

Our data-driven future in healthcare

People and partnerships at the heart of health related technologies

New data-driven technologies, powered by novel ways of linking and analysing patient data, are set to transform the way that health and social care is delivered as well as the ways in which we manage our own health.

Technologies such as wearable devices, mobile apps and intelligent monitoring devices that use machine learning, provide an opportunity for the NHS to harness the breadth and depth of patient data that it holds to support a healthier future for patients and the public.

The Academy of Medical Sciences has developed a set of principles designed to maximise the potential health benefits of new and emerging data-driven technologies. These principles reflect the values and expectations of patients, the public and healthcare professionals based on a programme of public dialogue carried out on behalf of the Academy by Ipsos MORI.

The principles are intended to guide the development, evaluation and deployment of data-driven technologies in health and social care, in ways that reflect the values and expectations of patients, the public and healthcare professionals. These views were explored through a dialogue programme carried out by Ipsos MORI on behalf of the Academy. Embedding these principles will be essential if we are to realise the anticipated benefits of these innovative technologies in health and social care whilst maintaining trust in their use. Central to this are meaningful partnerships with patients and the public and their health and care professionals.

What next?

Collaboration and coordination across multiple stakeholders are required to put these principles into practice and create a world-leading environment for the trusted development and use of data-driven technologies in health and social care.

This will demand:

- UK-wide improvements in the digital capabilities and competencies of NHS and social care systems and staff.
- A cultural shift within the NHS and across healthcare professionals that balances respect and protection of patient data with enabling data access. This will facilitate the development, evaluation and adoption of data-driven technologies that demonstrate health benefits.
- The development of robust evaluation mechanisms and an appropriate regulatory framework to guide the effective and safe deployment of these technologies.

Here 'patient data' means health-related information about patients that is created or used as part of their NHS care. It may also be linked to information they have collected themselves, or to information collected as part of their related social care.

Principles

<p>A. Purpose, value and benefits</p> 	<p>Data-driven technologies should be designed and used for clearly defined purposes that uphold the social values¹ of the NHS and benefit individuals, the NHS, or society.</p> <p><i>In doing so, they should</i></p> <ol style="list-style-type: none"> 1. Enable fair access to their benefits by all social groups. 2. Realise the value of patient data created as part of NHS care. 3. Not be used for direct marketing or similar commercial activities. <p><i>and, depending on their purpose, they should</i></p> <ol style="list-style-type: none"> 4. Preserve and enhance direct contact between healthcare professionals and patients. 5. Enable safe and effective health and social care. 6. Support people to manage their own health. 7. Enable research and innovation.
<p>B. Privacy and rights</p> 	<p>Data-driven technologies should be designed and used in ways and settings that respect and protect the privacy, rights and choices of patients and the public.</p> <p><i>Their design and use should</i></p> <ol style="list-style-type: none"> 1. Meet all ethical, regulatory and legal requirements. 2. Enable patients to know and decide when and where data about them are collected. 3. Be transparent about how, where, why, when, and by whom, patient data are collectively used and accessed. 4. Respect patient privacy and confidentiality. 5. Protect a person's right to choose to be in a state of less than optimal health. 6. Maintain rights to access health and social care and insurance. 7. Not discriminate unfairly based on genetic or other information.
<p>C. Public engagement and partnership</p> 	<p>Those determining the purpose and uses of data-driven technologies should include patients and the public as active partners.</p> <p><i>This means that patients and the public</i></p> <ol style="list-style-type: none"> 1. Are active partners in agreeing priorities for, and determining the acceptability of, data-driven technologies as part of an ongoing process. 2. Have easy access to clear information communicated in a way that raises awareness and understanding of these technologies.
<p>D. NHS data stewardship and responsibilities</p> 	<p>The NHS, and those acting on its behalf, should demonstrate their continued trustworthiness by ensuring responsible and effective stewardship of patient data and data-driven technologies in the NHS.</p> <p><i>They should</i></p> <ol style="list-style-type: none"> 1. Retain overall responsibility for where patient data and data-driven technologies are used. 2. Make sure those accessing patient data to develop data-driven technologies use it for agreed purposes (see A). 3. Ensure data access agreements are for defined purposes (see A), and set out how benefits will be shared fairly across the NHS. 4. Assure the consistency, accuracy and quality of patient data used by data-driven technologies. 5. Build skills and capacity in the NHS workforce to enable the use of data-driven technologies. 6. Introduce into the NHS data-driven technologies that have evidence about their effectiveness and safety, being clear about where responsibility lies for any harmful health or other consequences of their use.
<p>E. Evaluation and regulation</p> 	<p>Data-driven technologies should be evaluated and regulated in ways that build understanding, confidence and trust, and guide their use in the NHS.</p> <p><i>The use of data-driven technologies should be</i></p> <ol style="list-style-type: none"> 1. Supported by timely evidence on their benefits, accuracy, effectiveness, safety and security in line with regulatory, ethical and commissioning requirements. 2. Reviewed and periodically audited.

1. Department of Health & Social Care (2012). The NHS Constitution for England. www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england. 'Social values' are outlined in the NHS Constitution for England and similar documents for Scotland, Wales and Northern Ireland.