

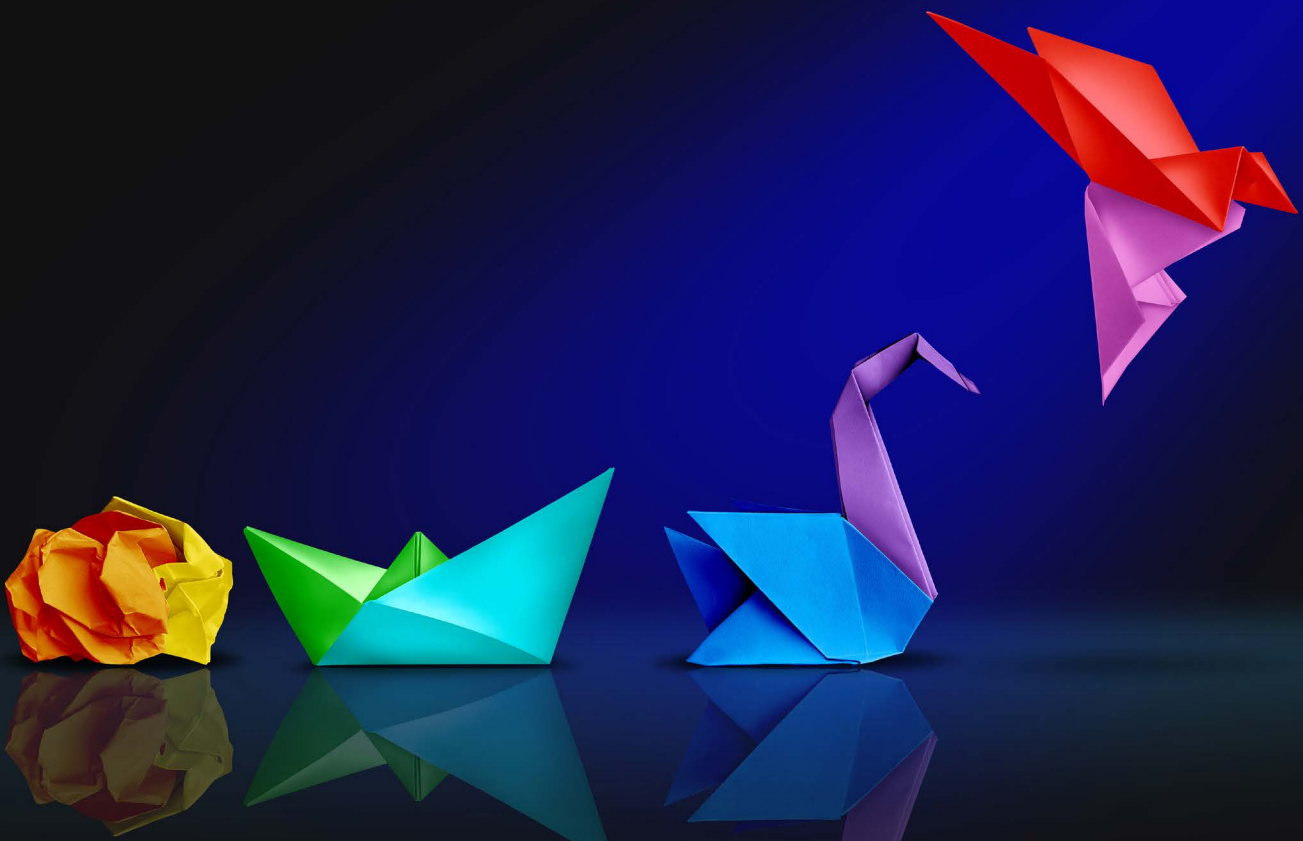


FROM RESEARCH TO REALITY

Research and innovation in the NHS as
key to enabling the 10-Year Plan

Full report

Sonja Marjanovic, Zuzanna Marciniak-Nuqui, Hampton Toole, Stephanie Stockwell,
Sarah Parkinson, Sorana Bucseanu, Jonathan Grant and Nick Fahy



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This report was updated on 9 April 2025 to correct a minor factual error in section 3.2.2.

Preface: reader's guide

This report shares the findings of a study commissioned by Wellcome and delivered by RAND Europe to help inform a vision for research and innovation in the health system, with a particular emphasis on the National Health Service (NHS). It discusses research and innovation as the fourth big shift needed to transform the NHS and help support the other key shifts emphasised by government in relation to the 10-Year Plan for health and care: shifts from hospital to community care, from sickness to prevention and from analogue to digital.

The report's contents are organised as follows:

- **Section 1** summarises the key project insights.
- **Section 2** ('Introduction') presents the project's context, aims and approach.
- **Section 3** discusses evidence on the impact of research and innovation in the health system (in and around the NHS) on patients, NHS service delivery and the wider health system, the economy and society.
- **Section 4** presents case studies of research and innovation in five key areas to reflect on the importance of a research-and-innovation-active health system and to consider the potential for future benefits. The case study areas include genomic testing, artificial intelligence (AI) applications in cancer detection and diagnosis, digital innovation in mental health, tech-enabled remote monitoring in healthcare and participatory research. Each case study considers the origins, evolution and progress of research and innovation in the field, its impacts on patients, the NHS and wider economy and society, key enablers and barriers, and a vision of what 'good' looks like ten years from now (i.e. ten years from January 2025).
- **Section 5** begins by briefly overviewing the history of research and innovation in the NHS and then presents an analysis of support mechanisms needed for a research-and-innovation active NHS in terms of the current landscape (what matters and key enabling organisations and initiatives), challenges that need addressing and a vision of what 'good' looks like in the future relative to each support mechanism. The support mechanisms for a research-and-innovation-active NHS discussed pertain to: (1) the NHS workforce, (2) data, information and evidence, (3) physical infrastructure, (4) funding, commissioning and procurement, (5) Research and Development (R&D) governance and regulation, (6) collaboration and coordination, and (7) patient and public involvement, engagement and participation.
- **Section 6** ('Conclusion') reflects on the insights gained in relation to the 10-Year Plan and the opportunities for research and innovation to support NHS reforms.

For more information on this document, please contact Dr Sonja Marjanovic (Director of Healthcare Innovation, Industry and Policy at RAND Europe) at smarjano@randeurope.org and Dr Nick Fahy (Research Group Director, Health and Wellbeing, RAND Europe) at nfahy@randeurope.org.

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Abbreviations

ABPI	Association of the British Pharmaceutical Industry
ADR	Adverse Drug Reaction
AF	Atrial Fibrillation
AI	Artificial Intelligence
AMRC	Association of Medical Research Charities
BHF	British Heart Foundation
BP	Blood Pressure
BRC	Biomedical Research Centre
CBT	Cognitive Behavioural Therapy
CGM	Continuous Glucose Monitoring
CLAHRC	Collaboration for Leadership in Applied Health Research and Care
COPD	Chronic Obstructive Pulmonary Disease
CPRG	Clinical Practice Research Datalink
CRUK	Cancer Research UK
DECIDE	Digitally Enabled Care in Diverse Environments
EVA	Early Value Assessment
ESRC	Economic and Social Research Council
EU	European Union
GDP	Gross Domestic Product
GVA	Gross Value Added
HEE	Health Education England
HES	Hospital Episode Statistics
HIN	Health Innovation Network
HTA	Health Technology Assessment

IAPT	Improving Access to Psychological Therapies
ICB	Integrated Care Board
ICS	Integrated Care System
IET	Internet-Enabled Therapy
IRLS	Innovation, Research and Life Sciences
MHRA	Medicines and Healthcare Products Regulatory Agency
MRC	Medical Research Council
MSAS	Memorial Symptom Assessment Scale
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
OLS	Office for Life Sciences
OSCHR	Office for Strategic Coordination of Health Research
PPIE	Patient and Public Involvement and Engagement
PCN	Primary Care Network
QALY	Quality-Adjusted Life Year
R&D	Research and Development
RCT	Randomised Control Trial
REF	Research Excellence Framework
RTT	Referral-to-treatment
SBRI	Small Business Research Initiative
STI	Science, Technology and Innovation
TEC	Technologically Enabled Care
TERM	Technologically Enabled Remote Monitoring
UK	United Kingdom
UKRI	UK Research and Innovation
VC	Venture Capital

Summary

The context: why research and innovation is the key platform for the NHS 10-Year Plan

Research and innovation are the fourth big shift needed to transform the NHS.

Mainstreaming research and innovation throughout the National Health Service (NHS) is the ‘fourth shift’ underpinning the 10-Year Plan. Without it, improvements in care quality, patient outcomes and experience, productivity and the sustainability of NHS services cannot be achieved. Healthcare is a knowledge-intensive sector, and if research and innovation are not actively supported and enabled, the gap between what is possible to achieve and what materialises in practice will grow. The government’s focus on developing a 10-Year Plan for health and care aims to respond to serious challenges to NHS sustainability and performance, emphasising three big shifts for the health care system to achieve by 2035: (1) from hospitals to communities, (2) from sickness to prevention and (3) from analogue to digital.¹ These depend on a fourth shift: from seeing research and innovation as a ‘nice to have’ to essential for transforming the NHS and making it fit for the present and the future. We call this shift: ‘from research to reality’.

Lord Darzi’s independent investigation of the NHS in England highlights that research and innovation have a key role to play in enabling a more sustainable NHS. Research and innovation should not be considered second-order priorities. The United Kingdom (UK) has a strong base in health research, from basic and applied biomedical research and clinical trials to evidence on how best to reorganise and reform the delivery of health services. From a health policy perspective, research and innovation should provide the evidence, insights and skills to support change and improvement throughout the NHS. However, this potential has not yet been realised; research and innovation in the NHS remains fragmented, beset by systemic inefficiencies, with weak links between NHS policy priorities and wider industrial strategy. Overcoming these challenges and embedding research and innovation throughout the NHS will be pivotal in achieving the aims of the 10-Year Health Plan and bringing wider societal and economic benefits.

Research aims and approach

The study aimed to inform a vision for research and innovation in the health system, with a particular emphasis on the NHS. This work is part of a wider collaborative project between the Wellcome Trust, RAND Europe and Nesta. RAND Europe’s work aimed to:



Examine key evidence on the importance and impact of research and innovation in and around the NHS.



Consider impacts more closely through case studies in five key areas of strategic importance to the NHS (genomics, artificial intelligence, digital innovation in mental health, tech-enabled remote monitoring and participatory research).



Examine the support mechanisms needed to enable a research-and-innovation-active NHS and deliver benefits for patients, the public, the NHS and wider health system, the economy and society, and identify what 'good' would look like in relation to the support mechanisms in the future.

The work was conducted from November 2024 to February 2025 and was informed by desk research, literature review, case studies, and stakeholder engagement through interviews and a workshop. It also benefited from the RAND Europe research team's long-standing work on research, innovation and health-systems transformation. We identified key insights by triangulating findings across data sources and methods via thematic analysis.

Key findings

Health research and innovation benefit the NHS, patients, the economy and society and should be a core part of wider efforts to put the NHS on a more stable footing.

The benefits stemming from research and innovation span (1) improved care quality, safety and productivity, (2) enhanced job satisfaction and NHS workforce retention, (3) improved patient health outcomes (e.g. mortality rates) and patient experience and (4) strengthened health system resilience for population health. Other benefits include positive impacts on the economy and broader society, such as those related to the UK's reputation as a global leader in research. Participating in research and clinical trials is linked to better NHS staff adherence to evidence-based practice, improved treatment protocols, high-quality care and earlier patient access to potentially lifesaving treatments. Research-active NHS organisations are linked to reduced mortality rates and increased patient confidence in healthcare professionals. Health research and innovation can also make NHS organisations more attractive as employers, create jobs and revenue, help reduce absenteeism and reap benefits from the UK's global reputation for scientific excellence.

The UK has a strong health research base to build on in NHS transformation efforts. Commercially sponsored clinical trials are a visible example of how collaborative action to address current obstacles can bring health and economic benefits. However, the potential of research and innovation to support NHS transformation extends beyond trials alone and is key to delivering in the three shifts the government identified: from hospitals to communities, from sickness to prevention and from analogue to digital. Basic research helps us understand the mechanisms underpinning health and disease, while applied research and innovation lead to novel prevention, diagnosis and personalised treatment approaches (often in collaboration between the NHS, academia and industry). These approaches include technologies that facilitate

early diagnosis and timely treatment to prevent unnecessary hospital admissions and digital technologies that enable care in the community and reduce waiting lists. Health services research and evaluation provide actionable insights to support the implementation of innovation in the health service across neighbourhoods and communities.

Research and innovation should provide the evidence, insights and skills that enable change and improvement throughout the NHS. However, the full potential to achieve this has not yet been realised. Research and innovation in the NHS happen sporadically and will take time to embed in NHS operations.

There are seven support mechanisms for mainstreaming research and innovation throughout the NHS to help achieve success in transformation efforts.

Each support mechanism matters in moving the NHS closer to a vision of what 'good' looks like in the future:



1. Workforce: A research-and-innovation-active NHS workforce is critical for achieving sustainable, high-quality, cost-effective healthcare. In ten years, achieving the fourth shift will have empowered NHS staff to help transform the NHS by ensuring evidence-based, innovative patient care. The NHS workforce will be motivated, skilled, rewarded and accountable for doing and adopting research and innovation, supported by better training and information.



2. Data, information and evidence: Improved access to data, information and evidence is essential for ensuring best practice in NHS care and responding to unmet needs. In ten years, data, information and evidence will be more widely accessible to researchers and innovators and will be used, shared, combined and analysed safely and securely, with public trust. An evidence-driven NHS will develop new solutions and adopt, spread and scale best practices.



3. Physical infrastructure: Upgrades to basic physical infrastructure, alongside investments in key high-tech facilities, are crucial for the NHS to provide safe care and for patients to access global scientific advances. In ten years, the fourth shift will have attracted investment to improve the NHS estate to support excellence in research and innovation for patient care. The 'basics' will be in place, reducing contradictions between world-leading facilities in some settings and dilapidated buildings and out-of-date equipment, hardware and IT systems in others.



4. Funding, commissioning and procurement: More strategic prioritisation of funding is crucial for reducing resource wastage and inefficient, ineffective care. In ten years, investments into research and innovation will be collaboratively prioritised to align the innovation pipeline with health needs and affordability, supporting improvements across prevention, diagnosis and treatment. Both financial and non-financial incentives will encourage research and innovation activity in NHS organisations.



5. Research and development (R&D) governance and regulation of innovation:

Efficient, robust and innovation-friendly R&D governance and regulation that ensures patient safety underpins the ability of research and innovation to translate into NHS, patient and economic benefits at scale. In ten years, close collaboration across research governance, innovation regulation and health technology assessment will cement a smoother pathway from lab to NHS practice, enabling patients' rapid access to novel solutions and an attractive UK market for innovators.



6. Collaboration and coordination: Closer collaboration and coordination between local, regional and national bodies is pivotal for more efficient and effective progress with research and innovation, and its translation and spread throughout the NHS. In ten years, the fourth shift will have enabled patients, the NHS and the economy to benefit from a landscape in which industrial policy and health policy initiatives reinforce each other, regional and national efforts are complementary, and the UK is a key partner in global developments.



7. Patient and public involvement, engagement and participation: Inclusive patient and public involvement, engagement and participation in research and innovation determine whether the UK population have a fair say in shaping what the NHS does and how. In ten years, it will be the norm for patients and the public across diverse communities to engage in meaningful and flexible ways, helping to steer a culture of constant improvement focused on actual needs and greater trust. Existing infrastructure (such as potentially the NHS App) will enable more effective recruitment of patients into research, including clinical trials.

Conclusion

Prioritising actions in each support mechanism area outlined will enable a feasible approach to translating research and innovation's potential to support NHS reforms. A coordinated national strategy informed by dialogue between actors in the research, innovation, health policy and industrial strategy landscape can help achieve this.

Only an NHS that embraces research and innovation can transition to meet the needs of the present and to futureproof the wider health system in a sustainable way. Realising this means linking multiple stages and actors across the NHS, academia, industry, patients and the public.

We have outlined seven support mechanisms to help ensure research and innovation deliver their potential and what must happen for this transition. As shown in Figure 1 below, these support mechanisms build on the health system building blocks outlined by the World Health Organization (WHO).² An ecosystem of support mechanisms is fundamental to delivering on the shift from seeing research and innovation as 'nice to have' to essential to achieving the three big shifts the government outlined. More specifically, **the shift from hospital to community** needs to be informed by health services and public health research and innovation that can

support feasible and effective, evidence-based policies. This shift must also be supported by patient access to innovative diagnostics, treatments and cures that can help avoid unnecessary hospital admissions. The **shift from analogue to digital** will require innovation in technology and data infrastructure, as well as research and evaluative evidence on workforce, service user, industry supplier and regulatory system determinants of implementation success. The **shift from sickness to prevention** will need to be informed by public health, health services and biomedical and life sciences research, leading to the implementation of innovation that can help keep people healthy while still responding to pressing needs to reduce waiting times and address the post-COVID backlog.

The support mechanisms are key to achieving the core values of modern health systems. We conceptualise these as being rooted in notions of excellence in care, effectiveness (including cost-effectiveness), efficiency, equity and supporting an evolving health system that is responsive, learning and adaptive. This vision includes proactively addressing the growing burden of chronic diseases and comorbidities, increasing health system costs related to the evolving nature of health service demand, ageing populations and emerging infectious disease threats.

A fourth shift to a research-and-innovation powered NHS must be a guiding principle of the future health service and the 10-Year Plan, with all actors empowered to help achieve it.

An extended summary of this report is available as a separate paper.*

* For an extended summary of this report, please see: Marjanovic, S, Z Marciniak-Nuqui, H Toole, S Stockwell, S Parkinson, S Bucseanu, J Grant and N Fahy. 2025. *From research to reality: research and innovation in the NHS as key to enabling the 10-Year Plan – Extended Summary*. Santa Monica, Calif.: RAND Corporation. RR-A3808-1.

Figure 1. The fourth shift from research to reality: research and innovation enable wider change

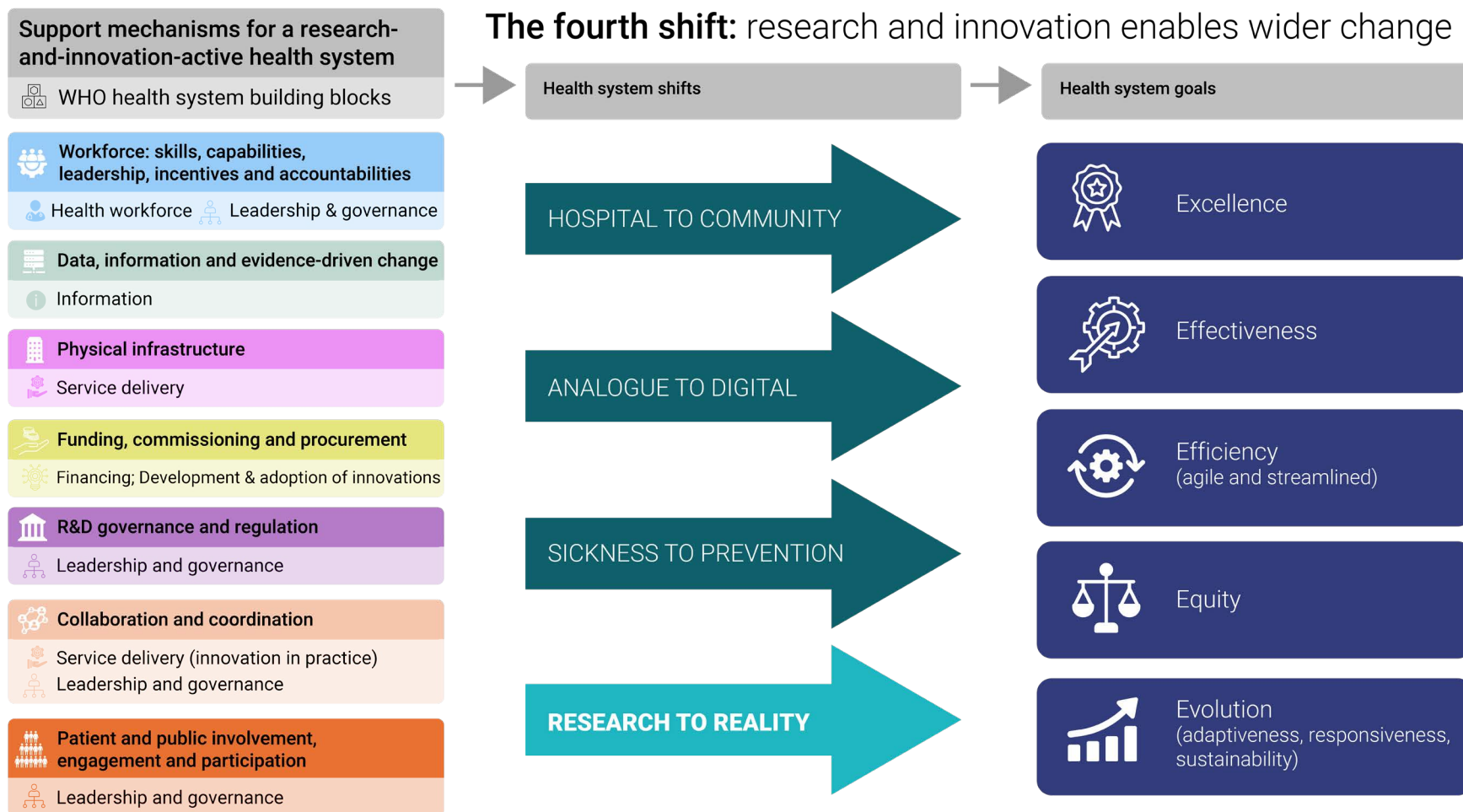


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Chapter 1. Introduction

1.1. The project context

Health research and innovation have a key role to play in directing the National Health Service (NHS) towards a more sustainable future and should not be seen as a second-order priority. A research-and-innovation-active NHS is essential for high-quality healthcare, improved patient outcomes and the United Kingdom's (UK's) wider economic and industrial competitiveness.

The transformative potential of a research-and-innovation-active NHS can only be harnessed via a system-wide shift from seeing research and innovation as a 'nice to have' to central to efforts to transform the NHS. We call this shift: 'from research to reality'.

Embedding research and innovation throughout the NHS is the fourth big shift the government must focus on in the 10-Year Plan to enable its three intended healthcare shifts from hospitals to communities, sickness to prevention and analogue to digital.¹ As healthcare is a knowledge-intensive sector, research and innovation capacity and a learning-and-improvement culture throughout the NHS are critical for enabling such shifts in practice. Commercially sponsored clinical trials are a visible example of how collaborative action to address current obstacles would bring both health and economic benefits. However, research and innovation's potential to support NHS transformation extends beyond trials alone. Basic research can help us understand the mechanisms underpinning health and disease, while applied research informs new prevention, diagnosis and more personalised treatment approaches. It also feeds into the development of innovations (often in collaboration between the NHS, academia and industry), including technologies that can facilitate early diagnosis and timely treatment to prevent unnecessary hospital admissions. This includes digital health innovations that can facilitate care in the community and help reduce waiting lists and patient backlogs. Health services research and evaluation provides actionable insights into implementing innovations and improving services in practice across UK neighbourhoods and communities.

The UK government's 10-Year Plan presents a fresh opportunity to embed health research and innovation at the heart of the NHS, provide the evidence, insights and skills to support change and improvement throughout the NHS and nurture a learning health system. Although the UK has a strong health-research-and-innovation base, its potential has not yet been fully realised.

Research and innovation in the NHS remain fragmented, beset by systemic inefficiencies, resource allocation and organisational governance approaches that do not optimally incentivise innovation, with weak links between NHS policy priorities and wider industrial strategy.

Overcoming these challenges and embedding research and innovation throughout the NHS will be pivotal to achieving the aims of the 10-Year Plan and bringing wider societal and economic benefits. The 10-Year plan offers renewed scope to create the conditions to embed, spread and scale research and innovation in the NHS in a way that recognises and proactively responds to the changing nature of scientific and technological developments and the changing global research and innovation landscape.

1.2. Project aims and approach

1.2.1. Aims and methods

In this context, Wellcome commissioned RAND Europe to deliver a study to help inform a vision for research and innovation in the health system, with a particular emphasis on the NHS. This work was part of a wider collaborative project between Wellcome, RAND Europe and Nesta. The project took place between 1 November 2024 and 15 February 2025. It was informed by desk research, a literature review, case studies and stakeholder engagement through interviews and a workshop. The work benefited from the RAND Europe research team's long-standing body of work on research, innovation and health systems transformation. To better understand the impact of research in the NHS, we also analysed Impact Case Studies submitted to the Research Excellence Framework (REF) 2021. The full analysis and methodology are available in Appendix 2: 'ICS NHS Analysis'.

More specifically, RAND Europe's work aimed to:



1. Examine key evidence on the importance and impact of research and innovation in and around the NHS.

We achieved this using a focused narrative review of scholarly and grey literature via Web of Science to identify academic sources on the role and importance of healthcare and life sciences research in the NHS. We limited our search to review articles and papers published in the last five years. We identified relevant studies outside this period by snowballing. We ran four searches, focusing on abstracts, using the following search strings: 'research in the NHS', 'research-active NHS', 'innovation in the NHS' and 'innovation NHS'. This search resulted in 2,220 hits, which we sifted based on titles and abstracts. To identify relevant grey literature, we undertook a search on Google. Due to the work's rapid nature, we limited the search to sources listed on the first two pages using three search strings: 'impact of research in NHS', 'life sciences and the NHS', and 'innovation in the NHS'. This search resulted in 63 hits, of which we downloaded 24.



2. Consider impacts more closely through case studies in five key areas of strategic importance to the NHS

(genomics, artificial intelligence, digital innovation in mental health, tech-enabled remote monitoring and participatory research). We achieved this through case studies informed by desk research and 16 key informant interviews conducted via MS Teams between 1 November and 19 December 2024 with informed consent (see Appendix 1). The interviews focused on understanding the evolution of research and innovation in each case study area, key impacts to date, key enablers and challenges and a vision for what 'good' would look like in the future in terms of support mechanisms needed to enable future transformative potential in each case study area.



3. Examine the support mechanisms needed to enable a research and innovation-active NHS and identify what 'good' would look like in relation to the support mechanisms for delivering benefits for patients and the public, the NHS and wider health system, the economy and society. This analysis was informed by desk research, insights from the interviews conducted for the prior case study work package and a stakeholder workshop convened by Wellcome and facilitated by Nesta and RAND Europe on 5 December 2024. The workshop included 23 key stakeholders representing diverse individuals from research and innovation funders, academic and research organisations, charities and non-governmental organisations, healthcare and patient and public involvement communities.

We conducted all desk research using Google, Google Scholar, Web of Science and PubMed, as well as consulting websites of specific organisations or initiatives identified by snowballing from the desk research or key informant interviews. In addition, we consulted RAND's internal Artificial Intelligence (AI) platform and SciSpace as a search source to complement the key databases. We reviewed all identified material and checked the content and sources before incorporating them.

We used thematic analysis to guide our findings and inferences based on desk-based analysis and synthesis, testing emerging insights from the stakeholder workshop, internal research team workshop and regular meetings. The research team was also sensitised by complex systems' theoretical and conceptual perspectives on health research and innovation (elaborated in Section 4).

1.2.2. Limitations

We conducted the study over a short timeframe, between 1 November 2024 and 15 February 2025, collecting most of the data before the end of 2024. As a result, we cannot claim to have covered all the potentially relevant literature on the impacts of research and innovation in and around the NHS on patients and population health, the NHS and wider health system, the economy and society. We also cannot claim to have spoken to all the individuals with potentially relevant insights to share on the wider support systems needed to enable a research-and-innovation-active NHS. However, we are confident that the diverse professional backgrounds, skills and experiences of those we spoke to, our use of both individual and group discussion approaches (interviews, workshop) and the breadth of sources consulted provide a robust and rounded analysis of the issues at play. The RAND Europe research team also benefits from a long history of research, evaluation and thought leadership on health services, health system transformation and innovation, lending further confidence to the findings and inferences.

Chapter 2. The contribution and impact of research and innovation in the NHS: an overview

Box 1. Summary: The impacts of research and innovation in and around the NHS

Research and innovation in and around the NHS lead to a wide range of benefits. These span:



Improving care quality, safety and productivity: Participation in research and clinical trials is linked to better NHS adherence to evidence-based practice, improved treatment protocols and high-quality, efficient care and greater openness to innovation.



Enabling job satisfaction and workforce retention: Research activity can make NHS organisations more attractive as employers and contribute to job satisfaction.



Improving patient health outcomes and experiences: Research and innovation give patients early access to novel, potentially life-saving treatments. Research activity is linked to reduced mortality rates and increased patient confidence in healthcare professionals.



Contributing to health systems resilience: Research underpinned the public health response to the COVID-19 pandemic, including surveillance research, pathogen genome sequencing, data modelling and vaccine innovation. All have key roles to play in pandemic preparedness. Research also informs adaptations in health service delivery that support resilience.



Supporting economic benefits: Alongside saving lives, health research and innovation create jobs and revenues, contributing to productivity. New treatments also improve people's quality of life, supporting their continued employment and reducing absenteeism.



Enabling wider societal benefits and the UK's reputation as a global research leader: The UK's reputation as a clinical research leader helps attract international collaborators, increases research reach and impact, and creates spillover benefits (e.g. patents).

2.1. An overview

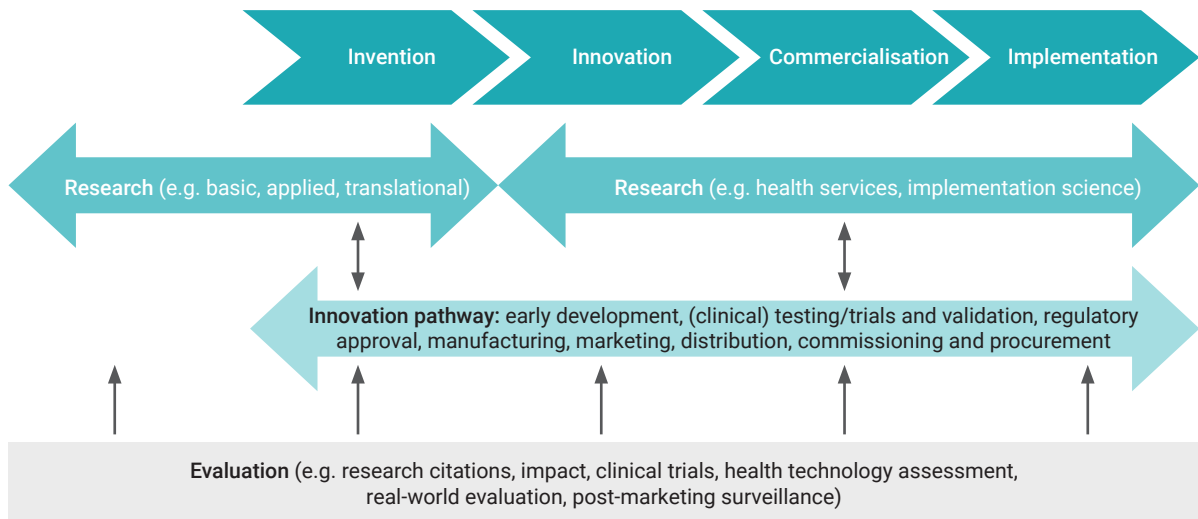
Research and innovation in the NHS can save lives, improve patient experience, population health and staff wellbeing, and bolster health system resilience. It can also support the economy and offer wider societal benefits, e.g. from the UK's reputation as a global research leader. Research and innovation's impact in and around the NHS concerns its influence on healthcare organisations and staff, patients and the wider public, and the wider economic and societal landscape. These impacts can be diverse. The NHS can also play multiple roles in research and innovation, whether as the funder, participant, and/or beneficiary of research and innovation (see Appendix 2: ICS NHS Analysis, illustrating these roles based on an analysis of insights from Research Excellence Framework impact case studies). However, these roles are not mutually exclusive, and participation in all research forms is associated with benefits for the NHS.

Research and innovation are distinct but interrelated and multifaceted concepts. Research can take many forms, e.g. curiosity-driven basic research, translational and applied research, clinical research and health services research. Likewise, healthcare innovation is multi-faceted and relates to diverse products and technologies, including medicines, vaccines, diagnostics, various medical devices, digital technologies and innovative service models. Healthcare innovation refers to developing new products, technologies or services or applying existing ones in new ways.³

Discovery or creation represents the first step toward innovation, i.e. generating initial research insights. The discovery becomes an invention after identifying one or more potential applications. Once an invention translates into a novel and useful product, technology or service, it is an innovation or invention put into practice. An innovation is commercialised with a view to subsequent implementation and potential diffusion (see Figure 2).

While research feeds into innovation, innovation can also generate new research questions. Therefore, innovation can be demand-driven (a response to an identified unmet health need, sometimes described as the innovation *pull*) or supply-driven (a response to scientific advances that enable further research and development activity, sometimes described as the innovation *push*). However, unmet needs can also generate research investments that enable scientific advances and further research and development (R&D) activity. Thus, supply and demand-driven innovation are not mutually exclusive concepts. Research and innovation are processes with distinct outputs (e.g. publications, patents, service models, new products, technologies and services). These processes are complex, emergent and non-linear, whereby different phases in the research and innovation pathway co-evolve. Research and innovation can lead to benefits but can also have unintended consequences that need mitigation and management. Although we do not assume in this report that innovation is always beneficial, we have focused on contexts and cases where evidence suggests likely benefit.

Figure 2. The research and innovation pathway*^{4,5}



The following contents explore research and innovation’s multifaceted impacts on healthcare service performance, patients, the economy and society, based on a focused narrative review of the evidence. The evidence suggests that active participation in research is associated with enhanced healthcare quality and safety, improvements in care delivery processes and better health outcomes.⁶ The benefits of research extend to healthcare institutions themselves, with the ‘trial effect’ leading to improved patient outcomes, adherence to guidelines and a stronger reliance on evidence-based practices,⁷ supporting the taxpayer-funded public-service model of the NHS that aims to deliver high-quality care that is free at the point of use. However, the distribution of research and innovation activity across the NHS is uneven across teaching and general hospitals, rural and urban settings, and secondary and primary care.⁸ Healthcare professionals face many barriers to undertaking research in the NHS, including insufficient time and resources, bureaucratic and regulatory hurdles, difficulties initiating clinical trials and recruiting sufficient participants, and challenges around adopting innovation in practice.^{4,9,10} These issues are further discussed in Section 4.

The UK has excellent health research strengths to build on, with expertise in strategic areas ranging from genomics, AI and machine learning to digital health, quantum computing, personalised medicine, medtech, neurotech and immunology, among others.¹¹ It also has world-leading academic institutions, government support, innovative companies and the NHS. Moreover, the UK has strong foundations for translating research into practice and ensuring that medical innovations reach patients promptly through translational infrastructure such as

* Adapted from Marjanovic, S, M Altenhofer, L Hocking, M Morgan Jones, S Parks, I Ghiga, C Cox, K Galai, and T Ling. 2020. *Innovating for improved healthcare: Policy and practice for a thriving NHS*, RAND Corporation, RR-2711-DH; and Fahy, N, N Mauer, and D Panteli. In press. *From ideas to reality: An introduction to generating and implementing innovation in health systems*. WHO, Regional Press for Europe.

Biomedical Research Centres, Health Innovation Networks and others (as discussed in Section 4).¹⁰ The UK's response to the COVID-19 pandemic highlighted its potential to undertake rapid research and innovation for patient benefit. The RECOVERY trial started in 2020 in the UK as an international randomised trial to test COVID-19 treatments for people admitted to hospital with COVID-19-related pneumonia. It has now been extended to test treatments for other types of pneumonia internationally.¹² The success of the RECOVERY trial and the effectiveness of the COVID-19 Vaccine Taskforce (VTF) was made possible through close collaboration between the government, academia, the private sector, the NHS and the public.¹⁰ Understanding research and innovation's potential impact on the NHS is key to keeping it at the centre of future NHS planning and strategies. It also highlights key areas for further exploration and potential strategies to enhance research and innovation engagement across the NHS.

As Figure 3 shows, research and innovation in and around the NHS span impacts the NHS and health system, patients and population health, and the economy and society. We elaborate on each of these impact areas in the following sections.

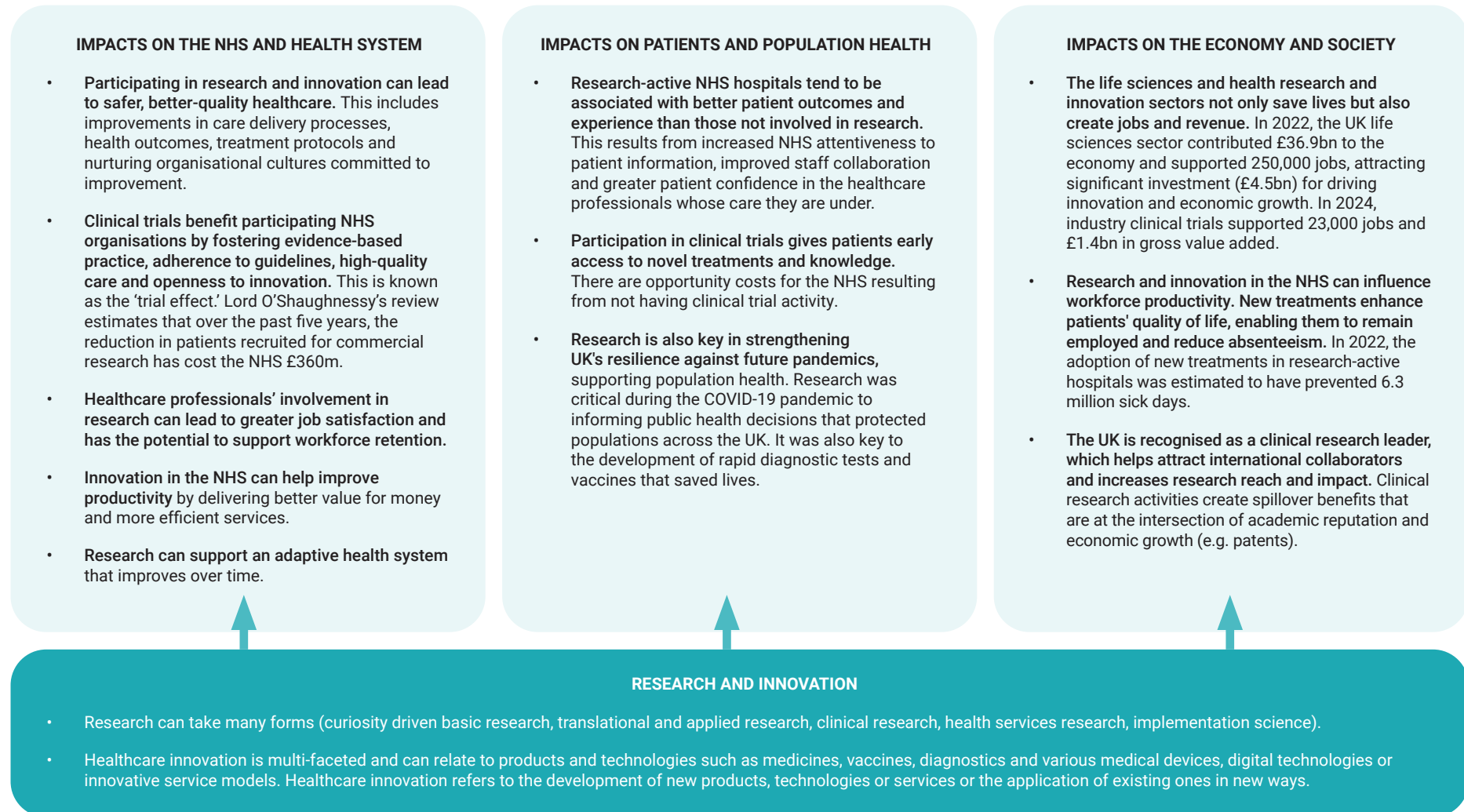
2.2. Impact on the NHS and wider health system

2.2.1. Healthcare quality, safety and productivity

The evidence base on the links between research and innovation in the NHS and health service performance is still evolving. However, several studies point to benefits for health service delivery's quality, safety and/or productivity and workforce well-being and retention.

Participating in research and innovation is linked to better quality and safer healthcare. A 2015 systematic review by UK researchers found evidence of observable improvements in care delivery processes and, in some cases, in health outcomes internationally, including the UK.⁶ The authors updated the review in 2024 with further supporting evidence of the impact on healthcare through improved treatment protocols, impacts on organisational cultures in healthcare and collaboration.¹³ The review highlighted that 86 of the 95 papers reported positive results for health organisations as an outcome of research engagement.¹³ This included improvements such as lower mortality and morbidity rates.¹³

Figure 3. Impacts from research and innovation in the NHS: an overview



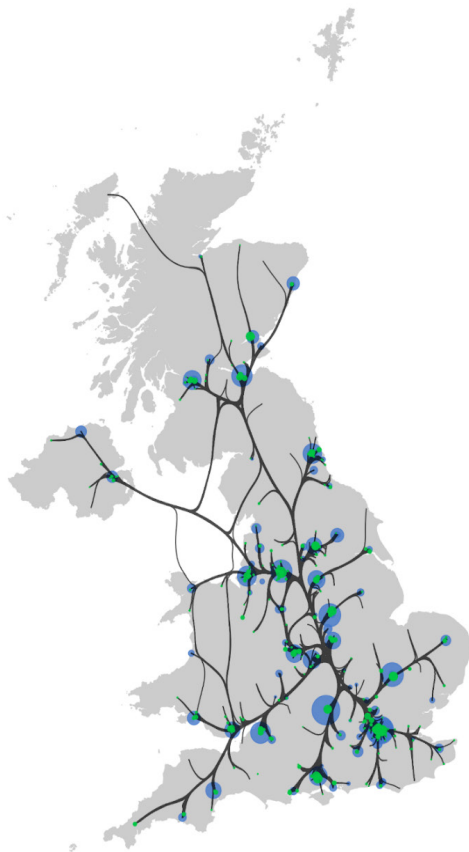
Box 2. Impact story: modelling study enables the MenB vaccine programme rollout in the UK

Research that led to the rollout of a new vaccine to protect young children from meningococcal group B disease (MenB), a leading infectious disease among young children, significantly impacted the UK's immunisation schedule.¹⁴ No vaccines existed for MenB before 2013, but once a vaccine was licensed, policymakers required evidence of its cost-effectiveness and impact. Models were developed to estimate the impact of widespread immunisation on reducing meningitis cases and assess the cost-effectiveness of potential immunisation programmes. The results informed recommendations for a MenB vaccination schedule for babies, with a booster at 12 months, projecting over a quarter reduction in meningitis cases in the first five years. This evidence was crucial for the UK adopting the MenB vaccine in 2015, becoming the first country to include it in its routine immunisation programme. The programme's success was evident, with Public Health England reporting that nine out of ten 10–12-month-old babies were vaccinated by 2018, significantly reducing meningitis cases and saving lives. The modelling study also resulted in an estimated £136m per year of NHS cost savings due to the successful vaccination programme.¹⁴

Clinical trials are also associated with benefits for the NHS institutions involved in running them regarding adherence to evidence-based practice, high-quality care and openness to innovation. Known as the 'trial effect', a Cochrane systematic review found that institutions involved in clinical trials have better outcomes, increased reliance on evidence and improved adherence to guidelines by healthcare professionals.⁷ A 2018 retrospective cross-sectional study looking at the correlation between NHS clinical trials and mortality rates found that in general, there is some association between clinical trials at NHS institutions and Quality-of-Care (CQC) ratings.¹⁵ As Lord O'Shaughnessy's review of clinical trials pointed out, research-active clinicians are also more likely to recommend innovative or newly-licensed treatments to patients.¹⁰ According to Frontier Economics' recent report on the value of clinical trials, participation in clinical research influences the entire institution's working culture, generating more willingness to adopt innovation and novel medications.¹⁶ Clinical trials are also linked to improved collaboration between clinical staff and academic experts, facilitating a broader reach of knowledge about medical advancements.¹⁶

Based on the results of our analysis of Research Excellence Framework impact case studies (see Figure 4), research collaboration between academic organisations and NHS hospitals is widespread across the UK and not confined to local partnerships alone. The map in Figure 4 shows institutional collaborations based on publications listed as 'underpinning research' in NHS-featured impact case studies between universities (blue points) and hospitals (green points), with the connecting lines based on the amount of collaboratively authored papers. Thicker lines reflect a greater level of collaboration. Only collaborations between universities and hospitals were counted (i.e. not university-to-university collaboration), and point sizes are proportional to the number of publications. This figure shows a considerable collaboration between UK universities and hospitals, both locally and across the UK, as evidenced by the collaboration cords connecting the full breadth of the UK. Additionally, universities tend to produce more publications (i.e. their point size is generally larger), whereas hospitals' contributions are more distributed, especially in metropolitan areas.

