



Nuffield Council on Bioethics

2024 Horizon Scan Longlist

Methods and evidence pack

Purpose of this document

The [Nuffield Council on Bioethics](#) (NCOB) annual Horizon Scan (HS) has been revamped for 2024 – displaying the identified emerging biomedical and health topics within a timeframe that external political, regulatory and public signals suggest they could raise ethical implications in the UK.

This is the first time the NCOB has timeframed our HS insights, which is why we are providing this supportive methods and evidence pack. We hope it will enable users of our annual HS data to better understand what we have done and why, and that this will facilitate beneficial feedback so that we can continue to evolve our HS and Foresight methodologies.

In this document you will find extended definitions and summaries for each of our 2024 HS topics. Alongside this is the evidence we found and used to assign each topic a timeframe score. We have displayed the topics in alphabetical order for ease of finding information.

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Methods

Identification of our 2024 HS topics was informed by a combination of qualitative stakeholder engagement and extensive desk-based analysis of a wide variety of sources including academic literature, reports, policy papers and news.

This year, we have engaged with professionals working across bioethics, law, social science, biomedical research, healthcare and policy through 50 workshops, conferences, roundtables and 1:1 meetings. We also collected the views of 22 organisations and 18 specialists through a survey.

Once identified, we ‘enabler’ assessed each topic on our 2024 HS against a series of external signal and trend data (table one). We weighted towards political, regulatory and commercial signals because ethical implications are most likely to occur when an emerging technology or innovation has these enablers. Having these enablers can result in an innovation or technology accelerating at a pace that can outstrip current regulatory frameworks or create tensions with public values.

Once completed, we used the enabler assessment to timeframe each HS topic (table two) into either short-term (<5 years), medium-term (5-10 years) or long-term (>10 years). For example, a topic which had substantive signals across all enablers was placed into the ‘short’ timeframe, meaning that we believe there are signs that it could raise ethical implications in the UK within the next 5 years.

Enabler	Data source
Political context	<p>Political interest and framing <i>Media statements and interviews, thought pieces, manifestos, party conference presentations, government announcements, departmental announcements and reports.</i></p> <p>Policy reports and papers <i>Government departments, national academies, arm's length bodies and Royal Colleges</i></p> <p>Consultation calls</p> <p>Debates</p> <p>Parliamentary questions and responses</p> <p>Qualitative insights through engagement</p>
Regulatory interest or concern	<p>News and reports from regulators</p> <p>Active regulatory projects <i>Relevant bodies include HFEA, HTA, HRA, MHRA, GMC, ICO, FSA, CMA, ASA, NMC, CQC, Environment Agency and the UK Health Security Agency</i></p> <p>Qualitative insights through engagement</p>
Level of funding	<p>Funder announcements and reports</p> <p>Project calls</p> <p>Qualitative insights through engagement</p>
Public interest or concern	<p>Media reports <i>Legacy media, trade and tabloid</i></p> <p>Public engagement findings <i>Citizens juries and assemblies, surveys, polls and public dialogues</i></p>
Commercial potential	<p>Clinical trial data</p> <p>Industry investment</p> <p>Industry and market reports</p> <p>International developments <i>For example, commercial translation or availability in other countries</i></p> <p>Qualitative insights through engagement</p>
Expert and academic-led commentary	<p>Editorials and opinion pieces</p> <p>Reports, publications and campaigns from major research and academic institutions</p>

	<p><i>For example, reports/publications from National Academies and Royal Colleges</i></p> <p>Qualitative insights through engagement</p>
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Table 1 shows the data sources used to determine the degree of enablers for each 2024 HS topic

Time	Score
Short (< 5 years)	<p>High in political context</p> <p>High in regulatory interest or concern</p> <p>High in commercial potential</p> <p>High to medium in funding opportunity, public interest and expert-led commentary.</p>
Medium (5-10 years)	<p>High in funding opportunities</p> <p>High to medium in public want</p> <p>Medium in political context OR regulatory interest / concern</p>
Long (> 10 years)	Everything else that doesn't meet short or medium criteria

Table 2 shows the scoring system for a topic to be timeframed as short-term, medium-term or long-term.

1. Abortion

Abortion is a polarised issue, with implications for other areas of medicine like prenatal screening. New buffer zone laws in England, Wales and Northern Ireland will make it a criminal offence to protest directly outside clinics, and a similar bill has been proposed in Scotland.¹

The expansion of access to abortion through telemedicine during the COVID-19 pandemic was preserved in 2022, with an amendment to the Health and Care Bill that allows access to at-home early medical abortion. This change in the law has dramatically reduced the number of people seeking access to abortion outside of existing legal parameters. However, several high-profile cases of women being prosecuted under the Offences against the Person Act, which dates back to 1861, have reignited debate about abortion law in the UK.

There was a cross-party amendment to decriminalise abortion in May 2024,² it is possible this could resurface since the Government changed after this.

Timeframe: <5 years

¹ GOV.UK (18 September 2024) [Protection zones around abortion clinics in place by October.](#)

² The BMJ (9 April 2024) [Abortion: MPs propose decriminalisation in England and Wales.](#)

Evidence:

- **Political:** The introduction of the buffer zones was fast tracked by the new Government and largely welcomed, judging by the tone presented in media. There is potential for reform of legislation in this area over the next 5 years following multiple amendments put forward pre-general election.
- **Public:** Public reactions and opinion seem to be unchanged with general interest in this issue and views expressed as they have always been on both sides.
- There are heightened conversations in the US, but as our horizon scanning is focused on the UK specifically and there is currently no perceived impact on the UK from the US ruling in *Roe V Wade*, we are ruling this out.

2. AI & Genomics

In recent years, interest in AI and genomics has grown with both fields receiving significant investment from the private and public sectors. As research in the two fields has progressed, AI and genomics have become increasingly intertwined.

Many key advances in genomics have been made possible by machine and deep learning techniques, and AI-powered genomics has emerged as a specialised field and area of commercial interest.

A horizon scanning exercise, conducted by the Ada Lovelace Institute and NCOB, explores potential advances in genomic analysis facilitated by AI in the next 5-10 years. These include accelerating drug development, advancing polygenic and multiomic analysis (analysis of genomic data alongside other layers of data, or 'omics', such as epigenetics and proteins), and enabling effective precision medicine.³ Research is also exploring the potential of AI in optimising genome editing techniques.⁴

AI-powered genomic health prediction (AIGHP) could play a significant role in prevention-focused healthcare. On an individual scale, AIGHP could provide insights into a person's genomic risk, informing beneficial lifestyle choices and vigilance for certain symptoms. On a collective scale, AIGHP could help target screening efforts and interventions to groups or areas more likely to need them. However, there is considerable uncertainty around the accuracy of AIGHP and the polygenic scoring techniques it is based on. Genomic datasets are largely biased towards populations of European genetic ancestry, making prediction less accurate for people with non-European ancestry, and for many common conditions, genomic variations only account for a limited proportion of overall disease risk. Ethical risks associated with the widespread use of AIGHP include surveillance and data privacy, discrimination (e.g. on the basis of disease susceptibility), over-dependency on AIGHP within the health system and disempowerment of clinicians and patients.

³ Ada Lovelace Institute and Nuffield Council on Bioethics (2023) [DNA.I. - Early findings and emerging questions on the use of AI in genomics](#).

⁴ Dixit S *et al.* (2024) Advancing genome editing with artificial intelligence: opportunities, challenges, and future directions *Front. Bioeng. Biotechnol.* **11**: 1-16.

Read our work on [AI & Genomics](#), including our recently published joint report with the Ada Lovelace Institute '[Predicting: the future of health?](#)'

Timeframe: 5-10 years

Evidence:

- **Political / Funding:** In many ways, the UK has been at the forefront of genomic research – e.g. 100000 Genomes Project, UK Biobank, Our Future Health – and NHS / DHSC are committed to further investment in genomic predictive / preventive medicine.
- This aligns with the government's goal of an efficient preventive health service. E.g. 2022 strategy - Accelerating Genomic Medicine in the NHS.
- **Expert:** Internal conversations with project team from AI & Genomics reports – including insights from their stakeholder engagement and horizon-scanning work.
- Accuracy, generalisability and utility of polygenic scores is still subject to scientific debate, although AI could help resolve these issues. Also, limitations due to digital infrastructure and skills as highlighted in the Darzi report amongst others.

3. AI in clinical practice

A wide range of AI applications are being explored in the healthcare sector, including in the detection and diagnosis of disease, the management of chronic conditions, and assisting in clinical decision-making. For example, researchers are exploring the potential of natural language processing and predictive AI modelling to 'unlock' the data stored in the free-text components of medical records and clinicians' notes and forecast future medical events.⁵

In the NHS, AI technologies are being considered as a way to improve system efficiencies, reduce waiting times and free up clinical capacity by supporting administrative tasks. Pilot schemes have successfully used AI tools to reduce missed appointments by predicting when a patient may not attend and prompting reminders, rearrangements or the provision of additional support.⁶

The WHO recommends that ethics be at the heart of design, deployment and use of AI in healthcare. Ethical challenges centre around data collection and usage, the encoding of biases in algorithms, and risks to patient safety, cybersecurity and the environment. In the face of rapidly advancing AI technologies, the government's 2023 pro-innovation approach to AI regulation outlines five key principles to guide regulators: Safety, security and robustness; transparency and explainability; fairness; accountability and governance; contestability and redress.⁷ The MHRA's AI Airlock, launched in Spring 2024, is a pilot regulatory sandbox that will bring together a range of UK regulatory bodies and organisations to examine real-world technologies and 'stress test' regulatory approaches. The project, which will initially run until April 2025, aims to inform the MHRA's regulation of AI as a Medical Device (AIaMD) to

⁵ Kraljevic Z *et al.* (2024) Foresight—a generative pretrained transformer for modelling of patient timelines using electronic health records: a retrospective modelling study *The Lancet Digital Health* 6: e281 -90.

⁶ Computer Weekly (15 March 2024) [NHS to extend use of AI to cut waiting times and missed appointments](#) and NHS Confederation (20 September 2024) [AI in healthcare: navigating the noise](#).

⁷ GOV.UK (2024) [A pro-innovation approach to AI regulation: government response](#).

ensure patient safety whilst avoiding undue obstacles to innovation.⁸ As well as ethical and regulatory issues, there are also concerns about preparedness for advanced technologies. Attention has been drawn to the varied and often poor digital infrastructure within the NHS and a lack of adoption pathways to utilise AI technology within existing services.⁹

[Read our briefing note on AI in healthcare and research.](#)

Timeframe: 5-10 years

Evidence:

- **Political:** Although there is interest in the role of innovation and tech adoption in improving NHS productivity, it seems like the government is focussed on digitisation and remote monitoring etc. in the near future.
- **Regulatory:** MHRA AI regulatory sandbox for evaluation of AIaMD. MHRA's response to pro-innovation AI reg white paper published in 2024 – states regulatory reform e.g. increase in workforce working on AI (from ~3 to 7.5 FTEs) [MHRA Impact-of-AI-on-the-regulation-of-medical-products.pdf \(publishing.service.gov.uk\)](#)
- **Public:** Public engagement has been conducted recently - 2024 survey - [AI in health care: what do the public and NHS staff think? - The Health Foundation](#). Public and NHS staff overall support AI in healthcare, although a significant minority is not supportive. Concerns around trust and AI limiting real interactions with HCPs.
- **Expert:** Insights and expertise from the Ada Lovelace team suggest 5-10 year timeframe.
- Darzi report highlights concerns around the readiness of the NHS' current digital/IT infrastructure to adopt AI, especially outside of individual advanced hospital/research settings. Health Foundation (June 2024): 'a strategy is needed to ensure the benefits of AI can be realised at scale across the NHS, rather than just a few pockets of excellence.' [Priorities for an AI in health care strategy - The Health Foundation](#)

4. AI in drug discovery

The discovery of new medicines can be a costly and uncertain process. It is estimated that the cost of bringing a new drug to market is approximately \$2.5 billion and that the probability of a phase 1 trial candidate successfully gaining regulatory approval is 9-14%.¹⁰

Considering this, the application of AI techniques has gained significant interest from researchers, pharmaceutical companies and regulatory bodies, as an opportunity to streamline drug discovery. Research in this area is exploring how AI can be applied to identify new drug targets, optimise the design of small molecules and vaccines, and to evaluate the safety and toxicity of potential new drug candidates. In silico, or virtual, clinical trials allow researchers to test medical devices and novel therapeutics on virtual populations,

⁸ GOV.UK (2024) [AI Airlock: the regulatory sandbox for AIaMD](#).

⁹ The Health Foundation (2024) [Priorities for an AI in health care strategy](#).

