled legally and securely:

1. IG approval processes are often duplicative, opaque and slow, with no single body accountable for decision-making.
2. Different organisations apply inconsistent interpretations of risk and compliance, leading to repeated negotiations for effectively the same permissions.
3. There is no clear national policy on whether permissions should be standardised upfront or accessed through a well-defined, responsive process.
4. In this environment, smaller organisations, clinicians, and academics are disproportionately disadvantaged, and responsible data use is discouraged rather than enabled.

3.v) Public Trust, Data Use and Partnerships

1. The panel felt public concern is driven more by confusion and lack of clarity than by outright opposition.
2. Patients are often unclear about how their data is used, particularly the distinction between:
    - Direct care (using data to treat an individual patient)
    - Indirect or secondary uses (research, service planning, AI development).
3. There is significant confusion around digital initiatives, including the NHS App, its purpose, and how it fits with existing services.
   Implication: Trust is weakened not by data use per se, but by poor communication, mixed messages and a perceived lack of transparency.

Examples of such public engagement include:

1. An initiative in Greater Manchester, which has included Citizens' panels, visible project listings, and feedback mechanisms to help normalise data use.
2. Another is the collaboration with Flat Iron, a data curation company in Leeds. Oncology patients were asked by a health trust for permission to share their data, and there was only 3% pushback following public engagement.

Implication: Objections are often preventable through better explanation, better data quality, and respectful communication.

3.vi) Data accuracy, validation, and partnerships

The panel felt that industrial partnerships are acceptable if well governed and clearly justified. Their view was that partnerships with private sector organisations were not inherently objectionable to the public, provided that the purpose was clearly explained, safeguards were in place, and patients retained the ability to opt out.

However, the nature of such partnerships raises important considerations:

1. Data controllership and accountability must be explicit. Unclear lines of data controllership, particularly between primary care, NHS bodies and third-party partners, undermine confidence.
2. Commercial reuse of curated datasets needs clear boundaries and public accountability.
3. Patients need to know who is responsible for their data, who can access it and who benefits from its use.
4. Current data protection protocols and partnerships can be appropriate, but require clearer accountability, better communication and stronger public participation to succeed.
5. Overly technical or legalistic framing fails to reassure.
6. Implication: The issue is not whether partnerships exist, but how transparently they are structured, governed and communicated.

Recommendations for Government Action.

Without addressing these foundational issues, the promise of personalised medicine and AI could, potentially, remain theoretical rather than operational.
Taken together, the panel’s evidence suggests that the Government must move beyond isolated initiatives and address structural, systemic reform, including:

1. Investment and incentives need to be aligned to long-term system value, not just immediate organisational need.
2. This includes having a structured plan to address basic issues, such as a lack of foundational IT infrastructure, documentation, and data quality.
3. A coherent national framework is needed for data access and data reuse, balancing scale with appropriate local autonomy.
4. Clear ownership and accountability for information governance decisions, with stronger national standards and contractual requirements for interoperability
5. Continuous, genuine and accountable engagement with the public, clinicians and researchers around data collection and use.

Q5 Translating cutting-edge medical science into routine NHS treatment has long been recognised as a problem. Considering personalised medicine and AI as an example, what are the key systemic barriers, such as procurement processes, workforce, or IT infrastructure, that prevent or delay the deployment of proven innovations across the NHS? Which of these barriers are the most important in practice?

5.i) Supporting innovation and its deployment is key.

Our panel's view is that translating personalised medicine and AI from proven innovation into routine NHS care remains difficult despite strong scientific progress. Our experts highlight that the challenge is not discovery, but deployment: regulation, evidence, infrastructure, and operational clarity have failed to keep pace with technological development. As one of our experts noted: "AI's almost taken over the market and is dictating pace… we're trying to do a catch-up game."

Key points:

1. The main systemic issue was how to structure an approach to innovation beyond the remit of individual organisations.
2. Barriers exist at almost every stage along the innovation pipeline. An example was given of academics at universities who carry out research, publish it, but find there are few incentives within the health care system to engage with it.
3. Long-term analysis of investment returns in the NHS is lacking, as is guidance on partnering with the private sector to improve the deployment of innovations.
4. When it comes to evidence and evaluation, it was felt that there is a reliance on anecdotal rather than robust, generalisable evidence, and that there is no agreed standard for "what counts as evidence" for deployment readiness.

5.ii) Procurement, Contracting and Incentives: Misaligned System Drivers:

A recurring theme, the panel thoughts, was the misalignment between local purchasing decisions and the system-wide value of data.