Figure 4. UK map showing collaborations between the NHS and universities based on the number of collaboratively authored papers



Much of the evidence on the links between research activity in the NHS and care quality and safety focuses on secondary care. This point was alluded to in the 2024 NHS report on research in the NHS, which states that only around 3% of GP practices participate in commercial research activities such as clinical trials.¹⁷ Despite this, a 2024 qualitative study of general practitioners in England highlighted that research participation improved GP relationships with patients and influenced GP work-style, including a higher reliance on evidence – partly enabled through improved access to resources.¹⁸ A 2024 study protocol noted that the impact of research in the NHS on general practice must be understood in light of regional disparities in GP participation and engagement in clinical research, pointing to significant differences between GP research activity across the country.¹⁹

Disparities between rural and urban NHS organisations affect GP research activity and result in lower research participation rates in rural areas.²⁰ Nevertheless, some evidence suggests that research benefits can extend beyond recognised centres of excellence across the UK.²¹ Although studies on the impact of research and innovation on rural NHS hospitals are limited, a 2019 Royal College of Physicians publication calls for wider-spread research participation to overcome the

concentration of research activity in southeast England and urban centres such as Manchester, Newcastle and Leeds.⁸ They argued that this could increase the positive ‘research effect’ in smaller, rural trusts to better align research in the NHS with the needs of patients most likely to benefit from it.⁸

A 2017 RAND Europe study explored the role of innovation in the NHS in enhancing productivity, highlighting its potential for delivering better value for money and more efficient services. The results also suggest innovation’s potential for addressing the growing and changing demand for health services while maintaining high-quality care with limited resources.²²

2.2.2. Job satisfaction and workforce retention

Healthcare professionals’ involvement in research can increase job satisfaction and support workforce retention.^{17,23,24} There was growing evidence that medical and nursing professionals were leaving their jobs and/or reducing their working hours even before COVID-19 induced an NHS workforce crisis.^{25–27} A 2019 literature review suggests that increased research opportunities for healthcare staff can positively impact workforce retention and job satisfaction.²⁸ A 2020 Royal College of Physicians study showed that most surveyed doctors reported positive attitudes towards research activity in the NHS, citing intellectual stimulation, improving patient care and continued skill development.^{8,29} A 2024 study of the impact of research on general practice reinforced these findings, drawing on interviews with healthcare professionals in general practice who described greater job satisfaction and increased attractiveness of their institution as a workplace due to research involvement.¹⁸ Another 2024 study of research interest and the culture of NHS staff suggests that healthcare professionals’ desire to engage in research has only increased after the COVID-19 pandemic due to greater awareness about the positive impact of research on health outcomes.³⁰ A study focusing on developing a research impact tool for nursing, midwifery, allied health professions, healthcare science, pharmacy and psychology (NMAHPPs) revealed that clinicians involved in research are typically perceived as more credible by their peers.²³ Despite this, many healthcare professionals find it challenging to engage in research due to a lack of protected time, difficulties with research funding, and preconceived notions in less research-active professions like nursing.

2.3. Impacts on patients and population health

2.3.1. Patient outcome and experience

A gradually evolving evidence base suggests that research-active NHS hospitals tend to be associated with better patient outcomes and patient experience than those not involved in research.^{6,31}

Although an earlier 2011 systematic review suggested that the evidence on patient benefits related to being treated by clinicians or institutions participating in clinical trials was inconclusive and merited further research,⁷ **recent evidence associates research-active NHS organisations with reduced mortality rates**, albeit without clear causal relationships. For example, a 2012 retrospective observational study highlighted a correlation between research publications and hospital mortality rates.³² Similarly, a 2015 study showed that research-active acute NHS Trusts

had lower mortality rates for acute admissions, even after accounting for structural factors such as staffing levels.³³ A 2017 study examining the impact of clinical trial involvement on colorectal cancer patients found a strong association between participation in interventional clinical trials and lower patient mortality rates.²¹ A 2018 retrospective cross-sectional study also found a general association between clinical trials at NHS institutions and improved health outcomes and quality-of-care (CQC) ratings.¹⁵

There is also some evidence suggesting that hospitals engaged in clinical research have better patient experiences due to increased attentiveness to patient information, improved staff collaboration and greater patient confidence in their doctors.³¹ A 2024 paper on research in the NHS argued that participation in clinical trials gives patients early access to novel treatments and knowledge,¹⁷ and an Association of the British Pharmaceutical Industry (ABPI) report pointed out that this is particularly important for patients who have exhausted all other treatment options, e.g. people with rare diseases.³⁴

Box 3. Impact story: The success of the CRASH-2 and CRASH-3 trials

The CRASH-2 trial, funded by the National Institute for Health and Care Research (NIHR) and led by the London School of Hygiene and Tropical Medicine, has significantly impacted global trauma care by demonstrating the life-saving potential of tranexamic acid for trauma patients.³⁵ This low-cost drug, previously used to reduce bleeding during surgery, was tested on over 20,000 trauma victims across 40 countries. The trial's results, published in *The Lancet*, showed that administering tranexamic acid within three hours of injury could prevent nearly 20% of trauma deaths, potentially saving around 400 lives annually in the UK and over 100,000 worldwide. The findings led to widespread changes in treatment practices, with tranexamic acid now recommended by the National Institute for Health and Care Excellence (NICE) and included in the World Health Organization's list of essential medicines. By 2016, it became standard care for severe injuries in England, with 90% of severely injured patients receiving the treatment.³⁵ The British and United States (US) Armies have also adopted it in their combat care guidelines, and the UK government invested in developing a tranexamic acid autoinjector for military use. The trial's success has spurred further research, including the CRASH-3 trial, which demonstrated that tranexamic acid reduces head injury deaths by 20%.³⁵

2.3.2. Health system resilience to support population health

Translational research is important for strengthening the UK's resilience against future pandemics. The COVID-19 pandemic showcased the impact of scientific innovations like genomic sequencing, vaccine development and data modelling, achieved through rapid collaboration among various sectors.¹⁰ The pandemic accentuated the importance of diagnostic lab capacity, vaccine strategies, real-time NHS research, efficient data sharing, public communication and genomic tools for surveillance.³⁶ However, despite a rapid research response, the initial absence of infrastructure linking genomic sequencing with patient data emphasised the importance of proactively integrating research and innovation into the NHS for timely, evidence-based responses to future pandemics.³⁶

There is evidence to suggest that research activity in the NHS can support adaptation and innovation, forming the foundations for healthcare resilience. A narrative meta-synthesis looking at balancing adaptation, innovation and resilience in different healthcare settings suggested introducing innovation boosts resilience.³⁷ Maximising innovation-related benefits requires balancing short-term adaptations, which can lead to complex, unintended outcomes without significant system changes and long-term adaptations that involve wider system restructuring and adoption.³⁷

2.4. Impacts on the economy and wider society

2.4.1. Economic impacts and productivity

A growing body of literature links investment in health research with high economic returns. While evidence is scarce on the impacts of research and innovation in the NHS, specifically on economic benefits, some insights are beginning to emerge. Further evidence may accrue with growing government emphasis on value for money, business cases, evaluation, learning and accountability. However, the historical siloes between health policy and life sciences industrial strategy mean NHS interventions are not systematically evaluated for their benefits to patients, health systems and the wider economy.

Such economic benefits span revenue generation, returns on investment, jobs and attracting investment. The life sciences, health research and health innovation sectors are key to innovation in health tech, diagnosis, treatments and vaccines, which save lives, create jobs and revenue and strengthen the UK's global competitiveness. Box 4 provides some examples of the economic contributions of research and innovation in and around the NHS.

Box 4. The economic impacts of a research and innovation active health system in and around the NHS

- According to the 2023 Government Advanced Manufacturing Plan, the life sciences sector generates over £90bn turnover,³⁸ with official statistics suggesting the sector exports goods worth £24bn.³⁹
- A series of papers co-authored by RAND Europe researchers between 2008 and 2018 found that medical research's internal rate of return on investment, in terms of the additional health gains, ranges between 7–10% per annum, with an additional 15% rate of return through broader economic benefits.^{40–42} These estimates are conservative compared to estimates in other countries that use different estimation methodologies, e.g. Aus\$3.32 in additional economic output (GDP) generated for every Aus\$1 of research funding in Australia in a study in 2023.⁴³
- Investment in UK life sciences also significantly impacts job creation and economic growth through innovation, productivity gains, talent acquisition and the creation of vibrant innovation ecosystems.⁴⁴ A 2024 report by Frontier Economics found that the clinical trials industry directly employed about 21,000 people in the UK in 2022, contributing £1.9bn to the economy.¹⁶ This impact rises to £3.2bn and 36,000 jobs when supply chain activities are included.¹⁶ Additionally, industry contracts with NHS providers for clinical trials support around 13,000 NHS jobs.¹⁶
- According to the same report, industry clinical trials support 23,000 jobs and £1.4bn in gross value added (GVA), including indirect and induced effects.¹⁶
- Based on a 2022 report by the BioIndustry Association and PwC, the UK life sciences sector contributes approximately £36.9bn to the economy and supports approximately 250,000 jobs, attracting significant venture capital (VC) investment (£4.5bn) for driving innovation and economic growth.¹¹
- According to a published interview with Professor Chowdary, participating in research offers significant financial benefits for the NHS, primarily through savings on drug costs. She reported that the Royal Free Haemophilia Centre saved approximately £15m over the past decade by engaging in various trials, including gene therapy.⁴⁵
- A KPMG report supports this, showing that clinical research contributed an estimated £8 billion to the UK economy and created around 47,467 full-time jobs in England between 2017 and 2019.⁴⁶

Public investment in health and other relevant research in the UK results in further private investment.^{41,47} A 2016 economic study found that for every £1 of public investment in research, an additional £0.83–1.07 is expended on private sector R&D.⁴¹ A 2023 study by Becker and colleagues found that investment in research through UK Research and Innovation (UKRI) is linked with spillover effects of private sector investment in innovation, particularly in regions with high concentration of research and for larger or high-tech firms.⁴⁸ A report by Frontier Economics estimated these spillover benefits at around £1.1bn.¹⁶ Two 2024 studies commissioned by ABPI highlighted that NHS-industry partnerships bring value to patients through improved patient

outcomes alongside value to the UK's economy.^{16,48} Spillovers from public investment in other fields of life sciences have also been observed in the US.^{49,50}

Research and innovation in the NHS have the potential to influence wider productivity, given that health significantly impacts a person's working ability.¹⁶ Poor health results in more absences from work and lower levels of productivity. Ill health can also affect employment indirectly, as individuals may need to care for others. New treatments can enhance patients' quality of life, enabling them to remain employed and reduce absenteeism.¹⁶ Research for the ABPI suggests that increased use of four innovative medicine classes* could yield a £17.9bn productivity gain for the UK.⁵¹ At the same time, quicker adoption of new treatments in research-active hospitals was estimated to have prevented 6.3 million sick days in 2022.¹⁶ Of these, 44% were attributed to industry clinical trials, resulting in approximately 3 million sick days avoided, equating to £0.9bn in GVA.¹⁶

Despite these benefits, falling levels of commercial research in the NHS are leading to significant opportunity costs related to reduced research and innovation and reduced funding flows into the NHS.¹⁰ As Lord O'Shaughnessy found in his 2023 review on Commercial Clinical Trials, one reason for the decreasing numbers of clinical trials in the UK is that industry partners see the UK as an untrustworthy and unstable partner, compounded by the Medicines and Healthcare Products Regulatory Agency (MHRA) administrative backlogs and long bureaucratic processes.⁵² Along with increasing competition from other countries and NHS workforce shortages, this led to a drop in clinical trials in the UK.⁵² The review estimates that the reduction in patients recruited for commercial research over the past five years has cost the NHS approximately £360m, with an estimated £570m in potential funding to cover the costs of running commercial trials lost.¹⁰

Box 5. Impact story: the 'Born in Bradford' air quality research

'Born in Bradford' (BiB) is a large-scale longitudinal birth cohort study based in Bradford, following 13,500 babies born between 2007 and 2010 and their families. For more information on BiB, read 'Box 26. Born in Bradford: how participatory research can reshape and facilitate health research in practice.' in Section 3.5).⁵³ 'Born in Bradford' focuses on multiple health and social issues, such as genetics, mental health and the environment.⁵⁴ BiB's recent research pointed to the importance of air quality for health, leading to the introduction of the Clean Air Zone in Bradford.⁵⁵ The introduction of the Clean Air Zone in Bradford is estimated to have led to 700 fewer respiratory health-related GP visits and saved the NHS over £30,000 after one year.^{55,56}

* The four medicine classes are direct oral anticoagulants, sodium-glucose cotransporter-2 inhibitors, severe asthma biologics and vasopressin V2-receptor antagonists.

2.4.2. Wider societal benefits: the UK's reputation as a global leader in research

The UK has a proven track record of successful clinical research with high scientific impact, boosting its international reputation as a centre for scientific excellence. As a result, many international organisations wish to conduct research in the UK and engage in collaborative work.⁸ International collaborations tend to enable greater reach than national initiatives, leading to the potential for increased impact.⁵⁷ Such impact can accrue through diverse collaboration mechanisms, such as contributions to international advisory boards and participation in international clinical trials, creating partnerships that allow UK researchers to contribute to developing new medical advances, including by hosting pan-European Union (EU) clinical trials and training up-and-coming researchers across the EU and beyond.⁵⁷

Some evidence suggests that collaboration with industry, including on clinical trials, contributes to the UK's status as a global leader in achieving scientific excellence in clinical research.¹⁶ A bibliometric analysis described in a 2024 Frontier Economics report examined publications from industry clinical trials, their spillover benefits into commercial activities and future collaborations.¹⁶ The analysis used UK documents related to clinical trials with pharmaceutical industry involvement. The study found that 27% of publications were by authors with industry affiliations and funding acknowledgement, 62% by authors with industry affiliations, and 10% acknowledged industry funding without industry-affiliated authors.¹⁶

Some evidence suggests that clinical research activities create spillover benefits at the intersection of academic reputation and economic growth. One example is the number of patents resulting from clinical trials.¹⁶ The Frontier Economics ABPI-funded study revealed that industry clinical trial publications were cited 330 times in patent literature, with 283 patents in the Derwent Innovations Index referencing these publications.¹⁶ This highlights the role of clinical trials in the development of innovative treatments and in supporting economic growth.¹⁶ Another example is the Clinical Practice Research Datalink (CPRD) resource, which enables access to anonymised patient data and has helped advance clinical guidance and good practice for over 35 years, impacting over 3,500 publications in diverse research and innovation areas.⁵⁸

Box 6. Impact story: the Clinical Practice Research Datalink (CPRD)

The Clinical Practice Research Datalink (CPRD) is a Department of Health and Social Care (DHSC) database collecting anonymised patient data from GPs across the UK.⁵⁹ Established in 1987, CPRD includes longitudinal, broadly representative data for the UK population.^{59,60} The data links to other health-related information, including from secondary care.⁶⁰ CPRD collates data on around 60 million patients, providing a valuable resource for researchers worldwide.⁵⁹ Research involving CPRD data has resulted in over 3,500 peer-reviewed publications and supported the development of clinical guidance and best practice in the UK.⁵⁹ It remains an important resource for enhancing public health and epidemiological research, improving patient safety and informing healthcare policy and planning, including chronic disease management.⁶⁰

2.5. Looking to the future: harnessing untapped potential

A research-and-innovation-active NHS has many implications for healthcare service performance, patient outcomes and experience, economic growth and societal well-being.¹⁰

Section 3 builds on these insights further, discussing how we achieved transformative impacts in some key strategic areas: genomic testing (Section 3.1), AI applications in cancer screening and diagnosis (Section 3.2), digital innovation in mental health (Section 3.3), technology-enabled remote monitoring (Section 3.4), and participatory research (Section 3.5). We also discuss how to maximise the potential and impact in these key areas for NHS transformation, sustainability and excellence.

Without a renewed focus on making the most of the potential of research and innovation, patients will not have ready access to treatments that can save lives, leading to an inefficient use of constrained health service resources. Simultaneously, the NHS risks missing opportunities to deliver excellence in care, while the economy and wider society risks being adversely affected through reduced quality of life, lower productivity and wider industrial competitiveness. We are currently seeing a decline in healthcare professionals' engagement in research, as highlighted in Lord Darzi's independent investigation of the NHS.²⁴ In addition, declining levels of commercially funded research and innovation pose further opportunity costs to capturing the range of possible benefits (and as we have illustrated thus far), emphasising the need for timely and urgent action.

Despite many positive associations, the literature highlights several challenges that need to be addressed to fully realise the benefits of research and innovation in healthcare settings sustainably and at scale. Barriers span issues related to workforce skills, capabilities and leadership for research and innovation; incentives (including freeing up time for health professionals to engage), accountabilities and culture; the data infrastructure and information and evidence environments; physical infrastructure related to needed facilities and equipment; funding, procurement and commissioning; governance of R&D and regulation; collaboration and coordination and support for opportunities across different regions and urban and rural settings and primary, community and secondary care; and challenges to the engagement of service users in research, including but not confined to challenges to recruitment into research studies and trials.

We discuss these issues further in Section 4 of this report,^{52,61–63} considering the status quo and where we could get to in the future if we take actions to address the current challenges and make the most of the untapped potential.

Chapter 3. Current benefits and future potential: case studies in areas of transformative science and innovation in the NHS

Research and innovation have a significant impact on the NHS, patients and population health, as well as on the economy and wider society (see Section 3). We consider these impacts more closely through five case studies focusing on genomic testing (Section 3.1), AI applications in cancer screening and diagnosis (section 3.2), digital innovation in mental health (section 3.3), technology-enabled remote monitoring (section 3.4), and participatory research (Section 3.5).

3.1. Genomic screening and testing in the NHS

Box 7. Case study summary: Genomic screening and testing in the NHS



Since the discovery of DNA's structure in 1953, the UK has played a key role in advancing research and innovation in genetics and genomics. The NHS has been a key partner in these efforts, providing patient samples for research and trials, clinical data, expertise, infrastructure and care pathways for genomic medicine. Examples of flagship UK initiatives include:

- The Human Genome Project, Wellcome Sanger Institute and Wellcome Genome Campus, UK Biobank, Genomics England and the related 100,000 Genomes Project and Genomic Medicine Centres, the Genomics Medicine Service, the National Genomics Board, Our Future Health and NHS Genomic Networks of Excellence.



Impacts on patients and population health:

- Genomics research and innovation has improved the diagnosis and treatment of cancers, rare diseases and developmental disorders, informed disease prevention and management approaches in areas like Parkinson's disease, dementia, diabetes and heart health and helped inform public health decisions and medical innovation during the COVID-19 pandemic.



Impacts on the NHS and wider health system:

- NHS transformation efforts have been bolstered by a Genomics Medicine Service that is directly informed by genomic data and research, enabling evidence-based practice.
- Genomics England, as a government-owned company, enabled national research programmes in high-risk areas that would not have otherwise been possible, such as newborn screening.
- Genomics research provided the impetus for establishing governance and oversight frameworks enabling genomic sequencing to be made available in the NHS for diverse indications.



Impacts on the economy and wider society:

- The genomics sector brings revenue and supports enterprise creation and jobs. According to government data, the UK genomics sector had a turnover of £3.6bn in 2021/2022, and the British Industry Association estimates that the sector could reach a market capitalisation of £50bn by 2040.
- The Association of British Pharmaceutical Industries points to the number of genomics-related jobs doubling between 2016/2017 and 2021/2022, from 3,200 to 6,800.

A Future Vision for Success: Genomic Screening and Testing in the NHS



A critical mass of well-trained NHS and health system staff and interdisciplinary teams will help ensure that scientific advances in genomics and related disciplines reach the health service and patients across the UK to improve care quality, patient outcomes and experiences, and wider economic and societal benefits.



Better data access, sharing and linkage, and the convergence of technologies (e.g. genomics, quantum, synthetic biology and AI) will enable new application areas, such as improving patient care and population health throughout the life course through better prediction of needs, timelier intervention and better health system resource allocation.



Organisations contributing to genomic science and genomic medicine will have more clarity on funding, commissioning and procurement flows, reducing uncertainty about rewards for their efforts and helping foster healthy collaboration.



R&D governance and regulatory requirements for data access, sharing, use and reuse will be more streamlined and simpler to navigate, supporting greater efficiency in genomic research, innovation and adoption in the NHS.



More localised genomic medicine in the community will be enabled via access to long-read sequencing technology in primary care, shortening turnaround times to results for patients (30–60 min) and enabling better collaboration and coordination between local and national genomic medicine efforts.



Active public engagement and outreach, coupled with transparency in ways of working of genomic initiatives, will support more diverse participants in research and innovation efforts, increasing the accuracy of genomic testing, reducing inequalities, improving the relevance of genomic medicine for diverse populations, and enhancing public trust.

3.1.1. Introduction

The UK has historically been a leader in genomics research. The NHS has played a key role in supporting research and innovation in this area, leading to major advances in clinical care, including disease prediction, risk management and diagnosis using clinical predictive tests and genetic testing.^{64,65} It also helps predict how an individual might respond to a drug (i.e. pharmacogenomics) and can inform what an effective treatment might be based on a person's genetic traits, facilitating more targeted and personalised treatments.⁶⁶ These applications are already revolutionising NHS care, most notably in cancer and rare diseases.^{67,68} They have also made major contributions to viral genome sequencing, testing and informing vaccine development efforts during the COVID-19 pandemic.

3.1.2. Origins, history and evolution of genomics research and innovation in the United Kingdom

Key initiatives and the role of the NHS

Since the discovery of the structure of DNA in 1953, the UK has played a key role globally in leading advances in genomics and its applications for patient, population and health services benefit. The UK was a partner in early efforts related to the Human Genome Project,⁶⁹ which ran from 1990 to 2003; UK contributions came via the Sanger Institute, funded by the Wellcome Trust, and with the Medical Research Council (MRC).⁷⁰ The Wellcome Trust also founded the **Wellcome**

Sanger Institute in 1992 and opened the **Wellcome Genome Campus** in 1994 to help with the UK's contribution to human genome sequencing.

Building on the momentum of the Human Genome Project, the UK set out an early plan and programme of work in 2003 to enable the NHS to seize the benefits of genetics and **committed to funding genetics and genomics research and development**.⁷¹ The **UK Biobank** was then established in 2006 to store genetic and other health information, including de-identified biological samples, to support research advances and discoveries.⁷² Since then, the UK Biobank has facilitated large-scale cohort studies that informed precision medicine efforts, providing researchers with genetic data from half a million volunteers⁷³ and enabling genome-wide association studies examining DNA differences in individuals with and without certain diseases. When linked with lifestyle, health and other data, these datasets help researchers understand the role of various factors in disease.

Between 2001 and 2008, the UK government invested approximately £70m into supporting genetics and genomics, paving the way for further advances within the NHS.⁷¹ A key milestone was the establishment of **Genomics England** in 2013, a company owned by the Department of Health and Social Care (DHSC), to deliver the **100,000 Genomes Project** via the **NHS Genomic Medicine Centres (GMCs)**, and with implementation support from **Illumina**.⁷⁴ The 100,000 Genomes Project focused on integrating whole genome sequencing and clinical real-world outcomes data to better understand the mutations associated with various types of cancer and rare diseases. Its impacts have been felt in both research and care, contributing to further strengthening genomics research capacity in the UK and making a significant difference for many patients who otherwise may not have received a diagnosis for their conditions, enabling the possibility of earlier treatment (Int4a).

Since the early days of genomic sequencing efforts in the UK, the NHS has played a central role in providing patient samples for research and trials, essential clinical data, expertise and infrastructure and pathways for genomic medicine. For example:

- NHS England has **created pathways for genomic medicine use in the health service**, including through the **Genomics Medicine Service**. The **GMS**, launched in 2018, is responsible for **delivering genomic medicine services**.⁷⁵ It aims to enable faster diagnosis, improve the effectiveness of medicines, reduce adverse drug reactions and increase the number of people surviving cancer and getting diagnosed and treated for rare diseases.⁷⁵ The **GMS** employs a unique approach to centralised data, enabling data from the 100,000 Genomes Project (conducted by Genomics England) to integrate directly into NHS clinical practice (Int4a). This novel approach has enabled Genomics England to directly implement a live national clinical service while also contributing to ongoing research. Consequently, this approach necessitated new funding, resources, and a consent model to support both research and service delivery activities (Int4a). NHS England facilitates **access to genomic samples and data** through the **NHS Genomics Medicines Service (GMS) Research Collaborative**. A partnership with Genomics England and the NIHR, this initiative offers anonymised genomic and clinical data and expert advice. NHS patients can also contribute to the **National Genomic Research Library**, supplying de-identified samples and data for research.⁷⁶ NHS England also provides crucial infrastructure and skills to translate genomic

research into practice within the health service. As part of the NHS GMS, NHS England commissions seven genomic laboratory hubs (NHS Clinical Genomic Services) to analyse genomic and related health data, as well as to provide and coordinate treatment and genomic counselling services for patients and families.⁷⁷

- Alongside these hubs, Health Education England and the GMS are focusing their efforts on building a workforce that can deliver genomic medicine while working with patient groups and communities and maintaining adequate data infrastructure. For example, Health Education England began delivering the Genomics Education Programme in 2014 to help NHS staff develop the skills needed to deliver genomic medicine.⁷⁸ The GMS has also convened a Genomics Clinical Reference Group to advise on clinical practice, policy and strategy and maintains the National Genomic Test Directory.⁷⁵ As of October 2022, this service had sequenced approximately 33,000 whole genome equivalents through the service for 190 clinical indications, with the service expanding to serve more patients with rare diseases and cancers within the NHS since its inception in 2018.⁷⁹

Genomics England is a crucial part of the UK's national infrastructure for genomics and has played a significant role in helping accelerate the pace of genomics advances and **improving the representativeness of UK genomic data**. Following a 2021 spending review, Genomics England embarked on new programmes of work, including workstreams to **accelerate genomic sequencing turnaround times** (especially for cancer), facilitated by Oxford Nanopore technology (Int4a) and to **increase participation in genomics programmes amongst underserved groups**. In doing so, Genomics England has sought to improve the accuracy of genomic sequencing insights across diverse populations through the **Diverse Data Initiative** (Int4b), establishing an inclusive patient and public input panel and commencing a **Newborn Screening** programme.

Building on the progress of genomics research infrastructure to date, the UK government announced the **Our Future Health** research programme in 2019, aiming to create a large-scale dataset where consenting participants' health and lifestyle data will be linked with genetic data. In doing so, the programme complements the work of the UK Biobank and Genomics England, adding further capacity and infrastructure for long-term, large-scale population studies to support biomedical advances (Int4a).⁸⁰

3.1.3. A long term-strategic vision, planning and a systems shaping approach

Organisations within the UK landscape have made substantial strides in genomics research in the past decade. The route to achieving impact through genomics has not been easy, and there are several aspects of genomic medicine (related to factors such as **workforce, ethical frameworks, data and participant diversity and funding flows**, for example) that make it difficult to integrate and mainstream into care pathways. There has nonetheless been much progress, **underpinned by government strategies throughout the years**. In 2022, NHS England published the first **five-year genomic strategy for the NHS**, 'Accelerating genomic medicine in the NHS',⁸¹ alongside a strategy implementation plan, '**The Genome UK: 2022 to 2025 implementation plan for England**'.⁷⁹ The strategy led to a plan for genomic medicine services rollout across all levels of care in the UK while ensuring equitable access and benefits for all patient groups and improving the robustness of UK digital and data transformation. This implementation plan emphasised

the central role of the NHS in advancing pharmacogenomics, evaluating genomic medicine applications, offering molecular testing for rare genetic disorders and cancer, sequencing pathogens for surveillance and providing international leadership in genomic medicine. It also highlighted the importance of NHS's efforts in developing data infrastructure, collaborating with research communities, and providing access to clinical test sequences.

In implementing these plans and strategies, the NHS is taking an active role in looking at ways to embed genomic medicine. For example, in January 2024, NHS England established **NHS Genomic Networks of Excellence**⁸² to generate evidence about and develop the **model for the adoption** of genomic advances in the NHS and to enable scale and spread. These networks consist of the NHS, academia, third-sector and industry stakeholders across eight areas and underscore the importance of collaboration across the genomics landscape.* Further progress is being made with national support and funding for genomic laboratory hubs since their establishment, as well as funding for posts in the NHS GMS alliances and transformation projects (such as an NHS-England-funded project for liquid biopsy and ctDNA use in the NHS).⁸³ While there is still a need to establish sustainable, clear and scalable commissioning models, progress with adoption is gradually evolving (Int4a).

Government investments, a policy focus and commitment to bolstering genomic medicine, NHS contributions to research, and industry collaboration have helped place genomics at the heart of UK life sciences research and innovation and introduce it to health service delivery.

Within the UK, there is a long history of public-private partnerships to support genomics research, innovation and service delivery. Major national initiatives and institutions such as the UK Biobank, the 100,000 Genomes Project and the Wellcome Sanger Institute entail collaboration between the NHS, academic organisations and industry partners, as well as patient and public engagement. Many also include international collaborations. In most recent initiatives, such as the Our Future Health programme, the NHS has partnered with companies to provide biological sample receipt and processing services, genotype assay design and genotyping services. NHS England has created a commercial partnership with GRAIL for genomic cancer testing, including a trial of these services and wider roll out, should early results indicate the programme is effective. These partnerships with the private sector help the government and the NHS to take advantage of the considerable expertise and skills built up over the last several decades within the UK and support the wider research and innovation ecosystem.^{84,85}

Collaboration, research and innovation have evolved with due attention to robust governance and oversight. The **National Genomics Board** (established in 2018 to help oversee and advise the UK government's genomic healthcare policy), as well as the work of the MHRA and the National Institute for Health and Care Excellence (NICE), has contributed to **regulation and evaluation** of innovations that are reaching the NHS. The NHS GMS, working with MHRA, NICE and the Accelerated Access Collaborative, are also conducting horizon scanning activities to stay abreast of developments in genomic testing.⁸³ Despite these efforts, some regulatory hurdles persist. One

* Prenatal genomics, tumour biomarker testing, haemato-oncology, rare and inherited diseases, infectious diseases, cardiovascular diseases, pharmacogenomics and medicines optimisation and genomics AI.

such hurdle relates to the blurred boundaries between research and service delivery in genomics that can complicate clarity on which regulatory pathways need to be followed (i.e. for research or service delivery approvals). This lack of clarity can risk regulatory criteria for service delivery being applied to research, potentially complicating a seamless flow and pipeline of research into practice. There are also risks associated with genetic data and the protection of privacy, as information related to an individual can potentially also reveal information about relatives. This raises questions about how to handle and report back on incidental findings (i.e. results that were not the primary aim of a genetic test).⁸³

Finally, progress with the efforts of key organisations, such as Genomics England, benefited from efforts to secure **active patient and public involvement** to inform decisions about research areas and health service needs. According to an interviewee, a patient and public engagement panel of 25–30 individuals contributes actively and is part of the governance structures of Genomics England today (e.g. access to data committee, ethics advisory committee, research network committee) (Int4b). As the interviewee highlighted, patient engagement has been key in Genomics England's work. It is currently proving critical in advancing a recent newborn screening programme, whose design and implementation have been heavily influenced by discussion of ethical considerations around which conditions to screen for (depending on actionability of genetic results), the need for genetic counselling and mental health services, the need to have accurate testing for people from ethnic minorities, the implications of newborn genetic screening for the wider family, consent processes and how to handle incidental results.⁸⁶

3.1.4. Impacts

As a result of advances in genomics research and innovation and its use in the NHS, the UK is already benefiting in terms of impacts on population health and healthcare service delivery, as well as harnessing benefits from a thriving genomics life sciences sector and industry.

Impacts on patients and population health

Genomics applications are revolutionising patient care in the NHS in many areas, most notably in cancer and rare diseases.^{87,88} The impacts of genomic screening on population health are considerable. Through genomic testing, patients can receive an earlier and more accurate diagnosis. This means patients can often receive better care earlier, and further disease progression can be avoided in some cases.⁸⁹ Understanding genetic mutations also enables more personalised medicine, and predictive genetic testing can improve health and well-being at a population level. Patients also benefit from pharmacogenomic services by receiving treatments that work better for them as individuals (depending on their genetic make-up) and by avoiding adverse drug reactions.⁹⁰ Box 8 illustrates some examples of the impact on patients and population health:

Box 8. UK genomics impact on patients and population health

1. Improving cancer diagnosis and treatment:

- Understanding gene mutations and disease risk and informing targeted therapies:** The Wellcome Sanger research informed the development of targeted cancer therapies (e.g. Cancer Genome Project,⁹¹ Human Cancer Models Initiative).⁹² The 100,000 Genomes Project helped identify BRCA1 and BRCA2 gene mutations that increase breast and ovarian cancer risk, informing targeted therapies (PARP inhibitors) that improve patient outcomes, help avoid unnecessary treatment and support preventative measures.^{93,94}
- Cancer pharmacogenomics and optimising treatment:** The 100,000 Genomes Project also helped advance the understanding of drug metabolism and supported developments in pharmacogenomics, allowing patients to get onto more appropriate treatments to optimise drug response (brain, colon, lung, sarcomas and ovarian cancer).⁹⁵ NHS GMS pharmacogenetic testing helped identify which patients may experience severe side effects from specific chemotherapy drugs, enabling clinicians to tailor cancer plans to produce fewer adverse drug reactions.^{96,97}

2. Improving diagnosis and treatment of rare diseases and developmental disorders:

- Receiving an accurate diagnosis:** Approximately 80% of rare diseases have a genetic basis, and many are difficult to diagnose. According to a 2021 study, approximately 25% of patients with a rare disease received a diagnosis due to whole genome sequencing in the NHS and building on the 100,000 Genomes Project. Such beneficiaries include children with developmental disorders who could receive better-targeted therapies, people with neurological disorders (e.g. specific types of epilepsy) and metabolic disorders (e.g. mitochondrial diseases).⁶⁴ The NHS GMS also helps support the diagnosis of rare diseases in newborns.⁹⁸
- Preventing unnecessary treatment through better understanding rare diseases:** 80,000 rare disease genomes were sequenced through the GMS with Genomics England, helping prevent unnecessary operations and treatments in some cases (Int4a).
- Informing the development of novel treatments for rare diseases:** The Wellcome Sanger Institute's work on databases, including OpenTargets⁹⁹ and DECIPHER,¹⁰⁰ helped researchers globally to understand rare diseases. Moreover, organisations such as Mosaic¹⁰¹ and Quotient¹⁰² have been pivotal in leveraging genomics research to develop novel treatments for rare diseases.
- Improving diagnosis and care for patients with developmental disorders and families:** The Wellcome Sanger's large-scale Deciphering Developmental Disorders (DDD) research initiative has already discovered new genes associated with development disorders and led to improved diagnosis and patient care through better management and support, as well as discussions with families around prenatal testing options advancing knowledge about the genetic basis of developmental disorders to improve clinical practices.¹⁰³

3. Wider contributions to public health across chronic conditions and infectious diseases:

- **Other contributions to public health needs, including prevention and disease management:** Research enabled by the UK Biobank is being used to develop diagnostics and treatments to improve patient care in areas like Parkinson's, dementia, diabetes and cancer. UK Biobank research is also helping understand various aspects of public health with implications for disease prevention and management (e.g. how diabetes impacts heart health, links between sleep, physical activity and health outcomes including risk of cancer and cardiovascular disease, and disease risk factors (polygenic risk scores)^{104,105} (Int7). Finally, UK Biobank is contributing to changing primary care practice for patients diagnosed with Type 1 Diabetes who may have been misdiagnosed,¹⁰⁶ and its work on polygenic risk scores has contributed to novel research on the treatment of patients with cardiovascular disease.¹⁰⁷
- **Supporting pandemic response:** Wellcome Sanger and other organisations were instrumental in sequencing COVID-19 genomes during the pandemic. This and other SARS-CoV-2 sequencing efforts (e.g. COG-UK) helped advance knowledge, informed key public health and policy decisions and informed medical innovation. Biobank data and characterised patient cohorts also enabled rapid response contributions to the COVID-19 pandemic, with frequent updates on patient deaths and hospitalisations, the establishment of datasets enabling a better understanding of severe COVID-19 determinants and collection of blood samples to understand viral infection and persistence.^{73,108–110}

Impact on healthcare services and the wider health system performance

While genomic medicine services, including genomic testing, represent a substantial investment for the NHS and the government, they also represent an area where the NHS can save resources and use resources more efficiently. For example, by providing earlier accurate diagnosis, genomic testing can reduce the healthcare resources needed to get a timely and accurate diagnosis and begin treatment for a patient.¹¹¹ This is important for all patients, creating unique opportunities for tackling the challenges of diagnosing rare diseases in children where a traditional diagnosis can take years and be uncertain.^{98,111} Earlier diagnosis for cancer, including childhood cancer, can also reduce disease progression by enabling timelines and better-targeted treatment,^{112,113} potentially reducing the need for more expensive treatments and pressures on NHS resources further down the line.¹¹⁴ Pharmacogenomic testing also reduces medicines waste within the NHS by increasing the chances that patients receive an effective medicine that does not cause adverse drug reactions (ADRs) the first time.⁸⁷ This could save significant resources in the NHS, as an estimated 1 in 16 hospital admissions are connected to ADRs, and unusable prescriptions that cause ADRs cost the NHS around £2bn annually.¹¹⁵

Advances in genomics impact not only the NHS but the wider health system. As the NHS GMS has expanded, both patients and the health service have realised benefits, including decreased time to diagnosis, a reduction in ineffective or harmful treatments and better access to earlier high-quality treatment. As more data is collected and analysed through this service, diagnostic yield (or the proportion of patients sequenced for whom a genomic cause or influence was

identified) has also improved, with an average diagnostic rate of 32%, according to the Genome UK Implementation Plan.⁷⁹

While the affordability of genomic testing has been a concern that has slowed the expansion of this technology in healthcare services,¹¹⁶ the cost of sequencing and analysis has decreased substantially,¹¹⁷ meaning that it is possible that genomic testing can be cost-saving within the NHS. As illustrated in Box 9, there are also wider cost-effectiveness-related impacts on NHS service delivery.

Box 9. UK genomics impacts on the NHS and wider health system

1. Health service transformation and research-informed practice:

- **Supporting innovative, high-quality, evidence-based clinical practice:** Genomics England created a centralised pipeline for genomics data flows and enabled a health service directly informed by a research service. Over 2,000 people who received a diagnosis would not have done so had it not been for the Genomics England dataset and infrastructure (Int4a).
- **Enabling scientific and technological advances in areas of unmet health needs that would not otherwise be possible:** Genomics England, as a government-owned company, also enabled national scale research programmes in high-risk areas that would not have been deliverable through the private sector due to public trust, most recently the newborn screening programme (Int4a).
- **Creating governance frameworks to enable genomic medicine:** Genomics England and the 100,000 Genome Project enabled an oversight and guidance framework to be established for genomic testing in the NHS, with whole genome sequencing now being offered through the NHS for various indications as part of the NHS Genomics Medicine Service.^{118,119}

2. Wider health systems impact - regulatory improvements and impacts on the cost-effectiveness of care:

- **Driving regulatory innovation and improvement:** Genomic data can help regulators make decisions about approving treatments, thus impacting regulatory decision-making. The MHRA is the first regulator in the world to maintain its own genomic database to help understand the safety of medicines through the Yellow Card biobank system.¹²⁰
- **Impacts on costs and cost-effectiveness of care delivery:** It is difficult to estimate the cost-effectiveness and cost savings to the healthcare system from genomic testing,¹²¹⁻¹²³ and the benefits of individual tests will vary greatly depending on the diagnostic yield, the actionability of results and other factors. However, one analysis of the 100,000 Genomes rare disease diagnosis pilot estimated that genomic testing in this programme mitigated £87m in costs to the NHS through reduced hospital care costs (from earlier diagnosis).¹¹⁶ Additionally, there is evidence that population-wide genetic testing for the BRCA1/2 genes is cost-effective in high-income countries, including the UK.¹²⁴ Wider evidence also suggests that genomic sequencing is a cost-effective option (compared to standard care) for diagnosing infants and children with rare or undiagnosed conditions,^{125,126} for

neurodevelopmental disorders,¹²⁷ for developmental and seizure disorders,¹²⁸ and for critically ill children.¹²⁹ However, this evidence is not specific to the NHS or the UK. Reviews of the cost-effectiveness of pharmacogenomic testing suggest that the potential for cost savings varies depending on the application, disease group and context. However, the majority of studies suggest positive results.¹³⁰ For example, one study found that implementing a 12-gene pharmacogenetic panel significantly reduced adverse drug reactions across different geographical settings (including the UK).¹³¹

Impacts on the economy and society

The field of genomics provides tangible value to the UK both in terms of high-impact global investments and the global influence it creates. Box 10 illustrates some impacts of UK genomics research on the economy and society.

Box 10. UK genomics impacts on the economy and society

1. Contributions to the economy:

- **The overall impact on the economy:** The 2021 Genomics England Annual Report estimated that the genomics sector at the time contributed £2.5bn per year to the UK economy, up from £2.3bn in 2018/2019 and £1.9bn in 2017/2018.¹³² In the same year, the UK BioIndustry Association found that UK genomics had a market cap of £5bn, and could reach £50bn by 2040.¹³³
- **Attracting investment:** Whilst public funding for innovations, including via Genomics England, has been central to growth, the ecosystem that this public funding creates for private sector expansion has also been key. The magnetism for external investment and attention is a particular strength for the UK genomics sector and creates benefits for the UK public (Int4b). The 2022 Genomics England Annual Report found that the sector has drawn £1.9bn in venture investment.¹³⁴ Key partnerships with multinational companies have been a hallmark of UK genomics research, with pharmaceutical investments in genome sequencing over the years contributing to UK Biobank activities and creating publicly available sequencing datasets for the scientific community (Int7). An ABPI report further highlighted the growth potential of UK investment in genomics as exemplified by Our Future Health, which was established with £79m from UKRI and has since drawn over £140m in life sciences industry funding as of 2022.⁸⁵ Oxford Nanopore, a key player in the UK genomics sector and a recipient of Genomics England support, received a valuation of £4.6bn in its 2021 IPO and has since drawn support from investment vehicles such as Novo Holdings.^{135,136}
- **Enterprise and job creation:** As a result of advances enabled by these genome sequencing efforts, the UK has also benefited in terms of growth in enterprise in the biotechnology sector and job creation. The role of public investment and subsequent private investment in genomics creates downstream benefits for job creation and business turnover – 2024 figures on the bioscience and health technology sector for 2021/2022 showed that

genomics job creation doubled between 2016/2017 and 2021/2022, from 3,200 to 6,800, with particular growth at genomics application sites.⁷⁰

- **Turnover:** Moreover, the UK genomics sector created a turnover of £3.6bn in 2021/2022, continuing a significant growth trajectory which took place between the mid-2010s and the end of data collection.¹³⁷

2. Wider societal benefits:

- **Social understanding of genomics and its potential:** The impacts of the 100,000 Genomes Project and Genomics England extend beyond clinical impacts alone, with wider societal benefits spanning greater public awareness of genetic conditions enabled by related educational initiatives and more focus on discussing legal, ethical and societal implications related to using genomic data.^{138,139}
- **Intellectual property and the advancement of knowledge and innovation:** Biobank UK has also had an impact on methodological innovation in applying computational methods to analyse large datasets and foster diverse national and international collaborations, as well as economic impact through attracting funding for research and for the biomedical innovation sector, including into biotech and pharmaceutical industries drug discovery and development.¹⁴⁰ Biobank UK work has supported 935 patent filings spanning patents for methods, therapeutics and imaging-related IP. Biobank-enabled research has fed into 9,528 (as of September 2023), demonstrating its immense value for the global research community.¹⁴¹

3.1.5. Reflecting on influences on progress: enablers and challenges

In reflecting on the above, it is clear that current progress has, in large part, been enabled by a combination of factors that have underpinned a strategic approach to building genomics medicine research and innovation and supporting its translation into patient, population, health service and wider societal and economic benefits (see Table 1).

