ROYAL STATISTICAL SOCIETY

DATA | EVIDENCE | DECISIONS

RSS EVIDENCE ON INNOVATION IN THE NHS: PERSONALISED MEDICINE AND AI

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1 Introduction

1.1.1 This is the Royal Statistical Society's (RSS) evidence to the Science and Technology Committee on Innovation in the NHS: personalised medicine and AI. The RSS is a membership organisation for statisticians and data scientists, and we advocate for the importance of statistics and data. Representing over 10,000 members, we champion the role of statistics and data in society and work to ensure that policy formulation and decision-making are informed by evidence for the public good. This involves advocating for a statistical system which delivers reliable and relevant statistics that help us better understand our society, and which underpin the effective delivery of essential public services.

1.1.2 Although the link between AI systems and statistics is not always recognised, statistical thinking is fundamental to the ethical and effective use of AI in a range of contexts.[1] Statistical methods help us to understand how AI systems work, evaluate their effectiveness, and interpret AI outputs.

1.1.3 AI models used in healthcare require rigorous and ongoing statistical evaluation to ensure that they are safe and effective. We believe that the UK has an opportunity to lead globally on AI evaluation, however this will require coordination and investment.

1.1.4 Improvements to data infrastructure, linkage and access are critical for health research and facilitating innovation in the NHS. The RSS has called for government departments to consider appointing dedicated data-sharing officers to drive improvements in data sharing across government, along with funded plans to strengthen the UK's statistical and data infrastructure. To improve linkage of health data, we recommend that the government explores using

[1] Royal Statistical Society (2026). 'AI is Statistics: Why statistical thinking is vital for the effective, ethical and safe use of AI', https://rss.org.uk/RSS/media/File-library/Policy/2026/AI-is-Statistics-FINAL.pdf

identifiers such as the NHS number in England and Wales to support record linkage while protecting patient privacy.

1.1.5 We believe that understanding and maintaining public trust in the government's use of personal data is essential to the effective functioning of an innovative national healthcare system, wider public services, and the UK's official statistics system. We recommend that the government adopt a coherent, cross-departmental approach to public engagement on use of personal data, alongside a programme of research to track public trust over time.

2 The role of AI in personalised medicine

2.1.1 Artificial intelligence systems are fundamentally statistical in nature; as a result, statistical thinking is essential for the safe, ethical and effective use of AI, particularly in high-stakes applications such as personalised medicine.

2.1.2 Statistical methods can provide the tools needed for effective AI evaluation. Evaluation must be proportionate and vary depending on the application of AI tools; different types of evaluation are required based on whether a product is intended to advise, recommend or decide.

2.1.3 With statistical evaluation, we can understand and communicate degrees of uncertainty in AI-generated outputs. Statistical approaches such as Bayesian models help quantify how confident a model truly is in its outputs. Statistical tests help quantify the significance of the distance between AI predictions and their expected values, and prediction intervals can communicate a range of plausible answers rather than a single definitive result. These are well established statistical principles; understanding how to apply them to models of the size and complexity of modern AI is essential if we want to apply AI tools in high-stakes environments.

2.1.4 Statistical evaluation allows different AI requirements, such as Security, Accuracy, Fairness and Explainability (SAFE), to be measured with consistent metrics, that can also be integrated in a single assessment score, and for which statistical tests can provide objective thresholds.

2.1.5 There is a clear parallel between today's urgent need to invest in AI evaluation methodologies and the situation in the early 1990s, when the UK recognised a similar gap in the evaluation of health technologies. At that time, many clinical trials were being funded, but there was no central body with the expertise to assess their cost-effectiveness and overall value. This led to

the creation of the NHS R&D Health Technology Assessment Programme, which successfully established a rigorous, coherent system for producing high-quality evidence on the impact of health technologies. That programme became a major success and helped position the UK as a global leader in healthcare evaluation. Given this strong track record, there is now a comparable opportunity to build world-leading capability in the evaluation of AI systems.

2.1.6 The need for this capability is clear. For example, in healthcare imaging, evaluation must check accuracy, generalisability, and the appropriate balance between sensitivity and specificity. First, the accuracy of the AI is critical, given the serious consequences of errors for patients; evaluation must therefore ensure that performance is at least at the level of human doctors. Second, models must be robust and generalise well. Medical images vary significantly, and evaluation must check whether systems perform reliably across different settings and populations. Third, evaluation must confirm that AIs strike a fair balance between sensitivity (detecting true positives) and specificity (avoiding false positives). If this balance is poorly calibrated, the system may either miss important cases or cause unnecessary anxiety for large numbers of patients.

2.1.7 The evaluation of AI capabilities must also review their explainability and interpretability. Most AI models are opaque (commonly called black box) and produce predictions or classifications which, while accurate, are not explainable in terms of why or how those conclusions were reached. When applied to medicine, AI outputs must also be interpretable, meaning that the underlying scientific theory or mechanisms should be clear.