1. NHS organisations procure IT primarily to deliver immediate clinical care, with little consideration of secondary data use, interoperability or long-term use.
2. Current funding and incentive structures do not reward organisations for investing in innovation, data quality, interoperability, or future-proof systems.
3. Contracts for digital systems frequently lack clear requirements for Application Programming Interfaces (APIs), connectivity, data access and standards compliance, leading to entrenched vendor lock-in and poor data flows.
4. The benefits of high-quality data infrastructure often accrue at the regional or national level, while the costs are borne locally, creating a disincentive to invest.

5. Without stronger national standards and incentives, organisations will continue to optimise for short-term cost and expediency, undermining the data foundations required for AI and personalised medicine.

5.iii) Regulation and assurance

1. Regulation is inconsistent, fragmented, and reactive rather than anticipatory.
2. Clinical safety, liability, data governance and post-deployment monitoring are not fully thought through, leaving organisations uncertain and risk-averse.

An example: The current self-declaration registry approach for Ambient Voice Technology (AVT) places the burden of assurance on suppliers and local organisations rather than establishing a clear national regulatory framework.

5.iv) IT infrastructure: see answer 3.ii above. Further points include:

1. Unclear integration with core systems (EPRs, GP systems, FDP) remains a major barrier.
2. Legacy infrastructure and variation across trusts undermine adoption.

5.v) Workforce and capability:

1. Clinicians and managers lack time, training, and capacity to lead implementation.
2. Digital, data, and clinical safety expertise is scarce and unevenly distributed.
3. Workforce pressure is a major but not the sole factor. Clinical academics are central to generating evidence, building confidence and translating research into pathways.
4. However, they are overstretched and often working outside reward and promotion structures that value deployment work.
5. Frontline clinicians face operational pressures that limit their engagement with innovation.

5.vi) Why have previous attempts not succeeded, and what would be effective?

1. Over-reliance on pilots without a clear route to scale or system-wide adoption.
2. Fragmentation: innovation spread thinly across ICSs, trusts, and programmes.
3. Tech-led rather than service-led approaches: vendors move faster than NHS governance.
4. Regulatory ambiguity leads to local caution and duplication of effort.

5 vii) What would be effective?

1. Nationally agreed deployment frameworks that go beyond procurement lists to include: clinical safety standards; integration requirements; post-market surveillance.
2. Clear ownership at the national level for AI deployment policy, not just policy statements
3. Alignment between NHS England, regulators, Health Innovation Networks, and Royal Colleges on evidence standards.

5 viii) Examples of good practice and how they could be scaled

1. Greater Manchester precision medicine programmes, integrating genomics, data, and clinical pathways at scale.
2. Chelsea and Westminster pilot using the Federated Data Platform, demonstrating a structured, if challenging, approach to evaluation.
3. Health Innovation Networks act as translation intermediaries, bringing together academia, industry, and delivery.

What would need to happen to scale them?

1. Mandated routes to spread successful pilots across ICSs.
2. Dedicated implementation funding, not just innovation funding.
3. Shared learning platforms so that evidence, failure, and operational insight are reusable.
4. Earlier engagement of regulators and clinical safety groups in pilots, not retrospectively.

5 ix.) What needs to be done in order to encourage uptake of personalised medicine in the NHS and provide a service that puts patients first?

From a patient perspective, uptake depends on trust, clarity, and benefit. Our panel believes the following needs to happen:

1. Transparency: Clear explanation of how AI and personalised medicine are used, including risks and safeguards.
2. Demonstrable benefit: Evidence that innovations save time, improve outcomes, or improve patient experience.
3. Equity: Avoid creating “postcode lotteries” where access depends on local innovation maturity.

4. Co-design: Patients are involved in the design, evaluation, and governance of new tools. A patient-centred service requires moving from “can we deploy this technology?” to “does this meaningfully improve patient care and experience?”

5. Recommendations.

The NHS does not lack innovation; it lacks deployable systems. As the discussion between our experts makes clear, AI and personalised medicine have outpaced regulation, infrastructure, and evidence frameworks. The most important levers for change are:

1. Clear regulation
2. Confident deployment pathways, including patient engagement
3. Workforce capacity focused on implementation rather than pilot activity.
4. Learning from places like Greater Manchester and embedding deployment expertise at the national level would turn innovation from exception into routine care.

Q6 How should the NHS and relevant regulators, including the Medicines and Healthcare products Regulatory Agency (MHRA) and the National Institute for Health and Care Excellence (NICE), as well as professional and clinical bodies, balance the need to evaluate new personalised and AI-driven treatments with making innovative treatments available to patients? To what extent is the regulatory framework around personalised medicine and AI appropriate and proportionate, and where could it be improved?