Table 1. Enablers and challenges to research and innovation in genomic testing and screening

Enablers of progress to date	Challenges to progress to date
<ul style="list-style-type: none"> • Sustained funding commitments for research and innovation in the key institutions driving genomic medicine and funding from public, not-for-profit and industry sources. This has helped strengthen the evidence base and provides a signal of government commitment to industry (Int4b). • National strategies and implementation plans for adopting genomic medicine in the NHS that consider system needs related to the wider data, science and technology infrastructure for genomic medicine, workforce issues and patient and public engagement needs.^{79,81,142} • Extensive collaboration within and across public and private sectors in delivering research and innovation activity,⁸⁵ including using genomic data for early drug target identification (Int4a). • NHS contributions to research and innovation and its key role in driving genomic medicine services to patients, alongside other institutions. • A dynamic approach to research informing the service and the service informing research in real time (i.e. Genomics England running a live national clinical service (interpreting clinical data) alongside a research service (Int4a)). • Efforts to train the NHS workforce,¹⁴³ including programmes developing new skills in interpreting and analysing genomic data. • Focus on public engagement: Efforts by key institutions (such as Genomics England) to include patients and the public in programme design and delivery¹⁴⁴ (Int4a). • Gradual significant reduction in the cost of genome sequencing (Int4a), allowing a scale-up in activity. 	<ul style="list-style-type: none"> • Ensuring a critical mass of workforce capacity and skills¹⁴⁵ was a key focus area from the onset of the GMS in England by those who designed and implemented it and led to the Health Education England (HEE) training programme.¹⁴⁶ • Including more diverse populations in genomics research and innovation: Genomics efforts have struggled with understanding genetic variants across populations, as 80% of genome-wide association studies focus on people of European ancestry, while only 2% involve those of African ancestry. This disparity makes genomic tests less accurate for non-White populations, with polygenic risk scores being up to four times more accurate for Europeans.^{147,148} Some progress is being made with initiatives such as the Genomics England Diverse Data initiative (Int4a). • Bolstering existing data architecture to facilitate localised sequencing with centralised data pipelines and flows. Data sharing remains complex, and data standards are still evolving; how data federation will work in practice remains in question (Int4a, Int4b). • Clarifying governance and regulation of data access and data sharing flows in the system: Most key institutions have consented data for re-use, but data sharing models and agreements need attention and data linkage remains a challenge, alongside the need for clearer, simplified and streamlined regulation¹⁴⁹ (Int4b, Int7). • Clarifying and establishing more sustainable and scalable, easier-to-navigate commissioning and procurement channels (Int4a), including national versus local commissioning.

3.1.6. Looking to the future: a vision for impact in genomics testing and screening ten years from now

Advances in genomics and other disciplines are opening up new frontiers that will influence how genomic medicine in the NHS evolves in the future. In a future vision for what 'good' looks like, genomics screening and testing in the NHS will include:

- **A critical mass of well-trained NHS and health system staff and interdisciplinary teams to help ensure scientific advances reach the health service and patients across the UK:** Staff will work in interdisciplinary teams (clinical, ethics, computational analysis, data science). This will help overcome earlier capacity and skills challenges in areas like interpretation of genomic data and data science.
- **Better data access, sharing and linkage, and the convergence of technologies (e.g. genomics, quantum, synthetic biology, AI) to enable new application areas, such as improving patient care throughout the life course through better prediction of patient and population needs, timelier intervention and better health system resource allocation.** Scientific advances at the interface of genomics, quantum, synthetic biology, advanced imaging and AI will enable even more accurate and quicker diagnosis, new predictive tools, and novel personalised treatment. These advances will build on earlier progress with genomics convergence with fields such as synthetic biology (e.g. CAR-T therapies for cancer, see Box 11). Genomic data will be linked at scale to other datasets (phenotypic, clinical, etc), with screening taking place at birth, adulthood and particular disease-specific diagnosis points to help identify and forecast both individual and population needs across the country and to more effectively prioritise and target resources for research, innovation and care delivery, potentially facilitated by a single patient genomic record (Int4a). Building on the opportunities created by UK Biobank and other efforts to access de-identified GP data, researchers will be able to address diseases for which preventative care is possible, including cancer and cardiovascular disease (Int7).
- **Organisations contributing to genomic science and genomic medicine will have more clarity on funding, commissioning and procurement flows, reducing uncertainty about rewards for their efforts. This will encourage collaboration (within healthy competition) but prevent siloed empires.** Challenges related to ownership and distribution of benefits from commercial initiatives will receive more policy attention, addressing uncertainties in how contributions are accredited and valued (Int4a).
- **R&D governance and regulatory requirements for data access, sharing, use and reuse will be more streamlined and simpler to navigate, supporting greater efficiency in genomic research, innovation and adoption in the NHS.** This applies to data access, sharing and re-use for increasingly complex purposes. It will be possible to deal with more complex ethical questions around consent, e.g. access to data for population management and predictive uses, requiring effective and transparent public engagement and safeguarding to prevent misuse (Int4b).
- **Access to long-read sequencing technology in primary care will enable more localised genomic medicine in the community, leading to faster turnaround times for patient**

results (30–60 min) and better collaboration and coordination between local and national genomic medicine efforts. Moreover, mobilising technological advances in protein profile measurement will enable patients to have blood tests at GP surgeries to predict their risk for diseases such as Alzheimer’s, enabling early prevention (Int7).

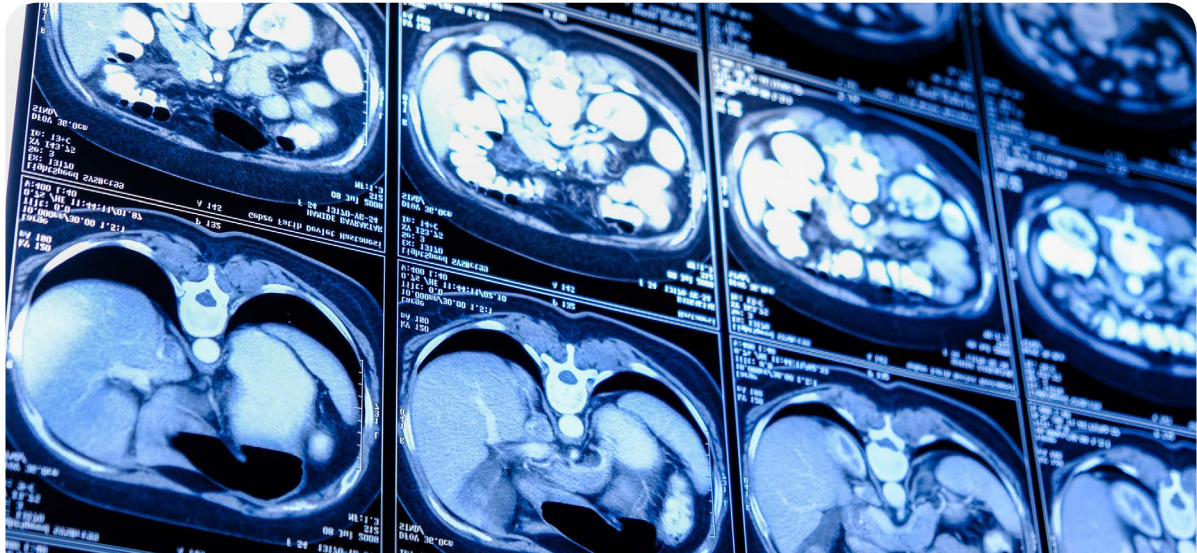
- **Active public engagement and outreach, coupled with transparency in ways of working of genomic initiatives, will support more diverse participants in research and innovation efforts, increasing the accuracy of genomic testing, reducing inequalities, improving the relevance of genomic medicine for diverse populations and enhancing public trust.** The use of community champions will help bolster outreach efforts (Int4b).

Box 11. CAR-T therapy

- Advances in genomics and convergence with synthetic biology advances have enabled the development and adoption of CAR-T therapies for cancer, where a patient’s own immune system cells are engineered (i.e. involving genetic modification of a patient’s T-cells) to help in the fight against cancers such as various lymphomas and leukaemias.¹⁵⁰
- England was the first European country to adopt a national service for delivering CAR-T therapy, with treatments needing approval from the National CAR-T Clinical Panel.¹⁵¹ There are currently three types of CAR-T therapies approved by the UK’s Medicines and Healthcare products Regulatory Agency, available for adults with lymphoma and some children with leukaemia who have not responded to standard treatment,¹⁵¹ CAR-T therapy through standard NHS reimbursement with an upfront cost regardless of success (or lack thereof) of treatment.¹⁵² CAR-T therapy is given via the Cancer Drugs Fund and other patient access schemes through the NHS, with the therapy delivered regionally through commissioned CAR-T centres. CAR-T became a treatment option in the NHS in 2018 when NICE approved axicabtagene ciloleucel (Yescarta) for use in adults with large-cell lymphoma who have stopped responding to prior treatments and had the cancer return.¹⁵³ Another CAR-T therapy, brexucabtagene autoleucel (Tecartus, Kite), is also recommended for treating relapsed or refractory B-cell acute lymphoblastic leukaemia.¹⁵⁴
- CAR-T therapies have received significant interest for their long-lasting effects, short treatment time,^{155,156} fast recovery time (especially compared to chemotherapy and radiotherapy),¹⁵⁵ and effectiveness for resistant cancers (with benefits lasting even for a few years),^{155,157} and non-immunogenic approach. However, their widespread adoption also faces challenges related to affordability,^{158,159} appropriate laboratory and clinical facilities, quality and regulatory processes.^{160,161}
- The specialised nature of the treatment imposes specific structural, logistical and infrastructural requirements, as well as the healthcare workforce’s capacity to enable the safe and effective delivery of the therapy.¹⁶² These challenges will need to be overcome to help fully capitalise on CAR-T potential and impact to date.

3.2. AI applications in cancer screening and diagnosis

Box 12: Case study summary - AI applications in cancer screening and diagnosis



Since the 2010s, the UK has placed significant policy focus on the potential of AI to support cancer screening, detection and diagnosis, and the NHS has played a key role in facilitating progress:

- The 2019 NHS Long Term Plan established the NHS AI Lab and the UK AI in Health and Care Award. The NHS has provided patient samples, data, infrastructure and clinical input.



Impacts on patients and population health:

- AI supports accurate cancer detection and diagnosis and can improve detection rates and access to timely diagnosis. Early results from the deployment of an AI tool for breast cancer detection (Khieron's Mia) identified 12% more cancer cases than traditional detection methods.
- AI can also reduce waiting times for access to diagnosis and associated patient anxiety. Skin Analytics provides simple-to-access mobile-phone-enabled technology to enable rapid melanoma diagnosis.
- AI can help protect cancer patients from unnecessary tissue radiation by better targeting where radiation is delivered, e.g. using OSARIS' auto-segmentation technology.



Impacts on the NHS and wider health system:

- AI can potentially enable efficiency gains by reducing clinician workload and enabling faster cancer diagnosis. AI can help rule out patients with a very low risk of cancer and accurately identify patients at high risk, enabling clinicians to prioritise these for review.

- While the evidence base on impact is still evolving, AI-enabled tools complement clinical decision-making. They can save specialists time and improve care quality (e.g. OSAIRIS for targeted radiotherapy, DERM for skin cancer detection, Pinpoint blood test for screening multiple cancers, Annalise.ai tool for interpreting tissue images).



Impacts on the economy and society:

- AI-enabled innovation could reduce healthcare costs, with earlier and more accurate cancer diagnoses mitigating the need for more expensive later treatments. A study using retrospective data and modelling of AI applications in lung cancer detection identified a £6,000 healthcare cost benefit per patient and economic productivity gains of £2.4m related to the ability to work.
- Investment in AI for cancer diagnosis also helps to promote growth in the UK life sciences sector.

A Future Vision for Success: AI for Cancer Screening and Diagnosis in the NHS



NHS staff will be trained to engage with AI for cancer detection and diagnosis effectively, safely and with good balance with clinical judgement. A greater understanding of the benefits, limitations and risks that need managing will help increase trust in using AI in routine care to facilitate early cancer diagnosis and inform prevention measures.



Technological advances and better data quality from more diverse populations will improve the accuracy and relevance of AI tools, helping mitigate inequalities. Data and evolving evidence will ensure AI algorithms and tools are regularly updated to optimise performance.



Investments in developing explicit regulatory regimes and innovation enabled by technological advances (e.g. synthetic data and digital twin technology) will improve the UK's attractiveness as a location for developing and testing AI solutions. The resulting increase in trial activity will support faster patient access to innovation.



Collaborations between academia, industry and the NHS will enable technological advances in areas such as quantum computing to benefit the quality and speed of AI-enabled cancer diagnosis and the ability to analyse more complex data sets.



More inclusive patient and public involvement, engagement and participation in developing and implementing AI tools for cancer diagnosis will increase public confidence that AI is being used ethically and transparently and trust in the quality of care they receive.

3.2.1. Introduction

The COVID-19 pandemic and its aftermath saw oncology waiting lists reach historic highs due to a combination of delays to cancer screening programmes, chronic workforce shortages in radiology and pathology and care backlogs from patients who could not seek cancer services during the pandemic.¹⁶³ There is substantial evidence suggesting that long referral-to-treatment (RTT) times create negative health consequences for patients, and while there is improvement in RTT waiting times for patients, achieving targets remains an ongoing challenge.¹⁶⁴ In this landscape, AI presents a promising solution for cancer care, particularly for cancer screening, diagnosis and clinical decision support.

New technologies for cancer screening and diagnosis can help address these issues, potentially supporting timelier diagnosis and treatment access and increasing the efficiency of workflows for frontline NHS staff.^{165,166} While this field is still evolving, early evidence from AI technologies for cancer care is promising, especially in enhancing existing cancer screening and diagnosis processes and facilitating quicker access to diagnoses.

3.2.2. Origins, history and evolution of AI in cancer screening and diagnosis in the UK

Computer-aided diagnostics have been under development in some form since the 1950s, but their adoption and advancement in health systems across the world was slow.¹⁶⁷ Momentum grew in the 2010s when **funding opportunities** improved, including from bodies such as the MRC, Innovate UK and the Engineering and Physical Sciences Research Council (EPSRC). Investment drove continuous research and development in AI and machine learning, boosting academic research and innovation, including through partnerships with industry and the NHS.¹⁶⁸ In the late 2010s, screening, diagnosis and detection of cancer also rose higher on the **policy agenda**. It was identified as a priority in key policy documents such as the NHS Long Term Plan, which flagged improved cancer survival as a key priority and set out aims to increase the proportion of cancers diagnosed early from approximately 50% to 75% by 2028.¹⁶⁹

In the late 2010s, national policymakers increasingly concentrated on exploring how AI could help transform cancer care while producing key economic benefits. The **2017 Life Sciences Industrial Strategy**¹⁷⁰ highlighted the importance of early cancer detection and opportunities for advanced research in AI cancer diagnostics. In the **2017 UK Industrial Strategy**, the UK government positioned AI as one of the key 'Grand Challenges' to help promote UK economic growth across sectors. This strategy informed later funding decisions, including the **2018 AI Sector Deal**,¹⁷¹ which included a £950m package of funding for AI research and collaborations across sectors, including AI applications in health and life sciences.

In translating this focus from research to health practice, the **2019 NHS Long Term Plan**¹⁷² included £250m in direct investment in AI via the **NHS AI Lab**¹⁷³ (established in 2019) and the **AI in Health and Care Award**¹⁷⁴ (launched in 2020). Doing so signalled growing interest in facilitating partnerships between academic institutions and industry players. These partnerships have been highlighted through publicly funded research programmes such as the NCIMI (National Consortium of Intelligent Medical Imaging)¹⁷⁵ and iCAIRD (the Industrial Centre for AI Research in Digital Diagnostics), two programmes launched in 2018 to encourage collaboration across academia, industry and clinical experts.¹⁷⁶ Early investments in cancer and AI from these

programmes included an AI-driven breast cancer screening technology produced by Kheiron Medical Technologies and an early lung cancer detection programme developed by Aidence (both of which have now been acquired by DeepHealth).¹⁷⁷

More recently, other funding programmes have also supported innovation in cancer diagnosis that uses AI developments, though they are not explicitly focused on AI only. Examples include the **NHS England Cancer Programme** and the **Small Business Research Initiative (SBRI) Healthcare**¹⁷⁸ open funding calls for implementation testing of novel cancer diagnostics (launched in 2021) that could help improve early cancer detection and diagnosis. The Department of Health and Social Care also launched the **AI Diagnostic Fund** in 2023 to accelerate the deployment of AI tools for imaging and decision support in the NHS,¹⁷⁹ with cancer being one of the key areas of interest, including prioritisation of technologies to support clinicians in analysing chest X-rays to assist in lung cancer diagnosis. This £21m fund aims to support 12 imaging networks across 64 NHS trusts in England.

Much current research and innovation in AI-enabled cancer screening and diagnosis involves **collaborations between academia, the NHS and sometimes industry**. Various collaborative programmes are focusing on AI applications in oncology as part of their remit. Examples illustrating collaborative activity include programmes such as DOLCE, PATHLAKE and DART:

- **DOLCE**¹⁸⁰ is a new programme examining applications of Optellum, a software programme that helps clinicians analyse lung nodules. The study is investigating¹⁸¹ if the software can improve clinicians' ability to diagnose lung cancer early and its impacts on patient outcomes and cost-effectiveness. The study is led by researchers across academia and the NHS in Nottingham and is being tested in ten hospital trusts across England.
- **PATHLAKE** is one of five UK Centres of Excellence in digital pathology, initially funded by the UKRI Industrial Strategy Fund in 2019.¹⁸² The purpose of the programme is to develop, validate and implement AI for cellular pathology, including a flagship programme of work on bowel cancer, building on the expertise of its NHS, academic and industry consortia partners, including Philips and Nvidia. In the long term, the programme aims to improve pathology reporting efficiency and patient outcomes by leveraging AI.
- **DART**¹⁸³ is a research programme that leverages data from the NHS Lung Health Check programme to develop, validate and implement AI for quicker lung cancer diagnosis. Launched in 2020,¹⁸⁴ the programme aims to improve the speed and accuracy of diagnosis, improve the patient experience of care, and change guidelines and how care is delivered within the NHS. It is currently evaluating two AI programmes. The programme draws together clinicians from the Brompton Hospital and Imperial College, Nottingham University, the University of Oxford, Royal Marsden and UCLH, as well as academics and industry partners from across the UK, including GE Healthcare. DART is funded by Innovate UK, Cancer Research UK (CRUK), GE Healthcare, Optellum and Roche Diagnostics.¹⁸⁵

The NHS is an active partner in these efforts, supplying patient samples, data and clinical expertise. These programmes leverage NHS clinician involvement and opportunities for partnership with hospitals and trusts to gain access to substantial expertise and grounds for trialling solutions. At present, substantial activity in the NHS focuses on research and innovation (R&I) projects, trials and pilots, and some integration and deployment of AI-enabled diagnostic

tools in cancer care.^{186–189} For now, these tools are not typically intended to replace a clinical expert's judgement but to aid in and accelerate decision-making and support efficiency in triage and referrals, e.g. by flagging scans that need urgent and immediate clinical review and action.¹⁹⁰

Some notable examples of projects and initiatives to bring AI-enabled cancer diagnosis into the NHS (at varying stages of development and deployment) **include:**

- **Annelise.ai:** An AI-driven diagnostic support application that helps clinicians read and interpret chest X-rays to support early lung cancer detection and avoid missed issues on scans. The application was already successfully deployed for clinical decision support in NHS Grampian, University Hospitals of Morecambe Bay NHS Foundation Trust and Epsom and St-Helier University Hospitals NHS Trust, and as part of the AI diagnostics fund will be available in Greater Manchester, North East and North Cumbria Imaging Network, Cheshire and Merseyside Radiology Imaging Network, East Midlands Imaging Network, Surrey, Sussex and Frimley Imaging Network and the Yorkshire Imaging Collaborative.^{191–193}
- **DERM (developed by Skin Analytics):** An AI as a Medical Device (AIaMD) tool used to analyse dermoscopic images of skin lesions to determine patient referral pathways after attendance at an imaging clinic. The tool aims to help make more appropriate referral decisions for patients, directing those with benign skin conditions to GP practices and those with malignant lesions to specialist dermatologists. The application has been piloted or implemented at Liverpool University Hospitals, Buckinghamshire Healthcare, Tameside and Glossop Integrated Care, Ashford and St. Peter's Hospitals, Chelsea and Westminster Hospital, Lancashire and South Cumbria Integrated Care Board, and West Suffolk NHS Foundation Trust.^{194–198}
- **Qure.ai:** An AI-powered solution that identifies abnormal chest X-rays from normal scans, aiming to improve the prioritisation of high-risk patients and the early detection of lung cancer. The solution was first trialled in Royal Bolton Hospital¹⁹⁹ during the height of the COVID-19 pandemic as a way of urgently addressing existing needs for lung cancer screening assessment and diagnosis and has since been trialled through the LungIMPACT study²⁰⁰ located within University College London Hospitals NHS Foundation Trust, Nottingham University Hospitals, and East Suffolk and North Essex NHS Foundation Trust.^{201–203} Moreover, Qure.ai technology for lung cancer diagnosis from chest X-rays is being used in NHS Frimley Health Foundation Trust, East Kent Hospitals University NHS Foundation Trust, and in the Greater Manchester Cancer Alliance, and being tested more recently in University College London Hospitals NHS Foundation Trust and University Hospitals of Leicester NHS Trust.²⁰⁴ It aims to improve the timeliness, speed and accuracy of detecting lung cancer and to assist in managing demands on NHS staff time, with the hope that it will improve patient outcomes and experiences.²⁰⁵
- **DeepHealth:** Provides AI-enabled solutions for lung cancer diagnosis and breast cancer detection. Its **DeepHealth Lung technology** aids lung cancer diagnosis and is used in over 40 sites in the UK to help with automatic detection, measurement, classification and growth tracking of lung nodules.²⁰⁶ Government policies, including a policy push for targeted lung health checks as part of a national screening programme and NHS England support for AI adoption in the NHS, have enabled uptake of the solution across NHS England. Moreover, **Kheiron Medical Technologies**, which was founded in 2016 and joined DeepHealth in 2024,

provides breast cancer screening solutions to the NHS. Kheiron and the breast cancer AI application, Mia, benefited from the NHS AI in Health and Care Award in 2020,²⁰⁷ which recognised the role of Mia in the NHS Breast Screening Programme (NHSBSP). Since then, Mia has been proven in a trial evaluation in Scotland to help clinicians detect an additional 12% of breast cancers and a 30% workload reduction by eliminating unnecessary recalls.²⁰⁸

- **OSAIRIS:** An AI tool that supports clinicians with radiology scan preparation using auto segmentation to delineate where the radiation should and should not be used, thus protecting healthy tissues from radiation. The tool supports clinicians conducting segmentation prior to radiotherapy and has been integrated into regular radiology pathways in Addenbrooke's Hospital (Cambridge) (Int12).²⁰⁹
- **The Pinpoint Test:** A blood test that uses AI to predict the probability of a symptomatic patient having cancer. This clinical decision support tool combines multiple measures from patient blood tests to support GPs and secondary care healthcare providers in making clinical decisions and informing patient care in multiple cancer pathways. The test was developed by NHS clinicians at Leeds Teaching Hospitals NHS Trust, utilising retrospective patient data, and built to integrate into existing clinical pathways without creating additional work for clinicians.²¹⁰ The test is being deployed to the NHS in stages, beginning with a feasibility study in GP practices in two parts of Yorkshire and expanding to other GP practices throughout the Yorkshire region.²¹¹
- **The Galleri blood test:** A test that GRAIL developed to detect multiple types of cancer earlier by identifying abnormal DNA shed into the blood from cancer cells from blood samples (liquid-biopsy-based) and to characterise cancers using genetic sequencing technology, with the potential for AI to help in the process. The NHS-Galleri trial involves 140,000 participants and is looking at the clinical utility of this test and its impact on cancer outcomes in the NHS.²¹² Early data suggests high test accuracy, but further evidence must accumulate before considering its rollout.²¹³ AI can be used in the GRAIL test to help look for shared cancer signals across multiple types of cancer at an early stage.²¹⁴

Along with research and innovation programmes, there has been a focus on **developing workforce skills and capabilities** to engage with AI. The 2019 Topol review highlighted the importance of digital skills in the NHS workforce, including in the context of AI.²¹⁵ To address this, HEE created resources to generate healthcare professional confidence in AI.²¹⁶ While these resources are not cancer-specific, they include skills directly relevant to using AI in cancer care contexts. The Royal College of Radiologists is also working to develop tools and resources, including clinical guidelines for using AI in chest X-rays, for example, and for auto-contouring in radiotherapy.²¹⁷ Nonetheless, trust in AI within the healthcare workforce is not uniform, and fear, misunderstanding and mistrust are common factors that dissuade adoption (Int8).²¹⁸ Recently, we have also seen increased focus on regulating AI use in healthcare and the NHS. Regulation for AI, including AI as a Medical Device (AIaMD), is an ongoing consideration within the UK MHRA. Building on various strategic approaches to AI, as set out in a 2023 government white paper, 'A pro-innovation approach to AI regulation'²¹⁹ and the 2024 MHRA strategy, 'Impact of AI on the regulation of medical products',²²⁰ the government announced its new AI Airlock (an initiative to clarify and improve AI-enabled medical devices) in May 2024, which will establish a regulatory sandbox for AI technologies in healthcare.^{221,222} The Airlock allows for testing AI solutions in a

real-world environment and will help the MHRA identify and respond to challenges associated with regulating AI-enabled medical devices.²²³

3.2.3. Impacts of AI cancer diagnostics in the NHS

Numerous AI technologies have been tested or integrated into healthcare pathways in the NHS, with varying levels of scale and adoption. Whilst the evidence base for many of these technologies is still emerging through pilot and trial programmes in NHS settings, early evidence suggests that AI for cancer diagnostics can lead to benefits for NHS patients, staff and the wider health and innovation system. Amid growing interest and extensive testing efforts, the evidence base for use cases and trials in the UK is expected to evolve rapidly in the coming years to complement existing international evidence.

Benefits for patients

A growing body of trial and real-world evidence suggests that applying AI tools for cancer diagnosis and guiding subsequent care has already shown benefits for patients in high-priority clinical areas, such as lung cancer, skin cancer and breast cancer.^{189,190,224,225} These benefits span improved patient experience through shorter diagnostic waiting times and better access to diagnosis, which may, in turn, help to reassure patients and provide peace of mind, as it reduces the time to wait for results and/or diagnosis.²²⁵

Box 13 provides some examples of evidence of impact on patients to date:

Box 13. AI and cancer diagnosis: emerging evidence of impact on patients

- **Enabling accurate and timely cancer diagnosis for patients:** SkinAnalytics' DERM showed good accuracy in detecting melanoma (100% sensitivity [51/51] in identifying all true cases, 99.5% sensitivity (218 of 219) for all skin cancers, and 96.3% sensitivity (235 of 244) for premalignant lesions) while using utilising accessible hardware (i.e. mobile phones).²²⁴ While the platform only identified benign lesions at 55.9% specificity, its ability to identify cancerous or pre-malignant lesions reflects its ability to translate urgent skin cancer referrals into rapid action, investing specialist dermatologist time into high-risk cases whilst assessing lower-risk lesions on more traditional pathways.²²⁴
- **Improving breast cancer diagnosis while reducing clinician workload:** Early evidence from deploying Mia in NHS Grampian revealed that the technology helped clinicians detect an additional 12% of breast cancers while reducing clinical workload by up to 30%.²⁰⁸ Building on a retrospective study in NHS Grampian, alongside evidence from 14 additional sites in the NHS, the technology could be used to screen over 500,000 patients per year, improving diagnosis rates as well as the survivability of breast cancer through early detection.^{208,226}
- **Protecting patients from unnecessary tissue radiation during treatment:** OSAIRIS was implemented in regular practice in Addenbrooke's Hospital (Cambridge) and found to be precise and accurate in the auto-segmentation of patient scans – improving on existing manual segmentation processes, which are used to delineate where radiation should be used and protect healthy tissue from radiation. Utilising technology-driven autosegmentation

to support clinicians has yielded positive results for patients and NHS staff alike, in particular by providing safe, faster care and producing substantial cost savings, which can then be re-invested into patient care (Int12).¹⁸⁹

- **Providing acceptable care to patients:** A study conducted by researchers at Chelsea and Westminster Hospital NHS Foundation Trust, Queen Mary University of London and Skin Analytics, looking at the use of AI in melanoma diagnosis, found that patients were broadly supportive of the use of AI as a medical device, particularly when AI supports critical outcomes such as urgent cancer referrals.¹⁹⁰ By reducing unnecessary waiting times and referrals, the system can also reduce patient anxieties prior to diagnosis or discharge.²²⁷

It is worth noting that Annalise.ai and Qure.ai have been tested internationally, including in Australia,²²⁸ Europe,²²⁹ South Africa²³⁰ and Turkey.²³¹ While these studies were not conducted in the UK NHS, all produced promising results from using AI solutions in AI cancer diagnostics, including improved patient care and increased clinical trust in AI solutions.²²⁸ This evidence can then be mobilised to pilot and potentially implement these programmes in the UK, as has occurred for both technologies.

Benefits for the NHS and the wider health system

Current studies and evaluations of the deployment of AI-based cancer diagnosis in the NHS (be it from trials, implementation pilots or evaluations of wider scale use) **have also shown some signs of benefits for the NHS more widely** in supporting more efficient workflows, prioritisation and better use of clinician time (e.g. releasing time for more focus on malignant cases), providing reassurance and acting as an aid to clinical judgement on diagnostic test results.

Box 14 illustrates some examples of evidence of the emerging impact on NHS staff:

Box 14. AI and cancer diagnosis: emerging evidence of impact on the NHS

Saving NHS staff time and supporting care decisions:

- A study on the use of the cancer image auto-segmentation tool OSARIS at Addenbrooke's Hospital in Cambridge showed that radiology segmentation time, or the time spent segmenting healthy from cancerous tissue prior to radiotherapy, was cut by an average of 93% whilst maintaining a level of clinical accuracy comparable to a human, as demonstrated in masked tests known as Turing tests.²³² The technology has since been integrated into the regular radiology pathway at Addenbrooke's, serving over 200 patients per month and making care run faster than nationally-defined targets (Int12).²³³
- A retrospective study of the performance of the Pinpoint Test,²¹⁰ looking at urgent cancer referral data from 371,799 referrals in Leeds from 2011 to 2019, showed high accuracy of the developed algorithms in ruling out patients with a very low risk of cancer and accurately identifying high-risk cases so clinicians can prioritise these for review and accelerate decisions about next steps in their treatment and care.²¹⁰

- Using DeepHealth Lung AI technology helps radiologists interpret pulmonary nodule scans faster. The application of this tool at Salisbury NHS Foundation Trust and University Hospitals Southampton NHS Trust has, according to one clinician and based on a case study, reduced her CT reporting time by approximately half.²³⁴

Providing reassurance:

- Many tools such as OSAIRIS,²³⁵ DERM,²²⁷ the Pinpoint Test,²³⁶ and Annalise.ai²³⁷ are specifically designed to complement clinical judgement in the NHS. Annalise.ai, in particular, highlights the role of the application as 'a second set of eyes' for clinicians to help facilitate faster diagnosis.¹⁹³ While evidence for many of these tools remains under development, their existing use and trialling in the NHS is intended to support clinical judgement to save time without compromising safety.

Benefits to society and the wider economy

Evidence of AI-enabled innovation and its impact on the economy and wider society is still emerging and likely to evolve and advance over the years. Some examples of the potential for economic benefit are summarised in Box 15 below:

Box 15. AI and cancer diagnosis: emerging evidence of economic impact potential

- **Job creation:** AI-enabled innovation in cancer also supports the UK life sciences sector and the creation of enterprises and jobs. The technologies mentioned above are being developed in companies with a UK presence and/or headquarters (e.g. The Pinpoint Test, OSAIRIS, Skin Analytics, presence in the UK from companies with headquarters elsewhere as well, e.g. DeepHealth, which is the digital health division of US company RadNet).
- **Healthcare cost savings, quality of life and economic productivity gains:** Investment in cancer research²³⁸ and envisaging AI applications as an important part of that investment is also expected to impact the UK economy with potential productivity gains associated with a healthier population and healthcare cost savings. A recent retrospective study of using AI image analysis for early lung cancer detection used real-world data from a population sample with high levels of socioeconomic disadvantage and health needs and estimated based on modelling that AI-enabled diagnosis was associated with a £6,000 healthcare cost benefit per patient with lung cancer, a £21m value of improved quality of like adjusted life years over ten years, and £2.4 million in economic productive gains related to the ability to work.²³⁹

3.2.4. Reflecting on key influences on progress: enablers and barriers

A diversity of technological, social and regulatory factors have influenced progress made with AI applications in cancer in the NHS to date. Table 2 (below) summarises the learning gained.

Table 2. Enablers and challenges to research and innovation in genomic testing and screening

Enablers of progress to date	Challenges to progress to date
<ul style="list-style-type: none"> • Funding from public sector programmes for AI research and innovation in oncology – for developing, trialling/testing and implementing solutions and supporting advances in the field, as well as where present (such as in the national lung health checks screening programme, a clear route to reimbursement). • Policy impetus from both industrial strategy and health policy bodies to help advance the AI sector. • Investment in developing workforce skills and supportive resources to help NHS staff engage with AI tools. • Collaboration between researchers in academia and industry and the NHS, with the NHS being a key source of not only imaging and patient data but also clinical expertise and testing infrastructure. Close collaboration between industry and NHS also helps industry develop products that work for NHS staff (Int11). This close engagement with the users was given as an example, supporting the progress and adoption of DeepHealth's AI for lung cancer screening, where the company developed a reporting template software application which simplified NHS staff engagement with the AI imaging analysis based on understanding user needs (Int11). 	<ul style="list-style-type: none"> • Clinical hesitance and mistrust in technology, partly related to a need to improve the evidence base on AI performance in real-world settings.²⁴⁰ Related to this is a need for clear evidence standards, including the alignment of industry impact data with the benchmarks required in the eyes of academics and clinicians to demonstrate impact.²⁴¹ There remains uncertainty as to whether AI algorithms are more accurate and less prone to errors than clinicians, and better evidence is needed on AI performance to increase clinical trust and acceptability, as well as to inform how clinicians engage with results from AI-based cancer biopsy image analysis in terms of exercise clinical judgement. There are also technical challenges with algorithmic drift-data advances compromising validity of algorithm performance over time (Int8). • Finding user-friendly ways of communicating to clinicians the levels of trust they should have in an AI-result (e.g. confidence levels) (Int8). • Algorithmic bias issues and associated ethical concerns related to challenges in learning from diverse populations when designing AI algorithms.²⁰⁶ • Data architecture, information and R&D governance is an ongoing challenge for developing and deploying AI cancer technologies within the NHS.^{240,242} Approvals for R&D in this space can take a long time, according to one expert we spoke to, who flagged that approval for studies involving AI can be subject to the same stringent approval requirements as those for routine care (Int 8, Int X). Data protection impact assessment (DPIA) approvals can involve different processes at different NHS Trusts, making it difficult and time-consuming for smaller and startup companies to navigate the diverse requirements (Int11). • A nascent regulatory field is also somewhat of a challenge for innovators in cancer diagnosis using AI, who need regulatory clarity and certainty. Its future influence will depend on how regulation keeps up with the rapid pace of developments in AI in healthcare, including in the context of new tools of interest to research and innovation in all fields (including cancer), such as the use of synthetic data and virtual twins for clinical trials (Int3, Int12).

Enablers of progress to date	Challenges to progress to date
<ul style="list-style-type: none"> • Policy push and guidelines: For example, NHS England issued a protocol for targeted lung cancer screening which included using AI in the protocol (Int11). 	<ul style="list-style-type: none"> • A need for compelling health economic evaluation to show value for money.²⁴³ • Support for commissioning certain solutions was also cited as a challenge, as the changing pathways for funding the adoption of innovations and fragmented funding channels (often commissioning via NHS Trusts) are complicated for innovators to navigate (Int12, Int11). With clearer funding pathways, these innovations could proceed through the NHS more cost-effectively, making the most of clinicians' existing work (Int12).

3.2.5. Looking to the future: a vision for impact from AI applications in cancer screening and diagnosis ten years from now

The applications of AI in cancer diagnosis are a rapidly evolving field. There will be much learning in the coming years from ongoing pilots, larger-scale implementation testing projects and real-world use. In a future vision for AI use in cancer diagnosis in the NHS, we are likely to see the following:

- **NHS staff will have received training and developed the requisite skills to understand and engage with AI for cancer detection and diagnosis effectively, safely and with good balance with clinical judgement.** In this vision, the NHS workforce is trained at scale to better understand how AI-enabled diagnosis works, its potential benefits, the risks associated with using it, what to look out for, and how to use it safely, securely and effectively alongside clinical judgement. AI-enabled tools are used in patient risk assessment and prognosis, potentially supporting risk mitigation and earlier diagnosis as well as potential behavioural and lifestyle-related preventative measures.
- **The NHS will operate as an effective learning health system for AI-enabled cancer care and provide appropriate and trustworthy care for diverse populations.** In this vision, data from more diverse populations informs algorithm developments and assessments, increasing clinicians' trust in algorithm performance. The quality of data on which algorithms are trained improves. Algorithm drift is addressed as the system has roles charged with updating algorithm performance as new data and insights accumulate.
- **Investments in developing clear regulatory regimes for AI in clinical use, including in oncology, will improve the attractiveness of the UK as a location for developing and testing AI solutions for innovators worldwide.** The regulatory landscape matures to balance pro-safety with promoting innovation, and innovators are clear on the regulatory and governance requirements related to research project approvals versus approvals for routine use. Advances in digital technologies, such as digital twins and synthetic data, lead to regulatory innovation that enables smarter designs for trials of AI applications in oncology (and beyond). The resulting increase in trial activity, coupled with smarter and more efficient trial design

enabled by technological advances and regulatory innovation (e.g. related to synthetic data and digital twin technology), will enable faster patient access to innovation.

- **Collaborations between academia, industry and the NHS will enable technological advances in areas such as quantum computing to improve the quality and speed of AI-enabled cancer diagnosis.** Collaborations between academic institutions, industry and the NHS will evolve to bring advances in quantum computing to AI-enabled cancer diagnosis, creating new prospects for improving and speeding up the analysis of complex imaging and patient data sets. Quantum computing and quantum sensors help with efforts to identify subtle abnormalities in early-stage cancer (by improving image processing steps such as contouring and edge detection).²⁴⁴
- **Key system stakeholders will prioritise patient and public involvement, engagement and participation throughout the development, implementation and use of AI for cancer detection and diagnosis.** Patients and the public will better understand the benefits and risks associated with AI applications in oncology diagnosis and how risks are managed. They will trust that AI is being used ethically and transparently, with greater confidence in the quality of care they are receiving. Further, patients are clear on how health professionals engage with AI tools, and patient engagement is integral to developing and deploying new solutions.

3.3. Digital and data-driven innovation in mental health

Box 16. Case study summary: digital and data-driven innovation in mental health



Since the Mental Health Act of 1959, the UK has continued making gradual progress in understanding mental health conditions and improving care:

- Research and innovation has played a key role in improving mental health care, with notable examples being digital and/or data-driven innovations such as Talking Therapies and AVATAR therapy using computer-assisted visualisations and communications for people who hear voices.



Impacts on patients and population health:

- Talking Therapies increased access and reduced waiting times for evidence-based psychological therapies (1.83 million referrals in 2023/2024, and 90.5% of people accessing treatment within six weeks).
- Many patients engaging with both Talking Therapies and AVATAR therapy show reductions in symptoms and increased quality of life (in the case of AVATAR therapy based on trial results).



Impacts on the NHS and wider health system:

- Talking Therapies have increased the capacity and skills of NHS mental health staff. Digital delivery formats have enabled NHS staff to see up to three times more patients, and current evidence supports their cost-effectiveness.
- Talking Therapies enabled a comprehensive data set on NHS service provision and patient outcomes, which is used to monitor and improve services.



Impacts on the economy and wider society:

- Digital innovations in mental health led to spin-out companies that develop treatments and health services tools and create jobs and revenue (e.g. Akrivia Health is creating large psychiatric datasets to inform service evaluation, clinical audits, research and service delivery).
- Talking Therapies can increase economic productivity by helping people return to work (a 7.92% increase in the probability of unemployed getting employment) and reducing welfare benefits (an estimated >£650 per person within two years of receiving therapy in England).
- Public health campaigns informed by research and media coverage increase public awareness and understanding of mental health conditions and help reduce stigma.

A Future Vision for Success: Digital and Data-enabled Innovation in Mental Health in the NHS



Investments in training a sufficient number and diversity of research and service delivery staff will enable innovative and evidence-based mental health services at scale, including through digitally enabled means. NHS trusts will be incentivised and enabled to engage with research and innovation in mental health.



Fewer but better integrated, linked and interoperable datasets and IT platforms will be used to inform mental health services. Access to data will improve, making it easier to innovate and for more people to benefit.



A policy push to collect output and impact data will enable a better understanding of mental health conditions, treatment effectiveness and links between mental and physical health.



More diverse population groups will engage with research and innovation efforts, and the resulting advances will be more relevant to the mental health care needs of diverse people and better target inequalities (e.g. related to digital exclusion, children and young people's mental health needs, better consideration of culture and language). Blended care approaches (i.e. face-to-face and digital-access options) will help widen access.



Closer working with communities coupled with enhanced public-private collaboration and incentives for NHS staff to engage will improve the appropriateness, diversity and effectiveness of mental health innovation and improve adoption in the NHS.



More centralised and streamlined research governance and regulation will allow for more efficient progress. Clear standards and regulations for internet-based therapies will support high-quality service delivery of evidence-based mental health interventions. Simplified commissioning channels will enable greater use of digital innovations.

3.3.1. Introduction

Mental health is central to an individual's health and well-being, influencing how people think, feel and act. Common mental disorders, such as anxiety or depression, are estimated to be experienced by 1 in 6 adults in England.²⁴⁵ Approximately 90% of adults with mental health problems are supported in primary care.²⁴⁶ In 2023/2024, 3.8 million people (69.5% aged \geq 18 years) were in contact with secondary mental health, learning disabilities and autism services in the NHS in England.²⁴⁷ Worryingly, 20% of children aged 8–16 and 23% aged 17–19 have a probable mental disorder in England,²⁴⁵ meaning continued increases in the number of adults with mental health conditions are likely as they age.²⁴⁸

Not only does poor mental health affect the quality of life of the individual and those around them, but it also impacts societal productivity, healthcare cost and service utilisation.^{248,249} A recent report by the Centre for Mental Health estimates the total cost of mental ill health in England in 2022 was £300 billion, comprising £110bn in economic cost, £130bn in human cost (reduced quality of life) and £60bn in health and care costs.²⁵⁰ Mental health disorders contribute to at least 21% of the UK disease burden, although research suggests this figure may be underestimated by at least one-third.²⁵¹

Mental health is one of the most neglected areas of global health concern.²⁵² Funding in mental health research and innovation has historically been sparse,^{253,254} and the number of researchers in mental health and development opportunities has been lacking, constraining the capacity to conduct research.^{254,255} While there has been some progress made in treating and preventing mental health, this has been slow compared to other common physical health conditions, and research and innovation in this space has been chronically underfunded for the burden of disease (Int02, Int06).²⁵⁵ In 2018, just 6.1% of the UK's health research budget was allocated to mental health²⁵⁶; this level of funding has not changed substantially for a decade.²⁵³

3.3.2. Origins, history and evolution of mental health research and innovation in the UK

Efforts to advance mental health services in the NHS have their origins in the initial **Mental Health Act 1959** (updated in 1983 and 2007),²⁵⁷ **due to be updated again in 2025.**²⁵⁸ The **closing of asylums, moving care into the community and the increased use of talking therapies** are some of the biggest changes in mental health in the NHS.^{257,259} Alongside **decriminalising suicide in 1961** and removing **homosexuality from the Diagnostic and Statistical Manual of Mental Disorders (DSM) in 1973**, the perception of mental illness has dramatically changed in the past century. The implementation of the **National Service Framework for Mental Health 1999**, various policy initiatives such as **'no health without mental health' in 2011**, **'Five Year forward view for mental health' in 2016**, **the focus on mental health in 'NHS Long Term Plan' in 2019** and **the 2021 'mental health recovery plan'** have also indicated perseverance to keeping mental health care within the NHS moving forward.