2.1.8 AI models are often employed to generate synthetic data to develop ‘digital twins’, which are used to conduct experiments which are otherwise too costly or inefficient. Data generation and simulation must be conducted in a statistically sound manner, informed by established principles in statistical simulation and experimental design methods.

2.1.9 More broadly, evaluation must reflect the wider system in which an AI tool operates and must be able to adapt as models evolve over time. This cannot be achieved through one-off pre-deployment checks, which are too limited to capture how performance and risks change in real-world use.

3 Health data research infrastructure

3.1 Data Linkage

3.1.1 Government departments and the wider public sector hold extensive data about individuals; to make full and effective use of this data, it is essential to ensure that data is fit for purpose and that there is an effective system of data sharing among different parts of the public sector. More streamlined data sharing can improve service delivery by enabling a deeper understanding of a person's needs, support more informed decision-making by bringing together data from multiple sources and improve efficiency by reducing duplication of data sets in different parts of the public sector.

3.1.2 The RSS has recommended that government departments consider appointing dedicated data-sharing officers – analogous to, and working with, data protection officers – to help drive the cultural and organisational changes needed to improve data sharing, while still adhering to data governance processes. The RSS has also called for funded plans to strengthen the UK's statistical and data infrastructure, ensuring that the UK Statistics Authority and wider system are properly supported to make full use of enhanced data-sharing practices and emerging technologies.[2]

3.1.3 Personalised medicine depends on large scale genomic and health data being accessible and linked together. This must include sources such as adult social care and local authority public health offices, with which NHS services are closely linked. The RSS has long called for health data to be accessible and comparable across the range of UK health and social care services, and improved data sharing both within government and in terms of improved access to data.[3] Research access to data is crucial as it has the potential to identify issues that might not otherwise be picked up.

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[2] Royal Statistical Society (2024). 'Post-election briefing: Better data for informed, transparent decision-making', https://rss.org.uk/RSS/media/File-library/Policy/2024/01-RSS-policy-briefing-Data-sharing.pdf?ext=.pdf
[3] 'INQ000183421 – Witness Statement of Andrew Garrett, on behalf of the Royal Statistical Society', UK COVID-19 Inquiry (Module 1), https://covid19.public-inquiry.uk/documents/inq000183421-witness-statement-of-andrew-garrett-on-behalf-of-the-royal-statistical-society-dated-21-04-2023/

3.1.4 Record linkage – joining up data relating to an individual while maintaining confidentiality – is important when dealing with data from multiple sources. Identifying people by a number - such as the NHS number in England and Wales, the Health and Care Number in Northern Ireland, or Community Health Index (CHI) number in Scotland - is an effective way to do this. Expanding the use of such identifiers merits further exploration as a way of supporting record linkage while protecting privacy.

3.1.5 While Scotland and Wales are world leaders in data linkage, it remains challenging to access NHS data for statistical purposes in England. In part this is due to public concern about privacy, so it is important that this is handled in a way that is transparent and builds trust. But the challenges also reflect fragmented governance, institutional risk aversion and complex data sharing processes. All of these barriers need to be removed.

3.2 Public Trust

3.2.1 We believe that maintaining public trust in the government's handling of personal data is of paramount importance. A further decline in public trust around data use would likely reduce people's willingness to share their data and reduce the quality of the information they do provide.

3.2.2 It is important to recognise that loss of trust and issues with data provision are not equally spread amongst different groups in society. The result of this can be a decline in the representativeness of Official Statistics which seek to enhance public understanding and inform decision-making.

3.2.3 To foster public trust and public understanding, we believe there is a need for government to have a cohesive cross-department approach to engaging with the public about the different uses of their data, the safeguards in place for different types of data and the value of the

resulting usage. This is particularly important where data is shared with private, profit-making institutions, with whom people in the UK are less willing to share their personal data.[4]

3.2.4 There is a strong case for government to develop a cohesive, broad-based, and continuous survey programme to track public attitudes to the government's handling of personal data over time. Such a programme would make it possible to assess how different government initiatives affect levels of public trust and would also help identify the wider factors that shape variations in trust. This is particularly valuable given recent research which suggests that the UK is comparatively relatively low in its trust of AI companies handling personal data.[5] It is important that the findings of any such programme are published as Official Statistics.

4 Conclusion

4.1.1 Effective use of AI in healthcare depends on public trust, robust data infrastructure and governance, and rigorous evaluation. Statistical expertise must be engaged in the challenges of integrating AI safely into healthcare, and communicating concepts such as uncertainty and bias to the public.

4.1.2 We believe that a cross-government approach will be essential to realise the benefits of data and AI, through reducing the barriers to data sharing, coherent public engagement and investment.

[4] Hirst et al. (2023). 'Understanding public attitudes and willingness to share commercial data for health research: Survey study in the United Kingdom', *JMIR Public Health and Surveillance*, 9. https://doi.org/10.2196/40814
[5] Ipsos (2025). 'The Ipsos AI Monitor 2025', https://www.ipsos.com/sites/default/files/ct/publication/documents/2025-06/Ipsos-AI-Monitor-2025.pdf