6.i) As we stated in our response to the MHRA’s National Commission into the Regulation of AI in Healthcare, BCS believes the NHS and regulators should move beyond viewing innovation and patient safety as competing objectives. Instead, they should adopt a lifecycle-based, proportionate regulatory approach that enables earlier access to safe innovation while strengthening oversight once technologies are deployed in real-world settings.

6.ii) Many personalised medicine and AI-driven technologies do not behave like traditional medical devices. They may adapt over time, depend on continuous data flows, or perform differently across patient populations and care settings. A regulatory framework designed primarily for static devices is therefore increasingly inadequate.

6.iii) BCS does not advocate lowering regulatory standards.
Rather, we recommend shifting assurance effort across the lifecycle, with, as per our previous answers: a proportionate pre-deployment evaluation; controlled real-world use within the NHS; and mandatory post-deployment monitoring for safety, bias, performance drift, and usability.

Earlier patient access should be conditional on clear accountability, transparency and continuous evidence generation, rather than reliant on one-off approvals that cannot reflect real-world performance.

6.iv) BCS' assessment is that the current framework for regulating personalised medicine and AI is not yet proportionate to either risk or benefit.
In particular, the MHRA framework:

1. Places excessive weight on pre-market approval relative to post-market assurance
2. Lacks clear, consistently applied expectations for clinical evidence for AI-enabled technologies.
3. Under specifies obligations for monitoring systems once deployed at scale in the NHS.

6.v) BCS does not call for wholesale legislative replacement.
Instead, we recommended targeted reform within existing medical device regulation to:

1. Explicitly recognise AI-driven and data-dependent software as a distinct regulatory category.
2. Align evidence requirements with the degree of clinical autonomy and risk.
3. Make post-market surveillance a core, enforceable regulatory requirement.
4. Greater alignment between MHRA approval, NICE evaluation and NHS adoption processes would further reduce delays and duplication once technologies have demonstrated value in practice.

6.vi) BCS recognises the MHRA's ambition to be a world-leading regulator of AI in healthcare. However, ambition must be matched by sustained investment in organisational capability.

Our evidence identified gaps in:

1. Specialist expertise in AI assurance, data science and human-computer interaction
2. The capacity to regulate adaptive and continuously learning systems
3. Resources and infrastructure for effective post-market surveillance at scale.

Without sufficient regulatory capacity, there is a risk that decision-making becomes either overly risk-averse, delaying patient benefit, or insufficiently informed, undermining safety and public confidence.

6.vii) Lessons from other regulatory regimes:
BCS emphasised the importance of international alignment and learning, particularly from:

1. The US FDA’s total product lifecycle approach to software as a medical device
2. International work through the International Medical Device Regulators Forum (IMDRF) on AI change management and real-world monitoring
3. Regulatory sandbox models that mature into predictable, routine regulatory pathways rather than remaining exceptional.

A key lesson is that regulatory agility depends as much on institutional capability and skills as on statutory powers.

6.vii) BCS considers the MHRA’s current framework for software and AI as a medical device to be partially effective but increasingly stretched by the pace of technological change.
Strengths of the current approach include:

1. A principles-based foundation
2. Avoidance of unnecessary “AI exceptionalism”
3. Recognition that software with a medical purpose should fall within medical device regulation.

6.viii) However, weaknesses remain, particularly in relation to:

1. Adaptive AI systems that do not fit well with existing change control and re-certification processes
2. Inconsistent interpretation of clinical evidence requirements
3. insufficiently specified and enforced post-market surveillance obligations

6.ix) BCS therefore recommended the formal adoption of a lifecycle-based regulatory model for AI-enabled and personalised digital health technologies, supported by:

1. Clear standards for monitoring bias, safety and performance drift
2. Stronger integration between regulation, professional guidance and NHS operational governance.

6. Recommendations.

From BCS’s perspective, in our response to the MHRA’s consultation, the central challenge is not balancing speed against safety, but replacing static regulatory models with dynamic oversight appropriate to modern personalised medicine and AI.

A proportionate, lifecycle-based framework, supported by sufficient MHRA capability and closer alignment with NICE and NHS decision-making, would enable innovative treatments to reach patients sooner while strengthening, rather than weakening, public trust.

Q8 Does the Government have the right structures in place to govern and oversee innovation in the NHS? Is it clear who has ownership of pushing research, innovation, and new technologies within the NHS?

8.i) The evidence suggests that governance and ownership of innovation within the NHS remain unclear and weakly coordinated, and may be deteriorating rather than improving in the short term.
One of our experts highlighted that the ongoing restructuring of NHS England into the Department of Health has created further opacity: "The understanding of new structures is still very, very vague and where this sort of responsibility lies within the new Department of Health."