There have also been some promising UK funding initiatives focused on developing mental health and innovation in recent years. This is largely from **the Mental Health Research Funders Group, including the Department for Health, Economic and Social Research Council (ESRC), NIHR, MRC, Wellcome and Mental Health Research UK.**^{253,262–264} However, it is estimated that only £9 is spent on research per year per person affected by mental health.²⁵³

The UK government announced the **Mental Health Mission in 2022**, followed by funding delivered through the **NIHR of £42.7m in 2023 for clinical research centres in the UK over five years under the mission**.²⁶⁵ The mission aims to establish the UK as a leader in innovative mental health research and to develop new treatment options, bringing together **academia, healthcare services and industry working in partnership**.²⁶⁵ This is likely to help foster breakthroughs in understanding and treating mental health conditions.

The UK has significantly **contributed to clinical trials of pharmacological therapies for mental health conditions commonly used within the NHS today**,^{266–269} and **continues to pioneer new pharmacological treatments** such as the use of psychedelics.^{270–273} However, the demand for mental health services consistently outweighs the NHS's capacity to provide services,²⁷⁴ with demand expected to continue rising.²⁴⁸ Not only is demand increasing, but the **complexity and number of severe cases are rising**.²⁷⁵ Despite a small increase in the NHS mental health workforce, including psychiatrists and mental health nurses, **this falls vastly short of meeting demands**.^{276,277} Retaining staff, especially those with greater experience, has been problematic and likely due to workforce burnout and high turnover rates, leading to gaps in service provision and longer patient waiting times.^{274,276,277} Another complexity in mental health is the **subjective nature of the conditions, measures and treatments currently used**, which typically require greater resources to find appropriate and effective treatment, whether pharmacological and/or therapy-based (Int02). The benefits of **patient and public involvement and engagement have not been well realised** in the domain of mental health,²⁷⁸ perhaps due to doubts about the capacity of mental health patients to do so. The **main barriers to the delivery of traditional mental health services are commonly considered to relate to accessing care and stigma**.^{252,279–285}

Technological and digital innovations have the potential to overcome some of the barriers in traditional mental health care^{252,279–285} and are perhaps the **most significant change in recent years in mental health in the NHS**, with shared records and connecting different clinical systems being a key development.²⁵⁹

There have been calls for health systems, like the NHS, to adopt innovative approaches and leverage technology to improve access to mental health care (Int01).^{279,286,287} One of the biggest **obstacles to overcome is the adoption of mental health innovations from research studies into the NHS** (Int05). The NHS promote some 'wellbeing apps' for mental health to their staff, such as Headspace and Unmind,²⁸⁸ and many trusts are creating their own catalogues of mental health apps they can recommend to patients.²⁸⁹ Whilst shared with good intention with patients or between staff, **many such apps are not (yet) fully evaluated** for appropriateness or effectiveness, which may lead to unintended consequences to patients. The **NICE early value assessment (EVA) for Medtech** tries to signal further evidence needs, identify potential technologies that may provide good value for the NHS, and highlight where further evidence is required so that patients can access technologies that support unmet needs in care.²⁹⁰

As highlighted by Lord Darzi in the independent review of the NHS,²⁴ the burden of mental health in the UK has changed substantially over the last decade, accounting for over 20% of the disease burden in the UK. However, with less than 10% of NHS expenditure, progress in developing and adopting mental health innovation has been limited. This makes new, emerging ways of treating mental health therapies more important and promising.

In this case study, we focus specifically on two innovations that have passed the NICE EVA: Improving Access to Psychological Therapies (IAPT)/Talking Therapies, which provides access to cognitive behavioural therapy for diverse conditions, and AVATAR Therapy for people who hear voices. These have been used within the NHS (to varying degrees and in either routine or trial contexts) and have had positive impacts. It is worth noting that various other solutions for psychosis and schizophrenia care are also being explored and trialled, such as a technology for monitoring symptoms of psychosis to prevent relapse (CareLoop),²⁹¹ virtual reality therapy for people living with psychosis with severe agoraphobia (gameChange)²⁹² and a smartphone app to predict and prevent schizophrenia relapse (MindLAMP).²⁹³

Other interventions show promise in helping people suffering from mental health conditions. Examples include SlowMo, a digitally supported therapy for managing distressing thoughts or paranoia that was developed in partnership with NHS trusts,²⁹⁴ the use of games like Tetris to help reduce disruptive and intrusive memories of traumatic events,²⁹⁵ internet-based cognitive behavioural therapies for social anxiety disorder²⁹⁶ and post-traumatic stress disorder²⁹⁷ and digitally enabled therapy for insomnia (Sleepio).²⁹⁸ Some solutions aimed at children and young people are being developed and have gone through a NICE Early Value Assessment, including a mobile phone game that combines exposure therapy and psychoeducation aimed at children aged 7–12 (Lumi Nova), a guided self-help digital cognitive behavioural therapy for children and young people with mild to moderate symptoms of anxiety or low mood (Space From) and online social anxiety cognitive therapy for adolescents (OSCA) developed to help treat those aged 11–19 with social anxiety.²⁹⁹ Psychosocial solutions such as exercise for depression are also being explored.³⁰⁰

Improving Access to Psychological Therapies (IAPT)/Talking therapies

The largest innovation in mental health care within the NHS is the **NHS Talking Therapies, previously known as IAPT**. Following NICE guidance advocating for the use of psychological therapies, clinical researchers and economists presented a case for the development of IAPT, suggesting that its use in treating anxiety and depression could positively impact costs of service delivery²⁴⁹ (Int05, Int01) and reduce overprescription of medications for depression and anxiety (Int01).

The first **IAPT pilot** began in 2006 in Doncaster and Newham, focusing on applications for treating people with depression and anxiety, but also stress, phobias and post-traumatic stress disorder.^{301–303} Prior to the national rollout of IAPT, patients were rarely offered evidence-based psychological therapies (in 2007, less than half of adults in the UK with depression or anxiety who received psychological therapy received evidence-based psychological therapy), and waiting lists were long (mean time between referral and first therapy session was 72 days, ranging from 16–182 days).^{249,304,305} The therapies in IAPT include Cognitive Behavioural Therapy (CBT), interpersonal therapy, couples therapy, counselling, brief psychodynamic therapy and mindfulness-based cognitive therapy.²⁴⁹ Based on **NICE guidelines**, IAPT advocates a **stepped-care approach**, whereby people with low to moderate depression and some anxiety disorders can receive ‘low intensity’ interventions, while those with moderate to severe depression and some other anxiety disorders receive ‘high intensity’ interventions.^{304,306,307}

Research has highlighted that prior to the IAPT programme, NHS mental health services were poor at recording patient outcomes, leading to overestimates of treatment effectiveness.²⁴⁹ IAPT was designed to **closely monitor patient outcome data**,^{249,306–308} with this **data being crucial for commissioners and clinicians to understand service performance and continue improving the care** of people with mental health conditions.³⁰⁶ According to one interviewee, IAPT is currently the only **comprehensive data set** on mental health service provision in the NHS (Int05), and data is publicly available.^{249,308} In addition, research has highlighted a large shortfall in trained therapists as the main barrier to the NICE guideline implementation.²⁴⁹ Thus, **training 10,500 new therapists was** central to IAPT, including ‘low intensity’ psychological well-being practitioners, ‘high intensity’ CBT therapists, and therapists trained in other therapeutic methods,²⁴⁹ which has helped improve patient access, alongside **creating a self-referral pathway**.^{249,304}

Following the pilot, **IAPT was scaled nationally with £709m funding between 2008 and 2015**, which was ring-fenced for IAPT in the first two years and absorbed into general NHS budgets from the third year onward.^{306,309} One of the challenges with funding later not being ring-fenced for IAPT was its absorption into general NHS budgets, meaning some was not spent on IAPT.³⁰⁶ **Waiting times for NHS talking therapies vary** from 4–79 days in England, depending on location.²⁴⁵ Patients with shorter waiting times tend to achieve better outcomes, which may be linked to a decline in individuals’ enthusiasm to engage in therapy after first reaching out for help (Int05).²⁴⁹ In addition, the geographical distribution of trained therapists across the different types of therapies provided under and beyond IAPT is unequal, constraining patient choice and access.^{249,255}

In recent years, expedited by the COVID-19 pandemic, the development of digital and remote delivery has increased the geographic scope and accessibility of NHS Talking Therapies (Int01, Int05).^{249,302,310,311} As a result, ‘low intensity’ NHS Talking Therapies now also include online and/or app-based programmes that contain CBT-based material and are supported by trained psychological well-being practitioners.^{301,312,313} Online psychological therapies are now being used successfully, with many achieving patient outcomes similar to face-to-face treatment³¹⁴ and superior outcomes compared with no treatment.^{311,315} A recent research trial found internet-delivered CBT through IAPT in stepped-care UK settings was effective in the short-term (eight weeks) and long-term (12 months) and potentially cost-effective in the long-term for treating depression and anxiety.³¹⁶

Many digital mental health innovations with NICE EVA approvals have been designed by university spin-out companies or university partnerships with external parties. Examples include Akriya Health, SilverCloud, OxCADAT and Koa Health (Int01, Int09).^{313,317} Due to the infancy of the innovations, most are not currently widely implemented across the NHS, so real-world impacts are yet to materialise. The IAPT workforce training and skill set encompasses a wide variety of NICE-recommended therapies, but these are unevenly distributed geographically and may limit patient options; however, moving to a digital and remote delivery model has the potential to overcome this challenge.

AVATAR therapy

Another promising digital innovation is AVATAR therapy for people who experience auditory hallucinations (e.g. in psychosis or schizophrenia), which utilises computer-assisted visualisations and communication (Int09).^{318–320} In AVATAR therapy, patients, with their therapist, build a digital

representation of the voice they hear inside their head (an avatar) (Int09).^{318,321} The therapist can then communicate with the patient via this avatar using phrases the voice may typically use for the patient to interact with, and the therapist can use their own voice to counsel the patient through the interaction in a three-way dialogue (Int09).^{320,321} Over the course of the therapeutic sessions, the AVATAR voice becomes less hostile and concedes power to the patient (Int09).³²¹ AVATAR therapy has recently received **NICE EVA approval**³²² (Int09), and there are now **38 trained AVATAR therapists in the UK**.³²⁰ The hope is that this promising innovation will be scaled for use and widely adopted in the NHS within the next five years and can gather real-world data.^{318,320}

AVATAR therapy was first **developed in 2008 and piloted in 2013. After nearly a decade of research, the first fully powered randomised controlled trial (RCT) began in 2017, funded by Wellcome** (Int09).^{318,321} The first **RCT** found that those treated with AVATAR therapy for six weeks had a significant reduction in the severity and frequency of voices heard compared with supportive counselling at the 12-week assessment point, with no adverse effects attributable to the therapy reported.³²¹ A 2020 Cochrane review of AVATAR trials highlighted that, whilst promising as a therapy for people with schizophrenia or related disorders, more large-scale, long-term, well-designed randomised controlled trials were needed to better understand the effects of the therapy.³²³

The **AVATAR2 RCT trial**, funded by Wellcome, aimed to assess the effectiveness of brief (six-week) and extended (12-week) forms of the therapy across multiple NHS sites, using multiple therapists (n=19) in demographically diverse locations, both combined with treatment as usual and compared to treatment as usual.³²⁴ Building upon the learning from previous research trials, AVATAR therapy was trialled in three NHS sites in England and one in Scotland from 2019 onwards.^{318,324} It also included **close work with 20 Patient and Public Involvement and Engagement (PPIE) members** and carers with experience in mental health conditions and recovery to inform the design, recruitment, analysis and dissemination of the research.³²⁴ The results of the AVATAR2 trial showed that both brief and extended versions of AVATAR therapy reduced the severity of voices heard and the distress caused by them, compared with usual NHS treatment.^{318,324} The extended version of AVATAR treatment led to a greater reduction in the occurrences of patients' heard voices and better-sustained effects over time. Therefore, the authors recommended that the extended version be the focus of future developments (Int09).^{318,324} This successful reduction in the occurrence of hearing voices has not been found in other psychological therapies.³²⁵ Patients who have engaged with the therapy also reported a reduction in the number of voices they hear and feeling like they had a better sense of control of their lives (Int09).³²⁶

3.3.3. Impacts

The IAPT and AVATAR examples exemplify how research and innovation can significantly enhance mental health services within the NHS through improved patient access, recovery rates and overall patient outcomes.^{249,327} What is more, the growing recourse to digital mental health services brings opportunities to expand access to care for diverse populations and to help tackle inequalities, including connecting those in rural and remote areas with mental health specialists to improve screening and treatment of common mental health disorders, and to serve large populations at a lower cost, ultimately increasing accessibility of mental health

services (Int01).^{252,279–281,328,329} Some digital services can also be used anonymously to overcome challenges with stigma, providing a helpful early intervention tool for those who may be reluctant to seek help through traditional routes that can be tailored to the individual's needs.^{281,328,329} In addition, newer technologies (e.g. smartphones, sensors, informatics and AI) have the potential to enhance existing care models and improve our understanding of mental illness, utilising real-time data and machine learning to identify behaviour patterns, personalise treatments and tailor interventions to enhance patient engagement and improve the effectiveness of treatments (Int01).^{280–282} However, the rapidity of development of the digital mental health space will require improvements in guidance and regulation to ensure safe (data privacy) and equitable access practices and find alternative ways to mitigate inequalities related to the 'digital divide', and support for at scale real-world evidence generation.^{281,328,330}

Research and evaluation have been instrumental in enabling progress and informing evidence-based practice,^{252,281,329} with the NHS providing access to patients to participate in studies, trial infrastructure and expertise (Int09). The results of studies, trials and evaluations have improved understanding of mental health conditions, thus improving the quality of treatments for patients and leading to continued innovation in treatments.²⁵⁵ Research has also been important for **informing public health campaigns in mental health**, such as the 'Time to Change' campaign that closed in 2021^{255,331} and the 'Every Mind Matters' Campaign in 2019.³³² Despite slow adoption in the NHS beyond IAPT/Talking Therapies, mental health research progress in the UK has shown impacts for patients, the healthcare system and wider society.

Impacts on patients and population health

Patients have benefited from research and innovation in mental health in diverse ways, most notably in terms of better and timelier access to needed interventions and improved patient outcomes.

Box 17 **presents further information on the types of benefits for patients and population health** based on the insights obtained from the case examples we have considered and associated literature.

Box 17. Digital and data-driven innovation in mental health: impacts on patients and population health

Improved access to mental healthcare, greater reach and reduced waiting times:

- **The period 2023/2024 saw 1.83 million referrals to NHS Talking Therapies, of which 1.26 million accessed the service – 90.5% within six weeks of referral.**³³³ The average number of sessions was 8.2, and 671,648 patients completed the course of treatment.³³³ However, despite the increasing number of referrals, the proportion of those finishing treatment in 2023/2024 was only 37%. This figure has remained comparatively stable for a decade, highlighting a need for further research to identify reasons for non-completion to help ensure more patients can benefit.³³⁴
- **Digital mental health interventions can also increase accessibility for diverse types of patients who cannot access face-to-face services, helping mitigate inequalities related to geography or inability to travel** [e.g. those in rural areas, unable to travel or requiring more specialist help from outside their geographical catchment (Int05)].^{252,279–281,328,329}

- **Digital delivery reduces waiting times, enabling earlier intervention** and helping improve outcomes.³⁰⁶ Digital mental health innovations **increase the number of patients clinicians can provide and care for.**^{252,279–281,328,329}
- **In 2023/2024, 530,229 sessions of Internet Enabled Therapy (IET) were recorded in England**, down 16.6% from 2022/2023.³³³ **In Scotland, 30,000 people are referred for computerised CBT each year.** Digitally offered therapies will likely become more prevalent in the future,³⁰⁴ as they allow people to more quickly access care and avoid waiting lists and may help overcome barriers to traditional face-to-face care (e.g. those who may find it challenging to leave their homes, have no child care) at a time that is most suitable to them, at their own pace, which could help reduce missed appointments (Int05).^{310–312,335}

Improved patient outcomes:

- **Online psychological therapies are being used with success, with many achieving patient outcomes similar to face-to-face treatment³¹⁴ and superior outcomes compared with no treatment.**^{311,315} A recent research trial found internet-delivered CBT through IAPT in stepped-care settings in the UK was effective in the short-term (eight weeks) and long-term (12 months) and potentially cost-effective in the long-term for treating depression and anxiety.³¹⁶
- **IAPT/Talking therapies and AVATAR therapy demonstrated reductions in symptoms for those who received treatments within the NHS.**^{249,318,324,327,336} For IAPT/Talking Therapies, rates have remained relatively stable around the 50% expected recovery rate for the past eight years.³³⁶ In 2023/2024, 50.1% of referrals moved to recovery.³³³ The reliable improvement rate in that period has remained at 66.4–68.3%.³³⁶ However, this applies to those who completed treatment.
- Some 26% of those who completed treatment showed no change in symptoms, and 6% deteriorated,³³⁴ which indicates that although the majority of those completing treatment improved, IAPT/Talking therapies are not a one-size-fits-all solution and further research and innovation is required for effective interventions in some population groups. IAPT/Talking Therapies also provided the first comprehensive and mostly complete dataset in mental health treatment in the UK, providing insights into how the continuous development of the programme impacts the effectiveness in improving patient outcomes (Int05, Int09).^{306,324,336}
- **Research and innovation in mental health has improved the quality of care patients receive, the effectiveness of treatments and patient outcomes.** Through research and innovation, new evidence-based treatments have been developed and refined to improve the **quality of lives of patients who live with mental health conditions.**^{255,304,321,324,327}

Impact on mental health services and the wider health system performance

While many research and innovation developments in the UK have not yet made it into the NHS care system beyond trials and pilots, a promising impact on health services is seen in the Talking Therapies space. As expanded on in Box 18 below, **these span capacity and skills building to deliver innovative healthcare amongst health services staff through improved training opportunities (Int09),²⁴⁹ better utilisation of clinician time to enable more patients to be seen (Int01, Int05),^{301,311,314,337} and improved resources to inform evidence-based service commissioning and improvement.**³⁰⁶

In addition, there is potential for these therapies to improve workforce well-being in terms of flexible ways of delivering care (such as digitally), potentially impacting retention – although there is a need for further evidence on this potential in practice.

Box 18 presents further information on the types of benefits for the NHS and wider health system based on the insights obtained from the case examples considered and associated literature.

Box 18. Digital and data-driven innovation in mental health: impacts on the NHS and health system

Improved mental health staff capacity:

- **More trained mental health staff:** IAPT/Talking Therapies introduction into the NHS increased the number of mental health staff, including new roles for psychological well-being practitioners and increased training opportunities for staff.²⁴⁹ Avatar received NICE EVA approval (Int09),³²² and there are now 38 trained AVATAR therapists in the UK.

Greater productivity (seeing more patients due to reduced time per patient):

- **The reduction in clinical time per patient enabled by digital services means up to three times more patients can be cared for by one clinician** (Int01, Int05).^{311,314,337} While some of this evidence is anecdotal and further data and analysis are needed, initial estimates suggested that digitally enabled therapies in England could save around 6,000 therapist hours per 1,000 people for anxiety disorders and 6,800 therapist hours per 1,000 people for depression compared to traditional face-to-face treatments.³⁰¹ Current practice estimates indicate savings of 2,500 therapist hours per 1,000 for Post-Traumatic Stress Disorder (PTSD), 1,000 for social anxiety and 600 for depression,³⁰¹ although further evidence is needed. The largest cost savings are expected to come from digitally delivering parts of the high-intensity treatment as these are the most resource-intensive (Int05).

Improved care quality and cost-effectiveness:

- **Evidence and resources to inform healthcare delivery and health service commissioning.** Prior to the IAPT programme, NHS mental health services were poor at recording patient outcomes, leading to overestimates of treatment effectiveness.²⁴⁹ IAPT was designed to closely monitor patient outcome data,^{249,306–308} which is crucial for commissioners and clinicians to understand service performance and continue improving care for people with mental health conditions.³⁰⁶ According to one interviewee, IAPT is currently the only comprehensive publicly-available data set on mental health service provision in the NHS (Int05).^{249,308}
- The average cost of IAPT treatment in 2009/2010 was estimated at £877, ranging from £493 (low intensity) to £1514 (low intensity stepped up to high intensity).³³⁸ For recovered patients, these estimates were higher, with the average estimated at £1776, ranging from £1,043 (low intensity) to £2,914 (stepped up).³³⁸ Digital offers were associated with reduced costs. For example, a randomised waitlist-controlled research trial of online Cognitive Behavioural Therapy (iCBT) within routine IAPT stepped-care estimated the interventions costing £94.63 per person with a high probability of Quality-Adjusted Life Year (QALY) gains

(an estimated £29,764 per QALY over eight weeks) but a low probability of cost savings in the short term (<0.5%).³¹⁶ When extrapolated to 12 months, higher probabilities of cost-effectiveness were estimated (>91% at £30,000 per QALY over 12 months).

- A study published in 2018 on the cost-effectiveness of IAPT for one of the 2007–2009 pilot sites found IAPT was 'probably' cost-effective within NICE guidelines: the cost per QALY gained ranged between £16,857 and £29,500 depending on the outcome measure (EQ-5D and SF-6D, respectively).³³⁸ The estimated cost per reliable and clinically significant improvement was £9440 per participant.³³⁸
- In patients with cardiovascular disease, chronic pulmonary obstructive disorder and diabetes, who also had depression and/or anxiety, IAPT treatment decreased their total treatment costs by £497 (95% CI: -£770 to -£224).³³⁹
- An estimated £650+ per year per person receiving IAPT could be saved in physical healthcare costs.³⁴⁰

Impacts on the economy and society

Research and innovation on CBT and digital interventions in mental health more widely has contributed to enterprise and job creation and job retention, e.g. by funding enabling academics to continue with their research projects and/or taking promising innovations to market (Int01, Int05, Int09), as well as improved mental health literacy amongst the wider population. Box 19 **presents further information on economic and societal benefits** based on the insights obtained from the case examples considered and associated literature.

Many digital innovations in mental health led to the creation of **spin-out companies from university research trials** to continue developing effective, evidence-based treatments for people with mental health conditions, creating **jobs and revenue within the UK** (Int01, Int09). Successful research and innovation in this space has attracted funding, enabling people to stay employed (Int05) while developing cost-effective treatments for people with mental health conditions.³¹⁶ Finally, public health campaigns (e.g. 'Every Mind Matters') based on research and media coverage of promising innovations from research studies help **improve public awareness and understanding of mental health conditions and reduce stigma**.^{332,341}

Box 19. Digital and data-driven innovation in mental health: impacts on the economy and society

Enterprise creation, job creation and job retention:

- Many digital innovations in mental health led to the creation of spin-out companies from university research trials to continue developing effective, evidence-based treatments for people with mental health conditions, creating jobs and revenue within the UK (Int01, Int09). Successful research and innovation in this space has attracted funding, enabling people to stay employed (Int05) while developing cost-effective treatments for people with mental health conditions.³¹⁶

Increasing societal productivity:

- In patients with cardiovascular disease, chronic obstructive pulmonary disorder and diabetes alongside depression and/or anxiety, IAPT was shown to increase the probability of employment among those unemployed by 7.92% (95% CI: 0.94% to 14.9%).³³⁹

Savings in welfare benefits and extra taxes:

- An estimated £650+ per person could be saved in welfare benefits and extra taxes within two years of someone receiving IAPT therapy in England.³⁴⁰

Public mental health understanding:

- Public health campaigns (e.g. 'Every Mind Matters') based on research and media coverage of promising innovations from research studies can help improve public awareness and understanding of mental health conditions, signpost beneficial resources and help reduce stigma.^{332,341,342}

3.3.4. Reflecting on influences on progress: enablers and challenges

Progress in mental health research and innovation, especially in digital interventions, has been driven by strategically positioned innovations that have received long-term funding and wider support to allow their development and adoption, initially at a small scale and then more widely (Table 3).

Table 3. Enablers and barriers influencing the progress in mental health research and innovation

Enablers of progress to date	Challenges to progress to date
<ul style="list-style-type: none"> • Continued and flexible funding for promising innovations to be adapted as new evidence emerges promotes continuous development and increases the likelihood of NHS adoption (Int09, Int05).²⁵⁵ • Clear communication to policy and decision makers about the innovation's value to the NHS, including economic and health systems impacts and alignment with policy initiatives and guidance (Int05).²⁴⁹ This was used in the development of IAPT (Int05).²⁴⁹ 	<ul style="list-style-type: none"> • A lack of long-term, sustained funding commitments impedes the journey from idea to adoption, with sparse, non-ring-fenced funding (Int02, Int06).²⁵³⁻²⁵⁵ Many promising innovations show effectiveness in small trials but lack larger-scale evidence for wide-spread adoption in the NHS (Int02).^{281,328,330} Non-ring-fenced funds complicate implementation, as allocated resources may not be spent as intended, leading to premature failures (Int05).^{306,343} • Wider systems policies, priorities and practices hinder the integration of research, e.g. the separation of mental and physical health in service delivery and research.^{255,255} This limits innovation potential and understanding of how multiple conditions influence best practice. Commissioning practices (e.g. supporting six sessions and not twelve) can also impede intervention fidelity (Int06). • Slow NHS adoption of mental health research and innovations is a significant challenge (Int05).

Enablers of progress to date	Challenges to progress to date
<ul style="list-style-type: none"> • Timely consideration of scalability in innovation design enhances funding prospects and NHS adoption (Int09).²⁴⁹ Key factors include staff capacity, capability and training needs, and existing IT infrastructure or ubiquitous technologies (Int09, Int01),²⁴⁹ e.g. optimising a training and supervision programme for digital delivery of existing Talking Therapies that patients can engage with using a smartphone they already own (Int01). • Commitment to collecting, sharing and using data (e.g. IAPT) captured in routine mental health settings and research trials helps decision-making about investments in effective innovations^{249,306} and supports commissioning decisions and continual improvement in service delivery (Int05). This includes patient outcome data. 	<ul style="list-style-type: none"> • The culture of additive innovation within NHS mental health services increases the stress and burden on frontline workers (Int02). Early, resolvable design issues lead to additive changes that are challenging to manage. • Workforce capacity and skills constraints in the NHS and research community: NHS mental health workforce chronically falling short of meeting increasing demands,^{249,276,277} limiting the ability to balance research with service delivery (Int09, Int02, Int06, Int01).²⁵⁴ Engaging NHS staff in research relies on cultivated relationships (Int09). Additionally, a lack of mental health researchers and training opportunities for researchers constrain research and innovation capacity.^{254,255} Upskilling is also a challenge due to a shortage of highly trained therapists within the NHS, which impacts the fidelity and adoption of many mental health innovations (Int05).^{249,321} • Insufficient collaboration between researchers, clinicians, commissioners and industry limits the development of user-friendly, easily integrated, effective and cost-effective innovations (Int09).^{254,255,344} • Complex data protection, regulation and IT infrastructure for mental health innovations result in lengthy negotiations (Int02, Int09).^{255,281,328,330,344} • A lack of routinely collected mental health outcome data (excluding IAPT/Talking Therapies) limits care improvements²⁵⁵ and understanding of mental health conditions.²⁵⁹ Much data is contained in free-text clinical notes that are not easily exported for research (Int02).

3.3.5. Looking to the future: a vision for impact from digital and data innovation for mental health ten years from now

The impacts of research and innovation on the NHS have been limited in scale yet significant in the context of a widely rolled out intervention such as Talking Therapies/IAPT. However, research and innovation are poised to transform mental health care through advancements in digital technologies, collaborative approaches and strategic investments, and wider science and technology advances. Mental health is a priority area requiring further research and innovation.^{345,345,346} A future vision for mental health in the NHS is as follows:

- **Investments in training a sufficient number and variety of mental health research and service delivery staff will enable innovative and evidence-based services to be delivered at scale to diverse populations in need, including through digitally enabled means.** There will be schemes that provide training, mentoring and support to mental health researchers,^{254,254,255} increasing the capacity for research and innovation within mental health.

- The NHS data and IT infrastructure will evolve to ensure that the platforms and data informing mental health services are more easily accessible, better linked and interoperable.** Fewer but more accessible platforms for mental health services data will enable innovators to design compatible innovations (Int01), encouraging adoption within the NHS and for more people to benefit. The use of new technologies (e.g. sensors, machine learning) will enable better data and, in time, more evidence-informed practice to improve patient care and outcomes (Int01).^{255,315,347}
- A conscious policy push to collect routine NHS clinical outcomes and impact data and make it accessible**²⁵⁵ (Int05) will help create large, longitudinal and linkable datasets (e.g. genomics, GP data and income data) containing data on diverse populations^{255,330} (Int02, Int05, Int06). Such data will enable researchers and innovators to better understand mental health conditions, links between mental and physical health^{248,255} and effectiveness of current treatments, and identify gaps for future innovations for widespread use in the NHS.
- More diverse population groups will engage with research and innovation efforts, resulting in advances that are more relevant to diverse population groups**²⁴⁸ and better target inequalities (such as digital exclusion, better prioritisation of children and young people's mental health needs,^{248,255} better consideration of culture and language³¹⁵ and equitable access³³⁰). Blended care approaches (i.e. face-to-face and digital access options) will enable more people to access NHS mental health support,³¹⁵ encouraging proportionate universalism and reducing health inequalities (Int01).
- Closer work with communities coupled with enhanced public-private collaboration from concept through implementation will improve the appropriateness, diversity and effectiveness of mental health research and innovations and adoption in the NHS**²⁵⁴
^{255,255,348,348} (Int01, Int02) and provide more real-world evidence for innovations.²⁷⁹ **Innovative research designs and better incentives for NHS trusts (e.g. prioritised and protected funding) to engage in research and innovation and implementing innovations in mental health will minimise the burden on service providers** (Int02, Int01, Int06, Int09).³⁴³ This will enable NHS staff to be involved in research whilst managing clinical duties²⁵⁴ (Int02), yielding real-world evidence generation and improved patient choice and access to mental health treatment, care and support in hospital and community settings (Int05).²⁴⁸
- More centralised and streamlined research governance and regulation will reduce the time researchers spend applying through different NHS Trusts**, hastening the timelines for research to develop innovations for the NHS (INT01, INT02, Int05).^{255,349} **Clear standards and regulations will be developed for internet-based therapy for use in routine NHS care**,³¹⁵ enabling innovators to design appropriate innovations and increase their likely adoption in the NHS.
- There will be increased, long-term and sustainable funding for promising mental health research and innovation**³⁵⁰ (Int02, Int05, Int06), enabling innovations to be refined for use within the NHS. **Commissioning channels will be improved and simplified, enabling widespread use of effective and cost-effective digital innovations**, especially those with NICE EVA approval (Int05).³³⁰

Box 20 illustrates ongoing progress and the potential of large-scale data sets in mental health with the example of Akrivia's work.

Box 20. Large psychiatric data sets and data linkage (Akrivia)

One innovation on the horizon is the creation of large psychiatric data sets that can link data across different settings, aiming to address the challenge of a lack of comprehensive data on mental health. Akrivia Health aims to utilise real-world data to inform service evaluation, clinical audits, and research to better understand mental health conditions and treatments (INT02).³²¹

The innovation began with grant funding from the NIHR but has since moved to a sustainability-focused funding model to allow for accelerated growth and continued development (INT02). This involves industry funding, allowing industry to securely access anonymised data for their own research, supplemented by grant funding from the Wellcome Trust (INT02). Akriva is currently in partnership with 20 mental health trusts across England and Wales, and they help NHS trusts access their own data in more efficient and useful ways for free (INT02).

Industry has an appetite to better understand mental health conditions and the populations affected by them (INT02). There is also the potential to link patient health records with genetic and other datasets, enhancing the holistic understanding of mental health conditions and populations (INT02). This is the first step in precision medicine in mental health care (INT02) and something that funders are keen to explore (INT06).

Many mental health conditions are beginning to show shared pathologies, and understanding these may provide key insights that could reshape the current diagnostic categories used in the NHS. The use of transdiagnostic markers has the potential to revolutionise the classification, identification and treatments of mental health conditions in a more personalised way (INT02),^{322–324} which will be improved by creating large and linkable datasets (INT02).³²⁵ Whilst it is too early to demonstrate impact within the NHS, this future vision of transdiagnostic markers and linked data is potentially one of the most impactful and transformative innovations in mental health care in the NHS and globally.

3.4. Technology-enabled remote monitoring in the NHS

Box 21. Case study summary - technology-enabled remote monitoring in the NHS



Since the early 2000s, the NHS has leveraged digital technology for remote healthcare monitoring. For example:

- Major initiatives like the **2011 Whole System Demonstrator Programme** examined the impact of technology-enabled remote care on chronic conditions like heart failure and diabetes.
- Scotland's **2014–2018 Technology Enabled Care Programme** aimed to understand tech-enabled care's effectiveness.
- The 2019 **NHS Long Term Plan** emphasised digital health and the potential of remote monitoring for personalised care. Initiatives like **BP@Home** and **MHF@Home** apply tech-enabled remote monitoring to hypertension and heart failure management.
- Key evaluations such as those undertaken by the DECIDE Centre and NICE's Early Value Assessment programme also highlight the importance of evaluation in maximising the potential of remote monitoring technologies.



Impacts on patients and population health:

- Remote monitoring has improved some clinical outcomes. Examples include helping patients control their blood pressure, reducing infection-related complications of post-kidney transplantations by 65%, reducing anxiety associated with patients undergoing chemotherapy, and enhancing patients' satisfaction and sense of control over their health.



Impacts on the NHS and wider health system:

- Evaluations of remote monitoring have shown some positive impacts on the NHS and the wider health system. For example, one longitudinal study found that admission to virtual wards reduced the length of hospital stay at NHS Wrightington, Wigan and Leigh Teaching Hospitals.
- A recent evaluation shows that virtual wards in Buckinghamshire, Oxfordshire and Berkshire West Integrated Care System (ICS) saved 46,685 bed days, significantly reduced emergency calls and readmissions and reduced calls to 111 for adults and children by 58% and 85%, respectively.



Impacts on the economy and wider society:

- As an innovation sector, tech-enabled remote monitoring in health fosters enterprise and job creation. It can have wider societal benefits beyond the impact on patients, such as improving the well-being of carers, as shown in a study of parents of children with Type 1 diabetes using continuous glucose monitoring.

A Future Vision for Success: Tech-enabled Remote Monitoring in the NHS



The NHS workforce will be trained to engage with tech-enabled remote monitoring and motivated to do so, supported by compelling evidence of its impact on care quality. Diverse clinical and non-clinical staff will have clear pathway delivery roles and collaborate within an efficient division of labour.



The data and IT architecture will improve to enable better data collection on costs, clinical outcomes, and health service utilisation, as well as support real-time analytics to monitor and enhance care effectiveness. This will be enabled by streamlined data sharing, interoperable IT systems, a skilled workforce and AI use.



Improved research and evaluation evidence will make it easier for tech suppliers' to convey the business case for adopting remote monitoring solutions and for commissioners to make evidence-based decisions. Better demand-signalling by policymakers will enhance transparent commissioning and reduce unwarranted variation in practices.



More efficient regulation will better support clinical practice. Greater regulatory clarity and less bureaucracy will make it easier to adopt innovative technology, including AI.



A community of practice will bolster collaboration between diverse stakeholders to share learning, adapt and improve practice. Better coordination between regional and national programmes and new roles (e.g. digital care coordinators) will support implementation.



Patients will be supported to onboard and engage with remote-monitoring technologies and trust the quality of care they receive. Clear communication channels between patients and NHS staff will bolster patients' trust in the quality of care they receive. Diverse patients (and carers) will contribute to service design and adaptation, including mitigating inequalities.

3.4.1. Introduction

Technology-enabled remote monitoring (TERM) is a model of healthcare that uses devices (e.g. pulse oximeters, blood pressure monitors, blood glucose monitors and activity trackers), apps, data analysis and conveyance technologies to help patients manage their health or well-being at home, with remote support from health and care professionals. TERM has been applied to diverse health conditions such as hypertension, chronic obstructive pulmonary disease, asthma and heart failure, among others, and in social care (e.g. home-based sensors).^{351–361}

This healthcare model aims to support patients and healthcare professionals in diagnosing, monitoring and managing people's health and well-being, managing demand on the NHS and supporting health system resilience. It aims to improve access to care, reduce waiting times and help ensure patients can get the right care at the right time and place, including preventing deterioration.^{24,351} As the field evolves and the technologies underpinning TERM continue to develop, many NHS organisations are testing or adopting technology-enabled remote monitoring services.³⁶² This applies across primary and acute care (e.g. virtual hospital wards).^{363–366} **There is also a growing interest in how tech-enabled remote monitoring can support neighbourhood and place-based health, e.g. hypertension and cardiovascular disease prevention.**

This growing recourse to tech-enabled remote monitoring is accompanied by an increasing recognition of the importance of evaluation and health services research to learn about what works, for whom, when, why and how, and to inform good practice in the NHS, for patient and health-service benefits. At present, the evidence base is fragmented and limited, presenting a barrier to informing NHS practice. In response, investments are being made in the research and evaluation infrastructure. One example is the NIHR Health and Social Care Delivery Research's investment in a national rapid evaluation programme focused on technology-enabled remote monitoring (DECIDE – Digitally Enabled Care in Diverse Environments). This programme is being delivered through a collaboration between RAND Europe and the University of Oxford.³⁶⁷ There have also been various other commissioned evaluations in this space.^{363,365,368–370} Health-services-focused research and evaluation can help inform decisions about the desired trajectory of technological innovation in remote monitoring, the design of service pathways around the technology and decisions about adoption, scale and spread.⁶¹

3.4.2. Origins, history and evolution of tech-enabled remote monitoring research and evaluation

The **NHS started exploring the potential of digital technology to help deliver healthcare services remotely in the early 2000s**, including **pilot projects that focused on remote consultations**

and diagnostic services, aiming to enhance access to care while reducing the need for patient travel.^{362,371} As technology advanced, the NHS expanded its use of digital solutions for remote care. For example, national programmes, such as the **2011 Whole System Demonstrator Programme**, were launched to explore the impact of telehealth and telecare services – specifically remote monitoring – on patient care.³⁷² This project was among the world’s largest trials of its kind at the time, including over 6,000 patients and 238 GP practices across three sites in England, and demonstrated the potential benefits of remote monitoring for managing chronic conditions like diabetes, heart failure and chronic obstructive pulmonary disease (COPD).³⁷³ **The 2014–2018 Technology Enabled Care (TEC) Programme** in Scotland was also a flagship effort to support tech-enabled care and to ensure effectiveness and cost-effectiveness evaluations were used to inform evidence-based decisions about roll-out.³⁶⁸

As a result of the promise held by technology-aided healthcare, **the NHS emphasised digital health initiatives as part of its 2019 Long Term Plan**, highlighting the transformative role of digital technologies in healthcare delivery.²⁴⁶ **Remote monitoring became a central component of these initiatives**, focusing on personalised care and integrated services to enhance patient care and system efficiency.³⁷⁴ These efforts aimed to improve patient outcomes and reduce hospital admissions, enabling quicker adoption of remote monitoring during the COVID-19 pandemic.

The COVID-19 pandemic accelerated the adoption of remote monitoring technologies across the NHS. The need to minimise virus transmission and maintain healthcare services expanded the use of digital tools for remote patient management.³⁷⁵ Several initiatives were launched across different settings and populations during the pandemic, focusing on safeguarding vulnerable patients. Examples include **using implantable electronic devices for remote heart failure management, using pulse oximeters in care homes for residents with COVID-19, monitoring COVID-19 incidence in patients with multiple sclerosis and diabetes and providing remote neurorehabilitation care.**^{351,376–380}

The interest in technology-enabled remote monitoring gained momentum during the COVID-19 pandemic, reflected in numerous national and regional policy initiatives and programmes.³⁶¹ For example, several national and regional programmes focus(ed) on various aspects of improving blood pressure (BP) control using remote monitoring, **e.g. BP@Home programme, Scale-Up BP programme and Connect Me in Scotland**, and efforts at Integrated Care Boards/Integrated Care Systems, Primary Care Network and GP practice levels. **NHS England’s BP@Home programme** was launched in 2020 and rolled out over 220,000 BP monitors during the COVID-19 pandemic to help enable remote monitoring approaches to the care of patients with hypertension.³⁸¹ NHS England’s **MHF@Home programme** was launched in 2021 to help people manage their heart failure condition at home and to prevent deterioration.³⁸² **In 2021/2022, the Health Foundation launched a Q Lab initiative focused on tech-enabled remote monitoring, which explored sustainable service models.**³⁸³ This initiative focused on building trust and confidence in digital health solutions among staff and patients, hopefully leading to easier adoption and scaling of TERM.³⁸³

Further policy momentum evolved over time, with the publication of key policy documents highlighting the importance of digitally enabled care. Examples include the **Plan for Digital Health and Social Care** in 2022³⁸⁴ and, **in 2024, Lord Darzi’s independent investigation of the NHS**, which discusses the importance of models such as virtual wards.²⁴

It is important to note that not all remote monitoring is tech-enabled to the same extent.

Some services rely on very basic technology such as phones or video links to enable remote consultations, while others use higher levels of tech-enablement such as various devices (pulse oximeters, blood pressure monitors, blood glucose monitors and smart inhalers) and various platforms for remotely conveying monitoring data and analytics from patients to healthcare professionals to support tech-enabled care.

The rapid implementation of remote monitoring technologies is accompanied by health services research and evaluations that assess their impacts.³⁷⁰

Examples include impact studies focused on the value of wearables,^{385–390} evaluations of tech-enabled remote monitoring programmes,^{391–394} and systematic reviews on remote home monitoring for people with chronic diseases, such as COPD,^{355,356,395–397} assessments of using pulse oximetry at home³⁹⁸ and in care homes,³⁷⁶ and the use of remote AI monitoring in social care.³⁹⁹ Currently, there are ongoing evaluations through the DECIDE national rapid evaluation programme in areas of hypertension, COPD, heart failure, digital health checks and home sensors in social care.³⁶⁷ The goal is to build a strong evidence base on the potential and limitations of technology-enabled remote monitoring in health and care, supporting patients, service users, carers and those commissioning remote monitoring services to ensure high-quality care and enable better-informed decision-making by policymakers. Other agencies are also supporting research and evaluation efforts to inform service delivery. For example, the NICE programme of Early Value Assessment (EVA) for Medtech, much of which focuses on remote monitoring solutions in diverse areas such as pulmonary rehabilitation for patients with COPD and weight management.⁴⁰⁰ NICE EVA outlines what the evidence gaps are, where further research and evaluation are needed, and the technologies that can be used safely while further evidence is sought.⁴⁰¹

Robust evaluation of what works, why, where and for whom is key to enabling evidence-based practice in the NHS and informing recommendations on improving the adaptation and scaling of innovation in remote monitoring practices.⁶¹ This is even more important given the rapid evolution of technology and its applications in healthcare. There is also variation in the ways of implementing care pathways, which is important to learn from to establish causal links between different service design approaches and their impacts on patient outcomes and experiences, service utilisation and quality of care in the NHS. **Despite promising developments in generating the evidence needed to support wider scale adoption, scale and spread, further research and evaluation are needed to help reduce uncertainties for decision-making and investment into this model of care.**

3.4.3. Impacts

Despite limited evidence, existing health services research and evaluation of tech-enabled remote monitoring is helping us better understand its impact on patient outcomes, access to care, patient experiences and disease burden control, impacts on health services and value for money.