¹⁰ Wellcome (2023) [Unlocking the potential of AI in Drug Discovery](#).

generating scientific evidence of performance and safety at a lower cost.¹¹ In silico trials also offer an opportunity to reduce the use of animals in research.¹²

Over the past decade, the number of AI-derived molecules in clinical trials has grown rapidly. Data suggests that their development time, costs and success rate in phase 1 trials are significantly better than industry averages, although clinical impact remains uncertain.¹³ Challenges and ethical considerations in the adoption of AI in drug-discovery relate to trust, intellectual property and ownership, diversity of datasets, and equitable access for researchers in low- and middle-income settings and for less commercially profitable use cases.¹⁴

Timeframe: 5-10 years

Evidence:

- **Funding:** There has been some funding in this space [New £100 million fund to capitalise on AI's game-changing potential in life sciences and healthcare - GOV.UK](#)
- **Commercial:** Substantial commercial drivers as drug development is so costly and these costs have remained stagnant for some time. There is interest from pharmaceutical companies and biotech companies in revolutionary techniques in this area. [Drug discovery \(2024\) \(sifted.eu\)](#)
- AI designed drugs have begun to enter clinical trial pipelines: [Inside the nascent industry of AI-designed drugs | Nature Medicine](#)
- UK company GoogleDeepMind Isomorphic labs spin off has received attention, especially following DeepMind's Nobel Prize win. [DeepMind spin-off aims to halve drug discovery times following Big Pharma deals \(ft.com\)](#).
- **Expert:** Insights and expertise from Ada Lovelace team suggest 5 to 10-year timeframe.
- Report by Wellcome published in 2023: [Unlocking the potential of AI in drug discovery | Reports | Wellcome](#)

5. Air and plastic pollution

Air pollutants can be emitted directly from a source or formed in the atmosphere through chemical reactions. Poor air quality causes damage to human health and ecosystems. In the UK, air pollution represents the biggest environmental threat to health. It is distributed unequally, exacerbating existing inequalities.¹⁵ Children, the elderly and those with pre-existing conditions are most vulnerable to its effects. Evidence illustrates people of colour face higher levels of air pollution than white people in Britain and are more susceptible to the

¹¹ Sarrami-Foroushani A *et al.* (2021) In-silico trial of intracranial flow diverters replicates and expands insights from conventional clinical trials *Nat Commun* **12**.

¹² European Medicines Agency (2020) [EMA Regulatory Science to 2025](#).

¹³ Wellcome (2023) [Unlocking the potential of AI in Drug Discovery](#) and Jayatunga MKP *et al.* (2024) How successful are AI-discovered drugs in clinical trials? A first analysis and emerging lessons [Drug Discovery Today](#) **29(6)**.

¹⁴ The Pharmaceutical Journal (03 July 2024) [How AI is transforming drug discovery](#).

¹⁵ GOV.UK (28 February 2022) [Air pollution: Applying All Our Health](#).

poor health outcomes caused by pollution.¹⁶ This population is also more likely to lack access to green spaces.¹⁷

Plastic waste contains many toxic substances, such as flame retardants, plasticisers and stabilisers.¹⁸ When burned or incinerated this waste can harm people's health by creating respiratory illness and increase the risk of heart disease.¹⁹

Timeframe: <5 years

Evidence:

- **Political:** The Environment Act 2021 established legally binding targets for air quality, waste, water, and biodiversity. It mandates the UK government to set long-term targets for fine particulate matter (PM2.5), one of the most harmful air pollutants. The government is required to develop national targets for PM2.5 concentrations by October 2024. [Environment Act 2021 \(legislation.gov.uk\)](#). And the Extended Producer Responsibility (EPR) for packaging: [EPR Consultation Government response template \(publishing.service.gov.uk\)](#) – implemented in 2024, moves the full cost of dealing with packaging waste from households away from local taxpayers and councils to the packaging producers.
- **Regulatory:** The Ultra Low Emission Zone (ULEZ) in London, expanded in 2023: [The Ultra Low Emission Zone \(ULEZ\) for London | London City Hall](#)
- **Commercial:** The UK's Plastic Pact is a voluntary agreement between government, industry and NGOs which aims to remove single-use plastics and reduce plastic waste: [A Roadmap to 2025: The UK Plastics Pact | WRAP](#)

6. Animal research

Many argue that the use of animals, such as genetically modified mice, is essential for research that benefits human health.²⁰ Nonetheless, major funding bodies are supporting moves to enforce the principles of replacement, refinement and reduction (the 3Rs).²¹

Research about animals has also grown recently, with many studies focusing on animals' minds and consciousness, which may add to our understanding of animal sentience. The UK's Animal Sentience Committee, established in 2023, advises the government in relation to matters relating to animal welfare, and specifically sentience.

¹⁶ Logika Noise Air Quality Consultants (2021) [Air Pollution and Inequalities in London: 2019 Update](#) and Brainard J *et al.* (2002) Modelling Environmental Equity: Access to Air Quality in Birmingham, England *Environment and Planning A* **34(4)**: 695-716.

¹⁷ CABE Space (2010) [Urban green nation: Building the evidence base](#).

¹⁸ Hahladakis J *et al.* (2018) An overview of chemical additives present in plastics: Migration, release, fate and environmental impact during their use, disposal and recycling *Journal of Hazardous Materials* **344**: 179-99 and Tearfund (2020) [The Burning Question](#).

¹⁹ Greenpeace UK (2021) [Trashed: How the UK is still dumping plastic waste on the rest of the world](#).

²⁰ Bruter AV *et al.* (2024) Genetically modified mice as a tool for the study of human diseases *Mol Biol Rep* **51**: 135.

²¹ Understanding Animal Research (n.d.) [The 3Rs](#).

Timeframe: <5 years

Evidence:

- **Political:** The government announced a plan to double funding of the 3Rs through UKRI, increasing the budget to £20 million for the financial year 2024-25. Funding aims to speed up the development and adoption of new technologies e.g. AI, in an attempt to reduce the need for animal models in scientific research: [UKRI policy for research and innovation involving animals – UKRI](#)
- The UK government announced that it will phase out the use of the forced swim test, a controversial method using animals to aid research for depression and anxiety in humans: [UK Government Announces Plan To End The Forced Swim Test - Animal Free Research UK](#)
- **Public:** The Animal Kindness Index is an annual UK-wide investigation into people's attitudes towards animals, there is a section that explores views on animal sentience - [Kindness Index Report 2024 - RSPCA - rspca.org.uk](#)
- **Expert:** Calls for the UK not to fall behind other countries in terms of animal welfare - [On animal welfare, the UK should lead not fall behind | British Politics and Policy at LSE](#)

7. Antimicrobial resistance

The emergence and spread of drug-resistant pathogens (bacteria, viruses, fungi, and parasites) threatens our ability to treat common infections. By 2050, it is estimated that deaths associated with antimicrobial resistance (AMR) will increase by 74.5% to 8.22 million people each year.²²

Drivers of AMR cited by the WHO include the misuse and overuse of antimicrobials, poor infection control and prevention in health-care facilities and farms, lack of awareness and knowledge, and lack of enforcement of legislation.²³ More recent attention has been focused on the interaction between AMR and climate change. Higher temperatures, extreme weather events and water shortages all create environments which enable bacteria to thrive and therefore increase the risk of antimicrobial resistant strains developing. A 2023 report by the UN Environment Programme emphasises the importance of considering the environmental dimensions of AMR, and of contextualising current AMR challenges within the 'triple planetary crisis' of climate change, biodiversity loss and pollution and waste.²⁴ Similarly, the WHO and others across the sector have also called for a One Health approach to AMR, in which the health of humans, animals and the broader environment are understood to be closely interlinked.²⁵

²² Naghavi M *et al.* (2024) Global burden of bacterial antimicrobial resistance 1990–2021: a systematic analysis with forecasts to 2050 *The Lancet* **404(10459)**: 1199-226.

²³ World Health Organization (21 November 2023) [Antimicrobial resistance](#).

²⁴ UN Environment Programme (2023) [Bracing for Superbugs: Strengthening environmental action in the One Health response to antimicrobial resistance](#).

²⁵ World Health Organization, Food and Agriculture Organization of the United Nations, United Nations Environment Programme and World Organisation for Animal Health (2023) [A one health](#)

In 2024, 'Confronting antimicrobial resistance 2024 to 2029' was published, the second in a series of 5-year national action plans to ensure progress towards the UK's goal of ensuring AMR is "contained, controlled and mitigated" globally by 2040.²⁶ The report highlights 4 key themes to address AMR: reducing unnecessary exposure to antimicrobials, optimising use of antimicrobials, innovation and access and international collaboration across human, animal and environmental health. It is hoped that the launch of a fixed-fee subscription agreement for antibiotics will reduce the incentive for overuse and encourage pharmaceutical companies to invest in next-generation antimicrobials.²⁷ Recent research to develop new antimicrobials has applied AI to mine existing databases and generate new potential molecular candidates.²⁸

AMR is receiving considerable international political attention in 2024 with the World Health Assembly and UN General Assembly both convening high-level meetings on the topic.²⁹ Solutions and research efforts have historically been focussed on high-income countries, despite 4.3 million of the estimated 5 million deaths associated with AMR occurring in low- and middle-income countries.³⁰

Timeframe: <5 years

Evidence:

- **Political:** The UK has a 20-year plan for tackling AMR by 2040 and the new 5-year national action plan was published for 2024 – 2029 in May 2024: [What is UKHSA doing about antibiotic resistance? – UK Health Security Agency](#)
- UN General Assembly meeting on AMR (26/09/24) – statement from Foreign Secretary, David Lammy, highlight's new government's aim to work with the Global South to improve access to antimicrobials and to support collaborative research into AMR. <https://www.gov.uk/government/speeches/the-uk-is-working-with-partners-around-the-world-to-prevent-global-health-threats-like-amr-uk-statement-at-the-un-general-assembly>
- First in world to pilot fixed annual fee for antimicrobials [NHS England » Antimicrobial Products Subscription Model: guidance on commercial arrangements](#)
- **Regulatory:** UKHSA strategic 3-yr plan (2023-26) includes reducing the impact of infectious diseases and AMR.

[priority research agenda for antimicrobial resistance](#) and Arnold KE *et al.* (2024) The need for One Health systems-thinking approaches to understand multiscale dissemination of antimicrobial resistance *The Lancet Planetary Health* **8(2)**: e124-33.

²⁶ Department of Health and Social Care (2024) [Confronting antimicrobial resistance 2024 to 2029](#)

²⁷ Financial Times (12 August 2024) [NHS launches 'subscription' scheme for antibiotics with pharma sector](#)

²⁸ Wan F *et al.* (2024) Deep-learning-enabled antibiotic discovery through molecular de-extinction *Nat. Biomed. Eng* **8**: 854–71; The Scientist (27 June 2024) [Harnessing the Power of AI to Design Novel Antibiotics](#) and Torres MDT *et al.* (2024) Mining human microbiomes reveals an untapped source of peptide antibiotics *Cell* **187(19)**: 5453-67.

²⁹ Wellcome (2024) [Driving action on antimicrobial resistance \(AMR\) in 2024](#)

³⁰ Naghavi M *et al.* (2024) Global burden of bacterial antimicrobial resistance 1990–2021: a systematic analysis with forecasts to 2050 *The Lancet* **404(10459)**: 1199-226.

- **Funding:** New funding for Global Antibiotic Research and Development Partnership - £7 million for 2024-27 [UK Government commits new funding for antibiotic development \(gardp.org\)](#).
- **Expert:** Wellcome report highlights 2024 as a key year to tackle AMR internationally [Wellcome Driving action on AMR 2024](#).

8. **Assisted dying**

In the UK, assisting or encouraging another person to end their life is a criminal offence. Attempts to change the law to align with some European countries, Canada and states in the USA have met with resistance. However, the Royal College of Physicians and the British Medical Association have now adopted a neutral stance on assisted dying, having previously opposed it.³¹

In UK Parliament, two Private Members' Bills for assisted dying for terminally ill adults have been introduced in the House of Lords and the House of Commons.³² A Member's bill has also been introduced to the Scottish Parliament.³³ Proposals to change the law are due to be debated by parliament this year.³⁴

Assisted dying is a highly complex and ethically charged issue. Tensions arise around autonomy and capacity, professional ethics, accessibility and standard of palliative and end-of-life care, and the moral implications for wider society.

[Read more about our project to explore public views on assisted dying in England.](#)

Timeframe: <5 years

Evidence:

- **Political:** Assisted Dying for Terminally Ill Adults Bill introduced in House of Lords (UK) and Scottish Parliament, private members bill from MP Kim Leadbeater – free vote for MPs forthcoming [MPs to get historic vote on England and Wales assisted dying bill | Assisted dying | The Guardian](#)
- Liam McArthur MSP introduced a [Member's Bill into the Scottish parliament](#). It will allow terminally ill adults in Scotland, who are eligible, to lawfully request, and be provided with, assistance by health professionals to end their own life. This is awaiting its second reading.
- Keir Starmer has stated that he is committed to giving MPs a free vote on assisted dying laws at some point over his term (he and Wes Streeting both supported changes to the law when voting as MPs 9 years ago). [Starmer sticks by promise of assisted dying free vote - BBC News](#)

³¹ Royal College of Physicians (2019) [The RCP clarifies its position on assisted dying | RCP London](#) and British Medical Association (2021) [Physician assisted dying](#).

³² [Assisted Dying for Terminally Ill Adults HL Bill \(2024-25\) 7](#) and [The Terminally Ill Adults \(End of Life\) HC Bill \(2024-25\)](#).

³³ [Assisted Dying for Terminally Ill Adults \(Scotland\) SP Bill \(2024\) 46](#).