8.ii) Rather than strengthening innovation governance, current efforts appear to be absorbed by organisational merger and restructuring, at the expense of defining:

1. Where accountability for innovation sits,
2. How innovation priorities are set,
3. How national programmes connect coherently to operational NHS delivery.

This points to a structural problem, not merely a lack of coordination: there is no clearly empowered body with both the mandate and resources to oversee the innovation pipeline end to end, from research through to adoption and scale.

8.iii) Ownership is fragmented across multiple bodies, with no single organisation responsible for ensuring translation into patient benefit
Another of our experts highlighted a deep structural gap between stages of innovation:

- MRC funding focuses on basic science
- The NHS is funded to support direct patient impact

Our panel felt the critical translational space in between is poorly owned and inadequately funded: "There's an awful lot that happens between those things that doesn't neatly fit within many of the medical funders."

This lack of ownership risks good research failing to become usable NHS innovation, particularly in complex areas such as AI, genomics, and advanced therapies.

8.iv) How effective are the links between Genomics England, NIHR/MRC, Catapults, and NHS patient care?
The links are conceptually strong but practically weak, constrained by:

1. Misaligned incentives.
2. Inconsistent business models and limited pathways into routine NHS care.

8.v) While initiatives such as Genomics England and the Cell and Gene Therapy Catapult generate world-leading innovation, participants highlighted that:

1. Innovations often depend on ad hoc local champions.
2. Adoption pathways vary significantly by trust.
3. Technologies developed in one part of the NHS are often sold back to the rest of the system at high cost.

Leads to:

1. Increases in overall NHS costs
2. The exacerbation of inequalities between large and smaller trusts,
3. It undermines the system-wide sustainability.
4. concerns that innovation remains too inward-looking, with insufficient focus on building solutions that can operate across global markets, limiting commercial scale and long-term investment.

8.vi) Are target-driven strategies (e.g. the National Cancer Plan) effective at driving innovation?

Participants were broadly sceptical about the effectiveness of target-driven national strategies in fostering sustained innovation. Participants noted that such strategies tend to:

1. Encourage short-term, reactive behaviour
2. Focus organisations on delivery against near-term metrics.
3. crowd out longer-term experimentation and system redesign
4. Frequent change in national strategies undermines confidence and alignment, discourages co-investment from industry and research partners, and weakens long-term innovation planning.

There was the feeling that.. “there is no sticking power … so there is no incentive for people to invest alongside them.”

Overall, while such plans may create focus, they were felt to be poor tools for driving durable innovation ecosystems.

8.vii) To what extent does fragmentation slow or uneven innovation adoption?

Fragmentation across trusts, Integrated Care Boards (ICBs), and national bodies is a major contributor to uneven and slow adoption.

Key issues highlighted include:

1. Variable digital and data maturity across trusts
2. Inconsistent procurement and contracting mechanisms

3. Duplication of pilots without pathways to scale
4. New suppliers are being introduced without improving system coherence.

One expert expressed concern that current procurement approaches, particularly in primary care IT, risk increasing fragmentation rather than resolving it.

8. Recommendations.

Are there realistic reforms that could address this?
The discussion pointed to several pragmatic reforms that could realistically improve innovation uptake:

1. Strong national coordination and clarity of accountability
   - A defined innovation leadership function within DHSC
   - Clear ownership of translational pathways
2. Sustained investment in Health Innovation Networks
   - Supporting them as brokers between the NHS, industry, and academia
   - Using them to standardise adoption and spread across systems
3. Reform of business models and commissioning
   - System-level investment rather than trust-by-trust purchasing
   - Avoiding internal market dynamics that inflate NHS to NHS costs
4. Place-based and cross-sector innovation
   - Treating systems as “sovereign local systems”
   - Integrating local authorities, economic partners, and non-health data
5. Meaningful patient participation
   - Involving patients in the design and prioritisation of innovation
   - Ensuring technologies address real clinical and population needs

Overall conclusion of BCS’ response

The evidence suggests that the UK has world-class innovation assets but insufficient governance, ownership, and system design to consistently translate them into NHS patient care. Without clearer national leadership, stable long-term strategies, and better system-wide investment models, it was felt that innovation would remain patchy, slow to scale, and unevenly distributed, despite strong research and industrial capabilities.

Who we are

BCS is the UK’s Chartered Institute for Information Technology. The purpose of BCS as defined by its Royal Charter is to promote and advance the education and practice of computing for the benefit of the public.

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