To date, rapid evaluations of technology-enabled remote monitoring intended to support health and social care have reported mixed results.³⁵¹ While valuable evaluations exist to date, not many explore how technology-enabled remote monitoring can and should be integrated within relevant care pathways and which patient groups would benefit most.

Given the high levels of policy focus on tech-enabled remote monitoring as part of wider efforts to support more digitally enabled care in the United Kingdom, further research, evaluation and evidence synthesis are vital to inform decision-making.

Impacts on patients and population health

Evidence from recent evaluations has begun identifying the potential of tech-enabled remote monitoring to positively impact patients and population health. However, further health services research and evaluation are needed to understand the impacts on diverse populations, given the lack of diversity amongst studied populations. Box 22 below illustrates some examples of the impact on patients and population health.

Box 22. Technology-enabled remote monitoring impact on patients and population health

1. Improving patient outcomes:

- **Improving clinical outcomes:** Remote BP monitoring has been shown to be effective in improving clinical outcomes for blood pressure control in service users. For example, a meta-analysis focusing on patients living in urban environments suggested that remote blood pressure monitoring is effective in reducing blood pressure and supports achieving target blood pressure levels for patients with hypertension.³⁵²
- **Reducing complications from infections and the need for hospitalisation**^{402–405}: Smartphone-assisted self-testing at home was found to be helpful in managing high-risk urinary tract infection patients (UTI). A retrospective cohort study of patients who have undergone kidney transplantation showed that the technology-enabled remote monitoring system reduced urinary tract infection-related hospitalisations by 75%. The study found that infection-related complications were 65% lower. The number of face-to-face clinical appointments was reduced slightly, with an increase in remote interactions.⁴⁰⁶ A randomised controlled trial of 76 GP practices participating in the Home and Online Management and Evaluation of Blood Pressure (HOME BP) pilot found that the tech-enabled remote monitoring resulted in better blood pressure control than traditional care.⁴⁰² In contrast, another randomised controlled trial focusing on 142 GP practices in the UK found no differences between the health outcomes of patients who underwent usual care, self-monitoring or tech-enabled remote monitoring.⁴⁰⁴
- **Improving patient recovery:** A mixed-method evaluation of a remote tracking and coaching system focusing on stroke patients in London showed a 63% increase in participant levels of physical activity. Patients partially attributed this to the targets they had set in the monitoring system, motivating them to achieve their daily activity targets for stroke recovery. Therapists agreed that the intervention was successful in motivating patients recovering from post-stroke motor and sensory impairment.⁴⁰⁷

2. Improving patient experience:

- **Remote monitoring of chemotherapy-related side effects:** A randomised controlled trial of 12 cancer centres showed an associated reduction in symptom burden and a decrease

in patient anxiety, measured using the Memorial Symptom Assessment Scale (MSAS) global distress index and MSAS psychological scores.⁴⁰⁸

- **Enabling convenience and self-management:** A user-experience study of patient experiences of wrist-worn devices for remote monitoring suggested that many patients were able to self-manage. However, some factors influenced patient success in operating the device, such as the patient's perception of their disease. Patients with higher levels of perceived disease burden and less controllable seizures were less able to manage the device independently. Half of the cohort needed initial support to use the devices, emphasising the importance of ready technical support for such programmes.⁴⁰⁹ A report on the public's experience monitoring their blood pressure at home described benefits such as the flexibility and convenience of care enabled by remote monitoring.³⁵³
- **Providing reassurance and a sense of control:** Multiple studies attributed high levels of patient satisfaction with tech-enabled remote monitoring solutions to the reassurance they provide users.^{353,354,357} Patients also reported having an increased sense of control over their condition, as well as a positive impact on their levels of motivation due to tech-enabled remote care.³⁵³ In a study of patients with atrial fibrillation (AF), all patients who responded to the questionnaire (90% of the patient cohort) reported being satisfied with the remote monitoring service and would recommend it to others.³⁵⁹
- **Providing support during the COVID-19 pandemic:** More than 487,000 NHS patients were supported by technology-enabled remote monitoring between the November 2020 and January 2023 Regional Scale Programme, supported by the National Innovation Collaborative.^{369,370}
- **Patients also benefit from reduced hospitalisation and shorter length of stay,** as discussed in Box 23 below.

Impact on healthcare services and the wider health system performance

Healthcare services and the wider health system performance are critical in assessing the impact and utility of technology-enabled remote monitoring. The insights we currently have based on existing research and evaluation suggest that there are some healthcare system-level benefits from introducing TERM to patient care. However, the evidence base is inconclusive, with different studies arriving at different conclusions on impact, possibly related to the diversity of tech-enabled remote monitoring interventions at play. The evidence on cost-effectiveness is also inconclusive. The limited number of studies on this topic makes it difficult to determine with confidence the impact that TERM has on healthcare services utilisation and cost-effectiveness, indicating the urgent need for further health services research and evaluation to inform decision-making, as well as the need for establishing the data infrastructure in the NHS to enable robust evaluations of impact on the NHS.

Box 23 illustrates some examples of impacts on healthcare services and wider health system performance based on the existing evidence base:

Box 23. Technology-enabled remote monitoring impact on healthcare services and wider health system performance

1. Reducing hospitalisations and the length of hospital stays:

- **Reducing AF hospital admissions:** A feasibility study focusing on a virtual ward for patients with AF demonstrated that out of 50 patients admitted to the virtual ward, 24 avoided hospital admission because of the programme. Another 25 patients avoided readmittance due to remote monitoring.³⁵⁹
- **Reducing the length of hospital stays:** A retrospective longitudinal study of virtual ward and hospital admissions at NSH Wrightington, Wigan and Leigh (WWL) Teaching Hospitals showed that virtual ward patients had shorter hospital stays before being admitted to virtual wards. Being monitored through the virtual ward setting slightly improved patient survival, while readmission was linked to a rapid decline in patient survival rates.⁴¹⁰
- **Reductions in hospital stays and lessened burden on associated services:** A mixed-methods service evaluation of a hospital at home system in Buckinghamshire, Oxfordshire, and Berkshire West ICS showed that between September 2023 and January 2024, the remote monitoring system served 6,500 adults and 320 children, freeing up 46,685 and 715 hospital bed days respectively. The average length of remote monitoring was seven days for adults and two days for children. Calls to 111 were reduced by 58% for adults and 85% for children. Emergency admissions dropped by 73% for adults and 85% for children, while ambulance incidents were reduced by 66% for adults and 85% for children.⁴¹¹

2. Reducing face-to-face appointments and increasing workforce productivity:

- In an evaluation of the Digital Access to Services at Home (D@SH) programme, NHS Dorset reported that their ability to access blood pressure readings of their patients through their technology-enabled remote monitoring programme allowed them to support over 450 patients since March 2022.⁴¹² However, different studies have arrived at different conclusions on the impact of tech-enabled remote monitoring on health service utilisation in the hypertension management space, indicating a need for both further robust evaluation in general, and more evidence synthesis.
- A real-world feasibility study of myCOPD, a self-management app, in a rural population showed that high app usage was associated with reduced NHS resource use, suggesting benefits for highly engaged patient groups.³⁵⁸

3. Impact on costs and cost-effectiveness of care:

- The evidence on cost-effectiveness is limited and needs developing. It is important to note that, in existing studies, the modelling approaches and their underpinning assumptions vary. However, there is evidence pointing to cost savings resulting from the use of virtual wards. For example, a study on virtual wards and hospital admissions estimated the daily cost savings by the hospital to be £935 as a result of virtual wards.⁴¹⁰ An NHS Dorset evaluation reported that their remote blood pressure monitoring programme led to 55% cost savings on GP appointments, a 45% reduction in appointments of patients with hypertension and an increase in productivity estimated at £181,000.⁴¹²

- An evaluation of a 2018 patient telehealth programme at two different sites in the UK found differences in the programme's cost-effectiveness. While one site had a reported increase in costs of £10,000, the other site saved £140,000 as a result of the programme. According to the study, the differences could be attributed to how the technology was introduced and how the care pathway was designed and implemented.⁴¹³

Impacts on the economy and society

Further research is needed to understand the impact of technology-enabled remote monitoring on the wider economy and on social issues such as inequalities and digital exclusion.³⁵¹ However, the landscape indicates a vibrant ecosystem of technology enterprises supporting remote monitoring efforts. Some wider societal benefits also extend beyond patients, e.g. to carers, as outlined in Box 24.

Box 24. Technology-enabled remote monitoring impacts on the economy and society

1. Enterprise creation:

- There is a vibrant sector of remote monitoring technology suppliers supporting job creation, including small and medium-sized enterprises and larger technology providers for remote monitoring equipment and data platforms.

2. Impact on the well-being of carers:

- **Impact of remote monitoring of children with Type 1 diabetes on their parents:** A qualitative study of parents of children aged 1–7 with Type 1 diabetes who were monitored remotely with continuous glucose monitoring (CGM) revealed the impact of the tech-enabled care on parents. Parents reported greater ease in monitoring their children's glucose levels, improved sleep while using CGM because of not having to wake up at night to perform finger-prick checks for their children, an increased peace of mind, a greater sense of confidence and freedom and a positive impact on wider family relationships.⁴¹⁴

3.4.4. Reflecting on key influences on progress

Based on insights from health services research studies and evaluations of tech-enabled remote monitoring to date, key enablers of progress include:

Table 4. Enablers and barriers influencing the progress in mental health research and innovation

Enablers of progress to date	Challenges to progress to date
<ul style="list-style-type: none"> • Support from national programmes to integrate tech-enabled remote monitoring into care pathways.^{370,391} • Collaboration between technology suppliers and NHS staff, e.g. enabling user-friendly data conveyance of monitoring data and supporting NHS staff onboarding to digital care pathways. • Support for service users in engaging with remote monitoring technologies from tech suppliers and NHS staff. • Evolution and adaptability in technologies: being able to improve functionalities, interoperability and user-friendliness of data displays for health service users.^{353,415-418} • Support from tech suppliers and providers for patients and healthcare staff is critical for effective engagement with the technology.⁴¹⁷ • Clear NHS staff roles for delivery of technology-enabled remote monitoring in the patient care pathway: this includes the mobilisation of healthcare assistants, clinical pharmacists, nurses, receptionists and practice managers, reducing demand on primary care GPs.^{415,418} • Increasing focus on robust evaluation and gradually improving evidence: the establishment of the newest rapid evaluation centre, DECIDE, to conduct rapid evaluations of technology-enabled remote monitoring and enable timely evidence to inform policy decision making.³⁶⁷ 	<ul style="list-style-type: none"> • Problems with data access and interoperability due to variations in digital infrastructure, data privacy^{363,417} and data security requirements across organisations and technology suppliers.⁴¹⁸ As a result, researchers need to develop strategies to access necessary data, including potentially complex data-sharing agreements. • Problems with data access and interoperability due to variations in digital infrastructure, data privacy^{363,417} and data security requirements across organisations and technology suppliers.⁴¹⁸ As a result, researchers need to develop strategies to access necessary data, including potentially complex data-sharing agreements. • Staff trust in technology-enabled remote monitoring and capacity for engagement: staff have varying degrees of trust in tech-enabled systems. Staff also can perceive the need to incorporate innovation as a burden due to a lack of capacity to engage and a need to upskill.^{353,383} • Digital exclusion and other inequality-related challenges: not all patients have equal opportunities to engage with tech-enabled remote monitoring due to a lack of digital, social, cultural and/or economic capital. • Funding challenges for the sustainability, scale and spread of innovation: funding is often available only for equipment or short-term pilots. • The diverse and complex NHS contexts into which technology-enabled remote monitoring is introduced³⁶³ make the implementation success less certain and must be accounted for in the evaluation design.

3.4.5. Looking to the future: a vision for impact in technology-enabled remote monitoring ten years from now

In the future, the nature and scale of technology-enabled remote monitoring within the NHS could evolve significantly, reflecting advancements in technology, healthcare delivery and policy. High-quality, cost-effective care will be enabled by an ecosystem of matured support mechanisms embedded in the health system based on learning from health services research and evaluations that support evidence-based practice. More specifically:

- **The NHS workforce will be motivated and supported to engage with tech-enabled remote monitoring pathways and will have access to evidence of its impact** on care quality and patient outcomes. Staff will be clear on their roles in the TERM pathway delivery – meaning that non-clinical staff such as GP practice managers and receptionists, nurses in primary and acute care, clinical pharmacists and clinicians will all contribute to an efficient division of labour.
- **The NHS data architecture for collecting impact information on costs, clinical outcomes and health service utilisation outcomes will have improved.** Research and evaluation of TERM will focus on continuous quality improvement, using real-time data analytics to monitor and enhance effectiveness. This will be enabled by streamlined data-sharing agreements with technology providers, interoperable systems across the NHS and a skilled workforce that can optimise existing healthcare data. There will be improved interoperability between different tech supplier IT systems and NHS platforms and better use of existing infrastructure (e.g. the NHS app) to enable more cost-effective service delivery.
- **AI will be applied more widely to help support clinical decision-making and for predictive purposes** (e.g. early warning signs of risks of potential deterioration enabling timely intervention).
- **The evidence from research and evaluation will mature, informing the scale and spread of tech-enabled care.** This evidence will inform the evolution of tech-functionalities as well as the design of NHS services to enable at-scale applications for preventative care, reduced waiting times and hospital admissions. Pathways to entry into the NHS will be easier to navigate for tech suppliers as improved research and evaluation evidence and synthesis, including on the cost-effectiveness of TERM, will reduce uncertainties for commissioners of care. Better demand-signalling by policymakers and payers will reduce variation in practice and inform more transparent, evidence-based commissioning.
- **The full potential of technology to inform clinical practice will be better supported by efficient regulation.** Barriers associated with regulatory bureaucracy and timelines that prevent full utilisation of a technology's potential will be reduced, meaning that more technology can be used to support clinical decision-making, including through integrating AI applications.
- **Evaluations of TERM will provide evidence to guide policy and regulatory frameworks, ensuring that remote monitoring technologies comply with standards and best practices, especially considering the rapidly evolving nature of these technologies.** The regulatory framework will be nimble enough to respond to technology developments thanks to horizon

scanning capacities. This will involve collaborating with policymakers to shape regulations that protect patient privacy and data security.

- **A community of practice will be established to exchange learning and to inform practice adaptations in tech-enabled remote monitoring.** This will bring together diverse communities (with subgroups) spanning patients and the public, healthcare professionals and providers, technology suppliers, policymakers, regulators and Health Technology Assessment (HTA). A continuously learning health system will reduce inefficiencies and promote adaptation to learning.
- **Coordination of TERM activities at regional levels,** e.g. Primary Care Networks (PCNs) and Integrated Care Boards (ICBs), will enable efficient capacity management in the system, with new roles established to support coordination (e.g. digital care coordinators at PCN levels) and work with GP practices as needed. There will be greater collaboration between disciplines involved in research and evaluation, enabling diverse experts to contribute to evaluations and to help develop a rounded evidence base. This will include disciplines such as health services, behavioural and implementation science, health economics and business studies.
- **Patients will trust that TERM supports high-quality, safe care and will be empowered to engage with tech-enabled services.** They will trust that the findings from their monitoring data are readily accessible to health professionals in user-friendly ways and that healthcare professionals and/or others involved in TERM services delivery will approach patients for any interventions which may be needed. Patients will also be supported to effectively onboard onto the pathway by NHS staff and/or tech suppliers and confident in engaging with the technology. The experience of service users and carers (where applicable) will be central to evaluation and research activity. It will contribute to service design and technology adaptation to ensure user-friendly approaches.

3.5. Participatory, community research

Box 25. Case study summary: participatory research in the NHS



The UK has been at the forefront of participatory research involving people who use and depend on health services to help design, implement and evaluate research and innovation efforts:

- Initiatives such as INVOLVE and the Public Involvement Standards Development Partnership paved the way for enabling participatory research.
- Programmes such as the NIHR's People in Research provide a wider support ecosystem that includes patients and the public in health research.



Impacts on patients and population health:

- Participatory research can improve the relevance and quality of research for patients and the public and, when carried out effectively, the experience of people contributing to research. For example, the Partner Priority Programme involved public advisors in evaluating new services aimed at reducing health inequalities and improving health and well-being.
- Engaging communities in the research process can also support more culturally appropriate services and improve the likelihood of target populations accepting services, increasing the potential for improved health outcomes and reduced health disparities.



Impacts on the NHS and wider health system:

- By focusing on local health issues, participatory research can help optimise the use of NHS resources. It allows for the identification of cost-effective solutions tailored to specific populations.

- Collaborative research structures involving academia, the NHS and other organisations, such as the Applied Research Collaborations, provide a distinctive structure for academic and clinical academics that lead research to engage with end users, and this can improve the pathway from research to implementation in practice.



Impacts on the economy and wider society:

- Commercially sponsored clinical trials are a key area of health research and a competitive field at an international level. Participatory approaches can help improve the quality of trial designs, which can impact the success of participant recruitment and retention efforts.

A Future Vision for Success: Participatory Research in the NHS



The UK will remain a global leader in participatory health research, leveraging its historical expertise in developing participatory research methods and evidence in this field. The evaluation of participatory research efforts will inform innovative participatory research practices.



A national institute for participatory health research will provide leadership, funding for capacity building, evidence generation and training to advance participatory research methods and support their scale-up and spread throughout the research landscape. It will also embody participatory approaches in its governance.



NHS professionals will scale up efforts to engage patients, the public and communities in health research. This will be enabled by skills and capacity-building in participatory research via tailored education and continual professional development opportunities.



There will be an increasing focus on engaging communities (as opposed to individual patients or public members) in research to address wider social, economic and environmental determinants of health through research, particularly targeting minority groups. This is important because community-based participatory research is pivotal to regional, place-based NHS services that can respond to the needs of their populations. Community-based participatory approaches will aid in identifying local health priorities, engaging communities in decision making regarding their health services, and mobilising broader resources. This will also help evolve the evidence base on how to conduct place-based participatory research most effectively.

3.5.1. Introduction

Involving the people who use and depend on health services in research and science about health brings many benefits; it helps to ensure that research is asking the right questions, strengthens the efficiency and effectiveness of how research is carried out, and ensures that research brings benefits to local people and communities including through better dissemination and uptake. Although there is some evidence that these participatory research approaches are effective in practice, evaluating the contribution of participatory research approaches is challenging, and more evidence is needed about how best to do it and the benefits it brings. However, a range of approaches already exist, some focusing on patients, some on individual participants and others on broader engagement of entire communities or neighbourhoods.

3.5.2. Origins, history and evolution

Recognising the value of involving patients and communities in health research has been a slow process. The initial approach of health research was to see patients and participants as people that research was done *to* rather than *with*. This approach was reflected in initial ethical principles, premised on the basis that the key involvement of a research participant was informed consent. However, in recent decades, there has been increasing recognition of the value of engaging participants as active partners in research, both because of the moral value of doing so and the practical improvements that doing so brings to the research itself. From a research perspective, the 'action research' concept developed by Kurt Lewin in the 1940s included client participation as a key element, which provided a key basis for participatory research methods.⁴¹⁹ From a societal perspective, a key moment was the emergence of patient activist groups such as HIV/AIDS groups who wished not just to be the subjects of research but to be part of actively shaping which questions to address and how.

The UK has been a leader in involving people in health research with a long-standing commitment to PPIE in health research⁴²⁰ and has made an outsized contribution to global evidence.⁴²¹ Beginning in the early 1990s, there was increasing recognition of the value of involving the public in health research and infrastructure to support it, which became **INVOLVE** between 1996 and 2020. However, although the subsequent abolition of INVOLVE raised concerns about commitment and capacity for continued involvement, the **UK Public Involvement Standards Development Partnership** developed a set of UK standards for public involvement in research, **led by the NIHR in collaboration with relevant actors from the four UK nations**.⁴²² The six standards are:

1. **Inclusive opportunities:** Public involvement partnerships are accessible and include a range of people and groups, as informed by community and research needs.
2. **Working together:** Collaborate in a way that values all contributions and builds and sustains mutually respectful and productive relationships.
3. **Support and learning:** Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.
4. **Governance:** Involve the public in research management, regulation, leadership and decision-making.

5. **Communications:** Use plain language for well-timed and relevant communications as part of involvement plans and activities.
6. **Impact:** Seek improvement by identifying and sharing the difference that public involvement makes in research.

Community-based participatory research goes beyond the involvement of individual patients or members of the public to engage local communities more broadly. As with patient and public engagement, this is argued to benefit the research itself and those engaged in it.⁴²³ This reflects wider evidence about the benefits of community involvement in decision-making more generally, benefiting health and well-being as well as wider community issues such as local living conditions and services.⁴²⁴ This can be particularly relevant in addressing social determinants of health, which are the wider social and economic characteristics of people and communities that strongly shape health outcomes. This is a particular challenge for the UK, which is a relatively unequal country by European standards, where addressing impacts on health inequalities is thus especially important.⁴²⁵ Better understanding of patients' social and economic context and mobilising community resources can help to ensure better treatment.⁴¹⁵

Box 26. Born in Bradford: how participatory research can reshape and facilitate health research in practice

Although Bradford is the sixth biggest city in the UK, Bradford district is one of the most deprived areas in England, with profound needs regarding health and wider health determinants, such as income, employment, education and housing. Despite this, local health research was also lacking when the Bradford Institute for Health Research (BIHR) was established in 2007 (Int10). The Institute worked to address that through deep participatory engagement with the local population, turning Bradford into one of the country's leading health research centres (Int10). Working closely with the local community, they developed the 'Born in Bradford' research programme,⁴²⁷ a large-scale cohort study of mothers expecting children at Bradford Royal Infirmary between 2007 and 2010. The study involved 16,000 people across the city and led to a wide range of powerful research about health and prevention, addressing issues ranging from genetics and obesity to activity, the environment and wider social factors.

The success of this research was built on deep community engagement⁴²⁸ that led to an extraordinary set of data, including biological samples and linked records across health and social care, local government, policing and social security. This engagement also shaped the research focus, moving away from a traditional medical research model approach to a greater focus on social determinants of health and local needs. This is reflected in their strategy for a 'City Collaboratory' approach, bringing together researchers, policymakers and communities to identify and test upstream preventative interventions in a whole city setting.⁴²⁹

The Bradford experience demonstrates the remarkable potential for community-based participatory research in terms of expanding the scope of what is possible from a research perspective, what is needed from the perspective of the local community, and the synergies that can be created by bringing these elements together through participation and engagement.

3.5.3. Impacts

Impacts on patients and population health

Participatory research approaches can improve the experience of patients and participants taking part in research and help improve the health of patients and the population more generally by supporting research to address the most important questions efficiently. Box 27 **provides some illustrative examples.**

Box 27. Impacts of participatory research on patients and population health

Improving the ability of patients and the public to contribute to research:

- For example, the Partner Priority Programme involved public advisors in evaluating new services aimed at reducing health inequalities and improving health and wellbeing. This approach helped to improve the skills of both participants and researchers in engaging with each other and improving the quality of the services provided.⁴³⁰

Enabling more culturally appropriate services to deliver health benefits:

- Engaging communities in the research process can lead to culturally appropriate interventions that are more likely to be accepted by the target population, improving health outcomes and reducing health disparities.⁴³¹ For example, one study that used large-scale data over a decade across both study communities and control communities found that the communities engaged through participatory research approaches showed significantly greater improvements in cardiometabolic health over that period.⁴³²
- Community engagement in research is key to tackling inequalities, particularly for minority communities or disadvantaged groups whose perspective is less likely to be understood by researchers.⁴³³ Research can be carried out as a co-creative activity and thus help to mobilise local communities and improve relevance and impact on their health.⁴³⁴ For example, the 'East London Genes & Health' study is a large-scale community-based research project involving the Bangladeshi and Pakistani communities in East London.⁴³⁵ By building trust and collaboration with these communities, the project successfully recruited participants for genetic research to improve health outcomes for these populations.

Enabling wider social determinants of health to be included in well-informed research and services:

- Mental health research is especially relevant. Since many factors affecting mental health are rooted in local social and economic conditions, engaging local communities in identifying and prioritising them can build a more accurate and relevant understanding of the challenges.⁴³⁶ As so many mental health interventions depend on application in the community rather than inside formal care settings, research to develop and test mental health interventions exemplifies where engaging with local communities can help to improve the relevance and effectiveness of research and help address a lack of capacity in mental health services.⁴³⁷

Impacts on the NHS and wider health system

By focusing on local health issues, community-based research can help optimise the use of NHS resources.

Box 28 provides examples of the impacts of community-based and participatory research on the NHS and wider health system.

Box 28. Impacts on the NHS and wider health system

Increasing the likelihood of cost-effective, relevant and applicable service delivery and supporting the translation of research into practice:

- Participatory research allows for the identification of cost-effective solutions tailored to specific populations. This approach increases the relevance and applicability of research findings to real-world settings, leading to more effective health interventions. This can include collaboration across academia, the NHS and other organisations, such as the Collaboration and Leadership in Applied Health Research and Care (CLAHRC) partnerships. These provide a distinctive structure for those leading research to engage with the end users of that research, including professionals and other practitioners. This participatory and collaborative approach can help to bridge the gap between research and implementation in practice.⁴³⁸ Although it requires additional effort and engagement, it can bring benefits via a more direct route from research to application in practice.
- Participatory approaches are particularly relevant in research addressing health technology assessments to decide the costs and benefits of particular treatments. Research must ask the relevant questions For these assessments (e.g. appropriate comparators). While there is increased awareness of the potential contribution of participatory approaches to such research, evidence is still lacking about how effectively this is being carried out to help ensure that research is as relevant as possible.³⁴¹

Improving recruitment and retention of clinical trial participants to enable higher quality clinical trials and greater likelihood of success:

- Participatory approaches can help improve the quality of trial designs and approaches.³³⁹ For example, recruiting and retaining participants is a key issue in the success of clinical trials (and for health research more generally) and is potentially affected by a wide range of factors not always well understood by researchers designing trials.³⁴⁰ Participatory research approaches can help improve recruitment and retention through better trial design.

Improving staff recruitment and retention and fostering an NHS culture of continuous learning:

- Taking part in research can also benefit staff engaged in it within the NHS. From a workforce perspective, research participation can also help improve staff recruitment and retention²⁸ and foster a culture of continuous learning and improvement within the NHS, helping support wider change. The longer a study goes on, the more important it is to consider participants' views. This was illustrated by the SIREN study, which looked at immunity and reinfection for SARS-CoV-2 infection in the UK between 2020 and 2023⁴³⁹ and showed that involving participants helped improve the study's design, recruitment, and implementation.

Impacts on the economy and wider society

Clinical trials are a key area of health research and a competitive international field. The proportion of clinical trials carried out in the UK compared to other jurisdictions is a key benchmark for the success of the UK's life sciences sector more generally. The UK's attractiveness to industry and ability to secure industry investment in clinical trials can be bolstered by recruiting diverse patients into trials at scale.

Box 29 illustrates how participatory research can support trials, which, alongside health-related benefits, attract revenue for the health system and generate wider societal benefits.

Box 29. The role of participatory research in clinical trials

Improving recruitment and retention to clinical trials and the attractiveness of the NHS for clinical trials and the revenue they bring:

- Despite the multiple positive impacts of clinical trials in the NHS, as outlined in Section 4, many clinical trials have difficulties recruiting a representative group of participants.⁴⁴⁰ Supporting the recruitment of diverse patients into clinical trials is necessary to achieve more reliable results and, what follows, to attract more investment in clinical research. There is evidence suggesting that a lack of patient engagement in recruitment can result in less equitable clinical trial participation due to clinicians' difficulties reaching diverse groups more representative of the general population.⁴⁴⁰ Participatory research approaches can help access more diverse patient groups. As of May 2024, through its commitment to participatory research, the Bradford Institute for Health Research (BIHR) has outperformed research centres in London and Cambridge, with 25,000 local patients registering to take part in live studies.⁴⁴¹

Enabling the NHS to be an effective 'anchor institution' bringing societal benefits to local communities and community resilience:

- One broader discussion strand about the impact of the NHS on the economy and wider society is the role of NHS organisations as 'anchor institutions', i.e. large public sector institutions bound to a local place that affect the health and well-being of those communities.⁴⁴² Although this concept does not integrate a research dimension, engaging local communities through community-based participatory research is an additional way NHS institutions can enhance their role as anchor institutions to involve and benefit the communities in which they operate. By involving local communities in this way, NHS institutions can help improve community resilience and health.⁴⁴³

3.5.4. Reflecting on key influences on progress

Table 5. Enablers and barriers influencing the progress in participatory research

Enablers of progress to date	Challenges to progress to date
<ul style="list-style-type: none"> • Policy support catalysing wider change: as described above and by Palm and colleagues,⁴²⁰ there has been long-standing support for participatory approaches in health research from the government, in particular through INVOLVE and the integration of patient and public involvement as a requirement for other NIHR funding. INVOLVE became more than a hub, which generated a wider social movement of people championing participation and engagement in research. This includes within academia (such as Centre for Social Justice and Community Action at Durham University), within health more broadly (such as through the UK Public Health Association, and their engagement with wider community change such as through the Health Housing and Fuel Poverty Forum). There has also been support from wider initiatives to promote participatory approaches, such as funding for public engagement by the four UK higher education funding councils, Research Councils UK, and the Wellcome Trust in 2008.⁴⁴⁴ However, there is concern that the recent ending of INVOLVE also undermines this policy support for participatory health research. • Reflections of wider social context: Participatory research in health in the UK reflects wider changes in the health service and society, such as the greater empowerment of citizens and strengthening of health research. Moreover, reflecting awareness of wider challenges around inequalities and the need to address wider challenges of public health in Britain has helped to broaden the focus of participation in health research from involving patients in specific health research projects to wider community engagement. • Building evidence and capacity for how to approach participatory research and its benefits. While the benefits of participatory research approaches remain challenging to quantify, INVOLVE played a key role in supporting collective learning and building an evidence base around how to do involvement and what it could bring. More broadly, the UK (alongside the US) has played a leading role in building evidence around participatory approaches in health research. • Increasing academic expectations of public involvement in health research. Academic journals increasingly expect to see patient involvement in the studies they publish, or even require it,⁴⁴⁵ as do research funders when making decisions on funding applications. This is supported by the development of reporting guidelines for patient and public involvement, although concerns remain about how far these expectations generate meaningful rather than tokenistic involvement.⁴⁴⁶ 	<ul style="list-style-type: none"> • Ensuring wide-scale and sustained trust from diverse communities and the public in research and innovation and a deeper understanding of its value. This is particularly critical for ethnic minority communities in the UK, which experience a range of health inequalities, intensified during the COVID-19 pandemic and leading to low levels of trust in health research.⁴⁴⁷ Low levels of trust in health research and innovation are further exacerbated by insufficient transparency about the research process, with a recent parliamentary committee report stating that around 50% of clinical trials do not publish their results.⁴⁴⁸ • Enabling equitable opportunities for diverse patients and communities to engage through cementing flexible and diverse engagement approaches. This can be achieved through increased PPIE, especially when approached as an opportunity to engage diverse groups to participate in and contribute to all research stages. A co-produced strategy for engaging UK ethnic minority communities in research outlined that this is only possible when PPIE is not tokenistic or seen simply as a tick-box exercise in light of mandatory requirements of funding bodies.⁴⁴⁷ Instead, PPIE partners should be sought early in the research process, enabling the development of a relationship with participants, and followed by regular co-production and consultation opportunities and continuous communication while being facilitated by a diverse research team.⁴⁴⁷

3.5.5. Looking to the future: a vision for impact from participatory research ten years from now

A successful future for participatory health research will include several key elements:

- **Sustained participatory policy and funding support:** A national institute for participatory health research will be established and funded to support capacity building and evidence generation, providing clear leadership and exemplifying participatory approaches in its own governance.
- **Community-based participatory research will be central to the anchor role of the NHS:** Every NHS organisation conducting community-based participatory research will help identify local priorities for health, involve communities in decisions around their health services and mobilise wider resources to support the implementation of health interventions in practice.
- **Embedding expectations:** Expectations of effective participatory approaches will be established as part of funding, training, publishing and implementing health research throughout the UK.
- **Capacity-building amongst the NHS workforce will ensure effective engagement with patients and communities in research and innovation activities.** Skills- and capacity-building will be introduced for all NHS professionals conducting research to engage patients, the public and communities in their health research.
- **Targeted engagement of marginalised or minority groups** will be enabled through participatory approaches. This will help address inequalities in health by providing specific support and action to engage marginalised communities (e.g. ethnic or religious minorities), groups with poor health outcomes or groups facing particular health challenges.
- **The UK will be at the heart of global collaboration on participatory health research.** Building on the UK's historically leading role in generating methods and evidence about participatory methods, participatory methods in health research will be established as part of the UK's distinctive research environment.
- **Participation in mobilising resources will address wider determinants of health.** Greater engagement of communities will address wider social, economic and environmental determinants of health and help overcome inequalities that undermine good health in the UK.

Chapter 4. Support mechanisms in the UK life sciences and health research and innovation ecosystem: current status, challenges and what 'good' looks like in the future

4.1. A brief history of research and innovation in the NHS

This section provides an overview of the history of R&D and innovation in the NHS, as summarised in Box 30. As described in what follows, the foundations for NHS R&D predate the formation of the NHS in 1948. However, since then, leaders of NHS R&D and innovation have grappled with two issues that have remained reasonably constant over time. The first is various attempts to seek a balance between scientific freedom, societal needs and the practicalities of healthcare delivery. The second is the interplay between broader government priorities, healthcare innovation and the challenges of coordinating a vast research infrastructure.

4.1.1. Early Days: the foundations of public health research (1911–1948)

The origins of publicly funded health research in the UK can be traced back to the 1911 National Insurance Act, in which Subsection 2 of Section 16 laid down that one penny for each insured person should be contributed annually to the expenses of sanatorium benefit out of money provided by Parliament but that the Insurance Commissioners might retain the whole or any part of that contribution 'for the purposes of research'.⁴⁴⁹ This led to the creation of the Medical Research Committee in 1913, later renamed the Medical Research Council (MRC) in 1920. The MRC focused on long-term, investigator-led research to support foundational scientific inquiry.

However, this era also revealed tensions between independence and state influence. The Haldane Report (1918)*,⁴⁵⁰ emphasised that research should remain free from ministerial interference to maintain scientific rigor. This principle underpinned the separation of operational research for immediate needs, handled by government departments, and curiosity-driven research, championed by the MRC.

From the perspective of innovation, this period saw the 1940 launch of the first mass vaccination program for diphtheria before the NHS was formally established, marking an early effort to integrate innovation into public health efforts.⁴⁵¹

The creation of the NHS in 1948 marked a pivotal moment. With a unified healthcare system, the NHS presented unprecedented opportunities for national research coordination. However, early

* It is worth noting that the Haldane (1918) report was on the government's machinery following the First World War. Whilst mythologised subsequently in science policy, the section that suggests research should be arms-length from the government is a minor recommendation in the report.⁴⁵⁰

Box 30. History of research and innovation in the NHS: a summary

1911–
1948

Early days and foundations in public health research: Notable milestones included the National Insurance Act (1911), the establishment of the Medical Research Committee (1913, renamed Medical Research Council in 1920), the Haldane report influencing the use of evidence in policy (1918) and the first mass vaccination programme (diphtheria, 1940).

1948–
1970

NHS creation and shift to applied research: Notable milestones included the formation of the NHS (1948), the Medical Research Council's emphasis on scientific freedom, NHS innovation focus on vaccination (e.g. tuberculosis, polio) and the first successful kidney transplant in the UK (1960s).

1971–
1990

Rothschild era – the customer-contractor model: The Rothschild report (1971) transformed the approach to public R&D funding with government departments and the NHS deciding on research priorities and commissioning research from MRC and other bodies. Other notable milestones included the establishment of the Medicines Commission (NICE's predecessor) and various technological advances in the 1970s, such as CT scanning and in-vitro fertilisation (IVF).

1988–
2000

Evidence-based medicine and the birth of NHS R&D: This period saw an increasing focus on evidence-based medicine, interest in systematic reviews and application of research in clinical practice. Notable milestones included the House of Lords Priorities in Medical Research Report (1988), the first NHS R&D Strategy (1991), the NHS and Community Care Act (1990), the NHS Direct advice-and-information service (1998) and growing interest in the role of information technology in the NHS.

1997–
2006

Expansion under new Labour: Increased investment in NHS R&D was supported via the NHS R&D programme. Other notable milestones included the establishment of the National Cancer Research Network (2000), NICE (1999) and the Patient Safety Agency (2001).

2006–
present

The formation of the NIHR and a centralised approach to R&D with a scaled-up focus on research and innovation as being key to healthcare quality, safety and efficiency: Notable milestones included the NIHR and Best Research for Best Health strategy (2006), Lord Darzi's 'High Quality Care for All: NHS Next Stage Review (2008)', NHS Right Care (2009), Getting it Right First Time (2012), Five Year Forward View (2014), Carter Review (2016), Next Steps on the NHS Five Year Forward View (2017), NHS Long Term Plan (2019), Accelerated Access Review (2016), Life Sciences Industrial Strategy (2017), Life Sciences Vision (2021), Accelerating Genomic Medicine in the NHS (2022), Wachter Review (2016), Topol Review (2019), Data Saves Lives (2022), Plan for Digital Health and Social Care (2022), Goldacre Review (2022), O'Shaughnessy review (2023), Darzi review (2024) and Sudlow review (2024).

NHS research initiatives were limited in scope and funding. The Ministry of Health focused primarily on public health and statistical surveys, leaving clinical and biomedical research to the MRC.

4.1.2. NHS creation and the shift to applied research (1948–1970)

The NHS's initial years were characterised by fragmented research efforts. While teaching hospitals conducted clinical research, the Ministry of Health faced challenges integrating applied research into the broader healthcare system.

At this time, the MRC remained the dominant player in the research landscape, prioritising scientific freedom and long-term goals. This period saw the emergence of large-scale projects, such as population screening programs and organ transplantation studies, which highlighted gaps in the existing research infrastructure. The lack of coordination between the NHS and the MRC created inefficiencies and missed opportunities for leveraging the NHS's unique data and patient access.

Vaccination continued to be a key focus of innovation in the NHS. The vaccination program, for example, was part of a nationwide effort to control infectious diseases; diseases such as tuberculosis⁴⁵² and polio⁴⁵³ were introduced during this time. The 1960s also saw the first successful kidney transplant in the UK enabled by innovation in surgical techniques and organ transplantation.⁴⁵⁴

4.1.3. Rothschild Era: the Customer-Contractor Model (1971–1990)

The Rothschild Report (1971) introduced a transformative approach to public R&D funding, advocating for a customer-contractor model. Government departments, including the NHS, would define research priorities and commission work from the MRC and other bodies. This shift aimed to align research with national needs but faced criticism for potentially undermining scientific independence.⁴⁵⁵

For the NHS, this model prompted a focus on applied research directly relevant to healthcare delivery and informing innovation. However, some critics argued that the model risked marginalising fundamental research and that the Department of Health lacked the capacity to manage its expanded role effectively. Despite this, the model laid the groundwork for structured research prioritisation, including developing health economics as a tool for assessing research value. The Committee on the Safety of Medicines oversaw medicines' safety and efficacy and essentially represented NICE's predecessor in terms of health technology assessments.⁴⁵⁶

The 1970s also saw technological advances in areas such as CT scanning,⁴⁵⁷ marking significant progress for innovation in diagnostic imaging and joint replacement surgery,⁴⁵⁸ benefiting patients and the NHS. IVF was also introduced into the NHS.⁴⁵⁹

4.1.4. Evidence-based medicine and the birth of NHS R&D (1988–2000)

The late 1980s marked a significant moment in the history of NHS R&D with the rise of evidence-based medicine, which emphasised the need for systematic reviews and the application of research to clinical practice. The 1988 House of Lords report, 'Priorities in Medical Research',⁴⁶⁰ was a seminal moment, calling for a more integrated and strategic approach to NHS research.

In response, the NHS established its first R&D strategy in 1991, led by Michael Peckham. This strategy introduced systematic reviews, the HTA program, and a commitment to using research to improve healthcare delivery. It also sought to involve patients and the public in research design, laying the foundation for future initiatives like the INVOLVE program. The introduction of the internal market in the NHS (including the 1990 NHS and Community Care Act) during this period created new challenges. The purchaser-provider split incentivised cost control, leading to concerns that research might be seen as a financial burden rather than an asset. However, it also prompted clearer identification and accountability for research funding, setting the stage for future reforms. At the same time, the 1990s saw more accountabilities introduced for the quality of care through the introduction of clinical governance frameworks.⁴⁶¹

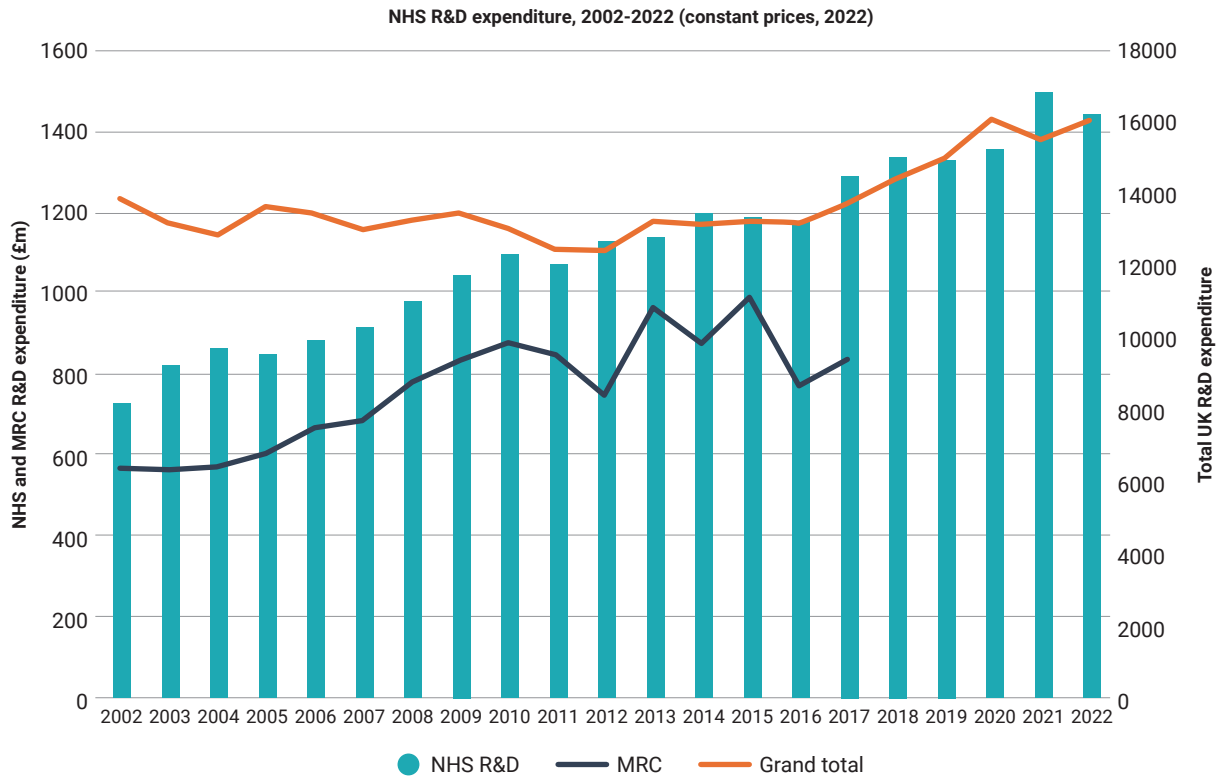
The 1980s and 1990s also saw a greater interest emerge in using information technology in the NHS, with the introduction of basic IT systems for patient record management in the 1980s⁴⁶² and the NHS Direct service telephone helpline service in the 1990s to provide health advice and information, laying the early foundations for digital healthcare.⁴⁶³

4.1.5. Expansion under New Labour: integration and growth (1997–2006)

The election of the Labour government in 1997 marked a period of increased investment in NHS R&D. The government's emphasis on 'investment for reform' aligned closely with the goals of the NHS R&D program, which sought to demonstrate measurable benefits from research. This alignment was exemplified by the establishment of the National Cancer Research Network (2000), which improved clinical trial recruitment. During this period, the NHS R&D budget grew (see Figure 5), increasing by a factor of two between 2002 and 2022, supported by policies linking research to economic growth. The establishment of NICE further focused on integrating research and innovation findings into healthcare policy and practice. Structural changes such as the abolition of Regional Health Authorities and centralised R&D management created a more streamlined and cohesive system.