³⁴ Politico (4 October 2024) [British parliament to get historic vote on assisted dying](#).

- **Public:** Recent public engagement in the form of our citizen's jury shows interest in exploring AD in certain circumstances. Interim AD report received significant media coverage and interest.
- **Expert:** BMA, RCN, RCS, RCP, RCPsych, RPS all hold neutral positions on AD. [A new parliament - what it means for assisted dying - My Death, My Decision \(mydeath-mydecision.org.uk\)](#)

9. Cryopreservation

a. **Egg, sperm and embryo freezing**

Reproductive cells can be frozen to potentially preserve and extend fertility in combination with fertility treatments such as IVF.

In 2022, the law changed to allow eggs, sperm and embryos to be frozen for up to 55 years in the UK.³⁵ The storage of frozen embryos requires consent from both people who provided the egg and sperm; if one withdraws their consent, it can no longer be stored or used in fertility treatment.

Unlike sperm and embryos, the rate of live births with frozen eggs is relatively low, especially when eggs are harvested at an older age. This raises questions about informed consent as some users may not be fully aware of statistics surrounding eventual live birth rate.³⁶ The results of a 15-year study at a single UK centre found an overall live birth rate per embryo transfer of 26% which varied according to the age the eggs were frozen. There was a lower rate in those over-35 but only 5% in over-40s.³⁷ If egg freezing success rates improve, it might enable more people to become parents at an older age. This may have implications for parent and children's health and for the social and cultural meanings of motherhood, parenthood and ageing.³⁸

The emergence of private sector companies offering egg freezing raises issues around the clarity of marketing claims, as well as the cost and accessibility of this treatment.³⁹

Other issues include posthumous sperm retrieval, a process whereby spermatozoa are extracted from a dead man and used to create an embryo. Policies regulating this procedure vary across jurisdictions, in the UK, there are strict stipulations – the current Human Fertilisation and Embryology Act 1990 (as amended 2008) states there must be express written consent from the man prior to his death.

[See our work on egg freezing.](#)

³⁵ HFEA (n.d.) [Egg freezing](#).

³⁶ Cascante SD *et al.* (2022) Fifteen years of autologous oocyte thaw outcomes from a large university-based fertility center *Fertility and Sterility* **118(1)**: 158-66 and BBC News (13 March 2024) [Egg freezing patients 'misled' by clinics - BBC News](#).

³⁷ Garratt J *et al.* (2024) Clinical outcomes of vitrified-warmed autologous oocyte cycles with 15-year follow-up at a single UK centre: consistent and predictable results *Reproductive biomedicine online*.

³⁸ NCOB (2020) [Egg freezing in the UK](#).

³⁹ *Ibid.*

b. Ovarian tissue preservation

Ovarian tissue can be excised through laparoscopy, then transplanted later. Although originally developed as a method of fertility preservation for cancer patients, it has more recently been touted as a potential method for ‘treating’ menopause. This is an expensive intervention, there is a lack of research into its efficacy and safety, and there is no evidence that it is more effective than other, less invasive, alternatives such as hormone replacement therapy (HRT).

c. Cryopreservation of organs (transplantation)

Further to b), some commercial companies are offering ovarian tissue cryopreservation and transplantation (OTCT) as an elective procedure to delay menopause,⁴⁰ aiming to postpone symptoms and potentially extend fertility.⁴¹ As with b) there is a lack of research about the efficacy of this for delaying menopause specifically.

Timeframe: >10years

Evidence:

- **Political:** In 2021, the limit for egg freezing storage limits was extended from 10 to 55 years, after a sector-wide and public campaign: [Gamete \(egg, sperm\) and embryo storage limits: response to consultation - GOV.UK](#)
- **Regulatory:** We have two active regulators in this space HFEA and HTA who have not reported any recent concern.
- **Expert:** The [academic community](#) appears to be focused on exploring whole organ / body applications or cryopreservation and the legal rights for people who have passed, but their tissue is still stored.
- **Public:** Recent reporting on egg freezing includes critique of lack of awareness of realistic success rates: [I feel for women misled over egg-freezing. If I'd believed doctors during my transition, my kids wouldn't be here | Freddy McConnell | The Guardian](#); [‘A lottery ticket, not a guarantee’: fertility experts on the rise of egg freezing | IVF | The Guardian](#)
- Other forms of cryopreservation have been reported on in mainstream media for some time and the tone of their write-ups suggest a degree of public acceptance that this is a procedure some people may opt for / try.

10. In-vitro derived gametes (IVGs)

Mouse sperm and egg cells have been created in the lab from other cells in the mouse's body, resulting in fertile offspring. If developed in humans, this method of creating sperm and egg cells (aka ‘gametes’) in vitro could create an opportunity for infertile couples or individuals, same-sex and single parents and older women to have children who are

⁴⁰ Profam (n.d.) [Welcome to ProFaM](#).

⁴¹ Anderson RA *et al.* (2021) Ovarian tissue cryopreservation: Clinical practice and considerations. *Human Reproduction Open* **2017(1)** and Donnez J and Dolmans MM (2017) Fertility Preservation in Women *New England Journal of Medicine* **377(17)**: 1657-65.

genetically related to them. It could also potentially increase the supply of gametes for research.⁴²

If sperm and egg cells could be created from any other cell in the body, this might lead to a risk of unwitting parenthood, where a child is conceived without a parent's knowledge or consent raising questions about the status and significance of genetic relatedness and parenthood.⁴³

Currently, the success rate in mice and other mammals is low. Whether an IVG that looks like a 'real' gamete, functions like one still needs exploring.

We are also currently working with the [Future of Human Reproduction](#) Project on a briefing note exploring the ethical and legal questions that arise from possible future uses of *in-vitro* derived gametes.

Timeframe: 5-10 years

Evidence:

- **Political:** There is no recent political interest in this, however, insights from our stakeholders indicate that the field is moving at pace and could soon leave researchers and funders requiring bespoke ethical guidance.
- **Commercial:** It has received commercial interest.⁴⁴
- **Expert:** There is significant research taking place in this area.⁴⁵

11. Current state of the NHS

Since the COVID-19 pandemic, the NHS has faced a significant backlog of care. Over 6.3 million patients are waiting for treatment in England alone and the median wait time of 14 weeks is almost double pre-pandemic figures.⁴⁶ The NHS has identified priorities for the whole service to improve patients' outcomes and experience. For 2024-2025, these include reducing wait times for elective care, improving emergency service responsiveness and making community, primary and mental health care more accessible.⁴⁷ There is also an overarching focus on reducing inequalities across all services.

a. Healthcare post-Brexit

A recent report on 'The future for health after Brexit' by the Nuffield Trust highlights changes to the NHS Workforce and recruitment, disruptions to medicine supply chains, challenges to life sciences research and slower regulatory approval of drugs and medical devices.⁴⁸

⁴² NCOB (2015) [Background Paper Artificial Gametes](#).

⁴³ *Ibid.*

⁴⁴ NPR (12 July 2023) [Biomedical startups are racing to revolutionize the way humans reproduce](#) and Ivy Natal (2024) [Next-Gen Fertility](#).

⁴⁵ Adashi EY *et al.* (2024) Ethical and legal challenges in assisted same-sex conception through in vitro gametogenesis *Nat Med* **30(2)**: 322–3; Murase Y *et al.* (2024) In vitro reconstitution of epigenetic reprogramming in the human germ line *Nature* **631**: 170-8 and Silber S *et al.* (2024) In Vitro Maturation, In Vitro Oogenesis, and Ovarian Longevity *Reproductive sciences* **31(5)**: 1234–45.

⁴⁶ BMA (12 September 2024) [NHS backlog data analysis](#).

⁴⁷ NHS England (2024) [2024/25 priorities and operational planning guidance](#).

⁴⁸ Nuffield Trust (2024) [The future for health after Brexit](#).

However, disentangling the effects of Brexit from other disruptions such as the COVID-19 pandemic, national strikes and the long-term impacts of austerity on population health, remains challenging.

Since the UK's exit from the EU, there has been a shift in the demographic of health and social care workers and an increasing reliance on recruitment from countries outside of the EU and European Economic Area to fill staff shortages.⁴⁹ Attention has been drawn to 'red list' recruitment from countries recognized as facing the most severe shortages in their healthcare services.⁵⁰ Despite active recruitment from this list being banned in the UK's code of practice for health and social care recruitment, NHS staff from red list countries rose by approximately 60% in England between 2019 and 2022. Data from Health and Care Worker (H&CW) visas also shows that four of the five top nationalities for care workers are countries on the red list (Nigeria, Zimbabwe, Ghana and Bangladesh).⁵¹ Nuffield Trust's 2024 report on *The future for health after Brexit* raises concerns that the NHS is becoming increasingly reliant on international recruitment, including from red list countries, rather than focusing on long-term workforce planning and domestic retention.⁵²

b. Drug shortages

In 2023, the NHS faced a record number of medicine supply chain challenges with over 100 products facing problems, including critical medicines for ADHD and epilepsy, hormone replacement therapies and antibiotics.⁵³ Reasons for supply problems include manufacturing issues, delays in regulatory approval and geopolitical factors such as Brexit, the conflict in Ukraine and the Covid-19 pandemic.⁵⁴

High-profile drugs such as Ozempic, a treatment for type 2 diabetes that received widespread media attention for its weight loss properties, have also highlighted how public awareness and media interest in certain conditions or medications can cause a rapid rise in demand which can result in shortages.⁵⁵

Serious Shortage Protocol (SSP) legislation was introduced in 2019 to mitigate the impacts of medicine shortages. If the Department of Health and Social Care decides that there is a serious shortage of a particular drug or medical device, they may issue a SSP which allows pharmacists to dispense a reduced quantity, a therapeutic/generic equivalent or an alternative dosage form. However, SSPs have faced criticism for being inflexible and bureaucratic.⁵⁶

⁴⁹ *Ibid.* and Royal College of Nursing (2022) [Nursing under unsustainable pressures: staffing for safe and effective care in the UK](#).

⁵⁰ The Guardian (14 August 2023) ['There won't be enough people left': Africa struggles to stop brain drain of doctors and nurses](#).

⁵¹ Migration Advisory Committee (2023) [Migration Advisory Committee \(MAC\) annual report, 2023](#).

⁵² Nuffield Trust (2024) [The future for health after Brexit](#).

⁵³ Wise J (2023) Record number of drugs hit by supply problems, trade body warns *BMJ* **383**: 2602.

⁵⁴ House of Commons (2024) [Medicines shortages](#).

⁵⁵ The Conversation (10 July 2023) [Ozempic shortages in the UK may last until 2024 – here's why](#).

⁵⁶ The Pharmaceutical Journal (9 March 2023) [Complex and inflexible: the shortcomings of serious shortage protocols](#).

Several organisations representing patients and pharmacists - Epilepsy Society, Parkinson's UK,⁵⁷ Community Pharmacy England,⁵⁸ Royal Pharmaceutical Society,⁵⁹ - have called on the government to reform the management of drug supply and provide a more pragmatic approach to allow pharmacists the flexibility to amend prescriptions and offer substitutions when a medicine is in short supply.

Timeframe: <5 years

Evidence:

- **Political:** The NHS is one of the UK Government's 5 key missions. Building an 'NHS fit for the future' is a priority for the new Labour government.
- Lord Darzi rapid independent investigation highlights need for reform and improvement.
- Darzi report / Labour 10-year plan - focus on shifting resources to primary care and community services – i.e. community pharmacy.
- Labour manifesto – create a community pharmacist prescribing service to grant more pharmacists independent prescribing rights [State of pharmacy: what's in store for the profession under Labour? - The Pharmaceutical Journal \(pharmaceutical-journal.com\)](#)
- NHS Long Term Workforce Plan – acknowledgement of shortages and failure for staff training and education pipeline to keep up with demand for NHS services.
- Number of SSPs issued has increased over the last two years with no sign of slowing. [Medicine shortages forced emergency rubber-stamp on 50 drugs in two years \(inews.co.uk\)](#)
- **Expert:** Recent polling shows the majority of NHS staff think that staff shortages are impacting patient care: [Most NHS staff say staff shortages and burnout are impacting patient care | YouGov](#)
- Royal College of Nursing has drawn attention to staff shortages across the devolved nations e.g. [Critical nursing shortages leave patients unsafe | Royal College of Nursing | Royal College of Nursing](#)
- **Public:** Public engagement and polling shows public dissatisfaction with the NHS and concern about limited funding. [Public attitudes to the NHS and social care | National Centre for Social Research](#)

12. Digital Twins

Digital twins (DTs) are computational models of a physical object or system, used to model the effect of different conditions and inform decision-making.⁶⁰ The use of DTs is being explored across healthcare. They can be used on a systems level to simulate wards,

⁵⁷ Epilepsy Society (24 April 2024) [Charities call on Health Secretary to carry out urgent review of medicines supply chain.](#)

⁵⁸ Community Pharmacy England (2023) [Briefing: Community Pharmacies and Medicines Supply.](#)

⁵⁹ Royal Pharmaceutical Society (n.d.) [Medicines Shortage Policy.](#)

⁶⁰ The Alan Turing Institute blog (21 March 2023) [What are digital twins and why do we need them?.](#)

hospitals and even whole cities to improve efficiency by predicting demand and optimising resource allocation.⁶¹