This period also saw more focus on digitisation and the introduction of electronic health records as part of efforts to support efficient and more integrated patient care. Initiatives like the Patient Safety Agency were established to help innovate in delivering safe care, reduce medical errors and improve the quality of care.⁴⁶⁴ We also began to see a focus on bolstering the innovation infrastructure with the establishment of the NHS Modernisation Agency.⁴⁶⁵

Figure 5. Growth in NHS R&D expenditure (current prices) compared to MRC and total Government Expenditure on R&D (GERD).*



4.1.6. The formation of the NIHR: a centralised approach (2006–present)

The creation of the NIHR in 2006 was a watershed moment for NHS R&D.⁴⁶⁶ Led by Sally Davies, the NIHR represented a ‘big bang’ approach to reform, centralising R&D funding and management. The centrepiece of the ambitious strategy, ‘Best Research for Best Health’,⁴⁶⁷ put the patient at the centre of the NHS R&D system. This reorganisation introduced competitive peer-review processes, ensuring that funding was allocated based on merit and national priorities. The NIHR introduced several innovative initiatives, including establishing Biomedical Research Centres and Clinical Research Networks. These initiatives provided infrastructure and support for translational research, bridging the gap between basic science and clinical application. The NIHR also prioritised researcher development, creating a clearer career pathway for clinician-scientists. Collaboration with industry and other funders, such as the Wellcome Trust and the MRC, became a cornerstone of the NIHR’s strategy. By fostering partnerships and improving the NHS’s capacity to support clinical trials, the NIHR positioned the UK as a global leader in health research.

In the past decade, various national policy initiatives and key policy publications have emphasised innovation more explicitly and strategically. One of the earliest influential moves to advance

* The MRC line stops after 2017 in Figure 5 because the government started reporting for UKRI rather than separate research councils after 2017.

innovation on the policy agenda can be attributed to *Lord Darzi's* 'High Quality Care for All: NHS Next Stage Review in 2008'.⁴⁶⁸ This review made the case for innovation being key to improving care quality and safety and focused not only on the need for robust frameworks for research and development activity but also for its adoption and for enabling cultural transformation so that innovation can be supported at all levels in the NHS, and that it can be enabled to spread across the NHS with the support of a networked infrastructure.

The growing policy emphasis on innovation evolved within the recognition of its importance in supporting efficiency in care delivery and reducing unwarranted variation in quality and safety (e.g. 'NHS Right Care' in 2009, 'Getting it Right First Time' in 2012, the Carter Review in 2016), supporting innovation in the NHS and its adoption (e.g. 'High Quality Care for All: NHS Next Stage Review' in 2008⁴⁶⁸ and the Accelerated Access Review in 2016), and supporting a life sciences sector with thriving university-industry-NHS collaboration (e.g. the Life Sciences Industrial Strategy in 2017 and the UK Life Sciences Vision in 2021)³⁴⁵. Innovation was also given some prominence as part of wider national policy and strategy efforts to support health system sustainability, access, affordability and quality at this time (e.g. the Five Year Forward View in 2014, the Next Steps on the NHS Five Year Forward View in 2017 and the NHS Long Term Plan in 2019).⁴

There was also a growing focus on innovation in the context of key strategic areas of importance to the UK, such as genomic medicine and digital transformation. For example, 'Genome UK: The Future of Healthcare'⁴⁶⁹ was published in 2020 and outlined the government's vision for genomics in healthcare regarding its potential to contribute to disease detection and diagnosis, prevention and personalised medicine, highlighting the critical role of supporting research and innovation, a conducive data infrastructure, workforce development and public engagement in achieving these aims. The strategy also focused on supporting the UK in maintaining and strengthening its position as a global leader in genomic medicine and international collaboration. In 2022, NHS England's 'Accelerating genomic medicine in the NHS'⁸³ strategy set out aims and priorities related to embedding genomics in the NHS across primary, community, specialist and tertiary care, enabling equitable access to genomic testing, positioning genomics as an exemplar and leader in wider digital and data transformation efforts in the NHS and supporting research and innovation to enable rapid access to advances by patients.

In terms of the power of IT and digital transformation, the 2016 Wachter Review was influential in how the NHS evolved its approach to digital health, flagging the sociotechnical nature of the required effort in clinical engagement and workforce upskilling, strategic planning, strong leadership and governance, and appropriate and proportionate regulation.⁴⁷⁰ The pandemic experience, alongside science and technology advances, continued to be an impetus for further focus on digital innovation in the NHS since 2019, with key national reviews and policy and strategy documents focusing on digital transformation, the integration of digital technology into the NHS, preparing the workforce and data-driven service delivery (e.g. The Topol Review in 2019, the Data Saves Lives strategy in 2022, the Plan for Digital Health and Social Care in 2022³⁸⁴ and the Goldacre Review in 2022).⁴⁷¹ The Goldacre review tackled the need to optimise how health data can be used safely and securely with public trust, protecting patient privacy and introducing the concept of trusted research environments. Most recently, the Sudlow Review (published in November of 2024) of the UK health data landscape⁴⁷² recommended establishing a coordinated

strategy between public bodies regarding data access and use in research and innovation, seeing data as key national infrastructure. One of the key recommendations of this review was establishing a national data service to support research and analysis in safe and secure ways and a UK-wide system of standards and accreditation for secure data environments. A 2025 report presenting industry views on how to improve the use of NHS data for research highlighted the importance of data infrastructure that meets the needs of academics and industry in order to support efficient, high quality and impactful research, and the need for a streamlined and integrated data access service with a single point of entry to a secure data environment network.

In summary, the 2010s and 2020s saw increasing interest in digital approaches to healthcare⁴⁷³ and an emphasis on advancing research and innovation in genomics⁴⁷⁴ to modernise healthcare. More recently, innovation has become increasingly prominent in the NHS's efforts to enable a sustainable healthcare service and to support high-quality care, with efforts spanning diverse key strategic areas, including digital care, remote monitoring and virtual wards, the use of artificial intelligence and machine learning²¹⁵ and further investment in genomic medicine.⁸¹

The research and innovation infrastructure has significantly improved in the last two decades, providing solid foundations on which to build. For example, the establishment of Academic Health Science Centres in 2008,⁴⁶⁸ Collaborations for Leadership in Applied Research and Care (now called Applied Research Collaborations) in 2008⁴⁷⁵ and the Academic Health Science networks in 2013 (now called Health Innovation Networks),⁴⁷⁶ represented major institutional shifts in supporting the coordination of both research and innovation activity and on partnering between universities, the NHS and industry organisations around both the development and adoption of innovation.

4.1.7. Looking ahead

The new Labour government has signalled an interest in strengthening the role of the NHS as a partner in innovation⁴⁷⁷ in improving NHS capacity for clinical trials and in revitalising the life sciences and health sectors through a focus on strategic investments and support mechanisms, enhanced integration of advanced technologies, fostering stronger collaborations between institutions⁴⁷⁸ and regulatory innovation.

Lord Darzi's independent investigation of the NHS²⁴ also points to a need for greater prioritisation of research and innovation as key vehicles for improvement in healthcare quality and productivity, pointing to the importance of digitally-enabled care (remote monitoring and virtual wards) and the necessity of NHS and life sciences industry collaboration (key to developing the Oxford Astra Zeneca COVID-19 vaccine and discovering the benefits of dexamethasone for patients with severe COVID). Lord Darzi called for working towards an NHS where research and innovation enable NHS sustainability rather than being seen as second-order priorities.

Despite promising developments and progress over the last two decades, considerable work is still needed to shape a system and infrastructure to embed, spread and scale research and innovation within the core of the NHS fabric. Lord Darzi's independent investigation of the NHS highlighted a worrying decline in the number of healthcare professionals practising research in the NHS, presenting a challenge to bridging the gap between research and clinical practice (as discussed in the section on workforce).

National policy efforts are again signalling a vision of supporting and bolstering the role of research and innovation in the NHS. However, further work is needed to build on past progress, sustain what has been achieved thus far and arrive at feasible implementation plans for new efforts to harness the benefits that science and technology currently offer and ensure the NHS and patients benefit from such progress.

4.2. An ecosystem of support mechanisms for research and innovation in the NHS: key considerations

Box 31. Section summary: an ecosystem of support mechanisms for research and innovation in the NHS

- **Success in establishing wider transformation efforts as part of the 10-Year Plan depends on delivering a research-and-innovation-powered NHS. Efforts to do so must consider the sociotechnical nature of research and innovation:** Appropriate social building blocks (e.g. values, norms, beliefs, attitudes, behaviours, relationships and motivations) and technical building blocks (formal rules, regulations, structures and processes) must be a key part of efforts to mainstream **research and innovation throughout the NHS**.
- **Seven support mechanisms for a research-and-innovation-powered NHS are key to achieving an efficient, effective and equitable health service. These support mechanisms need to work together for the system as a whole to work** and relate to:
 1. A research-and-innovation-active workforce.
 2. Information, evidence and data environments.
 3. Physical infrastructure.
 4. Funding, commissioning and procurement environments for undertaking and adopting research-and-innovation advances.
 5. R&D governance and regulation of innovation.
 6. Collaboration and coordination of research and innovation activity.
 7. Patient and public involvement, engagement and participation, including considering inequalities.

We have argued that embedding research and innovation throughout the NHS is the fourth big shift that the government needs to focus on in the 10-Year Plan to achieve success in wider transformation efforts and to put the NHS on a firm footing. Embedding research and innovation into the core fabric of the NHS and seeing it as a ‘must’ rather than a ‘nice to have’ can only be achieved through approaches that focus as much on the *social side* of research and innovation (i.e. people, culture, attitudes and values, relationships, beliefs, motivations) as they do on its *technical side* (i.e. formal structures, processes, formal rules and regulations).

Research and innovation is fundamentally sociotechnical. Conducting research and innovation and its adoption scale and spread in a health system depends on a complex nexus of interactions between diverse actors, organisations, networks, institutions, ideas and opportunities, capabilities, values, behaviours, regulations, policies and socioeconomic, political and cultural contexts.⁶¹

Historically, much of the literature and theoretical perspectives on research and innovation in health have suffered from siloed approaches between science, technology and innovation studies perspectives on the one hand and health services research perspectives on the other.

A more joined-up approach can enable policymakers to better support research and innovation across the value chain, from supply to adoption, scale and spread. That said, both science, technology and innovation studies and health-services research point to the complexity of forces at play.

Science, technology and innovation (STI) literature on innovation (across different sectors) adopted an industrial strategy perspective and focused on research and innovation as vehicles for economic competitiveness and growth.⁴⁷⁹

As the thinking about national, sectoral and regional systems of innovation matured and research into transitions and change evolved, this body of literature offered scope for much practical learning of relevance to policy and decision making, emphasising the importance of considering innovation as a process and not just as an output, and the dependence of innovation success on the fit between the properties of a product, technology or service and their use context (including its socioeconomic, scientific and technological, cultural, political, legal, policy and regulatory regimes). They also offered scope to see innovation processes as the result of both top-down orchestration by system leaders and bottom-up local, individual and organisationally driven experimentation efforts.

Health services theoretical perspectives, research frameworks and wider social sciences literature have emphasised a focus on research and innovation's role in transforming health services delivery and on its adoption, scale and spread.⁶³ Like STI studies, these perspectives emphasise the need for alignment between evidence-based research discoveries and innovation properties (including levels of complexity and scope for adaptability to local needs) with the nature of the implementation context (e.g. individual characteristics and attitudes, organisational acceptability, implementation costs, structural, relational, resource and cultural characteristics, wider local, regional and national conditions).³

Many common themes emerge across these perspectives regarding the core influences and support mechanisms for an effective research and innovation system. These span a diversity of issues, with some of the key ones relating to (1) **workforce (capacity, skills, capabilities, incentives, accountabilities for research and innovation);** (2) **information, evidence and data environments underpinning research and innovation;** (3) **physical infrastructure;** (4) **funding, commissioning and procurement environments for carrying out research and adopting innovation;** (5) **R&D governance and regulation of research and innovation;** (6) **collaboration and coordination landscapes;** and (7) **patient and public involvement, engagement and participation, including in consideration of inequalities.**

These support mechanisms need to work together for the system as a whole to work. We elaborate on each of these support mechanisms in the context of research and innovation in the

NHS in the following contents to arrive at how to enact each support mechanism in a vision for what 'good' looks like in the future.

4.3. Research and innovation in the NHS: the current landscape and a vision for the future

Box 32. Section summary: the current landscape and a vision for the future

- **Research and innovation should provide the evidence, insights and skills that enable change and improvement throughout the NHS. The UK has a unique opportunity to reinvigorate, spread and scale research and innovation to benefit patients, the health service, the economy and wider society. However, this potential has not yet been fully realised.** Building on the gradual progress made depends on proactively tackling key challenges. Research and innovation in the NHS remain fragmented, beset by systemic inefficiencies, insufficient opportunities and incentives for NHS staff to engage, and weak links between NHS priorities and industrial strategy.
- **In a vision for what 'good' looks like in ten years, an ecosystem of seven support mechanisms helps mainstream research and innovation throughout the NHS to support success in wider NHS transformation efforts.** More specifically:



Workforce: A research-and-innovation-active NHS workforce is critical for sustainable, high-quality and cost-effective healthcare. In ten years, research and innovation will empower NHS staff to help transform the NHS by ensuring evidence-based, innovative patient care. The NHS workforce will be motivated, skilled, rewarded and accountable for doing and adopting research and innovation, supported by better training and information.



Data, information and evidence: Improved access to data, information and evidence is essential for ensuring best practice in NHS care and responding to unmet needs. In ten years, data, information and evidence will be more widely accessible to researchers and innovators and will be used, shared, combined and analysed safely and securely, with public trust. An evidence-driven NHS will actively develop, adopt, spread and scale new solutions.



Physical infrastructure: Upgrades to basic physical infrastructure alongside investments in key high-tech facilities are crucial for the NHS to provide safe care and for patients to access global scientific advances. In ten years, the infrastructure investment attracted will improve the NHS estate in supporting excellence in research, innovation and patient care. The 'basics' will be in place, reducing contradictions between world-leading facilities in some settings and dilapidated buildings and out-of-date equipment, hardware and IT systems in others.



Funding, commissioning and procurement: More strategic prioritisation of funding is crucial for reducing resource wastage and inefficient and ineffective care. In ten years, investments into research and innovation will be more collaboratively prioritised to align the innovation pipeline with health needs and affordability, supporting improvements across prevention, diagnosis and treatment.



R&D governance and regulation of innovation: Efficient, robust and innovation-friendly R&D governance and regulation that ensures patient safety underpins the ability of research and innovation to translate into NHS, patient and economic benefits at scale. In ten years, close collaboration across research governance, innovation regulation and health technology assessment will cement a smoother pathway from labs to NHS practice, enabling patients to benefit from rapid access to novel solutions and providing an attractive UK market for innovators.



Collaboration and coordination: Closer collaboration and coordination between local, regional and national bodies is pivotal for more efficient and effective progress with research and innovation, as well as its translation and spread into best practice in the NHS. In ten years, patients, the NHS and the economy will benefit from a landscape in which industrial and health policy initiatives reinforce each other, regional and national efforts are complementary, and the UK is a key partner in global developments.



Patient and public involvement, engagement and participation: Inclusive patient and public involvement, engagement and participation in research and innovation determine whether the UK population has a fair say in shaping what the NHS does and how. In ten years, it will be the norm for patients and the public across diverse communities to engage in meaningful and flexible ways, helping to steer a culture of constant improvement focused on real needs and greater trust.

The UK has a unique opportunity to nurture, sustain and scale a research-and-innovation-active NHS that benefits patients, the health service, the economy and wider society. This will require a strategic and coordinated approach that brings together knowledge and policy remits across health, science and technology and industrial strategy spheres to make the most of the potential of an integrated health and innovation system.

In the following sections, we discuss what matters for a research-and-innovation-powered NHS, the current landscape of support mechanisms, challenges and a vision for what 'good' looks like in the future regarding each of the seven core support mechanism areas identified above.



4.3.1. Workforce considerations for research and innovation in the NHS

A. What matters to ensure a research-and-innovation-active NHS workforce?

Box 33. What matters- workforce considerations: key points

Workforce:

- Skills, capabilities and leadership
- Workforce capacity
- Incentives (time, headspace, recognition, reward) and accountability
- Opportunities for diverse staff groups.

Not everyone working in the NHS will be research-or-innovation-active to the same extent. However, more NHS staff need to understand what research and innovation is about, how it can help achieve high quality, safe, efficient, effective and value-for-money healthcare, how it can support NHS staff in their roles and how it can support wider societal and economic benefits.

Enabling NHS staff to engage with research and innovation requires supportive leadership, which is key to creating the time and headspace for staff to engage. This applies to clinical, operational and administrative leadership that can support teamwork across different professional groups and hierarchies.⁴⁸⁰ The idea of an NHS R&D workforce is in itself nebulous as it involves some individuals who have a clinical and research focus (such as clinical academics and research nurses), some solely engaged in research (such as statisticians, health economists, etc.) and others dedicated to facilitating and managing health and care research within the NHS (research leaders, managers, and support teams). Compounding this issue is how the 'innovation' workforce looks.⁴⁸¹ The literature on innovation would argue that this is the whole workforce, i.e. innovation can be initiated from a porter to the chief executive of the NHS, and that it needs to be diverse and inclusive.⁴⁸² Health research relies on a wide range of contributors, from traditional clinical academics to team scientists, interdisciplinary experts and lived experience researchers. However, conventional career structures often fail to accommodate this diversity.

It also requires attention to nurturing the requisite social and technical skills for research and innovation in the NHS. Some of these skills will transcend different types of research and innovation activity (e.g. knowing how to identify and prioritise unmet needs, critically assess evidence, effectively collaborate and network, and manage research, innovation projects and risk), while others will be specific to distinct research or innovation challenges (e.g. genomics and digital health research and innovation, specific clinical disciplines),⁶¹ as discussed in the case studies in Section 3. For example, Health Education England training programmes for NHS staff

helped develop the skills needed for engaging with, analysing and interpreting genomics data within the Genomic Medicine Service, as well as resources to build healthcare professionals' confidence in engaging with AI. Another example is the role of remote monitoring in the NHS, accompanied by efforts to upskill and onboard NHS staff to engage with data collected through remote monitoring platforms and onboard them onto digitally-enabled care pathways.

Advances in research and innovation also raise new NHS workforce capacity requirements.

For example, advances in genomics call for additional staff capacity in diagnostic laboratories. Breakthroughs in neuroscience, including for new Alzheimer's drugs for example, raise challenges for neurologist and neuroradiologist staff capacity.⁴⁸³ Using digital technologies to support remote care in the community may reduce capacity pressures on some types of staff (e.g. reduced needs for face-to-face GP or outpatient appointments) but may lead to new staff capacity needs to support onboarding of staff and patients into digitally enabled remote monitoring pathways. Some of this capacity can be built through training existing NHS staff with the skills needed to engage with innovation advances and some through efforts to recruit staff from elsewhere.

Motivations and accountabilities also influence the workforce's propensity to engage with research and innovation in the NHS. Research has shown that individuals in the NHS engage with innovation for a variety of reasons, spanning personal beliefs about its importance in supporting high-quality patient care, incentives related to funding availability, leadership support and organisational culture and potential reputational, financial and career-related benefits.⁴⁸³ Attitudes to risk can also influence the propensity to adopt innovation (stakeholder workshop). The challenge is aligning individual and organisational motivators spanning care quality and financial sustainability concerns. As noted in the Association of Medical Research Charities (AMRC) report, incentive and reward structures for academic researchers – including clinical academics – directly influence the research type conducted. Since such individuals often have joint appointments with universities, the university system's practice can impinge on NHS research and innovation.⁴⁸⁴ This includes incentives for academics that emphasise publication numbers, citations and grant funding, leading to hyper-competition for funding and tenure-track positions⁴⁸⁵ over the impact on practice. Various efforts to create incentives for NHS staff to engage with research and innovation do exist (elaborated on below) but are still relatively piecemeal and fragmented. One of the challenges with enabling NHS research and innovation activity amongst staff is freeing up time for engagement.

B. What is the current landscape of support mechanisms for a research-and-innovation-active NHS workforce?

Box 34. The current landscape of support mechanisms for a research-and-innovation-active NHS workforce: key points

Support mechanisms related to the workforce – current landscape and developments over time:

- **Programmes supporting clinical academic research careers**, e.g. NIHR fellowships, the integrated academic training pathway, Wellcome PhD fellowships for healthcare professionals and the Athena Swan Charter.

- **Policy impetus for research and innovation over time**, e.g. Best Research for Best Health, Accelerating genomic medicine in the NHS and the Innovation Ecosystem Programme report.
- **Innovation training programmes and support**, e.g. the Clinical Entrepreneurs programme, NHS Innovation Accelerator, NHS England Genomics Education Programme, NHS Digital Academy, NHS AI Lab, HEE Health Service Innovation Fellowships and Health Innovation Network support.
- **Initiatives to bolster NHS staff abilities to support patient recruitment into clinical trials**, e.g. the NIHR Research Delivery Network and National Patient Recruitment Centres.

Currently, the NHS and wider health research and innovation landscape is investing in various programmes to support requisite research and innovation skills, capabilities, capacity and incentives. Some efforts focus on the ability of NHS staff to *undertake* research and innovation, and others on the ability to adopt, spread and scale research and innovation.³ Such programs have aimed to bridge the gap between clinical work and research activity, enhancing the relevance of research to patient care. To illustrate:

- Over the past two decades, numerous policies and initiatives have been introduced to make clinical academic research more attractive, seeking to address challenges such as workforce retention, integrating research and practice, and the need for a supportive environment for clinician-researchers. A notable example is **NIHR support for clinical academic careers**,⁴⁸⁶ providing dedicated research funding and creating pathways for clinical academics to secure competitive grants. The creation of specific funding streams like the NIHR's Clinical Research Network has further enabled clinicians to participate in research without sacrificing their clinical roles. The **NIHR's Integrated Academic Training Pathway**⁴⁸⁷ offers a clear progression from academic foundation programs to senior research positions. This framework has been instrumental in retaining talented clinicians within academia by providing mentorship, funding and defined career routes. **Wellcome PhD fellowships for healthcare professionals** are another example.⁴⁸⁸ The Royal College of Physicians and the NIHR have called for explicit policies to safeguard research time for clinician-researchers. However, the implementation of these measures remains inconsistent, highlighting ongoing challenges. More recently, policies have sought to improve diversity within the clinical academic workforce. Initiatives such as the **Athena SWAN Charter** promote gender equity, while programs like the NIHR Research Professorships aim to attract candidates from underrepresented backgrounds, fostering a more inclusive research environment.
- Policies such as **Best Research for Best Health** (2006) emphasised the importance of making research a core NHS activity, thereby making research more accessible to clinicians and patients alike. Another policy impetus has supported the development of workforce innovation skills in the NHS over time, such as the first **five-year genomic strategy for the NHS, 'Accelerating genomic medicine in the NHS'**,⁸¹ alongside a strategy implementation plan, **'The Genome UK: 2022 to 2025 implementation plan for England'**,⁷⁹ and, most recently, the **'Innovation Ecosystem Programme Report'**.⁴⁸⁹ Efforts to embed non-clinical researchers within the NHS have also been helping promote interdisciplinary teams where their skills

complement clinical expertise. Such integration ensures that research is informed by both technical precision and practical application. Additionally, **diverse partnerships between universities and the NHS** (e.g. via **Biomedical Research Centres**⁴⁹⁰ and **Applied Research Collaborations**⁴⁹¹) have been strengthened to provide non-clinical researchers access to real-world healthcare data and settings.

- In the innovation space, the **Clinical Entrepreneurs**⁴⁹² programme was launched in 2016 to support clinical and non-clinical staff in developing technical and commercial skills needed to successfully develop innovations benefitting patients and the NHS. **The NHS Innovation Accelerator programme**⁴⁹³ focuses on enabling staff to develop the networks and skills for appraising innovation to support adoption, scale and spread. Some education and training efforts focus on specific areas of research and innovation, such as the **NHS England Genomics Education programme**⁴⁹⁴ provided through Health Education England. The **NHS Digital Academy**⁴⁹⁵ focuses on developing digital leaders who can enable digital transformation in the NHS, including as they relate to artificial intelligence. Although primarily focused on accelerating the safe and effective use of AI in the NHS and supporting AI innovation projects, the **NHS AI lab**¹⁷³ also provides educational support and resources to NHS staff working on AI-related projects. Healthcare Education England also offers **Healthcare Science Innovation Fellowships**⁴⁹⁶ that focus on developing and using innovations for diagnosing, monitoring and managing the health of people with long-term conditions, reducing inequalities and providing training and mentoring opportunities for healthcare scientists in the NHS. Various regional **Health Innovation Networks**⁴⁹⁷ offer training workshops, seminars, resources and support for innovators in the NHS.

These are just some examples illustrating a strong foundation to build on in efforts to develop capacity and skills in the NHS workforce for engaging with research and innovation. Some examples of the successful scale and spread of innovation (such as virtual wards) illustrate what is possible under concerted national efforts and conducive policy support (stakeholder workshop). However, considerable work is still needed to create, sustain and grow a research-and-innovation-active NHS workforce that can keep up with the pace of scientific and technological advances and the opportunities they create for improving care. There is also significant potential and need for the NHS to scale up engagement with clinical trials and innovative clinical trial designs. This is important for helping patients gain earlier access to treatments and providing a source of investment in the NHS.⁴⁹⁸ There is currently a solid foundation of supportive clinical trials, infrastructure and initiatives that can help bolster NHS staff abilities to support patient recruitment into clinical trials. Examples include support for the NHS through the **NIHR Research Delivery Network**⁴⁹⁹ infrastructure and resources to assist with recruitment into trials, dedicated research staff and process support and various national **Patient Recruitment Centres**⁵⁰⁰ in the NHS.

However, for a variety of reasons (some to do with skills, others with infrastructure, regulation and governance), much more must be done to build up NHS staff capacity and skills to support effective patient recruitment into trials and incentivise NHS staff to be able to do so at scale. The new Labour government has signalled an interest in strengthening the NHS's role as a partner in innovation and improving NHS capacity for clinical trials and staff training in clinical trial methodologies.

C. What are the challenges to a research-and-innovation-active NHS workforce?

Box 35. Challenges to a research and innovation active workforce: key points

Challenges related to a research-and-innovation-active NHS workforce:

- Remaining skills gaps (e.g. the need for enhanced education and training on research and innovation in career pathways).
- A decline in the number of health professionals practising research.
- An uneven distribution of opportunities across secondary, primary and community care and different professions (e.g. consultants, GPs, nurses and allied health professionals).
- Limited prioritisation of research and innovation as key to driving improvement in NHS policy and strategy.
- Challenges to freeing up NHS staff time and capacity to engage with research and innovation.
- A lack of sufficient incentives and rewards.

The current opportunities for a research-and-innovation-engaged NHS workforce are still geared toward the few, not the many. The NHS is currently grappling with significant challenges concerning its workforce and workforce planning, encompassing staffing shortages and evolving roles within the healthcare system, which will likely impact the 'NHS R&D workforce'. There are also disparities in the capacity to conduct research between primary, community and secondary care, with primary care often not having the requisite balance of clinical, administrative and managerial infrastructure to enable efficient research and innovation activity (stakeholder workshop). As highlighted in Lord Darzi's independent investigation of the NHS, there is a worrying **decline in the number of healthcare professionals practising research** in the NHS, presenting a challenge to bridging the gap between research and improvements in clinical practice that benefit patients.²⁴ There is, however, a need for further evidence to back this observation, as some evidence published by the Medical Schools Council suggesting that the level of clinical academics, for example, has broadly stayed the same over time. However, underpinning this stability are legitimate concerns that 36% of clinical academics are aged over 55. This trend is even more pronounced at the Professor grade, with 65% of Professors aged over 55. Having more than doubled since 2004 (31%), this suggests declines in experienced clinical academics are soon likely.⁵⁰¹ However, views supporting a concerning decline in clinical academics are echoed by other commentators. For example, the AMRC has also highlighted the necessity of integrating research into the NHS to enhance patient outcomes, boost workforce morale and maintain the UK's global research leadership. The AMRC has flagged the need to reverse the decline in clinical academics, support clinical research career frameworks and incentivise research across the NHS, including amongst groups that often face limited opportunities (e.g. GPs, nurses and allied health professionals).⁵⁰²

Lord Darzi's review also points to a need for more prioritisation of research and innovation as key vehicles for improvement in healthcare quality and productivity. This is not surprising, both in the context of supporting care quality and safety and economic competitiveness in a knowledge-based economy. **There is also still a degree of cultural resistance to clinical entrepreneurship and innovation** (seeing it as a 'dirty word' linked to profit-making by some in the NHS) and challenges in ensuring organisational cultures in the NHS (stakeholder workshop), where research and innovation are seen as fundamental inputs into delivering high quality and sustainable care (stakeholder workshop). There are substantial **challenges with finding sustainable ways to free up time for NHS staff and ensure sufficient capacity and staff equipped with the needed skills** to engage with both research and innovation activity. However, we are somewhat further along with the support system for research than for innovation in the NHS. Funding fellowships and other programmes that buy out staff time can help but also raise challenges in backfilling staff time in the current NHS workforce capacity climate. In addition, there is a need to modernise approaches to education and training about research and innovation, potentially learning from how the private sector is building skills in some emerging science and technology areas (e.g. data science, AI) to ensure education and training approaches are fit for purpose in developing the practical skills needed to translate knowledge into practice (stakeholder workshop).

Embedding research and innovation into job roles and responsibilities has happened in pockets (e.g. innovation director roles, clinical academics). However, the extent to which these roles are appropriately enacted in practice is variable. Some organisations have also implemented various awards to recognise research active and innovating staff, though this is still happening at a small scale.⁶¹ However, the fundamentals of NHS staff conditions need to be in place and support staff well-being to ensure they are motivated to engage with research and innovation (stakeholder workshop). Precarious employment, limited career paths for nontraditional roles and exclusionary cultures deter many from pursuing or remaining in health research and/or innovation. These barriers disproportionately affect underrepresented groups and those with non-linear career trajectories.⁴⁸² There is **a need for fresh thinking on how to incentivise and reward innovation** by staff at all grades, and both clinical and non-clinical staff, and to **ensure accountability** for engaging with evidence-based healthcare and innovative practices, including scaling and spreading innovation, to support excellence and value for money in healthcare delivery (stakeholder workshop). This needs to be coupled with enhanced focus **upskilling programmes and opportunities for education and training** related to research and innovation in career pathways, from early in healthcare professional education (stakeholder workshop).

D. A vision of what 'good' looks like in ten years and 'how we get there': NHS workforce

Ensuring a research-and-innovation-active workforce that is fit for the future depends on investing in the needed leadership, skills, capacities, capabilities, incentives and accountability regimes today. In turn, patients would benefit from a highly skilled and up-to-date NHS staff who would be motivated and empowered to undertake and use research and innovation to deliver excellence in care and facilitate improved patient access to research advances, trial opportunities and innovation in prevention, diagnostics, vaccines, medicines and therapies. Box 36 **outlines the**

future vision for the NHS workforce relative to research and innovation as the fourth big shift in NHS transformation efforts.

Box 36. A future vision for a research-and-innovation-active NHS workforce: what 'good' looks like

FUTURE VISION: In ten years, the fourth shift will have empowered NHS staff to help transform the NHS by ensuring evidence-based and innovative patient care. The NHS workforce will be motivated, skilled, rewarded and accountable for engaging with research and innovation to deliver sustainable and high-quality healthcare.

In this vision for the future, the potential of research and innovation to make NHS service transformation a reality is enabled because:

- **Leadership, skills and capacities support a culture of innovation and improvement:** Local, regional and national NHS leadership across clinical, managerial and administrative functions champion and promote NHS cultures in which staff understand and appreciate how research and innovation can support high-quality care and are incentivised to engage. Staff are exposed to training about research and innovation early on in their careers through reform in education curricula and have relevant skills updated over time through continual professional development. Staff understand and appreciate the importance and potential of research and innovation to support high-quality care. As a result, there is a critical mass of research and innovation active staff, including in professions which historically had limited opportunities (e.g. mental health, nursing). The NHS provides high-quality care and improved health outcomes (on par with other leading developed economies) as healthcare keeps up with science and technology advances rather than falling behind.
- **Incentives and accountabilities enable NHS staff to engage with research and innovation at the needed scale to deliver excellence in patient care:** Research and innovation are embedded in the identity of the NHS and are not seen as siloed out of NHS careers but embedded within them. Innovation is not mandated, but NHS organisations need to provide compelling evidence of why proven innovations or research-based practices are not taken up (if that is the case) through accountability and monitoring practices and inspection regimes. This helps tackle unwarranted variation across different healthcare providers. Incentives and rewards provide NHS staff with the time, permission, job roles, flexibility, recognition and career pathways to enable meaningful contributions.
- **The NHS workforce is motivated, and staff well-being is improved through job satisfaction and pride in high-quality care delivery:** Alongside wider NHS workforce reforms, greater engagement with research and innovation makes NHS staff feel motivated, rewarded and proud to deliver world-leading healthcare. Staff want to join the NHS partly because of its reputation for being innovative but also because policy efforts and investments will enable more sustainable job roles and careers and better staff well-being.



4.3.2. Data architecture, evidence and information environments for research and innovation in the NHS

A. What matters for a data, evidence and information-powered NHS research and innovation ecosystem?

Box 37. What matters for data information and evidence: key points

What matters in data information and evidence:

- Producing, accessing and sharing data, information and evidence to support the translation of research and innovation into service delivery and improve care quality, safety and cost-effectiveness.
- Infrastructure for data access and sharing.
- IT systems interoperability.

Data, information and evidence underpin all efforts to support evidence-based practice in the NHS and integrate research and innovation advances into improvements in care quality, safety and cost-effectiveness. Access to data and information is needed to undertake research and innovation and to adopt its outputs. For example, NHS staff developing innovations need access to datasets for research, information about evidence requirements for regulatory approval and health technology assessments, information on how to develop good business cases and protect IP, and information on how to communicate an unmet need and the value of their research and innovation efforts and to disseminate learning effectively. Staff making decisions about commissioning and procurement or those involved with implementing research and innovation advances need to be able to identify potential solutions and assess and critically interpret data on their performance from evaluative evidence.³ Research and innovation in the NHS also call for access to diverse data sets, e.g. clinical, administrative, genomic and behavioural.

B. What is the current landscape for using data, information and evidence for research and innovation in the NHS?

Box 38. Support mechanisms related to data, information and evidence: key points

Support mechanisms related to data, information and evidence – current landscape and developments over time:

- **Data infrastructure**, e.g. NHS electronic health records for the majority of population initiatives such as Integrated Data Service, UK Biobank, Our Future Health, Genomics England/100,000 Genomes, Health Data Research UK, Secure/Trusted Data Environments,

Hospital Episode Statistics (HES), CPRD, cohort study datasets, such as from the Born in Bradford Study and OpenSAFELY.

- **Support for building public understanding about data access, sharing and use**, e.g. Understanding Patient Data.
- **Support for access to evidence**, e.g. NIHR Evidence Synthesis groups, NIHR Innovation Observatory, Wellcome Evidence Synthesis Infrastructure Collaborative.
- **Support for navigating requirements for data and evidence generation**, e.g. NHS Innovation Service, Health Innovation Networks, MHRA guidance and NICE guidance.

We consider the current landscape in the context of (1) current data architecture and (2) the evidence and information landscape.

(1) Data architecture:

- Data sources like **HES data**⁵⁰³ on admissions, outpatient appointments and accident and emergency attendances, and the **CPRD**⁵⁸ anonymised patient data from GP practices are important for health services research as well as for linkage with genomics and other clinical data sets to support clinical research.
- Initiatives like the **Integrated Data Service (IDS)**⁵⁰⁴ seek to improve data accessibility for research by linking disparate datasets. Examples include the **UK Biobank**, which links genome data from 500,000 participants with NHS data,⁷⁹ and the **Our Future Health**⁵⁰⁵ research programme, which aims to create a large-scale dataset linking health and lifestyle with genetic data. Such initiatives are complemented by the establishment of **Secure/Trusted Data Environments (SDEs/TDEs)**,^{506,471} which aim to ensure that data access and sharing adhere to stringent privacy and safety standards.
- **OpenSAFELY**⁵⁰⁷ is a secure open-source software platform for analysing electronic health records data with transparent, publically logged activity. New research tools seek to enable user-friendly and wide-scale access to diverse patients and healthcare staff for research purposes (e.g. **the Thiscovery engagement platform**)⁵⁰⁸ for research purposes (stakeholder workshop).

(2) Access to evidence and information

Various institutions in the health system are helping curate evidence and information about research advances and innovations:

- Examples of support for access to data and evidence include the **NIHR Evidence Synthesis Groups**⁵⁰⁹ and **the NIHR Innovation Observatory**.⁵¹⁰ Wellcome has also announced the **Evidence Synthesis Infrastructure Collaborative**, committing £45m over five years to enhance the real-time aggregation of scientific data.⁵¹¹ This initiative aims to support open-science practices and provide policymakers, clinicians and decision-makers with up-to-date evidence, thereby reducing the cost and time required to produce evidence syntheses. By developing common data infrastructure and responsibly utilising AI, the project intends to streamline the extraction

and summarisation of scientific findings, facilitating the creation of living evidence syntheses that remain current as new research emerges. This effort underscores the need for dedicated resources and frameworks that facilitate the translation of research findings into actionable insights for NHS staff.

- Support for navigating data and evidence-generation requirements is available from structures such as **the NHS Innovation Service**,⁵¹² **Health Innovation Networks**,⁴⁹⁷ and guidance from the **MHRA**⁵¹³ and **NICE**⁵¹⁴ for HTA. **Health Innovation Networks** can also help with access to information that can support efforts to implement, scale and spread innovation.

The NHS serves millions of patients annually. In an age where data drives advancements in every sector, the NHS stands at a critical juncture, with its vast health data repositories also offering immense potential for R&D and innovation. The NHS is also unique in holding electronic health records for the majority of the UK population, which, in principle, presents an unparalleled resource for advancing medical research and innovation. From enabling HTAs to fostering breakthroughs in personalised medicine, the data infrastructure within the NHS has the capacity to transform healthcare delivery and outcomes. While there are many challenges to unlock (as elaborated in the following sections), efforts are underway to maximise this potential and enhance the NHS data environment. To illustrate:

- Various additional efforts are underway to enable linkage between different types of datasets (e.g. genomic and clinical). One challenge for this and all efforts to include patients and the public in research and innovation activity relates to securing the participation of diverse groups to ensure that research and innovation efforts can help target pronounced inequalities in health.
- The **Health Data Research UK (HDR UK)**⁶⁹ Health Data Research Innovation Gateway aims to provide a unified platform for accessing diverse health datasets.
- All platform activity is publicly logged, and data management and analysis code is shared under open licenses and by default for scientific review and efficient re-use.

C. What are the challenges to using data, information and evidence for research and innovation in the NHS?

Box 39. Challenges related to data, information and evidence: key points

Challenges related to data, information and evidence

Data architecture:

- A complex and fragmented NHS data landscape, including technical, organisational and societal challenges to data access, integration, interoperability and trust.

- A lack of interoperability within NHS IT systems and between NHS systems and tech suppliers.
- Overly complex R&D governance structures for accessing data in the NHS.
- A need to learn from past efforts to support data access and linkage (e.g. CRPD, Born in Bradford).
- A critical shortfall in data science expertise and insufficient data science training.
- A lack of clarity on data 'control' and patient and public agency.

Information and evidence landscape:

- A lack of NHS staff access to up-to-date information about innovations and their effectiveness.
- Organisational siloes limiting the dissemination of best practices.
- A lack of public trust in data security and privacy.

Data architecture

While the NHS's vast data resources are a significant asset, unlocking their full potential for R&D and innovation has proven difficult. The data access landscape for research and innovation in the NHS is complex and fragmented. Obstacles span technical, organisational and societal issues affecting data access, integration, interoperability and trust.⁵¹⁵

One of the most pressing technical issues is the lack of interoperability among NHS IT systems. Primary and secondary care settings often utilise disparate software platforms, each with unique data formats, standards and interfaces. This fragmentation limits the seamless flow of information, hindering both patient care and research efforts. For example, a researcher seeking to combine data from general practice records and hospital records might face significant delays due to incompatible systems, incomplete datasets and unclear ownership of data, accentuating challenges to data linkage (stakeholder workshop). **The absence of standardised data quality metrics exacerbates the issue.** Without clear guidelines, inconsistencies in data entry, coding and storage practices persist, further diminishing the reliability of datasets for R&D purposes. In addition, much data is captured in case notes rather than in streamlined and accessible datasets (Int1 and Int5). Furthermore, interoperability is an issue within the NHS and between the NHS and private sector technology providers.

As discussed in the regulation section below (Section 4.3.5), **navigating the complexity of NHS's governance structures for R&D** poses a significant challenge for researchers and innovators.⁵¹⁶ Data access approvals often involve multiple layers of bureaucracy, including ethics committees, data custodians and regulatory agencies. While these measures are vital for safeguarding patient privacy and ensuring ethical research practices, they can lead to delays that stymie innovation

if burdened with excess red tape. For NHS staff, the governance landscape can feel particularly daunting. Many are unfamiliar with the procedural requirements for data sharing and innovation, which may discourage their participation in research efforts. This disenfranchisement affects individual staff members and undermines the broader culture of innovation within the NHS.

Lessons can be learned from initiatives that have achieved good progress with data linkage and secure data access. For example, the CPRD collects primary care data and links it to other health-related datasets (see Section 2.4.2 for more information on CPRD). Another example is the Born in Bradford study, which collects longitudinal data on families, discussed in more detail in Section 3.5. In the mental health space, companies such as Akrivia are progressing with efforts to link large psychiatric datasets and make them available to the NHS for research and innovation. In addition, services such as IAPT/Talking Therapies have resulted in comprehensive datasets on mental health service provision in the NHS that inform improvement and service delivery efforts (see Section 3.3).

The rapid proliferation of health data requires a workforce capable of analysing and interpreting complex datasets. However, the NHS faces a critical shortfall in data science expertise (stakeholder workshop). **Education and training programmes have not caught up with the necessary data science.** A recent study estimated that the UK healthcare sector would require an additional 178,000 data specialists to meet current and future demands.⁵¹⁷ This shortage is particularly acute in machine learning, AI and big data analytics. The lack of data science skills is compounded by insufficient training opportunities for existing NHS staff. However, some programmes like the NHS Digital Academy are seeking to enhance digital and data-analysis-related skills, including as they relate to artificial intelligence (see Section 3.2). Clinicians and administrators often lack the knowledge to critically assess evidence from research studies, making it difficult to translate innovations into practice effectively. Without targeted investments in education and professional development, this skills gap threatens to hinder the NHS's ability to fully leverage its data assets.

The current system also faces concerns related to **public trust in data security and privacy**. Public trust is a cornerstone of any successful data-sharing initiative. In the NHS, maintaining this trust is particularly critical given the sensitivity of health data. High-profile data breaches⁵¹⁸ and controversies, such as concerns about the NHS's collaboration with some tech companies, have fuelled scepticism about how patient data is used. This mistrust can lead to resistance from both patients and staff, limiting the availability of data for research purposes. Public trust can also be a particular challenge for some population groups, challenging efforts to engage with diverse participants and data sets to develop needed research and innovation advances. Individuals may opt out of data-sharing schemes due to fears of misuse, reducing the representativeness of datasets and potentially introducing biases in research outcomes. Related to this are **challenges in clarity on data 'control'** and how to ensure patients have the key say in what data they can and do not wish to share. However, efforts such as **Understanding Patient Data**⁵¹⁹ are helping engage the public and patients to improve public trust and understanding. Charities also have a role to play in this regard (stakeholder workshop). Furthermore, **existing tools such as the NHS App present an underutilised resource** through which patients could consent to enable data sharing and use for research purposes (stakeholder workshop).

Evidence and information needed for innovation adoption, scale and spread

Even when innovative solutions are developed through NHS data, integrating them into practice remains a significant hurdle. **NHS staff often lack access to up-to-date information about available innovations and their effectiveness and do not know where to get it, calling for better signposting in the health system.**^{480,27} This issue is compounded by **organisational silos that limit the dissemination of best practices** across different regions and departments. At the same time, innovation adoption is not always evidence-based, and improved cultures and abilities to critically assess and interpret evidence are needed to support appropriate risk management (stakeholder workshop).

D. A vision of what 'good' looks like in ten years and how we get there: the data, information and evidence environment

The future of the NHS lies in harnessing its unique data assets to create a healthcare ecosystem that is proactive, predictive, and personalised. A data-rich NHS would not only transform patient care but also accelerate innovation and research, ensuring the system remains at the forefront of global healthcare advancements. In a future vision for the NHS, the service and patients will benefit from a data-rich environment and more timely data access to inform research and innovation efforts. In addition, there will be better signposting to information and evidence to support high-quality, efficient and effective patient care and make evidence-based decisions. Box 40 outlines a future vision related to data, information and evidence.

Box 40. A future vision for the data, information and evidence environments framing research and innovation in and around the NHS

FUTURE VISION: In ten years, the fourth shift will have bolstered efforts to make the most of data, information and evidence as key NHS assets and drivers of care excellence, efficiency and cost-effectiveness. Without this shift, the NHS would be unable to deliver on the need to adopt, spread and scale best practices.

In this vision for the future, the potential of research and innovation to make NHS service transformation a reality is enabled because:

- **Public support for access to, sharing and use of data for research and innovation significantly improves:** Public trust and buy-in for data use and sharing is enhanced through a combination of technological solutions (e.g. safely accessible federated data sets), regulation (e.g. clear data standards, accreditation for secure data environments), improved communications and public engagement (e.g. policy transparency, better dialogue with the public) and a coordinated national strategy to guide data access and use (e.g. informed by learning from prior efforts and enacted through the support of a national data service that facilitates engagement and interaction with local health systems). Engagement with the public is facilitated

by charities and not-for-profit initiatives focused on public communication and engagement and ensuring transparency in relation to data use. This also helps with building a better understanding of why industry access to data is essential for developing new diagnostics and treatments (and not just access by academics and the NHS) and how it is governed to be safe and to ensure privacy. Patients control what data they choose to share, when and how, enabled by existing tools, such as the NHS App. Solutions that enable public trust also contribute to more 'altruistic' cultures and greater public willingness to share data for research and innovation that can lead to public health benefits.

- **A national data infrastructure enables research and innovation to aim to make more preventative, personalised and innovative care a reality:** Investments into data as a key national asset result in individual and linked/linkable data sets and interoperable IT solutions supported by clear standards and demand-signalling that bolsters interoperability and improves data flows. This is partly enabled by the federation of data sets to support safe and wider-scale access to more diverse data. Interoperability and integration between different IT systems and linkage between diverse data sets are improved and supported by clear data standards. As recommended by the Sudlow Review, a coordinated strategy guides data access and use in research and innovation. A national data service also supports access to data, research and analysis safely and securely, coupled with a UK-wide system of standards and accreditation for secure data environments.^{23,520} Learning from successful efforts to link data and secure access (e.g. the Born in Bradford Study, CPRD) informs the evolution of the data landscape. Data architecture also supports more predictive and proactive care and better health decisions, supported by new technologies such as AI and quantum computing. This is complemented by investments in training and workforce development in data science skills (e.g. via an expanded NHS Digital Academy training offer and public-private collaboration in training and on-the-job learning) and skills for critically appraising evidence. In turn, this enables high-quality and efficient translation of data into information and innovation so that advances reach patients quicker and are more effective.
- **NHS staff find it much easier to access the information, evidence and support they need to pursue research and innovation, whether to develop new solutions or to adopt evidence-based best practices. Good practice spreads and scales.** Staff are supported in doing so through better signposting to sources of information, advice and evidence. Repositories of evaluative evidence, such as those curated by the NIHR and based on learning from such efforts, are linked to regional hubs and healthcare boards, ensuring clinicians can easily access up-to-date information. This accessibility helps streamline the adoption of innovations, reducing the time lag between discovery and implementation. NHS staff are also more aware and make greater use of existing support services to enable innovation, such as Health Innovation Networks, the NHS Innovation Service and NICE Advice.



4.3.3. Physical infrastructure for research and innovation in the NHS

A. What matters for a fit-for-purpose physical infrastructure to support research and innovation in the NHS?

Modern infrastructure is key to enabling research and innovation in health systems. This spans research **facilities, equipment, information and communication systems and data infrastructure** (the latter is discussed in the previous section and not repeated here). A well-resourced, carefully maintained and upgraded physical infrastructure in the NHS is **essential for conducting high-quality research and innovation, attracting talent and industry investment and collaborations.**

Box 41. What matters for physical infrastructure: key points

What matters for physical infrastructure:

- Ensuring that basic infrastructure and equipment are safe and function well in NHS settings across the UK, not just in high-tech facilities.
- Fit-for-purpose information, communication and data-management systems.
- Resourcing, maintaining and keeping up-to-date with science and technology advances.

B. What is the current landscape in terms of the physical infrastructure needed to support research and innovation in the NHS?

Box 42. Support mechanisms related to physical infrastructure: key points

Support mechanisms related to physical infrastructure – current landscape and developments over time:

- **Leading life science clusters**, e.g. Cambridge, Oxford, London, North-East England, Manchester, Liverpool, Edinburgh and Glasgow, and research institutes, e.g. Francis Crick, MRC Laboratory of Molecular Biology, Wellcome Sanger, Roslin Institute and Manchester Institute of Biotechnology.
- **Some modern equipment**, e.g. automated labs, genomics labs, high throughput screening, advanced imaging and momentum/focus on improving data infrastructure.
- **Some funds to support capital investments**, e.g. the DHSC capital investment budget, UKRI capital investment fund, NIHR infrastructure funding and some charity support.

The UK is world-renowned for many aspects of its physical infrastructure for research and innovation in the health system. Examples include:

- **Leading life-science clusters in Cambridge, Oxford, London, Manchester, Liverpool, Edinburgh, Glasgow and North-East England, spanning diagnostics, health technology, biopharma and manufacturing capacities.** These clusters include **facilities and lab infrastructure** for life sciences and healthcare research, as well as development and innovation that **support university-industry-NHS collaboration**. They house world-leading universities and specialised research institutes (e.g. the Francis Crick Institute, MRC Laboratory of Molecular Biology, Wellcome Sanger, Roslin Institute, Manchester Institute of Biotechnology and others), start-ups and large life sciences companies and often work closely with the NHS.
- **The UK infrastructure also benefits from modern equipment, such as automated laboratory systems, high throughput screening and advanced imaging. As discussed earlier, there is also a strong policy focus on improving the data and IT infrastructure** needed to support data-intensive computational, bioinformatics and genomics research and innovation.⁴⁷¹ Data infrastructure for electronic health records, genomic and biobank datasets is key for life sciences and healthcare research and innovation, as are platforms for data sharing (such as Health Data Research UK).
- **There are some funds supporting capital investments into life sciences premises and NHS estates, facilities and equipment.** Examples include the **DHSC capital investment budget** and the **UKRI Research Capital Investment Fund or NIHR funding for infrastructure supporting clinical research**, e.g. biomedical research centres (BRCs), and **some charities**. NHS Trust Boards can also occasionally support capital investments but face very tight budgets.

C. What are the key physical infrastructure-related challenges?

Box 43. Challenges related to physical infrastructure: key points

Challenges related to physical infrastructure:

- Ageing buildings and equipment.
- IT systems that need attention (outdated computers, data storage and transfer systems).
- A significant shortage of investment for upgrades and maintenance.
- Contradictions and disparities in the status quo between world-leading facilities in some areas and out-of-date equipment in others.
- A lack of sufficient capacity and skills in the workforce to maintain modern facilities and equipment.

Despite strong foundations, there are currently significant challenges to the infrastructure for supporting research and innovation in the NHS, relating to ageing physical equipment, buildings, facilities and IT systems needing attention. Particular IT challenges relate to outdated paper-based systems, computers, and approaches for data storage and transfer, accentuating interoperability challenges and compromising the ability to research and innovate efficiently. These issues also increase costs and enhance risks to patient safety and NHS performance (stakeholder workshop). Different NHS settings using different IT systems further compound interoperability challenges (stakeholder workshop), exacerbated by the bureaucracy that NHS staff often need to navigate to make needed upgrades.

There is also a significant shortage of investment needed to maintain and upgrade existing infrastructure⁵²¹ and to purchase needed equipment. This includes establishing and upgrading the infrastructure needed to keep up with the rapid pace of science and technology development in many areas, such as new diagnostic technologies (e.g. liquid biopsy, neuroscience breakthroughs and AI advances). The cost of tackling the backlog of maintenance issues in NHS trusts has been growing. According to King's Fund research, the total stood at £6.5bn in 2018/2019.⁵²² The UK also faces significant shortages of modern CT and MRI scanners compared to other comparable high-income countries,⁵²³ meaning patients often lack access to basic diagnostic imaging (stakeholder workshop).⁵²³

Thus, we face an NHS full of contradictions: dilapidated buildings in some cases and state-of-the-art equipment and labs in others. The King's fund flags this as partly related to the reprioritisation of capital investment to support day-to-day service delivery.⁵²²

Finally, modernising facilities and equipment also require investing in a workforce that is able to operate and maintain them (stakeholder workshop).

D. A vision of what 'good' looks like in ten years and how we get there: physical infrastructure

In a future vision for the physical infrastructure for research and innovation in the NHS, investments into infrastructure are prioritised and focus on supporting changes in capability in areas of strategic importance in light of feasibility and potential for impact considerations. Box 44 outlines a future vision related to the physical infrastructure underpinning research and innovation in the health system.

Box 44. A future vision for physical infrastructure framing research and innovation in and around the NHS

FUTURE VISION: In ten years, the fourth shift will have mobilised improvements in the NHS estate that are essential for research and innovation to support safe and excellent care. Investments into high-tech facilities in some settings will not come at the expense of investments into the 'nuts and bolts basics' (repaired buildings, modernised computing equipment and functional IT systems) needed across the NHS.

In this vision for the future, the potential of research and innovation to make NHS service transformation a reality is enabled because:

- **Basic facilities, computer equipment and IT systems have improved, making it more feasible for NHS staff to make use of existing modern high-tech infrastructure for both research and patient care.** Strategic and carefully considered capital investments reduce the disparities and contradictions between 'bells and whistles' world-leading facilities in some settings (e.g. for genomics, AI, machine learning, advanced imaging and synthetic biology) and unmet needs for 'nuts and bolts' basics (e.g. restoring dilapidated buildings, modernising computing equipment and basic IT systems, reliable Wi-Fi and sufficient diagnostic imaging scanners) that need to be in place across the UK, not just in the 'golden triangle'.
- **Staff well-being is improved because they have greater trust in the ability to deliver care in safe environments, supported by better facilities where research-informed practice can thrive.** Staff feel they are delivering safe patient care without limitations imposed by outdated infrastructure. Standards for quality control and compliance are monitored and followed.
- **A longer-term capital funding settlement enables the NHS to balance planned investments with an ability to respond to emerging opportunities.** NHS leaders can access and use capital to make necessary and planned investments in upgrading, maintaining and modernising facilities, equipment and IT infrastructure. They have also ring-fenced some flexible resources in anticipation of emergence and the need to adapt to science and technology developments (improved genomic lab infrastructure, data storage, processing and analytics infrastructure). Part of this strategy also considers the workforce that needs to be trained and in place to operate requisite facilities and equipment. Closer consideration of needs across industrial strategy and health service delivery supports better investment of available resources.



4.3.4. Funding, commissioning and procurement for research and innovation in the NHS: from development to adoption

A. What matters for fit-for-purpose funding flows for undertaking and using research and innovation in the NHS?

Box 45. What matters for funding, commissioning and procuring research and innovation: key points

What matters for funding, commissioning and procuring research and innovation:

- Sufficient, stable and reliable funding
- Prioritisation of funding allocations
- Supporting both supply/push and demand/pull
- Diverse funders (public, not-for-profit/charity, industry/private).

Funding is a **prerequisite for all research and innovation activity in the health system, although it is not sufficient on its own.**

Funding of research and innovation in a research-and-innovation-active health system needs to balance concerns for **securing sufficient amounts of funding, providing stability and** certainty in funding opportunities, **prioritising areas of investment** and **supporting both research and innovation push** (the doing of R&D) **and research and innovation pull** (the use of evidence and the adoption, scale and spread of innovation).

Without a vibrant **ecosystem of public, not-for-profit and industry funding, venture capital and private equity investors**, a research and innovation ecosystem in and around the NHS cannot be sustained and grown.

B. What is the current landscape for funding, commissioning and procuring health research and innovation in the NHS?

Box 46. Support mechanisms related to funding, commissioning and procurement: key points

Support mechanisms related to funding, commissioning and procuring research and innovation – the current landscape and developments over time:

- **Historically, there has been more focus on R&D than real-world testing, commissioning and procurement of innovation in the NHS** (i.e. less attention given to adopting, using, spreading and scaling than producing research and innovation).

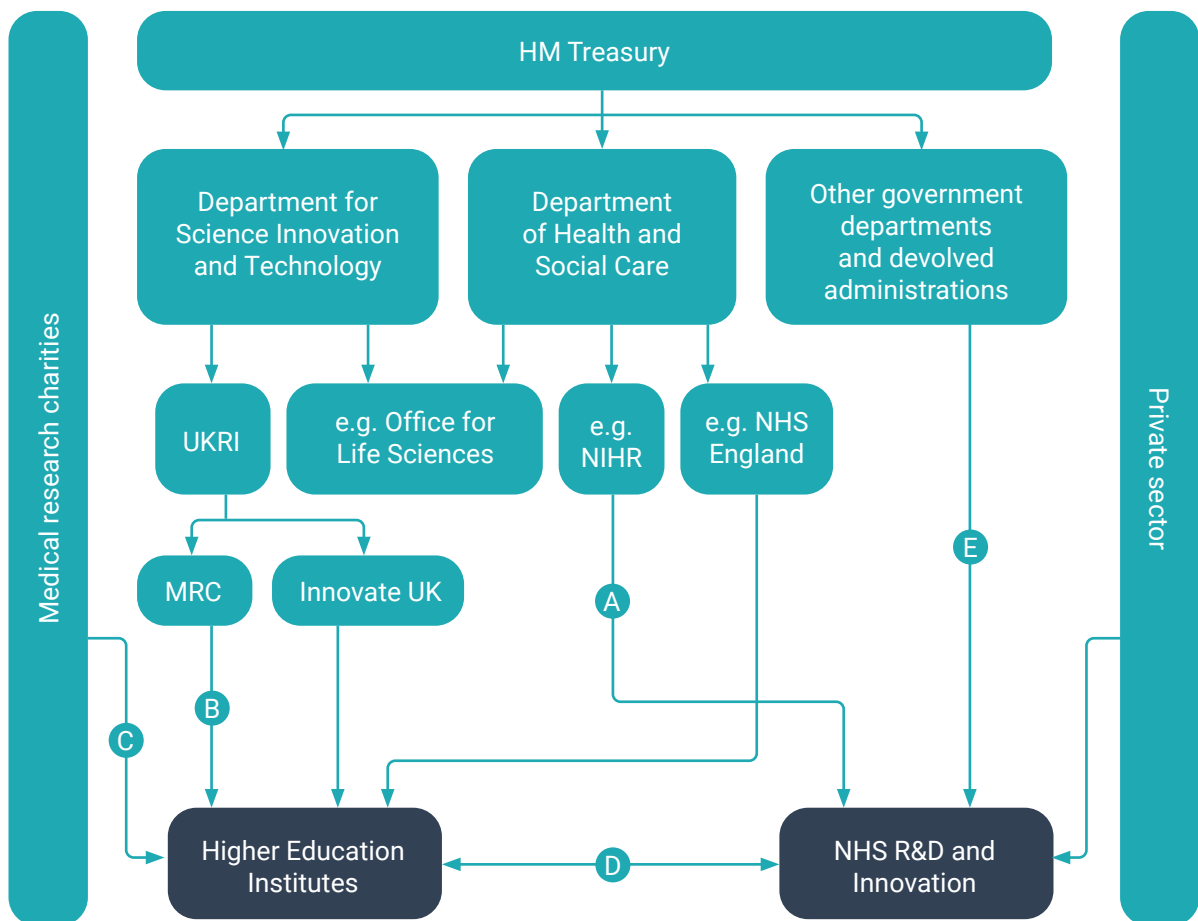
- **NHS R&D funding from the NIHR, various government departments and arms-length bodies (e.g. Office of Life Sciences), MRC and charities** can go directly into the NHS or via universities partnering with the NHS.
- **Innovation-funding programmes**, e.g. SBRI Healthcare, the NHS-England-funded NHS AI Diagnostics Fund and the NHS AI lab.
- **Medtech funding mandate** (innovation pull).
- **Industry and other private sector investment**, e.g. angels, VCs and biopharma.

Although the landscape for funding research and innovation activity in the NHS has evolved, there has **historically been more focus on funding for research and development than real-world testing, commissioning and procurement pathways for adopting, spreading and scaling innovations**. Quantifying the exact amount invested directly into NHS R&D and innovation is complex due to the diverse funding sources and collaborative nature of healthcare research, as illustrated in Figure 6. However, several key funding streams and initiatives provide insight into the scale of investment:

- In addition to the £1.2bn **NIHR funding** in 2020–2021 (label A in Figure 6), **NHS R&D and innovation will benefit from funding from the MRC** (label B in Figure 6) **and the medical research charities** (label C in Figure 6). In both cases, however, the majority of funding goes via a Higher Education Institute that will then have a partnership agreement with the collaborative NHS entity (D). This relationship is bi-directional, i.e. the NIHR funding (which goes directly to the NHS) will include partnerships with HEIs. Although it is not possible in the current data to isolate the actual amount of funding that goes directly into the NHS, the total MRC budget in 2018 was £814m,⁵²⁴ while the total budget of the Association of Medical Research Charities was nearly £2bn in 2021/2022.⁵²⁵ Finally, the **devolved administrations** will also fund research in the NHS via NHS Research Scotland and Health and Care Research Wales (label E in Figure 6).
- **NHS staff also participate in innovation-funding programmes**, such as **the SBRI for Healthcare, the NHS England-funded NHS AI Diagnostic Fund and the NHS AI Lab**. NHS staff can also access funding for clinical entrepreneurial activity, often in collaboration with academics and industry. This funding can come from **charities, business angels, venture capital and biopharma industry investments**. Again, the data do not allow a detailed breakdown of the funding via these routes. However, as illustrated in Figure 6, public innovation funding in the NHS can come **via Innovate UK (part of UKRI), which supports the SBRI Healthcare (as does the Accelerated Access Collaborative), from government bodies such as the Office for Life Sciences, and from the aforementioned NHS schemes on AI and other specialised funding pots for testing innovations in the real world for implementation, scale and spread (e.g. the NHS England Cancer programme and SBRI Healthcare diagnostic innovation funding call¹⁷⁸ and NHS Test Beds programme).**⁵²⁶
- **Industry and other private sector investments** (angels, venture capital, biopharma) **are also key to enabling research and innovation activity, including public and private partnerships**

involving the NHS. For example, the Life Sciences Industrial Strategy (published in 2018 so under the previous government) outlined ambitions to treble industry contract and R&D collaborative research in the NHS over ten years, aiming to reach nearly £1bn by 2028.⁵²⁷ However, it is hard to quantify how much private investment is actually flowing into the NHS, largely for commercial confidentiality reasons. We know from national data that private R&D investments are larger than the total public investments, but the breakdown flowing into the NHS is unavailable.

Figure 6. Key R&D and innovation funding flows in the the NHS



C. What are the challenges related to funding, commissioning and procuring research and innovation in the NHS?

Box 47. Challenges related to funding, commissioning and procurement of research and innovation: key points

Challenges related to funding, commissioning and procurement of innovation:

- Disproportionate focus on funding for doing R&D compared to funding for adoption scale and spread as a barrier to NHS and patient benefit.
- Shifting policy priorities and the need for better prioritisation and demand signalling of research and innovation needs, including considering the willingness to pay and national and regional/local agendas.
- Insufficient prioritisation of research and innovation as a fundamental enabler of improved and more sustainable health services.
- Uncertain, complex, unclear and bureaucratic routes to entry regarding commissioning and procurement.
- Gaps in evidence to support commissioning decisions.
- Short-term perspectives focused on cost-savings.
- Post-Brexit challenges to attracting venture capital and biopharma investment (regulatory environment, uncertainty in trade agreements and market access).
- Uncertain return-on-investment timeframes for private sector funders given the slow adoption of innovations in the NHS.

Historically, funding for innovation in and for the NHS had focused more on push and supply than innovation pull. In the research space, there has been progress to prioritise investments through initiatives such as the James Lind Alliance Priority Setting Partnerships (PSPs).⁵²⁸ However, in the innovation space, the disproportionate focus on supply over adoption funding creates a significant barrier in getting much-needed novel medicines, treatments, therapies, diagnostics, devices and service model innovations to patients.³ Funding commitments are needed to ensure both a push and pull of research and innovation into the NHS and their sustainability can be linked to policy efforts that provide clear signals on priority areas for research and innovation (stakeholder workshop). There are also challenges with balancing investments in basic and applied research. Partly due to the founding of the NIHR, the proportion of funding for basic discovery research has decreased in recent years, falling by 17.3% from 2004 to 2022, according to an analysis by the UK Clinical Research Collaboration (2023). Relative decreases in 'basic science' are offset by the increases in other research activities focused on translating research and application in healthcare and clinical settings. This includes research in areas such as prevention, detection and diagnosis, treatment development, treatment evaluation, disease management and health services funding, which have collectively grown as a proportion

of health research total since 2004/2005.⁵²⁹ *A longer-term and more certain funding settlement for key public sector funders could also help reduce premature failures.*

Effective funding for research and innovation is distinct from the amount of available funding. It is influenced by how well funding allocation is prioritised and how well allocated funding is used – it is a matter of ensuring value from investments made (stakeholder workshop). This is particularly important in a funding landscape where making the case for research and innovation investments competes with urgent service delivery funding needs, even though the former can enable the latter (stakeholder workshop). **Further work is needed to prioritise investment areas in ways that can align the supply of research and innovation with areas of demand and willingness to pay.** Prioritisation also needs to recognise that different parts of the country have different baseline capacities for research and innovation, and government policy needs to consider how research and innovation investment (e.g. into existing centres of excellence and areas and organisations with lower baseline capacity) will be supported as part of overall socioeconomic development policies and agendas (stakeholder workshop). These decisions need to consider that investment in established centres can help with quickly developing or testing research advances to enable faster adoption, scale and spread. At the same time, investing in building capacity in less established research and innovation settings can support a longer-term vision of excellence and enable jobs and economic development (stakeholder workshop).

Discussions with local commissioning bodies (PCNs and ICBs) and specialised commissioners (centralised) can help understand **routes to commissioning and procurement**. However, innovators find the NHS pathways to adoption very difficult to navigate. Payment schemes can be fragmented (various pre-commercial procurement agreements or outcome-based payment channels and diverse procurement frameworks) and obscure, with short-term commitments. Efforts such as the **Med-tech Funding Mandate** seek to reduce the time it takes for innovative technologies to reach the NHS and provide financial support for implementing proven value-for-money innovations.⁵³⁰ In addition, good systems for accountable and efficient funding use need to be in place to minimise the risk of cross-subsidies between R&D and service delivery funds.

There are numerous challenges to overcome regarding commissioning and procurement, including uncertain, complex and bureaucratic routes to entry, gaps in evidence to support commissioning decisions, a lack of clear alignment between local and national agendas⁵³¹ and changes in policy priorities and challenges related to short-term perspectives on costs⁵³² not aligning with the timelines needed for benefits to accrue and make a difference within the system.

Attracting venture capital and biopharma investment faces challenges due to a complex regulatory environment and post-Brexit uncertainty about trade agreements and market access. The NHS plays a critical role in healthcare innovation, yet attracting venture capital and biopharma investment into its ecosystem faces significant challenges. Among these, the complex regulatory environment and uncertainty stemming from post-Brexit trade agreements and market access stand out as critical barriers. Post-Brexit, the UK's departure from the EU has introduced uncertainty around regulatory alignment with the European Medicines Agency.⁵³³ This divergence increases the complexity and cost for biopharma companies seeking approval for new products in both the UK and EU markets.⁵³⁴ The lack of clarity in the regulatory pathway may deter international investors and biopharma firms, who often prioritise larger, harmonised markets

for their innovations. Trade agreement uncertainties can compound these challenges. While the UK has sought to negotiate favourable agreements to sustain its life sciences sector, concerns persist about market access for UK-developed products in the EU. These issues can discourage investors who view market accessibility as a key factor in determining returns on investment.

Further challenges include the NHS's stretched resources, making it difficult to prioritise the rapid adoption of innovative technologies influencing return-on-investment timelines for private equity and industry investors. Innovators often face delays in implementing and scaling solutions within the NHS due to fragmented procurement processes and sometimes inertia and resistance to change in established systems (Int4).⁴ While crucial, the NHS's focus on cost containment can deter investment in high-risk, high-reward innovations unless cost savings can be captured in the short term, which is rarely the case.

Finally, competition from other nations with more streamlined regulatory processes and generous fiscal incentives compounds the difficulty. Countries like the US and Germany offer favourable tax credits and less restrictive frameworks, making them more attractive for venture capital and biopharma investment.⁵³⁵

D. A vision of what 'good' looks like in ten years and how we get there – funding, commissioning and procurement

In a future vision for funding research and innovation and the adoption, scale and spread of good practice, the funding of research and innovation in the NHS builds on lessons from history. Box 48 **outlines a future vision related to funding, commissioning and procuring research and innovation in the NHS.**

Box 48. A future vision for funding, commissioning and procurement

FUTURE VISION: In ten years, the fourth shift will have enabled research and innovation funding to better respond to unmet needs, with fewer bottlenecks for solutions to reach patients

In this vision for the future, the potential of research and innovation to make NHS service transformation a reality is enabled because:

- **Strategic demand-signalling supports well-prioritised investments into research and innovation that patients need and the NHS can afford:** Collaborative decision making on research and innovation priorities happens through engagement between local and national health system levels, informed by consultation with patients, NHS staff, policymakers and payers as well as by horizon-scanning to stay abreast of new developments. This supports a health system where the supply of research and innovation is better aligned with areas of demand and willingness to pay, enabling clearer, more stable funding flows. This also helps to simplify and streamline supply chains.

Efforts are made to reduce the bureaucracy in the funding process and pathway. Both financial and non-financial incentives will encourage research and innovation activity in NHS organisations. Coupled with efforts by NHS decision-makers and key policy bodies to ensure clearer research and development funding and product, technology and service commissioning and procurement pathways, this makes the UK a more attractive market for both national and international innovators and investors. A greater focus on real-world implementation testing for promising innovations helps inform better decisions about adoption, scale and spread. This is all nested within wider government efforts to ensure that decisions on the design of key services are informed through active regional and national consultation to ensure the accountable, responsible and well-informed use of financial resources.

- **Balancing short and longer-term research and innovation priorities helps the NHS deliver on immediate needs to reduce waiting lists while sustainably supporting key shifts to more preventative, personalised and community-based care:** NHS investments into research and innovation help the NHS catch up on the backlog associated with the COVID-19 pandemic. Health services research and evidence help implement service delivery changes, including supporting more technology-enabled remote care. Longer-term investments enable research and innovation to support shifts towards prevention, care in the community and the spread of digitally enabled care, bolstered by government awareness of their importance within a system that also supports those who need care in the hospital/in NHS settings and treatment to access it.
- **Industry and international investors scale up support for research and innovation in the UK, which enhances the sustainability of services and the provision of high-quality, modern healthcare:** The health system benefits from public and not-for-profit sector funding, leveraging further private sector and international investments into research and innovation. This is accompanied by incentives to attract private sector investment and reduce risk (fiscal policies, tax incentives, streamlined regulation, enhanced market accessibility, a reinvigorated focus on public-private partnerships and streamlined visa processes).⁵³⁶ This improves patient care through trial participation and timelier access to global developments.



4.3.5. R&D governance and regulation of innovation

A. What matters for R&D governance and regulation of healthcare innovation?

Box 49. What matters for R&D governance and regulation of innovation: key points

What matters for R&D governance and regulation of healthcare innovation:

- Effective regulation of R&D processes to support efficiency, scale up and incentivise activity.
- Effective regulation of innovation that balances safety with promoting innovation in timely ways.
- Compatibility with international regulation in key jurisdictions.

The aim of effective research governance is to ensure that research is carried out safely, ethically and effectively and to maintain public confidence that this is the case. This is especially important for health research, where the research itself may involve potential safety issues for participants (and there have been serious problems in the past), and decisions made based on research will have major consequences for health and wider costs and benefits to society. However, over-regulation also has costs; too restrictive or demanding governance and regulation might prevent valuable research, with potential loss of evidence and resulting harm to health. Moreover, such governance is not purely a national issue. While there are international standards and expectations about research governance, there is also competition among jurisdictions to provide the best balance and appropriate environment conducive to research and innovation. The aim for UK governance and regulation is thus to strike a balance that ensures safe, ethical and effective research whilst also providing a research environment that creates as little burden as possible and maximises opportunities for research and innovation that can benefit health.

B. What is the current landscape for R&D governance regulation of healthcare innovation?

Box 50. Support mechanisms related to R&D governance and regulation of innovation: key points

Support mechanisms related to R&D governance and regulation of healthcare innovation – the current landscape and developments over time:

- **Good progress with research ethics approvals architecture**, e.g. NHS Health Research Authority (HRA) efficiency and clarity - although one of several bodies in devolved nations, UK Policy Framework for Health and Care Research.

- **Continuously evolving regulatory and HTA architecture** (MHRA, NICE) that keeps pace with science and technology developments.

Establishing a supportive governance and regulation environment for health-related research has been a longstanding priority for the UK, with various initiatives aimed at creating oversight mechanisms for research and innovation activities.

Following the establishment of the NHS, ethical review emerged at the local level, which led to a wide diversity in ethical approval for health research⁵³⁷ that still remains to some extent. Since then, however, there has been a range of efforts to harmonise and centralise the approval standards and processes, now led by the **NHS HRA**. It is only one of several relevant bodies at a national level and within the devolved administrations, with different responsibilities for ensuring safe and ethical research across specific areas (e.g. medicinal products) and jurisdictions (e.g. devolved administrations). However, the **UK Policy Framework for Health and Care Research** published in 2017 and updated in 2023 does provide an overall framework for the governance of health research across the UK.⁵³⁸

This emphasises that research is a core function of healthcare and aims to create an environment that facilitates and promotes research whilst ensuring appropriate protection of patients, service users and the public. There are also specific legal requirements for clinical trials, particularly clinical trials, based on the EU rules that set out detailed requirements for the approval and execution of clinical trials, including reporting requirements if things go wrong or adverse events occur.⁵³⁹ Box 51 highlights the importance and opportunities to improve the governance and regulation of clinical trials.

Two important areas of regulation focus on how innovations from research are implemented. The first involves licensing, which allows the sale of these innovations in the UK. The second is evaluating their cost-effectiveness, determining whether they should receive funding through the NHS. The Medicines and Health Products Regulatory Agency regulates medicines, medical devices and blood components for transfusion in the UK, ensuring that these products meet quality, safety and efficacy standards. This is still largely conducted based on a large body of legislation on licensing medicinal products and medical devices built up by the EU and retained by the UK following the UK's departure from the EU. In principle, these regulatory requirements come after research has taken place and products are ready to be put on the market, i.e. *after* the research has been conducted. However, when conducting research to obtain licensing approval, the environment and support from the licensing authority play a crucial role in health research. The MHRA has a range of initiatives to provide information and advice during the pre-licensing R&D stages.⁵⁴⁰ This was at its most extreme during the COVID-19 pandemic, with a range of innovations to the advice, research processes and regulatory review.⁵⁴¹

Box 51. Improving the regulation and governance of clinical trials**Improving clinical trials**

Clinical trials are a key focus for getting the right balance between effective regulation and undue bureaucracy. This is not just a case of 'more' or 'less' regulation. While there were excellent examples of innovative trial designs during the COVID-19 pandemic, e.g. the RECOVERY trial, many trials were also poorly designed, meaning many patients participated in trials that did not generate meaningful evidence – arguably a breach of ethics.⁵⁴²

Improving the effectiveness of clinical trials in generating meaningful evidence is a crucial challenge for research and governance.⁵⁴³ But who is responsible for addressing this issue? Are the researchers the ones who must ensure appropriate trial designs? The funders, who must select high-quality projects to support? The ethics committees, responsible for evaluating the impact on participants and determining whether it is reasonable? Or the regulators, who are responsible for approving trials but often focus primarily on legal requirements?

The answer to this question for the UK's governance and regulation of clinical trials is still unclear. While this is a challenge, it is also an opportunity. Rethinking the governance and regulation of clinical trials in the UK has the potential to create an environment that can obtain much greater efficiency of results from the investment of time and resources already spent on clinical trials, improve patient recruitment (including through innovative digital channels), and be supported by learnings from the experience during the pandemic embodied through initiatives such as the PROTAS platform. The PROTAS platform aims to improve clinical trial design and delivery through more effective use of data and technology and by supporting collaboration towards policy development.⁵⁴⁴

In addition to regulations specific to health research, there are cross-cutting regulatory requirements, particularly on data protection and processing of personal data. Again, this is based on retained EU law, which also ensures the recognition of the adequacy of the UK's data protection controls by the EU. This, in turn, enables continued data transfer between the UK and the EU, which is highly relevant for larger multi-country research. Health data is treated as a special category under data protection rules, with additional restrictions on how it can be processed. These requirements are legally separate from ethical and regulatory approvals, resulting in complex and sometimes conflicting requirements for researchers and innovators to navigate.

After licensing approval, the decision about whether to purchase specific products remains. While that is up to the purchasers within the health system, NICE provides central advice to purchasers about the best care and value for money. NICE reflects a wider international trend of creating a 'fourth hurdle' of health technology assessment (beyond the licensing requirements of quality, safety and efficacy) to ensure care provision and innovation adoption based on rigorous evidence, not just novelty. However, NICE is world-renowned and has positioned the NHS as a particularly price-sensitive market in global terms. While this helps to ensure value for money, it also makes the NHS a challenging environment for innovators to bring their products to market. This reflects an underlying tension between promoting research and innovation and ensuring value for money.

C. What are the challenges related to R&D governance and the regulation of healthcare innovation?

Box 52. Challenges related to R&D governance and the regulation of healthcare innovation

Challenges related to R&D governance and the regulation of healthcare innovation:

- Significant bureaucracy and lack of consistent practice across settings in the R&D governance approval process, with time-inefficiencies presenting a big challenge for NHS, academic and industry research and disincentivising industry/trials. This is compounded by legal liabilities, staff attitudes to risk in R&D offices and the need to upskill R&D office staff.
- An insufficient focus on learning from international practice in R&D governance.
- Brexit-related challenges (especially regulatory uncertainty, despite limited divergence to date in practice).
- Keeping regulation up-to-date with science and technology advances in some areas (e.g. AI and convergent technologies).

The bureaucracy of R&D governance approvals and diversity in local requirements and practices is challenging for NHS researchers. In principle, a national framework for health and care research and a large, relatively integrated NHS should facilitate research, enabling centralised approval, easier recruitment, research within an integrated environment across different stages of care, and access to comprehensive data. However, this potential is far from realised in practice, with those seeking to conduct health research in the NHS often experiencing confusing and burdensome governance.^{52,516} Although there are increasingly centralised approvals at the national level, local approvals are also needed. Different organisations and trusts within the NHS have their own approval processes, and data is fragmented. Moreover, the greater the clinical care pressures, the more they displace research. This reflects the complex structure of the NHS overall, such as the purchaser/provider split, multiple lines of accountability, the pressure to account for and control costs, and attitude to risk, which can lead to behaviours related to high-risk avoidance over risk management in R&D governance processes (stakeholder workshop). There are also challenges in balancing quality and safety and managing the time demands associated with R&D governance approvals. Decisions are sometimes made by staff in R&D offices who do not have the expertise needed to manage approvals efficiently (stakeholder workshop). Being smaller and more nimble than the EU and the USA in regulatory terms, there is an opportunity for the UK to find more effective ways of enabling efficient R&D governance, potentially centralising the process, or even taking research approval and liability centrally rather than at the level of individual organisations.

Better evidence is needed on effective practices in R&D governance, including in the context of international learning and comparisons: There is a lack of robust comparative data or analysis about the impact of governance and regulation on health research between different countries. Although there is a national set of indicators about how the UK performs compared to other

jurisdictions around the world (the Life Sciences Competitiveness Index)⁵⁴⁵, this does not include indicators on the governance and regulatory environment. There is some specific data about clinical trials, which shows recent falls in the number of industry clinical trials in the UK,⁵⁴⁶ but it is unclear how these differences relate to governance and regulation.

Adapting regulation to the increasing pace of innovation is a constant challenge. The regulation licensing model reflects the processes and timelines of developing medicinal products, which typically happens over a decade or more with initial discovery, progressive development and trials. Medical devices already present a challenge of increased pace, with much shorter development lifecycles of one or two years. With the emerging importance of digital health tools such as AI, the speed of development has increased to a matter of days – or even constant development in the case of software with an inherent learning and adaptation capacity. This presents regulators with an acute example of the more general governance challenge of balancing quality and safety while enabling the quickest possible access to good-value innovations that benefit health.

The UK's departure from the EU involved a broader regulatory shift that has had a largely negative impact on health research in various ways, including funding, collaboration and indirect issues such as customs and visas.⁵⁴⁷ In principle, the UK's departure from the EU offers scope for adapting decisions to the UK's specific circumstances, e.g. modifying data protection rules to facilitate data-sharing within the NHS or linking licensing more tightly to NHS product monitoring. It also opens up the possibility of moving more quickly than larger jurisdictions such as the EU and the US, which could help address the challenge of adapting regulation to the increasing pace of innovation. However, despite much rhetoric during the Brexit processes about more nimble regulation and competitive divergence of the UK from the EU, this has largely not materialised in practice.⁵⁴⁸ Perhaps the most significant area of divergence is the regulation of AI, where the EU has adopted a formal overarching regulation categorising different types of AI by risk whilst the UK has taken a decentralised approach of oversight through sectoral guidance. However, even in this case, for applications in health, given the extent of existing retained European law on medical devices (including software such as AI used for medical purposes), the actual divergence in regulatory requirements for innovators is limited, and the UK's strategic approach remains unclear.

D. A vision of what 'good' looks like in ten years and how we get there: R&D governance and regulation

The future vision for R&D governance and regulation of innovation is summarised in Box 53.

Box 53. A future vision for R&D governance and regulation of research and innovation

FUTURE VISION: In ten years, the fourth shift will have enabled regulation to meet researchers' and innovators' needs better. Researchers and innovators will see the UK R&D governance and regulatory environment as leaner, more efficient, robust and innovation-friendly than before whilst still being compatible with international regulatory developments.

In turn, patients will benefit from an NHS that is more active in research and trials and from quicker access to novel solutions.

In this vision for the future, the potential of research and innovation to make NHS service transformation a reality is enabled because:

- **A more standardised R&D governance landscape reduces the bureaucracy that complicates and disincentivises researchers and innovators:** Unwarranted variation in R&D approvals practices will be reduced as processes are streamlined across the UK. Levels of research activity scale, including attracting more commercial trials. More efficient R&D governance and regulation enables studies and trials to start quicker and patients to be recruited quicker, supported by a national recruitment infrastructure well connected to local and regional health systems. More centralised processes alleviate previously inefficient behaviours associated with the concerns over legal liabilities and risk-avoiding versus risk-managing cultures in some NHS R&D offices and governance functions.
- **Regulatory efficiency improvements make the UK a more attractive market for testing innovations, and more patients benefit through timelier access to novel advances:** Regulatory disincentives related to lack of clarity and bureaucracy are reduced, especially regarding emerging technologies. Information is also better signposted, leading to a regulatory landscape that academic, industry and NHS innovators can more easily navigate. UK regulatory agencies have become more agile in supporting regulatory approval submissions in ways compatible with regulation in key international markets. In turn, the full potential of the NHS as both a testing lab and a market is better supported.
- **Regulation keeps pace with science and technology advances, enabling the NHS to optimise its use of innovation for excellence in patient care with confidence and timeliness:** There is a better balance of risk management and pro-innovation regulation. Connectedness to international debates in emerging technology areas, coupled with national public and expert dialogue, allows regulation to keep up to date with the pace of science and technology advances in some key areas (e.g. AI, quantum, synthetic biology, *omics). This helps to support a better balance between risk management and pro-innovation regulation. There is also closer collaboration and better alignment across the R&D approval pathway, regulatory approvals, and health technology assessment pathway, supporting a more efficient flow of research and innovation from the lab to NHS practice.

The future vision of UK regulation compared to the EU and other comparator jurisdictions is beyond this report's scope, relating to overall strategic choices about the future direction of the UK economy and trading relations. However, given the importance of health and life sciences research to the wider UK economy and society, this sector and its regulation should be a key part of that wider strategic approach.



4.3.6. Collaboration and coordination in research and innovation

A. What matters for a fit-for-purpose collaboration and coordination landscape for research and innovation in and around the NHS?

Box 54. What matters for the collaboration and coordination of research and innovation: key points

What matters for collaboration and coordination:

- Collaboration and coordination across the value chain from R&D to regulation, adoption, scale and spread to promote optimal use of resources, reduce waste and unnecessary duplication, and maximise the chances of success and timely progress.
- Coordination and collaboration across public research/academia, not-for-profit, NHS and industry sectors.
- Balancing collaboration and (healthy) competition.

Collaboration and coordination in life sciences and health research and innovation are needed across the value chain, from identifying priorities for investment and conducting research and innovation to its regulation, adoption, scale and spread. This is important for making the **most of resources for research and innovation, avoiding unnecessary duplication and waste, and maximising chances of success and timely progress.**

A well-coordinated, collaborative research-and-innovation landscape needs to support collaboration across public, private and third sectors, given that no single actor has all the skills, resources and capabilities needed to deliver across the research and innovation pathway. This means that an effective architecture for research and innovation *in* the NHS must consider the system *around* the NHS and the role that the NHS can play in wider university-industry-NHS research-and-innovation architectures. Related to this, **collaboration and competition** must be balanced in efforts to drive progress towards shared aims.

There has been a long history of concerns about and solutions for coordinating health research in the UK. For example, the Office for Strategic Coordination of Health Research (OSCHR) was established in 2006 following Sir David Cooksey's review of UK health research funding.⁵⁴⁹ The review identified significant strengths in the UK's scientific base but also highlighted cultural, institutional and financial barriers hindering the effective translation of health research into clinical practice. The OSCHR continues to serve as an independent forum where public funders of health research collaborate with stakeholders to enhance coordination and funding arrangements. In recent years, the OSCHR has focused on strategic areas such as translational medicine, public health research and e-health records research. It has established boards to provide strategic oversight in these areas, aiming to address barriers to research collaboration and support the application of basic research into patient care and economic benefit.