On an individual scale, DTs can be used to model individual's organs or conditions enabling personalised predictions about disease progression and treatment outcomes. Future possibilities include DTs generated at birth to act as life-long health companions, enabling early diagnosis and influencing individuals' lifestyle choices.⁶² The concept of psychological DTs has also sparked interest as a way to predict the preferences of individuals who are medically incapacitated, for example in a coma, to assist in difficult decisions around treatment and life support that are typically left to an individual's family.⁶³

Alongside advances in AI and data-collection technologies, such as wearables, DTs have potential benefits in disease prevention, reducing healthcare costs, enabling patient autonomy and more equal treatment. At the same time, DTs present ethical risks in relation to privacy and data ownership, access and inequalities. For example, DTs may leave patients feeling guilty and powerless if they lack the resources or knowledge to act upon the information and advice provided.⁶⁴ DTs have implications for our understandings of health - overly individualising health risks overlooking social and environmental determinants. They also raise questions around the role and responsibility of clinicians, and the value we place on patients' experiential knowledge.⁶⁵

Timeframe: 5-10 years

Evidence:

- **Political:** No specific mentions of DTs in a healthcare context by the government, however, DTs align with government missions around digitisation of the NHS, prevention and personalised medicine.
- **Funding:** [Digital Twin centre](#) opening autumn 2024 in Belfast but initial use cases are focussed on maritime, aerospace and defence sectors. Similarly, the National Digital Twin Programme is focussed on modelling the national infrastructure / policy interventions etc. rather than healthcare applications. [National Digital Twin Programme - Digital Twin Hub](#)
- **Commercial / Translation:** In silico trials is where there is most current interest, but the purposes of this list, this is covered more in AI in drug discovery.
- There have been individual trials of digital twins in healthcare settings – e.g. digital twin heart models trialled at Imperial and trialling of ward digital twins in Scottish NHS trusts – but these are still in the early stages / one-offs. [Glasgow-based Simul8 Helps NHS Cut](#)

⁶¹ Katsoulakis E *et al.* Digital twins for health: a scoping review *npj Digit. Med.* **7**.

⁶² The Royal Society (2023) [Machine learning and AI in biological science, drug discovery and medicine - conference report](#).

⁶³ Earp BD *et al.* (2024) A Personalized Patient Preference Predictor for Substituted Judgments in Healthcare: Technically Feasible and Ethically Desirable *The American Journal of Bioethics* **24(7)**: 13-26.

⁶⁴ Huang PH *et al.* (2022) Ethical Issues of Digital Twins for Personalized Health Care Service: Preliminary Mapping Study *J Med Internet Res* **24(1)**.

⁶⁵ Popa EO *et al.* (2021) The use of digital twins in healthcare: socio-ethical benefits and socio-ethical risks *Life Sci Soc Policy* **17**.

[Waiting Times With Digital Twin Tech | Glasgow City Of Science & Innovation \(glasgowcityofscienceandinnovation.com\)](#), [‘Digital twin’ heart modelling project will monitor patients virtually | Imperial News | Imperial College London](#)

13. Diversity in clinical research

Diversity in clinical research enables researchers to better understand the effectiveness of medicines, devices and care across different groups. If clinical trials do not have diverse samples, both patients and research can suffer, as results may not be generalisable, innovation stifled and equitable access to healthcare restricted.⁶⁶

Historically, the female body and the impacts of pregnancy, birthing, breastfeeding and menopause have been understudied, both in biomedical research, where male cells and animal models are more likely to be used,⁶⁷ and in clinical trials.⁶⁸ This has implications for the effectiveness and safety of developed drugs, treatments and diagnostics for people with female physiology.⁶⁹

Attention has also been drawn to other groups underserved by health research, for example ethnic minority groups, LBGTQ+ people, socio-economically disadvantaged people and disabled people, and how this may contribute to health inequalities.⁷⁰ UK legislation does not currently require representative inclusion in biomedical and clinical research, with expectations currently set by individual Research Ethics Committees.⁷¹

Proposals to update clinical trial legislation have highlighted a need for clearer guidance on patient and public involvement and the inclusion of underserved populations in clinical research.⁷² Some research funders, such as Wellcome, have already made diverse and representative participants a requirement of funding, and cross-sector initiatives such as the MESSAGE (Medical Science Sex and Gender Equity) project are developing policy frameworks to ensure inclusive research design.⁷³

a. Clinical research in pregnant people

Pregnant and lactating people are often excluded from clinical trials in the interests of preventing harm to them and their fetuses, they may also be reluctant to participate in trials

⁶⁶ MedCity, Faculty of Pharmaceutical Medicine and Imperial College Healthcare NHS Trust (2023) [Advancing Clinical Trials - Making the UK a global leader in inclusive and diverse clinical trials.](#)

⁶⁷ Kim JY *et al.* (2021) Sex omission and male bias are still widespread in cell experiments *Am J Physiol Cell Physiol* **320**: C742–9 and Karp NA and Reavey N (2019) Sex bias in preclinical research and an exploration of how to change the status quo *British Journal of Pharmacology* **176**: 4107-18.

⁶⁸ Schmucker DL and Vesell ES (1993) Underrepresentation of women in clinical drug trials *Clin Pharmacol Ther* **54**(1): 11-5.

⁶⁹ The Financial Times (2 August 2024) [How medical research is failing women.](#)

⁷⁰ National Institute for Health and Care Research (7 August 2020) [Improving inclusion of underserved groups in clinical research: Guidance from INCLUDE project.](#)

⁷¹ Medicines & Healthcare products Regulatory Agency (21 March 2023) [Consultation outcome Proposals for legislative changes for clinical trials.](#)

⁷² Medicines & Healthcare products Regulatory Agency (2023) [Government response: Consultation on legislative proposals for clinical trials.](#)

⁷³ Medical Science Sex and Gender Equity (2024) [About Us.](#)

because of concerns about this.⁷⁴ Yet, their exclusion can inhibit research that may directly benefit them and undermines their ability to participate. People still need access to medical treatments while pregnant, and there is a need to understand which drugs and vaccines are safe and effective, and what dosage is appropriate given the physiological changes pregnancy brings about.⁷⁵

A 2023 report by the Academy of Medical Sciences highlights a lack of research and new therapies for pregnancy-specific conditions and calls for greater investment and a more supportive regulatory requirement for pregnancy research.⁷⁶

Machine learning is being explored as a non-invasive complement to traditional clinical trials, allowing researchers to model and predict how existing medicines and pre-clinical compounds may impact a pregnant person and fetus.⁷⁷

Timeframe: <5 years

Evidence:

- **Political:** 2023 consultation on proposals to update UK legislation around clinical trials (Medicines and Medical Devices Act 2021 provides the powers to amend/supplement law in this area). Government response: no new legislation, however, explicit guidance to be produced on PPI in clinical trial design and diversity in clinical trial populations [Clinical Trials Final government response to consultation.pdf \(publishing.service.gov.uk\)](#)
- No other political interest more recently, slightly older strategy's such as the Women's Health Strategy (2022) and The Future of UK Clinical Research Delivery (2021) highlight research into women's health issues and inclusion of underserved groups.
- **Funding:** Significant interest from major UK funders, medical research charities and regulators. Inclusion requirements are increasingly being implemented by funders. E.g. MESSAGE project (launched in Jan 2023) is supported by AMS, MRC, HRA, MHRA, NICE, Wellcome. [In 2024, momentum is building for improved integration of sex and gender in medical research | MESSAGE \(messageproject.co.uk\)](#)
- **Public:** In news and media, recent articles have highlighted the association between the gender health gap and poor representation in trials. [How medical research is failing women \(ft.com\)](#)
- **Expert:** Academy of Medical Sciences report on understanding pregnancy.
- MBACE 2023 report highlights need for pregnant and breastfeeding women (language used by report) to be included in vaccine / drug research.

14. Early developmental research

⁷⁴ Jacobson MH *et al.* (2024) Understanding willingness and barriers to participate in clinical trials during pregnancy and lactation: findings from a US study *BMC Pregnancy Childbirth* **24**: 1-14.

⁷⁵ Zur RL (2023) Protected from harm, harmed by protection: ethical consequences of the exclusion of pregnant participants from clinical trials *Research Ethics* **19(4)**: 536-45.

⁷⁶ Academy of Medical Sciences (2023) [Understanding pregnancy: Accelerating the development of new therapies for pregnancy-specific conditions.](#)

⁷⁷ Evangelista JE *et al.* (2023) Toxicology knowledge graph for structural birth defects *Commun Med* **3**: 1-14.

a. Embryo research

Embryo research raises questions around the moral status of the embryo. In the UK and many other countries, the law stipulates that embryos used in research must be destroyed after 14 days. This is the point at which the primitive streak usually forms, which was taken to signify individuation based on knowledge at the time the rule was proposed. This ‘14-day rule’ was decided upon by the Warnock Committee in the Warnock Report (Report of the Committee of Inquiry into Human Fertilisation and Embryology) 1984,⁷⁸ which laid the groundwork for the Human Fertilisation and Embryology Act 1990. The report explored and addressed ethical and legal issues focused on reproductive technologies and embryo research.

In the UK, there is increasing literature highlighting how further significant advances to help both basic understanding and provide potential clinical benefit could be made by extending the 14-day rule.⁷⁹ In 2023, the results of a public dialogue run by the Human Developmental Biology Initiative and UKRI Sciencewise were published, exploring public views on the regulation of research involving human embryos.⁸⁰ The results suggested that the majority of the public engaged showed support towards an extension or modification of the current 14-day limit.⁸¹ The existing legislation that governs embryo research in the UK is currently under review.⁸²

b. Stem cell-based embryo models

When cultured under appropriate supporting conditions *in vitro*, pluripotent stem cells have been shown to assemble into organised, three-dimensional structures that model the characteristics of human embryos at an early stage of development. These structures are widely defined as stem cell-based embryo models (SCBEMs).

Potential applications for SCBEMs include research to improve fertility treatment, non-hormonal contraception, prevention of diseases that stem from exposure to alcohol, medication or epigenetic factors in early development and the creation of organoids for research or even transplantation. SCBEMs may permit some types of research that cannot be carried out on normal embryos, such as screens for relevant genes and factors, or for embryo-toxic substances.

The International Society for Stem Cell Research (ISSCR) issued guidance on the use of such models in research in 2021.⁸³ The ISSCR are now revisiting these guidelines.

⁷⁸ [warnock-report-of-the-committee-of-inquiry-into-human-fertilisation-and-embryology-1984.pdf](#)

⁷⁹ Deglincerti A *et al.* (2016) Self-organization of the *in vitro* attached human embryo *Nature* **533**: 251–4 and McCully S (2021) The time has come to extend the 14-day limit. *Journal of medical ethics* **47**: e66.

⁸⁰ Human Developmental Biology Initiative (2024) [Public dialogue on early human embryo research](#).

⁸¹ Babraham Institute (25 October 2023) [Public support for extending the 14-day rule on human embryo research indicated by foundational dialogue project](#).

⁸² Department of Health & Social Care (2023) [Independent review of the Human Fertilisation and Embryology Authority \(HFEA\): final report and recommendations](#).

⁸³ [Guidelines — International Society for Stem Cell Research](#)

In 2024, a consortium of researchers from across the UK created a SCBEM Code of Practice (CoP)⁸⁴ aiming to provide guidance and oversight, and bring the research the transparency required to garner public trust.

The NCOB will publish its own rapid ethical and regulatory review of SCBEMs in late November 2024.

[Read about our current work on SCBEMs here.](#)

Timeframe: <5 years

Evidence:

- **Political:** We know Government has commissioned a review by the regulatory authority to develop the central regulatory innovation office, which was a manifesto commitment, to seek to ensure the UK can has regulation that supports innovation.
- We also know there is a willingness to open the HFE Act in 2025.
- **Expert:** We are aware that these models are advancing at pace and that they currently reside outside of regulatory frameworks, putting them in an ethical grey area. Funders and scientists want guidance, which is why the UK consortium of researchers suggested an oversight group in their Code of Practice.