B. What is the current landscape for collaboration and coordination of healthcare research and innovation?

Box 55. Support mechanisms for collaboration and coordination: key points

Support mechanisms for collaboration and coordination – the current landscape and developments over time:

- **Regional and local coordination and collaboration support structures**, e.g. Health Innovation Networks (HINs), Applied Research Collaborations (ARCs), Innovation Hubs, BRCs, ICBs/ICS, PCNs, accelerators, tech transfer offices.
- **National orchestration bodies**, e.g. the Office for Strategic Coordination of Health Research – the OSCHR; Innovation, Research and Life Sciences (IRLS) in NHS England, the Office for Life Sciences (OLS) and coordination via funding bodies like the UKRI, MRC, Innovate UK, charities like Wellcome, CRUK, British Heart Foundation (BHF) and associations like AMRC).
- **Participation in EU/international research programmes.**

Many life sciences and health-research-and-innovation ecosystem initiatives play various network coordination roles and foster collaboration amongst universities, industry and the NHS. Examples include:

- Regional and local structures such as **Health Innovation Networks**,⁴⁹⁷ **ARCs**,⁴⁹¹ **Innovation Hubs**,⁵⁵⁰ **NIHR Biomedical Research Centres**⁴⁹⁰ and other structures like **ICBs and PCNs** who engage with research, its translation, and innovation in the NHS amongst wider remits,³ as well as **various accelerators, enterprise and technology transfer offices. Local NHS hospital trusts also have agency in health systems and impact on the research and innovation efforts** (stakeholder workshop).
- National structures like the **OSCHR**, the **Innovation, Research and Life Sciences team in NHS England and Accelerated Access Collaborative**⁵⁵¹ and the **OLS**,⁵⁴⁵ as well as **large funding bodies like the UKRI**,⁵⁵² **MRC**,⁵⁵³ **Innovate UK**,⁵⁵⁴ and **charities like Wellcome and disease-specific charities (e.g. BHF, CRUK) and associations (AMRC) also impact on coordination of funding investments.**
- Various sector-specific initiatives, such as the NHS AI lab and Genomics England, help with research and its translation into practice.

The European dimension was historically a strong part of the health research landscape, with health being the single largest strand of the EU's research funding programmes and the UK playing an outsized role in successfully winning and leading research across Europe. While the UK has now rejoined the current **EU research programme**, the immediate aftermath of Brexit and the period outside the programme was highly disruptive,⁵⁵⁵ and the UK is no longer part of wider EU coordination of health-related research priorities. How all this positions the UK relative to other countries is assessed through the Life Sciences Competitiveness Index.⁵⁴⁵ However, it is worth

noting that the NHS is still one of the world's most visible and highly researched health systems, and with NICE's reputation and robustness in health technology assessment, it is seen as a health system committed to evidence-based practice.

Beyond Europe, the NHS can play a leading role in global research collaborations, especially in health challenges that require multinational efforts, such as pandemics and antimicrobial resistance. Strengthening ties with institutions in the US, Asia, and low-and-middle-income countries through co-funded initiatives and knowledge exchange programs can amplify the NHS's impact.

C. What are the challenges to the collaboration and coordination of healthcare research and innovation in and around the NHS?

Box 56. Challenges related to collaboration and coordination

Challenges related to collaboration and coordination:

- A lack of awareness and clarity about the roles and remits of different orchestration bodies, alongside siloed working, staff turnover and competition for owning specific agendas, resulting in 'initiativitis'.
- Insufficient collaboration and coordination across industrial and health policy spaces – the NHS is seen more as a testing ground than an attractive market.
- A need for better signposting of entry routes into the NHS.
- A need to balance collaboration and productive competition better and to challenge the 'not invented here' syndrome in the NHS.

Despite existing institutions, there are challenges to effective coordination and collaboration of research and innovation activity in and around the NHS. These relate to issues such as **a lack of awareness of the remits and roles of different organisations, siloed working, turnover in lines of leadership and authority, and risks of a degree of competition for owning specific agendas.**³

There is also **scope for better coordination across bodies involved in health policy and industrial policy** to make the most of the capacity and resources in the health system towards shared impact goals.⁶¹ At present, many key areas of national strategic importance for research, innovation and care delivery in the NHS are funded by a mix of bodies working on health policy (e.g. NHS England and other arms-length bodies, NIHR, DHSC), industrial policy (e.g. UKRI, Innovate UK), charities and industry. Closer working between government departments responsible for health, life sciences, industrial strategy and business and trade could enable better use of limited public sector resources. Part of the current challenge is aligning industrial and economic competitiveness in health and life sciences R&D with goals for public health, population and NHS service delivery benefits. The risks working in siloes are that research and innovation in the NHS benefits UK's position as a global science and innovation powerhouse, at the expense of prioritising the uptake of the benefits of research and innovation investments in the NHS at scale, for the benefit of UK patients, populations and the health service.

At present, and though more often voiced informally rather than officially documented in the evidence base, innovators tend to see the NHS as a testing ground for their innovations rather than as a key or attractive market. The reasons for this are complex and relate partly to funding and regulatory challenges to market entry. There are also challenges related to pricing models which differ from those in markets seen as more attractive to industry (like the US, which has no price controls), although centralised NHS purchasing power for some types of innovations (such as key drugs) aids in negotiations with industry. However, these challenges also point to the importance of a **national architecture for coordinating, signposting and enabling entry routes into the NHS and for clearly signalling demand** so that NHS patients and the health service can benefit from innovations developed and/or tested in and with the NHS.

A further challenge is to find a better balance between collaboration and competition in the research and innovation ecosystem. While competition for research and innovation funding can support excellence, it can sometimes impede productive collaboration with and across the NHS at scale, especially given what are often small-scale funding efforts. Relatedly, though rarely evidenced in public outputs, those working in and around the NHS will often mention **the ‘not invented here’ syndrome** – the tendency for scepticism towards innovations developed elsewhere and a preference for home-grown advances. Better evidence on innovation success, performance and impact criteria can help mitigate this, but architectures that promote a more joined-up and collaborative NHS innovation ecosystem are required. Similarly, there needs to be a clearer procurement and commissioning pathway for innovations tested in the NHS so that investments into developing much-needed solutions do not hit a ‘valley of death’ regarding adoption.

D. A vision of what ‘good’ looks like in ten years and how we get there: collaboration and coordination

A future vision of a research-and-innovation-active NHS in an effective collaboration and coordination national framework is described in Box 57.

Box 57. A future vision for collaboration and coordination of research and innovation in the NHS

FUTURE VISION: In ten years, the fourth shift will help ensure that collaboration and coordination of research and innovation activity support the effective spread, scale and sustainability of innovative and evidence-based patient care. Patients, the NHS and the economy will benefit from a landscape in which industrial policy and health policy initiatives reinforce each other and where the UK is a key partner in global discoveries and developments.

In this vision for the future, the potential of research and innovation to make NHS service transformation a reality is enabled because:

- **Joined-up thinking across industrial strategy and health policy spheres benefits health service delivery, patient outcomes and experience as well as industrial strategy and economic competitiveness:** Research and innovation better support benefits for patients,

the NHS and the economy due to close collaboration and coordination across decision makers in industrial and health policy spheres that the government actively facilitates. Key policy decision makers and government departments now see benefiting the NHS, economy and industrial competitiveness as an 'and', not an 'or', and this helps overcome historical siloes, making it easier for the fruits of UK-led industrial strategy investments to enter into the NHS and benefit the UK population.

- **Closer collaboration and engagement between national and regional research and innovation initiatives leads to clearer remits for organisations with roles in fostering collaboration and coordination:** Resources devoted to supporting research and innovation are better coordinated between regional and national decision makers and orchestration bodies with a greater focus on priority efforts of appropriate scale (over short-term pilots), and there is also a growing number of individuals with boundary-spanning roles in the NHS who enable collaboration. Improved engagement between localities, regions and central government drives this improved strategic coordination. As a result, there is a reduction of unnecessary overlap and duplication. 'Initiativitis' and the unintended consequences of the 'not invented here syndrome' are reduced. This enables the adoption of best practices, regardless of their origins. The risks of multiple, overlapping and short-term initiatives leading to wastage of resources and compromising opportunities for sustainable and scalable impact are minimised.
- **International embeddedness supports UK efforts to benefit from global advances, industrial and economic competitiveness, and reputation as a global leader:** UK patients and the public benefit from international health research and innovation advances in timely ways. The government makes a conscious effort to ensure that the UK actively participates in EU and global research and innovation collaborations, with key national bodies enabling efficient international collaboration regarding R&D governance, visa arrangements for researchers and other factors.

In this vision, the health system benefits from better use of limited resources, avoiding the risks of multiple overlapping efforts and initiatives. The NHS benefits from longer-term, better-coordinated research and innovation investments supporting sustainable and scalable efforts over short-term, small-scale pilots. The health system benefits because investments align industrial strategy concerns for enterprise, job creation and economic competitiveness better with health policy concerns for patient and population benefits from research and innovation advances. The UK actively participates in European and global research collaboration, leveraging expertise and capacity to be part of global funding and research to maximise impact domestically and internationally.



4.3.7. Patient and public involvement, engagement and participation in research and innovation in the NHS

A. What matters for effective patient and public involvement, engagement and participation in healthcare research and innovation in the NHS?

Box 58. What matters for patient and public involvement, engagement and participation: key points

What matters for patient and public involvement, engagement and participation:

- PPIE to enhance relevance, quality and impact of research and innovation.
- Patient participation in research studies and trials to accelerate and scale the development of preventative interventions, diagnostics, health tech, treatments and cures.

There is a growing focus on patient and public engagement and involvement in research and innovation, as well as an increasing emphasis on patient participation in research studies.

Involvement and engagement are generally used interchangeably in the literature and refer to processes where patients and the public are involved with designing, informing and supporting implementation and helping disseminate research findings. In contrast, participation refers to processes where patients and the public are study subjects (e.g. participants in clinical trials).⁵⁵⁶

Patient and public involvement and engagement (PPIE) in health research is increasingly recognised as a cornerstone for enhancing the relevance, quality and impact of health-related research.⁵⁵⁶ This collaborative approach ensures that research priorities align with patients' actual needs and preferences, leading to more user-centric designs and facilitating the adoption of innovative advancements. PPIE transforms the traditional research paradigm. Instead of conducting research 'to' or 'for' individuals, PPIE emphasises research conducted 'with' or 'by' them. This shift fosters a partnership where patients and the public actively contribute to the design, execution and dissemination of research, ensuring that studies address real-world concerns and are more likely to be implemented in practice.⁵⁵⁷

One significant benefit of PPIE is the alignment of research priorities with patient needs. Patients bring unique insights based on their lived experiences, highlighting issues that may be overlooked by researchers.

For instance, the NIHR emphasises that involving patients in setting research agendas ensures that the studies undertaken are pertinent to those they aim to help. Moreover, PPIE can enhance the quality of research by incorporating diverse perspectives, leading to more comprehensive and robust study designs. Engaging patients in the research process can improve the clarity and accessibility of information, making it more understandable and relevant to a broader audience. This collaborative approach also promotes ethical research practices, as patients can

provide valuable feedback on study protocols, ensuring they are respectful and considerate of participants' needs.^{556,558}

The impact of PPIE extends to the dissemination and implementation of research findings. When patients are involved in the research process, they are more likely to trust and engage with the outcomes, facilitating the translation of research into practice. This engagement can lead to improved health outcomes, as interventions developed with patient input are more likely to be accepted and adhered to by the target population.⁵⁵⁹

However, effective PPIE requires careful planning and support. Researchers must ensure that patient involvement is meaningful and not merely tokenistic. Training and resources for both researchers and patient contributors can facilitate productive collaborations. Additionally, recognising and valuing the contributions of patients and the public is essential for sustaining their engagement and fostering a culture of mutual respect.⁵⁶⁰

In addition to opportunities for PPIE, patient participation in studies and trials is key to advancing research and innovation in new preventative interventions, diagnostics, treatments and cures. It requires an effective system for recruitment, consent, onboarding, follow up and feedback on study findings.

B. What is the current landscape for patient and public involvement, engagement and participation in health research and innovation?

Box 59. Support mechanisms for patient and public involvement, engagement and participation: current landscape and developments over time

Support mechanisms for patient and public involvement, engagement and participation – current landscape and developments over time:

- **National-level bodies**, e.g. National Voices.
- **Groups focused on underserved groups**, e.g. People Street.
- **Charity PPIE panels.**
- **A growing body of guidance on how to do PPIE well and of support for raising awareness of opportunities**, e.g. from INVOLVE studies, UK Standards for Public Involvement from NIHR, Research Champions and NIHR People in Research.
- **Some progress in prioritising research**, e.g. James Lind Alliance Priority Setting Partnerships.
- **A Growing focus on research participation platforms and recruitment efforts**, e.g. COVID-19 registry, Our Future Health.
- **A policy focus on tackling inequalities**, e.g. Core20PLUS5.

There is **growing recognition of the importance of involving and engaging service users** in prioritising research and innovation challenges to address, questions to ask in research and the design of innovations as a way of maximising the likelihood of developing fit-for-purpose products, technologies and services. Various programmes exist to support PPIE in research and innovation. To illustrate:

- **Many research charities manage their own PPIE panels**, and organisations such as **National Voices** and **People Street**, alongside many medical research charities, work to ensure diverse inputs can be reflected in research and innovation efforts and support inclusive design.
- There is also increasing **guidance on how to do PPIE well** from organisations such as **NIHR**, research on the topic and a series of efforts to raise awareness of opportunities for involvement. Some examples include **UK Standards for Public Involvement**,⁵⁶¹ the appointment of **Research Champions**⁵⁶² (community volunteers who help raise awareness and promote research opportunities among peers, patients and carers) and web portals such as **People in Research**.⁵⁶³
- Individual sector-specific efforts have also evolved to engage diverse patients and the public (see genomics case study and the Diverse Data Initiative in chapter 4).
- There has been some progress with prioritising research, e.g. the **James Lind Alliance Priority Setting Partnerships**.⁵²⁸

The UK landscape also focuses on bolstering the architecture to recruit patients and the public into research and innovation efforts. The potential for effective and rapid patient recruitment was evident during the COVID-19 pandemic, with the **NHS COVID-19 Vaccine Research Registry** enabling people to sign up in a user-friendly way to participate in trials at pace (the registry launched in 2020 and recruited 500,000 volunteers by June 2021). Efforts such as **Our Future Health** are also seeking to recruit patients into research efforts in an integrated way. The UK performs relatively well in recruiting patients for non-commercial trials but less well in commercial, industry research and innovation efforts. NIHR also hosts the platform **Be a Part of Research**, which provides information on participation opportunities.⁵⁶⁴

C. What are the challenges related to patient and public involvement, engagement and participation in healthcare research and innovation?

Box 60. Challenges related to patient and public involvement, engagement and participation in healthcare research and innovation

Challenges related to patient and public involvement, engagement and participation in healthcare research and innovation:

- Despite progress in the research space (e.g. with the James Lind Alliance Priority Setting Partnerships), there can still be significant biases at play in both what is prioritised, how and

for whom in innovation and research (more focus is needed on solutions that can benefit underserved populations and tackle inequalities).

- Reduced opportunities for PPIE contributions and participation in studies for people from minority groups/underserved populations.
- Resource constraints and power dynamics, affecting meaningful and appropriate PPIE input into studies.
- Significant challenges in patient recruitment for clinical trials, especially when commercially led.

Research and innovation have key roles to play in supporting more personalised care and medicine and improving access, outcomes and patient experience. However, **significant biases operate in what is prioritised, researched and developed, as well as how and for whom.**⁵⁶⁵

National efforts, such as Core20PLUS⁵⁶⁶ developed by the NHS, provide a good foundation to build on in future efforts and identify key areas of health inequalities among underserved populations such as ethnic minority communities, people with learning disabilities, multiple long-term health conditions and other groups with protected characteristics. These inequalities span five focus areas of national priority: maternity, severe mental illness, chronic respiratory disease, early cancer diagnosis and hypertension case-finding/lipid management. Efforts to involve diverse and underserved populations are highlighted as crucial for equitable research outcomes.

There are also significant challenges to patient recruitment into commercial trials. Lord O'Shaughnessy's review flagged that the UK has seen a 44% drop in patient enrolment into commercially led but NIHR-supported studies. The reasons are complex and span systemic issues related to recruitment approaches and how the NHS engages and communicates with patients about research opportunities¹⁰ (among other factors, such as burdensome regulation and slow approval processes deterring industry). There is a relatively low public awareness of research opportunities and limited recruitment to clinical studies (stakeholder workshop), exacerbating challenges in certain areas, such as rare diseases. Addressing this requires embedding discussions about research into routine healthcare interactions, as seen in only 43% of cases in cancer care.⁵⁶⁷ Public trust and willingness to engage must also be supported by transparency in sharing clinical trial results.⁵⁶⁸ Trusted organisations (e.g. charities) and individuals (community champions) are needed to help mobilise public trust and understanding of the importance of research and innovation and participating in it (stakeholder workshop).

People from minority ethnic groups or economically disadvantaged backgrounds often face reduced opportunities for PPIE activities and actual participation in research studies, limiting the applicability of research findings.^{569,570} **Scaling initiatives to include underrepresented groups and decentralising both PPIE activities and actual opportunities to participate in research trials –bringing research closer to local communities or homes – can bridge these gaps.** This requires clarity in research designs about the types of inequalities that seek to be addressed and the types of communities that need to engage (stakeholder workshop). Decentralised trials can also improve access, especially for those in remote or underserved areas,

making participation feasible. Programs like NHS DigiTrials and charity-led initiatives, e.g. patient recruitment services, may need further investment. Clarifying patient data use policies for trial recruitment is another priority to build public trust and enhance recruitment efficiency.

Resource constraints and unequal power dynamics between researchers, innovators and service-user contributors can also challenge optimal patient and public involvement,⁵⁵⁶ and compromise efforts to ensure meaningful involvement and engagement (stakeholder workshop). Addressing these power imbalances is key to efforts to meaningfully engage patients and the public in research and innovation involving the NHS.

There is a need to maximise opportunities for everyone to participate in research. The Association of Medical Research Charities (AMRC) made ‘maximising opportunities for everyone to take part in research’ one of its three themes in responding to the Darzi review.⁵⁰²

In doing so, the AMRC emphasised the need for inclusive, accessible and effective engagement strategies. These efforts need to be considered within the wider context of government policy and efforts to build a fairer Britain (stakeholder workshop).

D. A vision of what ‘good’ looks like in ten years and how we get there: public engagement and participation in health research and innovation

In a future vision for patient and public involvement in research and innovation in the NHS, we have built on current developments and progress. Patients benefit from research that is better aligned with their needs and informed by their voices, the uptake of good practice increases and trust in institutions improves. The NHS benefits from clear and more accessible ways of engaging service users in research and innovation activity, delivering better care quality and patient experience.

This vision for public engagement, involvement and participation is summarised in Box 61.

Box 61. A future vision for patient and public engagement, involvement and participation in research and innovation

FUTURE VISION: In ten years, the fourth shift will enable diverse patients and the public to have more say and input into shaping the care they need and receive based on evidence and continual innovation and improvement. Patients and the public across diverse communities will be better enabled to engage in research, innovation and NHS service improvement efforts in inclusive ways and will be more aware of and trusting of opportunities to do so.

In this vision for the future, meaningful and diverse patient and public contributions to research and innovation help make NHS service transformation a reality because:

- **Recruitment into research and trials is scaled such that the NHS and patients contribute to global innovation and benefit from timely access to it.** Better awareness of clinical trials and other opportunities to engage with research and innovation is enabled through more

considered communication strategies, signposting of information (nationally, regionally, digitally and through direct community mobilisation, utilising existing platforms and apps such as the NHS App), transparency and more active outreach. This also supports better public trust in research and innovation, including industry-led ones. There is an active effort for trusted organisations (nationally and in local communities) to champion efforts to build public trust and ensure responsible practices.

- **More diverse patients contribute to research and innovation, and inclusiveness that leads to advances that help tackle inequalities towards a fairer UK:** Barriers to engagement for underserved groups are lowered by efforts to enable more flexible participation approaches, addressing issues such as digital exclusion and supporting culturally appropriate outreach. Communities have greater input and impact on research and innovation agendas and better access to resulting solutions. Advances better address the needs of marginalised and underserved communities within wider government policy efforts to achieve a fairer country.
- **Better coordinated infrastructure for engagement in research and innovation makes it easier for patients and the public to play a key role in shaping the future of NHS care:** Those driving research, innovation and NHS service delivery efforts find it easier to elicit the input they need from patients and the public, and patients and the public feel that they are making a meaningful contribution that is reflected in the outputs of research and the design and implementation of innovative products, technologies and services. Closer collaboration between research, innovation and quality improvement efforts facilitates better use of existing patient and public involvement and engagement capacity in the system – both lay and expert. Local initiatives are well connected to national patient engagement, involvement and study recruitment efforts. Local health systems know their patients best and can help ensure the right people are involved to meet specific studies' needs. Good practice guidelines mitigate against the unintended consequences of researcher-service user power dynamics. NHS staff and academic researchers are better trained to effectively engage with participatory research and are accountable for demonstrating meaningful and not tokenistic engagement, reducing some of the previous power imbalances.

Chapter 5. Conclusion

Box 62. Conclusion: key points

- An NHS that embraces research and innovation is essential for meeting current and future needs sustainably. The intended government shifts from hospital to community, analogue to digital and sickness to prevention cannot materialise without a research and innovation-powered NHS.
- We have identified seven key support mechanisms that need to be in place to deliver this: (1) workforce, (2) information, evidence and data environments underpinning research and innovation, (3) physical infrastructure levers, (4) funding, commissioning and procurement, (5) R&D governance and regulation, (6) collaboration and coordination and (7) patient and public involvement, engagement and participation.
- These support mechanisms can deliver an ecosystem in which research and innovation shifts from being seen as a 'nice to have' to being seen as essential and at the heart of wider NHS transformation efforts. The support mechanisms are also key to achieving the core values of modern health systems: excellence in care, effectiveness (including cost-effectiveness), efficiency, equity and support for an evolving health system that is responsive, learning and adaptive.
- Prioritising actions related to each support mechanism will help achieve the shift from seeing research and innovation as nice-to-have to seeing them as essential, underpinning the delivery of NHS reforms and the 10-Year Plan. A coordinated national strategy, informed by dialogue between actors in the research, innovation, health policy and industrial strategy landscape, can help achieve this.
- A fourth shift to a research and innovation-powered NHS needs to be a foundational building block of the 10-Year Plan. It is essential to tackling many of the health challenges we face, including proactively addressing the growing burden of chronic diseases and comorbidities, ageing populations, growing health system costs, waiting times and the backlog, the increasing and changing nature of demand for health services and emerging infectious disease threats.

The 10-Year Plan presents a fresh opportunity to embed research and innovation at the heart of the NHS as part of wider efforts to deliver NHS reforms and societal benefit. Healthcare is a knowledge-intensive sector, and this research has highlighted the importance of a research-and-innovation-active NHS for meeting the health service's current and future needs. It has shown the impacts that research and innovation can have on the quality and safety of care, NHS staff job satisfaction and workforce retention, patient health outcomes and experience, health system resilience, the economy (e.g. job creation, revenue, labour productivity due to reduced absenteeism) and wider society (e.g. its reputation for excellence in science). We are already

seeing these impacts in various areas with the potential to scale and spread innovative practice throughout the NHS (as shown in our case studies of genomic medicine, AI applications in cancer diagnosis, digital and data-driven innovation in mental health and technology-enabled remote monitoring applications).

Only an NHS that embraces research and innovation can transition to meet needs in a sustainable way. Research and innovation matter not for their own sake but for tackling monumental challenges to NHS performance. If research and innovation are not mainstreamed in the NHS as the fourth shift, the health service and patients will be left behind, impeding the government's intended shifts from hospital to community, analogue to digital and sickness to prevention. Realising a research and innovation-powered NHS means linking multiple actors across the NHS, academia, industry, policy, regulatory and health technology assessment experts, and patients and the public to support an effective translation of research evidence and novel products, technologies and service model innovations into routine practice. Diverse research and innovation types matter for these shifts and for the NHS's future. For example, health services, public health research and innovation are key to implementing the shift from **hospitals to communities** and supporting feasible, effective, evidence-based policies about the spread, scale and sustainability of effective novel interventions. Access to innovative diagnostics, treatments and cures that can help avoid unnecessary hospital admissions is also key for this shift to materialise. The shift from **analogue to digital** will require innovation in technology and data infrastructure, as well as research and evaluative evidence on workforce, service user, industry supplier and regulatory system determinants of implementation success. Public health, health services, health tech (e.g. virtual wards and tech-enabled remote monitoring) and biomedical and life sciences research and innovation are essential to efforts to help keep people healthy while at the same time responding to pressing needs to reduce waiting times and address the post-pandemic backlog, and as such are key to the shift from sickness **to prevention**.

We have outlined seven support mechanisms to help ensure research and innovation deliver on their potential. In summary, a research-and-innovation active NHS **workforce** is critical to achieving sustainable, high-quality, cost-effective healthcare based on the most up-to-date evidence. Improved access to **data, information and evidence** is essential for translating research and innovation into high-quality NHS practice and responding to unmet needs in a timely manner. Upgrades to basic **physical infrastructure** alongside investments in key high-tech facilities are crucial for the NHS to provide safe care and for patients to access global scientific advances and not be left behind. More strategic prioritisation of **funding, commissioning and procuring** research and innovation is crucial for reducing resource wastage and inefficient, ineffective care. Clear and streamlined **R&D governance and regulation** underpins the ability of research and innovation to benefit the NHS, patients and economy at scale. Closer **collaboration and coordination** between local, regional and national bodies is pivotal for progress in research and innovation and its translation into best practice in NHS care. Finally, more inclusive **patient and public involvement, engagement and participation** in research and innovation are essential for the UK population to have a fair and meaningful say in shaping what the NHS does and how.

We also presented a vision of what 'good' looks like in ten years relative to each support mechanism, emphasising that achieving this vision will depend on a coordinated strategy and implementing actions that could lead to a supported and enabling ecosystem. In summary, the

NHS could deliver sustainable care and healthcare excellence with research and innovation at its heart if this vision is successfully enacted:

- NHS staff will be empowered to help transform the NHS by ensuring evidence-based, innovative patient care. The NHS workforce will be motivated, rewarded and accountable for doing and adopting research and innovation, supported by better training and information. Incentives and accountabilities will enable research and innovation at the needed scale to deliver excellence in patient care. Staff well-being will be improved through job satisfaction and pride in high-quality care delivery. Committed leadership and wider NHS staff skills and capacities will support a culture of innovation and improvement.
- Data, information and evidence will be more widely accessible to researchers and innovators. It will be used, shared, combined and analysed safely and securely, with public trust secured through a mix of technological solutions to data privacy and safety, regulation (e.g. clear standards), and effective public engagement and transparency. Patients will have control over what data they share, and an evidence-driven NHS will actively develop, adopt, spread and scale new solutions. Improved signposting to sources of information, evidence and advice will make it easier for NHS staff to conduct and use research and innovation to deliver best practice in care.
- Attracting infrastructure investment will enable the NHS to support excellence in research, innovation and patient care. The 'basics' will be in place, reducing contradictions between world-leading facilities in some settings and dilapidated buildings and out-of-date equipment, hardware and IT systems in others. Staff well-being will improve because they will have greater trust in delivering care in safe environments.
- Strategic demand-signalling (i.e. clear information on what requirements are needed to address an unmet need) will support well-prioritised investments by UK and international public and private sector investors in research and innovation, focusing on innovation patients need and the NHS can afford. The NHS will balance short and longer-term research and innovation priorities to deliver on immediate needs and reduce waiting lists while sustainably supporting key shifts to more preventative, personalised and community-based care.
- Regulation will better meet researcher and innovator needs and, in turn, patients will benefit from quicker access to high-value solutions. A more standardised R&D governance landscape will reduce the bureaucracy that complicates and disincentivises researchers and innovators. Regulation will keep pace with science and technology advances, making the NHS better able to confidently and in timely ways make the best use of innovation for excellence in patient care.
- Closer working and engagement between national and regional research and innovation initiatives will enable clearer remits for organisations with roles in fostering collaboration and coordination. International embeddedness will support UK efforts to benefit from global advances, industrial and economic competitiveness, and its reputation as a global leader. There will be closer collaboration across research governance, innovation regulation and health technology assessment. This will cement a smoother pathway from the lab to NHS practice, affording patients rapid access to novel solutions and making the UK a more attractive market for innovators.

- **Research and innovation will be better understood by patients and the public, not as abstract concepts but as a way to help support their health and achieve NHS needs.**

Recruitment into research and trials will be scaled so that both patients and the NHS contribute to global innovation and benefit from timely access to it. More diverse patients will contribute to research and innovation, and this inclusiveness will lead to advances that help tackle inequalities towards a fairer UK.

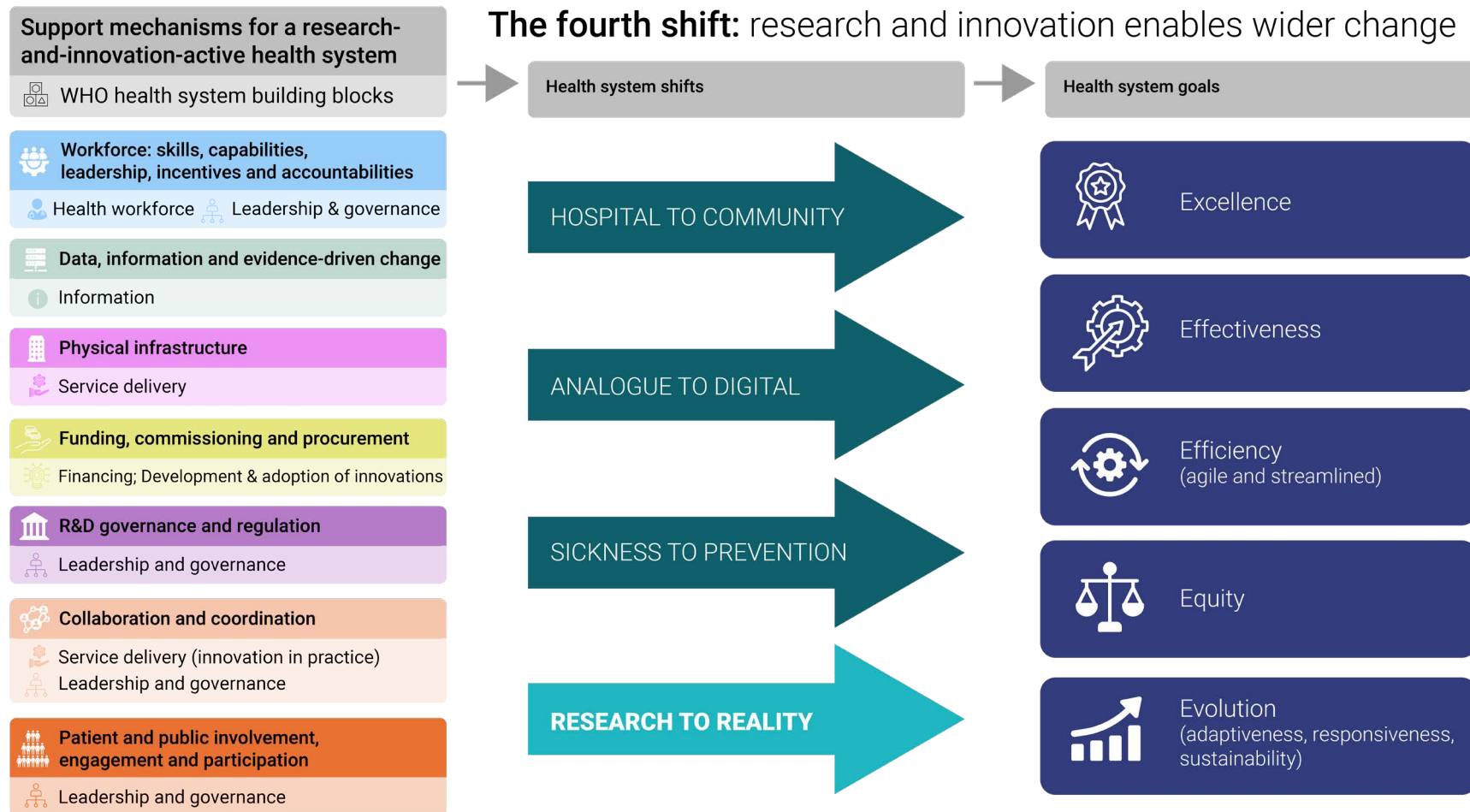
As shown in **Figure 8** below, the support mechanisms we have outlined are backed by evidence on key health system building blocks outlined by the World Health Organisation. **The support mechanisms outlined are also key to achieving the core values of modern health systems.** We conceptualise these as being rooted in notions of **excellence** in care, **effectiveness** (including cost-effectiveness), **efficiency, equity** and supporting an **evolving health system** that is responsive, learning and adaptive. This includes proactively addressing the growing burden of chronic diseases and comorbidities, ageing populations, growing health system costs related to the increasing and changing nature of demand for health services and emerging infectious disease threats.

Getting to where the NHS needs to be and can be is possible, but it will take planning, prioritisation and coordination of short-term, medium-term and longer-term actions to support the 10-Year Plan. Prioritising actions in each of the support mechanism areas we have laid out will enable a feasible approach to translating the potential of research and innovation to support NHS reforms into practice. A coordinated national strategy informed by dialogue between actors in the research, innovation, health policy and industrial strategy landscape can help achieve this.

The fourth shift to a research and innovation-powered NHS needs to be a foundational building block of the 10-Year Plan. Decision-makers should be mindful of not picking technology and product winners but thinking about how the wider ecosystem of support mechanisms can support the opportunities presented by novel diagnostic, digital and treatment paradigms.

The ecosystem is the enabling platform, not technologies and areas of innovation alone. We must embrace science and technology as part of a solution to NHS challenges while ensuring we do not miss the opportunities for impact that can happen if science and technology outpace society's ability to deal with it. The fourth shift we have outlined can help ensure that this does not happen and that society rises to the opportunity ahead.

Figure 8. The fourth shift: research and innovation enable a wider change



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Appendix 1. Interviewees

We are thankful to all the interviewees for giving us their time to inform this project. We provide the list of interviewees below, all with informed consent.

Table A1. List of stakeholders interviewed for the project

Interviewee Name	Organisation
Oliver Harrison	KOA Health
Mike Denis	Akrivia Health
Pooja Sikka	KHPV - Innovation in MH Fund
David Clark	Oxford Centre for Anxiety Disorders
Anke Ehlers	Oxford Centre for Anxiety Disorders
Janet Valentine	The Association of the British Pharmaceutical Industry
Natalie Banner	Genomics England
Chris Schonewald	Genomics England
David Snead	Pathlake
Naomi Allen	UK Biobank
Ed Sykes	UK Biobank
Philippa Garety	Kings College London (Psych)
Thomas Ward	Kings College London (Psych)
John Wright	Bradford Institute for Health Research
Lloyd O'Mahoney	DeepHealth
Prof Rajesh Jena	OSAIRIS and Addenbrooke's Hospital

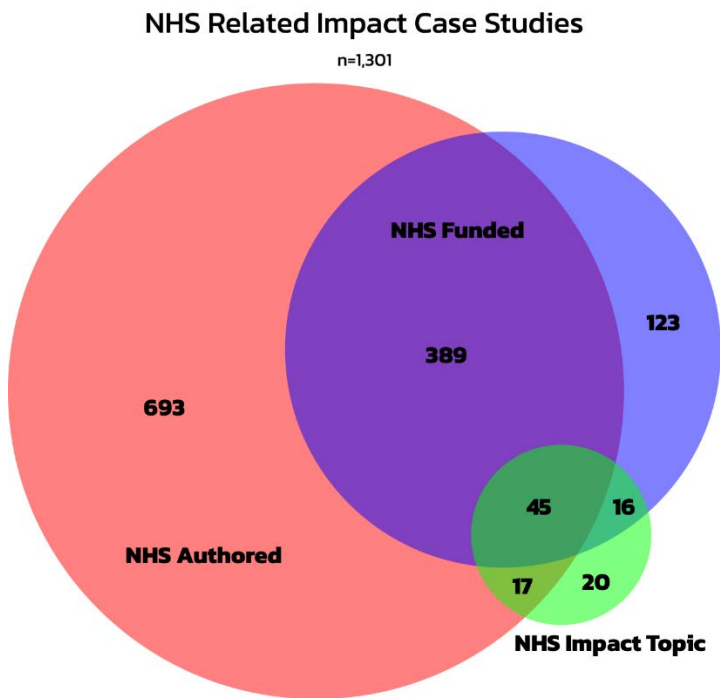
Appendix 2. The impact of UK university research on the NHS

Every 5–7 years, the four UK funding councils audit the quality of research in UK universities, known as the Research Excellence Framework (REF). The Research Excellence Framework is a system used in the UK to assess the quality of research in higher education institutions. In 2021, this included assessing the impact of the research on wider society by drafting four-page impact case studies. An impact case study has several components, including a section that describes the ‘underpinning research’ (including bibliographic references) and a section on the ‘details of the impact’ explaining and evidencing the nature of the impact ‘beyond academic’. The content of these impact case studies can be ‘mined’ using various data and text science approaches.⁵⁷¹

To provide an overview of the impact of university research on the NHS, we identified 1,301 (out of 6,361) impact case studies either funded by the NHS (identified via funding acknowledgements in the case study), involved an NHS researcher (identified via an NHS author affiliation) or for which the NHS was a beneficiary (based on the impact case study being assigned an NHS topic*). As illustrated in Figure 7, there is an expected overlap between these three categories. We refer to these in the analysis below as ‘NHS impact case studies’. Based on this analysis of the 1,301 ‘NHS impact case studies’, several relevant observations can be made.

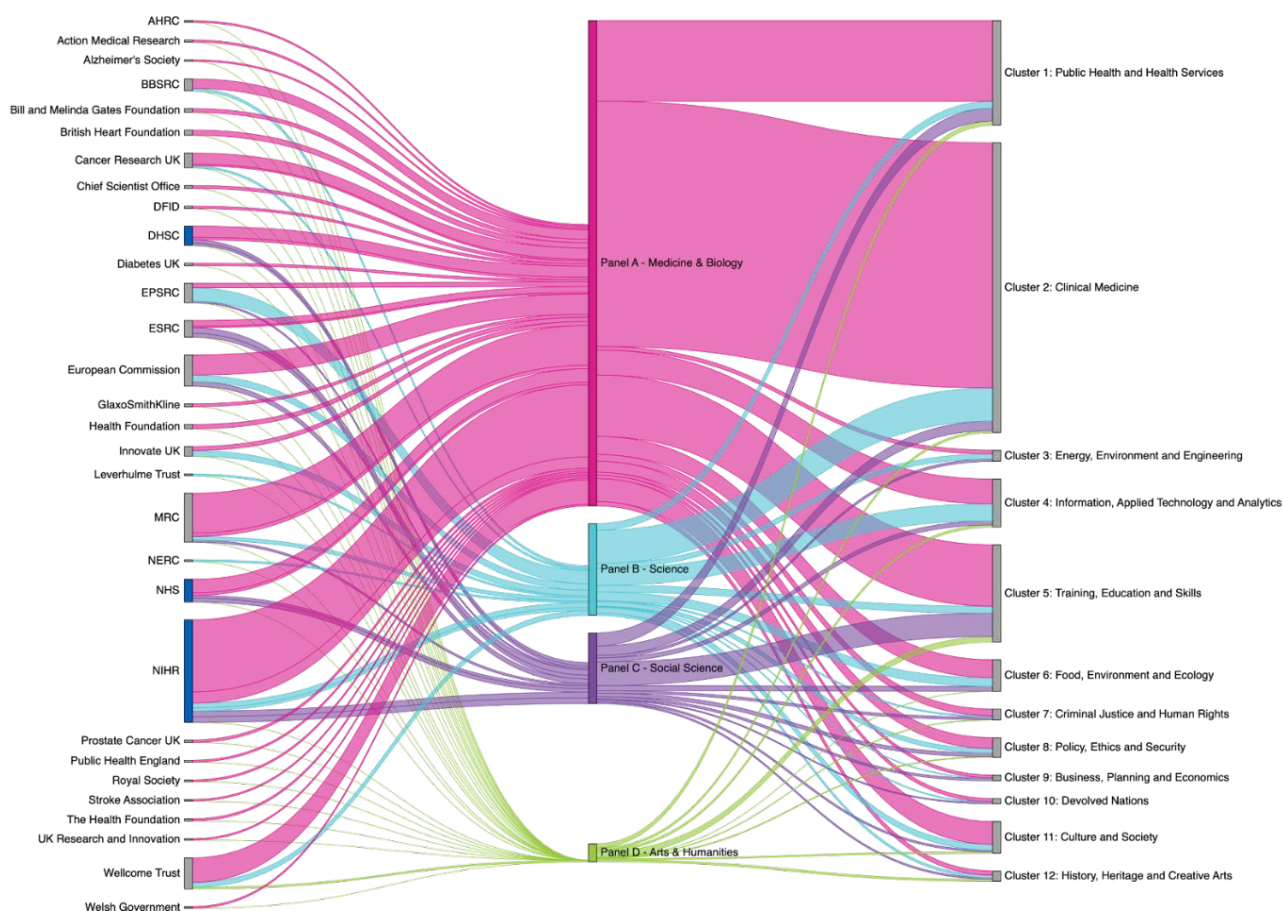
NHS R&D is part of a complex ecosystem of different funding streams, supporting different research disciplines, resulting in multiple types of impact. The alluvial diagram in Figure 8 shows the flow of funding from organisations (left) that underpinned the research in the impact case studies submitted to disciplines (or Units of Assessment and Panels in REF language; centre) that resulted in impacts (right). The lines’ thicknesses are proportional to the number of impact case studies (i.e. the NIHR funded about twice the amount of impact case studies in the sample compared to the MRC). Top funders are listed on the left (more than 50 impact case studies). NHS funders, i.e. the DHSC, NHS and NIHR, are highlighted in dark blue. **The funders that contributed to the most impact case studies were the NIHR (443), MRC (214), European Commission (148) and Wellcome Trust (141).** Overall, 44% of impact case studies with NHS authors (365 of 833) were funded by the DHSC, NHS or NIHR. Funders generally had a similar distribution in terms of panel contribution, except for those not health-related, such as the EPSRC, Innovate UK and NERC (i.e. mostly to Panel B). Panel D Impact Case Studies comprise a small amount of all NHS-related impact case studies (26 in total), featuring research relating to various artistic health and well-being projects.

* An impact topic is derived from a natural language processing technique that determines how researchers can use specific clusters of related words (or topics) to categorise the underlying data. A total of 79 topics (including one on the NHS) were identified from the analysis of all 6,361 impact case studies. These topics were grouped into 12 cognate clusters. The results of this search were disambiguated on the funder names in contextual data. This included focusing on all UKRI councils, including everything mentioning the NHS, normalising DHSC names over time, and adding ten other funders (e.g. the Wellcome Trust and CRUK). The number of impact case studies totalled 1,301.

Figure 7: NHS-Related Impact Case Studies

This analysis shows that the majority (70%) of NHS impact case studies are unsurprisingly concentrated in Panel A (907 out of 1,301), which is for the life sciences and provides the majority of impact pathways to Public Health and Health Services (Impact Cluster 1), Clinical Medicine (Cluster 2), Training, Education and Skills (Cluster 5) and Culture and Society (Cluster 11). Perhaps of more importance is the diversity of funders on the left-hand side, the fact that NHS research involves all four disciplines (centre) and the range of impact clusters on the right.

Figure 8. Alluvial Diagram: funding flows



To focus on the underpinning research (i.e. the centre in Figure 7), the 'impact wheel' in Figure 9 shows the percentage of the 1,301 NHS impact case studies that were submitted from each of 34 research disciplines (or 'unit of assessments' in REF language). In this figure, pink shades represent the life sciences, blue represents the physical and engineering sciences, purple represents the social sciences and green represents the arts and humanities. This figure illustrates that whilst **the majority of NHS ICSs are based on research in the life sciences, engineering and social sciences both make an important contribution to NHS R&D.**

Figure 9. Impact Wheel: NHS impact case study disciplines