15. Ecology and biodiversity

Biodiversity refers to the variety of life on Earth, ranging from microorganisms and genes to whole ecosystems and diverse human communities,⁸⁵ whilst ecology is the study of how these living organisms interact with the physical environment.⁸⁶ Biodiversity and ecological damage can be caused by the effects of climate change, such as extreme weather (e.g. droughts, wildfires and heat), changing weather patterns, ocean acidification and melting ice caps and glaciers,⁸⁷ as well as human activities such as deforestation.⁸⁸ The need to protect biodiversity has been recognised in the 2022 Kunming-Montreal Global Biodiversity Framework, which sets out targets to achieve the goal of a society that “lives in harmony with nature”.⁸⁹

The notion of interconnectedness between human societies and non-human animals has been acknowledged for centuries through different Indigenous and Non-Western perspectives.⁹⁰ However, contemporary policy approaches, such as ‘One Health’, emphasise the importance of interventions that take a holistic approach to human, animal and plant

⁸⁴ Cambridge Reproduction and Progress Educational Trust (2024) [Code of Practice for the generation and use of stem cell-based embryo models](#)

⁸⁵ American Museum of Natural History (n.d.) [What is Biodiversity?](#)

⁸⁶ Ecological Society of America (2024) [What Is Ecology?](#)

⁸⁷ Greenpeace (n.d.) [What are the Effects of Climate Change on Biodiversity?](#)

⁸⁸ United Nations (2020) [Report of the UN Economist Network for the UN 75th Anniversary Shaping The Trends of Our Time.](#)

⁸⁹ Convention on Biological Diversity (1 October 2024) [Kunming-Montreal Global Biodiversity Framework.](#)

⁹⁰ Romanello M *et al.* (2024) The 2024 report of the Lancet Countdown on health and climate change: facing record-breaking threats from delayed action *The Lancet*, page 9.

health, and the responsible stewardship of ecosystems and natural processes.⁹¹ Another approach is 'Planetary Health'.⁹²

Approaches to biodiversity and ecology raise questions about how we think about the rights of non-human animals and the environment. For example, some countries have taken action to protect the environment directly through providing legal personhood to environmental areas, creating legal rights 'to a healthy environment' and considering some forms of harm to the environment as a criminal offence through 'ecocide' legislation.⁹³

Timeframe: 5-10 years

Evidence:

- **Political:** There is significant policy interest in ensuring that biodiversity is protected as we find ways to mitigate the effects of climate change.
- The UK government is introducing a National Biodiversity Strategy and Action Plan, the government aims to restore nature by protecting 30% of land and sea by 2030. The aim is to highlight the crucial role of biodiversity - [UK calls for accelerated action to protect global biodiversity - GOV.UK \(www.gov.uk\)](#)
- The Joint Nature Conservation Committee (JNCC) publish a UK Biodiversity Framework, which sets shared objectives for nature recovery and highlights the link between biodiversity and climate adaptation - [New UK Biodiversity Framework published | JNCC - Adviser to Government on Nature Conservation](#)
- **Expert:** WWF are calling for 'nature-positive pathways' to provide businesses with the information needed to align their operations with biodiversity goals - [Government urged to launch industry-specific plans to restore nature | The Independent](#)

16. Ectogestation

Ectogenesis is a process enabling the partial or full extrauterine development of an organism that *mimics* conditions of gestation in the womb/in utero conditions. What distinguishes ectogestation from ectogenesis is that ectogenesis simply speaks of outside development while ectogestation stresses the kind of development that is occurring. So, while ectogenesis could refer to any kind of outside development – it is a general concept about growth happening in an external environment (where development happens), ectogestation specifically highlights the stages of pregnancy and growth of a fetus outside the human body (how the development process mimics the stages of pregnancy).⁹⁴

⁹¹ ClimaHealth (n.d.) [One Health](#).

⁹² Cena H *et al.* (2024) Biodiversity and planetary health: a call for integrated action *The Lancet* **403(10440)**: 1985-6.

⁹³ NCOB (2024) [Legal and Regulatory Review: Climate Change, the Environment and Health in the UK](#).

⁹⁴ Kingma E and Finn S (2020) Neonatal incubator or artificial womb? Distinguishing ectogestation and ectogenesis using the metaphysics of pregnancy *Bioethics* **34(4)**: 354–63.

Researchers have been able to keep premature lambs alive in artificial wombs for several weeks.⁹⁵ If applied successfully in humans, this could help support infants born prematurely and raise questions about when a foetus might be considered viable. Some implications include whether ‘artificial’ wombs might be used to circumvent the need for a human womb in gestation. If this became possible, it would likely be an expensive option, and availability would be limited.⁹⁶ Yet, they could also make it possible for gay or single men and transgender or lesbian women to have genetically related children without the need for surrogacy. Future applications of ectogestation may also have implications for gender equality. Some have suggested the possibility of a more equal balance of childcare between men and women,⁹⁷ whilst others have highlighted forced ‘fetal rescue’ and possible restrictions to abortion rights.⁹⁸

Timeframe: >10years

Evidence:

- **Political:** No UK political interest in this developing area as yet.
- **Regulatory:** Currently it would likely fall under the HRA remit and that of funders to assess ethical set-ups. No one has suggested they are unable to do this.
- Were the tech to mature, it would likely have HFEA and HTA to cover it in some way between them.
- **Commercial:** This technology is largely in early research stages (i.e. in animals) and there is limited data available on its effectiveness / success rate. Until this positive data exists there has yet been no in-depth discussions on how human trials would ethically run.

17. Emerging neurotechnology

Neurotechnologies include brain-computer interfaces (BCIs), non-invasive vagus nerve stimulation and deep brain stimulation. These technologies have current and potential applications in treating a range of neurophysiological, neuropsychiatric, and neurological conditions.⁹⁹

Neurotechnology may have implications for personhood – perceptions of self, identity, agency and the ability to exercise autonomy authentically.¹⁰⁰ Attention has also been drawn to the legal status and protection of neural data and ‘neurorights’, including mental privacy.¹⁰¹

⁹⁵ Partridge E *et al.* (2017) An extra-uterine system to physiologically support the extreme premature lamb *Nat Commun* **8**: 1-16.

⁹⁶ Cavaliere G (2020) Gestation, equality and freedom: ectogenesis as a political perspective *Journal of Medical Ethics* **46**:76-82.

⁹⁷ *Ibid.*

⁹⁸ Cambridge Reproduction (2022) [Ectogenesis: ethics, rights, regulation.](#)

⁹⁹ NCOB (2024) [Literature review: neurotechnology.](#)

¹⁰⁰ Gilbert F *et al.* (2019) Embodiment and Estrangement: Results from a First-in-Human “Intelligent BCI” Trial *Sci Eng Ethics* **25(1)**: 83-96.

¹⁰¹ NCOB (2024) [Literature review: neurotechnology.](#)

The NCOB has an [active research project](#) looking at the ethics of neurotechnologies.

Read our recent [neurotechnology literature review](#) and our 2013 report on [Novel Neurotechnologies: Intervening in the Brain](#).

Timeframe: 5-10 years

Evidence:

- **Regulatory:** The new regulations on medical devices have impacted the usage and regulation of neurotechnology in the UK, prompting a need to define which neurotechnologies fall under medical devices.
- Recommendations for [the regulation of neurotechnology](#) published by Regulatory Horizons Council in 2022. These recommendations were accepted by the Government in 2024, clarifying that the MHRA will regulate all neuromodulation devices, invasive neuroimaging devices, and only non-invasive devices that record neural information for medical purposes.
- Information Commissioner's Office (ICO) has highlighted neurotechnology and neurodata as a key area and 'tech future': [Regulatory issues | ICO](#).
- **Commercial:** Growing investment in the neurotechnology market, estimated to be worth £14 billion by 2026: [Neurotechnologies | ICO](#).
- **Expert / Sector:** The increasing prevalence of neurotechnology, including as a consumer technology, and the potential risks of them becoming increasingly invasive- and potentially societally mandated much like mobile device usage was highlighted in multiple survey responses.
- A study published in *Nature* discusses the rise of brain-reading technology and the challenges it presents, including privacy concerns and the potential for misuse: <https://www.nature.com/articles/d41586-023-03423-6>
- The OECD has highlighted the need for responsible innovation in neurotechnology enterprises, emphasizing the importance of addressing ethical, legal, and policy questions as these technologies evolve: https://www.oecd.org/en/publications/2019/10/responsible-innovation-in-neurotechnology-enterprises_2d346c46.html

18. Emerging treatments in mental health

Researchers are working on new ways to prevent and manage mental health issues. There is a pressing need for novel therapeutics in the field particularly for people who do not respond to current treatment.¹⁰²

¹⁰² Rodriguez CI and Zorumski CF (2024) Rapid and novel treatments in psychiatry: the future is now *Neuropsychopharmacol.* **49**: 1-2.

Areas of exploration include identifying genetic factors for mental health problems;¹⁰³ machine learning algorithms to analyse brain scans and identify abnormalities;¹⁰⁴ and brain stimulation techniques using electricity to target specific areas of the brain.¹⁰⁵

Research is also exploring the potential of psychedelic drugs as treatments for a range of psychiatric conditions including depression, eating disorders and PTSD. In 2023, Australia became the first country in the world to legalise MDMA and psilocybin for therapeutic use by approved psychiatrists.¹⁰⁶ Psychedelic-assisted therapy raises ethical concerns including questions around informed consent,¹⁰⁷ professional boundaries, vulnerability and drug stigma.¹⁰⁸ For example, research suggests that race, socioeconomic background, and experiences with the criminal justice system may impact how much an individual benefits from psychedelic therapy.¹⁰⁹ Scholars have also highlighted the importance of recognising and respecting the indigenous knowledge and traditions on which Western psychedelic research is based.¹¹⁰

More broadly, novel treatments for mental health conditions raise questions around efficacy and evidence base, and the extent to which we are taking an overly medicalised approach to mental health.

[Read more about our work on mental health.](#)

Timeframe: >10 years

Evidence:

- **Political:** No mention from politicians or policy decision makers on the use of these technologies for UK health provision and no mention from regulators on their concerns being sparked. Appears to be largely in the research domain.
- **Funding:** There are a large number of larger clinical trials underway to look at the use of psychedelics for MH treatment with the companies who are making and testing the drugs (some UK based) claiming that once they have reported, they will seek US license (has so far been rejected), then EU and then UK. It is likely that UK will be last in line as drugs need to go through NICE approval.

[Psychedelic therapies are coming to Europe, but face barriers before reaching patients \(msn.com\)](#)

¹⁰³ Taquet M *et al.* (2021) A structural brain network of genetic vulnerability to psychiatric illness *Mol Psychiatry* **26**: 2089-100.

¹⁰⁴ Brossollet I *et al.* (2023) Machine Learning and Brain Imaging for Psychiatric Disorders: New Perspectives in, *Machine Learning for Brain Disorders [Internet]*, Colliot O (editor).

¹⁰⁵ Nature News (21 October 2024) [Brain stimulation at home helps to treat depression.](#)

¹⁰⁶ BBC news (30 June 2023) [Australia legalises psychedelics for mental health.](#)

¹⁰⁷ Jacobs E (2023) Transformative experience and informed consent to psychedelic-assisted psychotherapy *Front. Psychol.* **14**.

¹⁰⁸ McGuire AL *et al.* (2024) Developing an Ethics and Policy Framework for Psychedelic Clinical Care: A Consensus Statement *JAMA Netw Open* **7(6)**: e2414650.

¹⁰⁹ Viña SM and Stephens AL (2023) Minorities' diminished psychedelic returns *Drug Science, Policy and Law* **9**.

¹¹⁰ Celidwen Y *et al.* Ethical principles of traditional Indigenous medicine to guide western psychedelic research and practice *The Lancet Regional Health – Americas* **18**.

- **Public:** Public perception has not been robustly reported, but some claim populations are more open minded to this ‘new age’ treatments for MH problems.
- Brain simulation treatments either alone or in combination with another appear to be largely in their infancy with participate sizes being small and specific.
[Combining virtual reality and electric brain stimulation may be a promising treatment strategy for PTSD \(msn.com\)](#)
- **Expert:** Trying to utilise brain scan data as an indication of mental health problems, or a person being at risk of developing them tends to involve the research team using AI learning. This is something the NCOB and the Ada Lovelace Institute have warned about, saying that these technologies and their findings cannot be widely rolled out yet.

19. Engineering biology

Engineering biology (which encompasses synthetic biology) combines and applies the principles of biology and the tools of engineering to create usable economically viable products. Examples include bacteria engineered to produce chemicals, synthetic genomes and stem-cell derived organs.

The UK Government’s Department of Science, Innovation and Technology (DSIT), has highlighted the expansive potential of engineering biology to drive advances across health, agriculture, chemicals, materials, and energy and its commercial plausibility.¹¹¹ It has also acknowledged that a culture of responsible research and innovation (RRI) is required for the sector to garner the trust of the public and consumers as we address the social, cultural, legal and ethical questions that may be raised by the development and use of certain applications. In late 2023, the previous government published the National Vision for Engineering Biology,¹¹² stating it wanted the UK to become a world leader in responsible research and innovation by 2030.

Timeframe: <5 years

Evidence:

- **Political:** There is significant political interest and investment in engineering biology, which is mirrored internationally: <https://www.gov.uk/government/publications/national-vision-for-engineering-biology/national-vision-for-engineering-biology>
- [Game-changing tech to reach the public faster as dedicated new unit launched to curb red tape - GOV.UK](#)
- Our engagement with DSIT and GoScience has confirmed this is an area of great interest with plans to increase the level of public awareness and understanding.

20. Epigenetics

¹¹¹ Department for Science, Innovation and Technology and Prime Minister’s Office (9 February 2024) [The UK Science and Technology Framework: update on progress](#).

¹¹² Department for Science, Innovation and Technology (5 December 2023) [National vision for engineering biology](#).

Epigenetics refers to changes in gene expression not caused by changes in DNA sequence. Chemical tags, termed epigenetic modifications, act as an additional layer of information on DNA, changing how it is packaged, accessed and used in cells.¹¹³

Research in the field explores how environmental factors, such as diet, stress, smoking, and childhood trauma, affect epigenetic patterns and gene expression. Ethical considerations include the handling and storage of epigenetic data, discrimination and stigmatisation related to environmental and 'lifestyle' factors, and questions about personal and societal responsibility.¹¹⁴

Emphasising epigenetic effects in fetal development may also have implications for the expectations placed on pregnant people to take responsibility for their children's future health.¹¹⁵ Research is ongoing into the potential of epigenetic editing, raising questions around equitable access to future applications and how the targeting of particular traits might reinforce stigmas, for example around disability.¹¹⁶

[Read about a workshop we held to explore the issues raised by epigenetics.](#)

Timeframe: >10 years

Evidence:

- **Political:** From a political point of view, it appears much of the focus remains on genetics and does not step towards epigenetics in a way to suggest this is an area of research / tech that has huge potential yet. There is a case study of epigenetics in the [2020 Genome UK paper](#), but it is fleeting and doesn't go beyond one example.
- **Funding:** There is clear scientific and funding interest in this area which suggests the field is well supported and is working to show translational ability (see new centre link below). One of MRC's flagship institutions (the LMS in London) specialises in epigenetics and the Babraham Institute, Cambridge also specialises in this field.
- <https://www.bci.qmul.ac.uk/general-news/2024/01/new-epigenetics-hub-set-to-advance-early-disease-detection/>
- **Commercial:** Commercial interest and biotech startups in the area: [Fine-tuning epigenome editors | Nature Biotechnology](#)
- <https://www.gov.uk/government/publications/genome-uk-the-future-of-healthcare>
- **Public:** Epigenetics often gets touted as 'precision medicine' and this can confuse the public narrative somewhat, making public perception harder to assess. There are clear enablers here but given the lack of (or seeming lack of) political interest and regulatory

¹¹³ UK Trauma Council (March 2021) [Epigenetics and Mental Health: A brief guide to the research](#).

¹¹⁴ Santaló J and Berdasco M (2022) Ethical implications of epigenetics in the era of personalized medicine *Clin Epigenet* **14**: 1-14.

¹¹⁵ McMahon C and Mills C (2024) Against epigenetic responsibility: The problem of causality in 'foetal programming' science *Bioethics*: 1-10.

¹¹⁶ Zeps N *et al.* (2021) Ethics and regulatory considerations for the clinical translation of somatic cell human epigenetic editing *Stem Cell Reports* **16**: 1652-1655 and Knight A (2023) Gene Editing Technologies, Utopianism, and Disability Politics *The Journal of Philosophy of Disability*.

concern, and the time it will take to convert basic understanding into tech, we have placed it in longest timeframe.

21. Equitable access to medicines and therapies

Global health focusses on achieving equity in health for all people worldwide.¹¹⁷ It is estimated that essential medicines are inaccessible to 2 billion people worldwide.¹¹⁸

The current system of medical research and development does not benefit patients equitably and the development of drugs and vaccinations is unduly influenced by factors beyond patient need, such as profit.¹¹⁹ Recent outbreaks of mpox in Africa have drawn attention to global health inequities and unequal access to necessary vaccines.¹²⁰

As genomics and precision medicine develop, some have raised questions about equity of access due to cost and because the databases they rely on may not include enough information about genetic variants, for example in people with non-European ancestry.¹²¹ Tiered pricing, generic drug manufacture, bulk purchasing and public-private partnerships are all strategies highlighted by the WHO to reduce the cost of medicines and ensure access to those most in need.¹²²

[Read our briefing note on equitable access to COVID-19 treatments and vaccines.](#)

Timeframe: <5 years

Evidence:

- **Political:** There were commitments from the UK during and straight after Covid that spoke to our attempts to boost equity of access to medicines and tech, particularly vaccines.
- https://www.aomrc.org.uk/wp-content/uploads/2021/04/210426_Enhancing_UK_action_promoting_access_global_COVID-19_vaccines_Statement.pdf
- Internationally, pandemic preparedness conversations are based around lessons learnt and ensuring a global, equitable response as pandemics require collective global action. [Strengthening democracy and pandemic preparedness go hand in hand - Bulletin of the Atomic Scientists \(thebulletin.org\)](#)

¹¹⁷ Koplan JP *et al.* (2009) Towards a common definition of global health *The Lancet* **373(9679)**: 1993-5

¹¹⁸ Access to Medicine Foundation (2017) [5 billion people have access to medicine 2 billion to go: Strategic direction 2017-2021.](#)

¹¹⁹ World Health Organization (2017) [Access to medicines: making market forces serve the poor.](#)

¹²⁰ The Guardian (1 September 2024) [African nations hit by mpox still waiting for vaccines – despite promises by the west](#) and UN News (6 September 2024) [Mpox: Equitable vaccine access crucial for Global South.](#)

¹²¹ Duncan L *et al.* (2019) Analysis of polygenic risk score usage and performance in diverse human populations *Nat Commun* **10**: 1-9.

¹²² World Health Organization (2017) [Access to medicines: making market forces serve the poor.](#)

- **Expert:** There hasn't been anything on this recently, but we know through working with NHS England that the team responsible for assessing the inequality risks of new treatments is one of the few teams that have not shrunk in size.

22. Farming and agriculture

There are a many factors and stakeholders to consider in policy and practice addressing climate change in the agriculture sector. This includes both human health and non-human animal health, as well as food security, biodiversity loss and environmental degradation.

a. Food systems

The UK government's 2024 Food Security Index,¹²³ highlights that while global food availability is sufficient, food security risks remain due to reliance on imports and climate vulnerabilities affecting supply chains.

Globally, food systems are responsible for 30% of greenhouse gas emissions.¹²⁴ In the UK, this number is higher, with almost 45% of all greenhouse gas emissions produced by the agricultural sector in 2020.¹²⁵

b. Cellular agriculture

In summer 2024, Britain became the first country in Europe to approve the use of laboratory-grown meat.¹²⁶ This initiative aligns with the government's aims to reduce greenhouse gas emissions from the agriculture sector, which accounts for around 45% contribution of the UK's greenhouse gas emissions.

c. Genome editing in farmed animals and plants

Genome editing extends traditional selective breeding methods, allowing for precise and targeted alterations to be made in the living cells of farmed animals. It could address some challenges such as making animals resistant to diseases or more productive. But it might also be used to circumvent animal welfare considerations, for example breeding animals able to withstand poor living conditions rather than improving their conditions. Genome editing should be assessed alongside other alternative food production techniques in terms of accessibility, animal welfare, food sustainability, biodiversity loss and environmental degradation.¹²⁷

[Read our report on genome editing in farmed animals.](#)

d. Livestock welfare

It is clear that a balance between meeting production demands and ensuring the healthy wellbeing of animals should be found. Some farming practices, have targets of high yields

¹²³ GOV.UK (2024) [UK Food Security Index 2024](#).

¹²⁴ Romanello M *et al.* (2023) [The 2023 Report of the Lancet Countdown on Health and Climate Change: The Imperative for a Health Centred Response in a World Facing Irreversible Harms](#).

¹²⁵ *Ibid.*

¹²⁶ Financial Times (17 July 2023) [UK becomes first European country to approve lab-grown meat](#).

¹²⁷ NCOB (2021) [Genome editing and farmed animal breeding: social and ethical issues](#).

and this may compromise living conditions for the animals¹²⁸. The UK government has outlined an agricultural transition plan that focuses on investing in innovation and improvements to agricultural production, food production and animal health and welfare.¹²⁹ Other schemes, such as the Sustainable Farming Incentive, are available to support farmers improve environmental sustainability and maintain animal welfare standards.¹³⁰ When we think about tackling the climate crisis we must think about these types of trade-offs, particularly when taking a multi-species approach.¹³¹

Timeframe: <5 years

Evidence:

- **Political:** There is high political interest - new legislation to support precision breeding and boost Britain's food security: <https://www.gov.uk/government/news/new-legislation-to-support-precision-breeding-and-boost-britains-food-security>
- UK becomes first country in Europe to approve the use of lab-grown meat: [UK becomes first European country to approve lab-grown meat \(ft.com\)](#)
- Agriculture Transition Plan: [Agricultural Transition Plan update January 2024 - GOV.UK \(www.gov.uk\)](#)
- **Funding:** Sustainable Farming Incentive (SFI) and other schemes to support farmers in improving environmental sustainability while maintaining animal welfare standards. [Sustainable Farming Incentive: guidance for applicants and agreement holders - GOV.UK \(www.gov.uk\)](#)
- **Public:** A systematic review of public attitudes revealed that consumers are increasingly aware of the ethical implications of animal welfare in food production, influencing their purchasing decisions - [A Systematic Review of Public Attitudes, Perceptions and Behaviours Towards Production Diseases Associated with Farm Animal Welfare | Journal of Agricultural and Environmental Ethics](#)
- Recent research at Edinburgh also shows that peoples' attitudes towards cultured meat are related to moral values around purity and naturalness - [Meat and morality: The moral foundation of purity, but not harm, predicts attitudes toward cultured meat - ScienceDirect](#)
- 2022 deliberative workshop - farmers care about environmental sustainability and seek 'nature-friendly' policy and funding in the face of financial precarity. Farmers are also aware of the impacts of climate change and environmental degradation on agriculture, and are thinking about climate adaptation. [Farmers and environmentalists agree – food security is only possible if farming is environmentally sustainable | IPPR](#)

23. Fetal intervention

¹²⁸ Food and Agriculture Organization of the United Nations (2023) [Sustainable livestock transformation – A vision for FAO's work on animal production and health](#).

¹²⁹ Department for Environment Food & Rural Affairs (2024) [Agricultural Transition Plan update January 2024](#).

¹³⁰ GOV.UK (30 March 2022) [Sustainable Farming Incentive: guidance for applicants and agreement holders](#).

¹³¹ NCOB (2023) [Health, climate change and ethics – an overview](#).

Surgical interventions can be performed on fetuses in utero to manage life-threatening conditions and prevent disability. Examples include repairing heart valves and draining blocked bladders. These interventions can involve complex trade-offs between fetal and maternal benefits and risks.

Researchers are exploring prenatal treatments for Down's syndrome, potentially offering parents additional options following a prenatal diagnosis. In what cases should fetal interventions be offered, and what are the implications for prenatal testing or screening in relation to conditions for which fetal interventions might be a treatment option?¹³²

Intervention made on behalf of the fetus could mean an irreversible change, and it would be one that the fetus did not make themselves, this raises questions about autonomy.¹³³ It is perhaps particularly pertinent when the health concern being addressed is non-life threatening. Further to the autonomy of the fetus, maternal autonomy is also worthy of exploration. These interventions may carry significant health risks for the mother and possibly impact their future fertility.¹³⁴

Availability of fetal intervention raises concerns around equity of access, these interventions may only be available in specialist centres and particular geographical locations. Not all patients will have the means to access these facilities. For example, the NHS has specialist Fetal Medicine Units (FMUs), specifically designed to provide specialised care for complex fetal conditions. However, these are concentrated in major urban centres, meaning that many requiring treatment but they are from rural areas are likely at a disadvantage.^{135,136}

Timeframe: <5 years

Evidence:

- **Political:** The UK is focused on reducing perinatal mortality and improving maternity services. This includes efforts to address fetal well-being through various interventions, such as the Saving Babies' Lives Care Bundle (SBLCB), which aims to reduce stillbirths, neonatal deaths, and brain injuries during childbirth by 2025
- [Is the Government on track to halve baby deaths by 2025? - Committees - UK Parliament](#)
- [NHS England » Saving babies' lives: version 3](#)
Expert: Academic review - [Saving babies and families from preventable harm: a review of the current state of fetoplacental monitoring and emerging opportunities | npj Women's Health \(nature.com\)](#)

24. Gender Identity

¹³² NCOB (2017) [Non-invasive prenatal testing: ethical issues](#).

¹³³ Isaacs D (2003) Moral status of the fetus: fetal rights or maternal autonomy? *Journal of paediatrics and child health* **39(1)**: 58–9.

¹³⁴ Pinkerton JV *et al.* (1996) Resolving the clinical and ethical dilemma involved in fetal-maternal conflicts *American Journal of Obstetrics & Gynecology* **175(2)**: 289-95.

¹³⁵ [Standards for Maternity Care | RCOG](#)

¹³⁶ [Local Maternity System - Equity and Equality](#)

Following publication of the final Cass Review report in 2024, NHS England announced the establishment of up to 8 new children and young people's gender services in hospitals across the country and a review of adult gender dysphoria services.¹³⁷ The government has also recently renewed a temporary ban on puberty-suppressing hormones for children and adolescents outside of clinical research settings.¹³⁸

With greater visibility and acceptance of people with divergent gender identities, there are ongoing debates about the rights of trans and non-binary people. These have centred on the existence of single-sex spaces and activities, the requirements for access to a Gender Recognition Certificate and the prescription of puberty-blockers to under-16s.

Timeframe: <5 years

Evidence:

- **Political & Public:** Evidence is hard to navigate and hotly contested when disagreed with (e.g. Cass review). There is strong public interest and some distrust in whether Government knows 'best', and for the most part the people most at risk are those who cannot legally advocate for themselves due to their age.
- Political interest and public attitudes were laid bare during the 2024 general election campaign: <https://www.bbc.co.uk/news/articles/c4nng2j42xro>; <https://www.bbc.co.uk/news/education-69017920>; <https://www.bbc.co.uk/news/articles/c6ppp1zpn17o>
- Scotland at odds with Westminster and suggestions that they want to take up the conversation again now Labour is in power: <https://www.bbc.co.uk/news/articles/c97zv90d77do>; <https://www.bbc.co.uk/news/uk-scotland-scotland-politics-66315485>
- NHS support from U18s: <https://www.bbc.co.uk/news/articles/cjrd3yylylro>

25. Gene drive technology

Gene drives alter or suppress animal populations through the introduction of a mutation or foreign gene. Potential applications include the control of disease vectors such as mosquitos, rodent pests, and invasive species.

Gene drives raise ethical questions about balancing potential benefits to human health against ecological risks, which may not be fully understood or anticipated. For example, species could evolve resistance to the gene drive sequence and their populations rebound.¹³⁹ Further, those who take a rights-in-nature approach, that is, ecosystems, species or individual organisms have intrinsic rights to exist and thrive independently of human interests, may argue that introducing gene drives interferes with the natural process

¹³⁷ NHS England (2024) *NHS England's response to the final report of the independent review of gender identity services for children and young people*.

¹³⁸ GOV.UK (22 August 2024) *Puberty blockers temporary ban extended*.

¹³⁹ NCOB (2016) *Genome editing: an ethical review*, pp76-93; Claudia Emerson *et al.* (2017) Principles for gene drive research *Science* **358**: 1135-6 and Bier E (2022) Gene drives gaining speed *Nat Rev Genet* **23**: 5–22.

and infringe upon the 'rights' of these organisms. Also, it is unclear what the impact of gene drives on ecosystems will be; for example, they could disrupt biodiversity, so this again violates the rights of species and ecosystems to maintain their natural states.¹⁴⁰

It is important that the affected communities are included in the development of these technologies and that rigorous environmental monitoring is in place where they are used. It is also important to monitor the regulation governing this technology. Any future legislative changes to gene drives would likely involve significant public consultation and international alignment.

Timeframe: >10 years

Evidence:

- **Political:** While genome editing and precision breeding have gained significant legislative traction in the UK, gene drive technology does not appear to have come into policy prominence yet. However, climate change may put pressure on this timetable so we will continue to monitor this.
- [Gene Drives as Interventions into Nature: the Coproduction of Ontology and Morality in the Gene Drive Debate | NanoEthics \(springer.com\)](#)

26. Geoengineering

Geoengineering refers to large-scale interventions in the Earth's climate system, aimed at mitigating the effects of climate change. There are several ways this can be undertaken, for example, the removal of CO₂ from the atmosphere using methods such as carbon capture. Another example is Solar Radiation Management (SRM), which works by reflecting a small percentage of the Sun's light and heat back into space to cool the planet. However, criticism over its expensive and long-term suitability remain.¹⁴¹

The UK's Advanced Research and Invention Agency (ARIA) recently committed to providing £56.8million to explore climate cooling.¹⁴² In its funding call, it notes that these interventions hold promise, but as they interfere with natural processes and environments - the risks of planet-scale interventions must be considered.

Timeframe: >10 years (this may be 5-10 years so would be good to discuss with AG)

Evidence:

- **Political / Expert:** There is clear policy interest - The Met Office has posted a position statement on geoengineering research, arguing that impartial research is needed to further understand geoengineering, alongside mitigation measures, to ensure any future

¹⁴⁰ National Academies of Sciences, Engineering, and Medicine (2016) [Gene Drives on the Horizon: Advancing Science, Navigating Uncertainty, and Aligning Research with Public Values](#).

¹⁴¹ UNESCO (2023) [Report of the World Commission on the Ethics of Scientific Knowledge and Technology on the Ethics of Climate Engineering](#).

¹⁴² ARIA (2024) [Exploring Options for Actively Cooling the Earth, Programme thesis](#).

discussion of options to tackle climate change is based on the best available evidence and information: [Met Office position on geoengineering research - Met Office](#)

- [Government reignites industrial heartlands 10 days out from the International Investment Summit - GOV.UK \(www.gov.uk\)](#)
- **Funding:** There is significant funder interest in geoengineering, but most techniques are still largely in the development and experimental stage.
- ARIA: [ARIA-Actively-cooling-the-earth-programme.pdf](#) UKRI (the Natural Environment Research Council (NERC)) has opened a new 5-year research programme to model the impact of solar radiation management: [Research programme to model impact of solar radiation management – UKRI](#). The programme will deliver risk-risk analyses to inform policymakers.

27. Global warming

The world is warming at a faster rate than at any point in recorded history.¹⁴³ The world is currently on track to reach almost 3°C above pre-industrial levels by the end of the century.¹⁴⁴ And the UK is not on track to reduce our emissions in 2030 by 68% compared to 1990 levels.¹⁴⁵

A 2024 World Economic Forum report highlighted that with even a 1.1°C increase in the Earth's temperature, extreme weather events are causing substantial destruction to nature and infrastructure, widespread economic losses, sickness and death.¹⁴⁶

Timeframe: <5 years

Evidence:

- **Political:** Clear policy interest - during a UN General Assembly speech in September 2024, the UK government committed to stronger climate action, emphasising the need for immediate and bold action to prevent further breaches of the 1.5°C limit.
- [This government will show global leadership on the climate crisis: UK statement at the UN - GOV.UK \(www.gov.uk\)](#).
- [The UK's plans and progress to reach net zero by 2050 - House of Commons Library \(parliament.uk\)](#)
- [2024: First chance of 1.5 °C year - Met Office](#)
- **Expert:** There is extensive expert-led commentary in this space, providing insights in a way the public can understand and engage with: [The 2024 Europe report of the Lancet Countdown on health and climate change: unprecedented warming demands unprecedented action - Grantham Research Institute on climate change and the environment \(lse.ac.uk\)](#)

¹⁴³ World Meteorological Organisation (2023) [State of Climate Services: Health](#).

¹⁴⁴ *Ibid.*

¹⁴⁵ UK Climate Change Committee (2024) [2024 Progress Report to Parliament](#).

¹⁴⁶ World Economic Forum (2024) [Quantifying the Impact of Climate Change on Human Health, Insight Report](#).

28. Health Data

The digitisation of health data and expanding methods of collection, such as wearables, self-tracking apps and direct-to-consumer testing, have increased the amount and availability of health data accessible to researchers, clinicians and patients. This brings with it challenges around data protection and cyber security, as well as ethical considerations around trust, accountability, inequality, and justice. Some have also drawn attention to a ‘data divide’, in terms of whose data is collected and who benefits from data-driven medical approaches.¹⁴⁷

A recent report published by the Ada Lovelace Institute explores the implications of clinical data systems for transgender and non-binary people, including the risk of their medical information being lost or inaccurately representing them. This can result in distressing and poorer quality care, as well as erasure from health datasets more broadly.¹⁴⁸

Genomic data raises issues in terms of identifiability – both for the patient and their biological relatives – and uncertain future uses, highlighting challenges around consent and the right to know, or not know, about predictable health conditions.¹⁴⁹ Healthcare institutions and companies that provide genetic testing services are collecting large amounts of personal genetic information that could be used for secondary purposes. Human DNA can also be inadvertently captured in environmental samples.¹⁵⁰ Attention has also been drawn to the environmental cost of storing and processing big datasets.¹⁵¹

Timeframe: <5 years

Evidence:

- **Political:** Government has shown clear interest in utilising NHS health data to improve healthcare. [Response to government announcement paving way for access to GP data \(ukbiobank.ac.uk\)](https://ukbiobank.ac.uk)
- Government announces plans for NHS England to take over GP primary care data in a move to make this more accessible (BMA had previously refused to come out in support of GPs sharing this data where patients are participants in studies) [NHS England to take on responsibility for sharing patient records for research - Pulse Today](#)
- Science strategy includes data science as one of five themes.
- [Nearly £50 million unlocked for world-leading UK Biobank following new industry backing - GOV.UK \(www.gov.uk\)](https://www.gov.uk)
- **Regulatory:** MHRAs first Data Strategy was produced for 2024 to 2027 [Data strategy 2024 4.pdf \(publishing.service.gov.uk\)](#)

¹⁴⁷ Ada Lovelace Institute (2021) [The data divide](#), Ibrahim H *et al.* (2021) Health data poverty: an assailable barrier to equitable digital health care *The Lancet Digital Health* **3(4)**: e260-5 and Nuffield Trust (2021) [Ethnicity coding in English health service datasets](#).

¹⁴⁸ Ada Lovelace Institute (2024) [‘The computer won’t do that’](#).

¹⁴⁹ Horton R & Lucassen A (2022) Ethical Considerations in Research with Genomic Data *The New Bioethics* **29(1)**: 37–51.

¹⁵⁰ Whitmore L *et al.* (2023) Inadvertent human genomic bycatch and intentional capture raise beneficial applications and ethical concerns with environmental DNA *Nat Ecol Evol* **7**: 873–88.

¹⁵¹ Lucivero, F (2020) Big Data, Big Waste? A Reflection on the Environmental Sustainability of Big Data Initiatives *Sci Eng Ethics* **26**: 1009–30.

29. Health screening

Screening for diseases such as heart disease, diabetes and cancer can enable early diagnosis and intervention and reduce morbidity and mortality. At the same time, potential harms include over-diagnosis and treatment, uncertainty in results, anxiety, stigma and false reassurance.¹⁵²

The UK National Screening Committee (UK NSC) advises ministers and the NHS on the “viability, effectiveness and appropriateness” of screening programmes. This involves ensuring robust evidence for the implementation and maintenance of screening programmes, considering whether potential benefits outweigh potential harms, and cost effectiveness.¹⁵³ The UK NSC’s ethical framework for screening highlights the importance of fair resource allocation, respecting individuals’ choices about screening, and equity of access.¹⁵⁴

Uptake of NHS-provided screening is lower in the most ethnically diverse and deprived areas of the UK, as well as among people with learning disabilities.¹⁵⁵ Disparities in screening have been linked to health inequalities, particularly as many of the conditions screened for disproportionately affect underserved communities.¹⁵⁶

The potential for genome sequencing and polygenic scores to be utilised in future screening programmes raises questions about what results and information should be returned or withheld and why; how much uncertainty people are willing to accept; and whether screening should be motivated solely by the potential benefit for screened individual or also their family, the NHS and wider society.¹⁵⁷

Timeframe: <5yrs

Evidence:

- **Political:** The Government has been very clear, both before its election success and since that prevention is at the cornerstone of their health policies.
- [Labour's health mission must be radical – and much wider than the NHS - LabourList](#)

¹⁵² WHO Regional Office for Europe (2020) [Screening programmes: a short guide. Increase effectiveness, maximize benefits and minimize harm.](#)

¹⁵³ UK National Screening Committee (29 September 2022) [Criteria for a population screening programme.](#)

¹⁵⁴ UK National Screening Committee (10 August 2021) [UK NSC ethical framework for screening.](#)

¹⁵⁵ NHS England (8 December 2022) [Health and Care of People with Learning Disabilities, Experimental Statistics 2021 to 2022: Cancer Screening](#); BMC Medicine (2023) One size does not fit all: working towards increasing participation of minority groups in cancer screening programmes *BMC Med* **21**: 1-2 and Health Equity Evidence Centre (2024) [What works: Addressing inequalities in the uptake of cervical screening.](#)

¹⁵⁶ Office for Health Improvement & Disparities (2022) [Population screening: review of interventions to improve participation among underserved groups.](#)

¹⁵⁷ Maftai A and Dănilă O (2022) The good, the bad, and the utilitarian: attitudes towards genetic testing and implications for disability *Curr Psychol* **17**: 1-22 and Cornel MC *et al.* (2024) Genetic Screening—Emerging Issues *Genes* **15(5)**.

- [How can a preventative approach to health and care help Labour deliver for patients? - New Statesman](#)
- **Funding:** Significant funding for blood tests for cancer (in line with [2024 cancer mission](#)). However, Galleri and other blood cancer tests have faced scrutiny around over-hype and whether they are an effective use of resources – this may have shaped public perception.
- [Government to fund £120 blood test that could detect 12 most common cancers | Cancer research | The Guardian](#)
- [Galleri promises to detect multiple cancers—but new evidence casts doubt on this much hyped blood test | The BMJ](#)

30. In/fertility provision

NICE recommends that women under 40 should be offered three rounds of NHS-funded IVF treatment and women aged 40-42, offered 1 full round.¹⁵⁸ However, in England, there is a ‘postcode lottery’ and many patients in England are unable to access the number of rounds recommended by NICE.¹⁵⁹ A recent intervention, developed by the Progress Educational Trust (PET), helps patients understand what level of fertility provision their Integrated Care Board (ICB) provides.¹⁶⁰

It is argued that more should be done to ensure equal access to fertility treatment. The debate over IVF provision also includes concerns about the access barriers for LGBTQ+ couples, who are often required to self-fund several cycles of artificial insemination before qualifying for NHS-funded IVF.¹⁶¹

Timeframe: <5 years

Evidence:

- **Political:** [NHS-funded IVF in England - GOV.UK \(www.gov.uk\)](#)
- **Regulatory:** There were some law changes announced around female same-sex couples undergoing reciprocal IVF that were welcomed by the HFEA: [HFEA welcomes announcement on law changes to IVF provision in the UK | HFEA](#)
- **Public:** A review of ICBs in early 2024 revealed only a small fraction of areas offer the full three cycles. [Londoners least likely to access IVF on NHS as women face 'postcode lottery' | Evening Standard](#)

31. Innovation and digitisation in health and care

In the face of increasing demands, an ageing population and significant staff shortages, innovation and technology adoption presents an opportunity to support health and social care services. Existing uses of technology in the NHS centre around facilitating

¹⁵⁸ NICE (2023) [Infertility: NICE quality standards](#).

¹⁵⁹ Department of Health & Social Care (2024) [NHS-funded in vitro fertilisation \(IVF\) in England](#).

¹⁶⁰ PET (2024) [Starting your IVF journey? | Fertility Policy Tracker - now available | PET](#).

¹⁶¹ HFEA (n.d.) [HFEA welcomes announcement on law changes to IVF provision in the UK](#).

communication between staff (such as video calls and digital messaging), integrating patient care (electronic health records)¹⁶² and providing remote monitoring and care (digital consultations and virtual wards).¹⁶³ State-of-the-art surgical robotics are also being developed and used across NHS trusts.¹⁶⁴ However, poor IT and digital infrastructure, as well as insufficient training, remain barriers to effective technology use.¹⁶⁵

Lord Darzi's independent investigation into the NHS in England, identifies a lack of investment in technology and calls for a major shift towards digital technology, particularly in community-based services, to boost productivity and improve care.¹⁶⁶ As the NHS looks to adopt new innovations, such as AI-powered administrative and diagnostic technologies, immersive AR and VR, mobile health apps and wearable technologies, these barriers will need to be addressed. Recent surveys suggest overall public support for the use of health technologies and data to improve care, however, consideration of the needs and desires of different communities, and meaningful public dialogue will be key in implementing technologies effectively and maintaining trust.¹⁶⁷

In social care, patients and carers use reminders and alarms on phones to keep track of medication, smart personal alarms and e-rostering amongst care workers. Assistive technologies could provide practical, social and emotional support to people at home and assist carers with monitoring but could also disempower older and disabled people. Automation and increasing reliance on technologies give rise to questions about reliability, safety, transparency and accountability. In a social care context, concerns have also been raised about digital exclusion and whether these technologies might exacerbate loneliness and social isolation.

Timeframe: <5 years

Evidence:

- **Political:** *'From analogue to digital'* – one of three key shifts for the NHS highlighted by the Government.
- Darzi report identifies important themes for repairing the NHS (likely to inform Labour's 10-year plan due in 2025) including: "*Tilt towards technology*. There must be a major tilt towards technology to unlock productivity. In particular, the hundreds of thousands of NHS staff working outside hospitals urgently need the benefits of digital systems." [The Darzi investigation: what you need to know | NHS Confederation](#)
- **Regulator:** NICE priorities for 2024 – 25 – clear focus on digital health technologies for diabetes management, early detection of cancer and mental health. [Forward view - our priority topics | What we do | About | NICE](#)

¹⁶² The Health Foundation (2024) [Which technologies offer the biggest opportunities to save time in the NHS?](#)

¹⁶³ The Health Foundation (2024) [What do virtual wards look like in England?](#)

¹⁶⁴ Royal College of Surgeons (2023) [Robotic-assisted surgery: a pathway to the future](#).

¹⁶⁵ [Which technologies offer the biggest opportunities to save time in the NHS? - The Health Foundation](#)

¹⁶⁶ Darzi A (2024) [Independent investigation of the National Health Service in England](#).

¹⁶⁷ The Health Foundation (2023) [Exploring public attitudes towards the use of digital health technologies and data](#).

- **Public:** Recent public engagement and surveys show that the public is overall in favour of health technologies / digital technologies in healthcare – particularly if they empower people to better manage their health or communicate with healthcare providers.
- [Majority of public happy to use health technology to avoid going into hospital, new research shows | NHS Confederation](#)
- [Exploring public attitudes towards the use of digital health technologies and data - The Health Foundation](#)

32. Longevity research and treatments

Ageing is associated with many long-term conditions, such as heart disease, stroke and dementia. This is a key issue in ageing societies such as the UK, where the number of people aged 65-79 is expected to increase by 30% over the next 40 years, and has significant economic, social and public health implications.¹⁶⁸ For example, dementia – for which ageing is the primary risk factor - is predicted to be the costliest health condition in the UK by 2030.¹⁶⁹

Researchers are working to understand biological ageing and potential interventions from drugs to dietary restriction, boosting mitochondria, stem cell therapy and blood transfusions from younger donors. Emerging research examines how ‘epigenetic clocks’ could help identify and predict health risks, and the potential for epigenetic reprogramming to rejuvenate cells.¹⁷⁰ Studies are also exploring fertility, menopause and potential treatments to slow age-related fertility decline.¹⁷¹

Treatments for biological ageing could reduce the burden of age-related disease on health and social care and allow people to live healthier, independent lives for longer. Alongside potential benefits, longevity research raises several complex ethical questions: How might these treatments impact quality of life and population demographics? Is it helpful to medicalise ageing, rather than accepting and valuing it as a stage of life? Should we be more focussed on social determinants of healthy ageing and promoting a more equitable society? In relation to climate change, the impact of an ageing society on carbon emissions is not yet fully understood, however, research suggests that a higher proportion of senior citizens is likely to have implications for climate change mitigation efforts.¹⁷² Given the growing commercial anti-ageing market, questions also arise around regulation and ensuring treatments are evidence-based, as well as equitable access and outcomes.

[Read our report on the future of ageing.](#)

Timeframe: 5-10 years

¹⁶⁸ Centre for Ageing Better (2023) [State of Ageing 2023](#).

¹⁶⁹ Alzheimer’s Research UK Dementia Statistics Hub (n.d.) [The economic impact of dementia](#).

¹⁷⁰ Pereira B *et al.* (2024) Epigenetic reprogramming as a key to reverse ageing and increase longevity *Ageing Research Reviews* **95**: 1-12.

¹⁷¹ Wang H *et al.* (2024) Rejuvenation of aged oocyte through exposure to young follicular microenvironment *Nat Aging* **4**: 1194–210 and The Guardian (22 July 2024) [‘Dream come true’: study suggests drug could extend women’s fertility by five years](#).

¹⁷² Zheng H *et al.* (2022) Ageing society in developed countries challenges carbon mitigation. *Nat. Clim. Chang.* (**12**): 241–8

Evidence:

- **Political:** Political awareness of the increasing demands and pressures of an ageing society (e.g. recent references by Keir Starmer and Wes Streeting in relation to health and social care). However, focus is largely *improving quality of life rather than longevity intervention* - i.e. prevention, social and public health interventions, and preparing the NHS and care systems rather than geroscience and ‘anti-ageing’ drugs/research.
- [A consensus on healthy ageing - GOV.UK \(www.gov.uk\)](https://www.gov.uk)
- **Commercial:** Significant commercial interest, commercial translation will likely be accelerated as many potential anti-ageing therapeutics are already authorised drugs. <https://english.elpais.com/economy-and-business/2023-07-17/the-boom-of-the-anti-ageing-market-how-to-get-people-to-live-to-be-120-and-in-good-health.html>
- 7% of all geroscience companies are based in the UK, several show promise of introducing new drugs to clinic in the medium term.
- Geroscience based drugs – estimated global market value of \$64 billion.
- [Several pharma companies are looking to repurpose already approved drugs for anti-ageing purposes.](#)
- [Longevity: Anti-ageing drugs, watch out, here we come... | pharmaphorum](#)
- **Funding:** Currently funded initiatives include BBSRC ‘healthy ageing across the life course’, UKRI ‘healthy ageing challenge’ (£98 million). However, UK spending on ageing research is much lower than comparative economies and a large amount of this goes to single disease investigation rather than biological ageing.
- **Public:** This topic tends to receive substantial and consistent media attention. E.g. [Weight-loss drugs ‘slow down the ageing process’, scientists suggest | Ageing | The Guardian](#); [New anti-ageing therapy extends life of mice by 25%, study finds \(ft.com\)](#)
- **Expert:** 2024 Royal Society briefing on [policy implications of geroscience](#) summarises the state of geroscience in the UK and identifies key challenges including fragmented research, a scarcity of specialist researchers/clinicians, and limited funding. The briefing advocates for increased investment in research and a central centre like the US’ National Institute on Ageing. [Bringing Geroscience into the Mainstream: From Education to Clinical Practice, What Will It Take? | The Journals of Gerontology: Series A | Oxford Academic \(oup.com\)](#)

33. Maternal, perinatal and neonatal health

The 2024 Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK), published a perinatal mortality report increases in the neonatal mortality rate in England and Wales and that existing inequalities – particularly ethnic and deprivation – remain in the rates of stillbirth and neonatal mortality¹⁷³

¹⁷³ MBRRACE-UK Collaboration (2024) [MBRRACE-UK Perinatal Mortality Surveillance: UK Perinatal Deaths of Babies Born in 2022 - State of the Nation Report.](#)

In 2023 the Care Quality Commission (CQC), England's healthcare regulator, found that of all the hospital services it inspects, maternity units fared worse.¹⁷⁴

A recent report from NHS Resolution highlights that of the £2.8 billion that was paid out for clinical negligence claims in 2023/24, 41% are maternity-related payments.¹⁷⁵ An increase in litigation in maternity care, was also identified in our horizon scanning stakeholder survey.

Timeframe: <5 years

Evidence:

- The work of MBRRACE-UK spotlights maternity care in the UK and the need for targeted investments to address both inequalities and staffing issues.
- **Political:** There is extensive policy interest and government funding - £35million investment was announced in 2024 to improve maternity safety across England, focusing on specialist training and increasing the midwifery workforce. [£35 million investment to boost maternity safety - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/news/35-million-investment-to-boost-maternity-safety)
- **Regulatory:** [Most NHS maternity units not safe enough, says regulator - BBC News](https://www.bbc.com/news/health-67845678)
- **Sector:** <https://www.sands.org.uk/about-sands/media-centre/news/2024/01/sands-responds-latest-mbrpace-uk-data-maternal-death-rates>, <https://www.rcog.org.uk/news/rcog-responds-to-mbrpace-uk-perinatal-mortality-report/>

34. Mental health and technology

Emerging mental health technologies include mental health apps (providing clinical support, meditation exercises, sleep and mood tracking), portable brain stimulation devices, immersive technologies, digital phenotyping, and AI-driven predictive analytics.

These all have the potential to provide flexible and tailored mental health support, lower barriers to accessing mental healthcare, and offer insights into the mental health and wellbeing of individuals and populations.¹⁷⁶ At the same time, mental health technologies raise ethical concerns relating to reductions in face-to-face contact; the effectiveness, quality, and safety of care; cost, access and potential exacerbation of health inequalities; and data privacy and security.¹⁷⁷

A 3-year project, initiated in 2023 and conducted jointly by the MHRA and NICE, aims to address some of these challenges by developing clear guidance and regulations for the rapidly evolving market of digital mental health technologies (DMHTs).¹⁷⁸

As well as utilising technology as a tool to improve mental health, research is also considering the negative effects of technology use and 'screen time' on mental health and

¹⁷⁴ BBC news (16 November 2023) [Most NHS maternity units not safe enough, says regulator](https://www.bbc.com/news/health-67845678).

¹⁷⁵ NHS Resolution (23 July 2024) [NHS Resolution continues trend of resolving more cases without need for litigation](https://www.nhs.uk/news/2024/07/nhs-resolution-continues-trend-of-resolving-more-cases-without-need-for-litigation).

¹⁷⁶ NCOB (2022) [The role of technology in mental healthcare](https://www.ncob.org.uk/reports/the-role-of-technology-in-mental-healthcare).

¹⁷⁷ *Ibid.*

¹⁷⁸ GOV.UK (7 May 2024) [Update on pioneering initiative on regulation and evaluation of digital mental health technologies](https://www.gov.uk/government/news/update-on-pioneering-initiative-on-regulation-and-evaluation-of-digital-mental-health-technologies).

wellbeing.¹⁷⁹ A recent report by the House of Commons Education Committee drew particularly attention to potential harms to children and young people, such as exposure to cyberbullying, pornography, racism and misogynistic abuse, the links between social media and body dissatisfaction, and negative impacts on sleep habits and physical activity.¹⁸⁰

[Read our briefing note on the role of technology in the future of mental healthcare.](#)

Timeframe: <5yrs

Evidence:

- **Public / Commercial:** Research and news are saturated with apps to download and try for mental health support. They are commonly touted as ways to prevent crisis and reduce demand on NHS.
- To match this there is a boom in research attempting to look at their effectiveness and sustainability impact also – which is what regulators like NICE need to support recommendations and guidance
- **Regulatory:** As the effectiveness data comes in, there is mounting pressure to have governance on data privacy, particularly where data is collected and used to train AI for spotting warning signs etc.
- [New AI apps promise mental health support at a student's fingertips. But can you trust a chatbot? | CBC News](#)
- [Digital mental health technologies could save NHS time, says NICE \(digitalhealth.net\)](#)

35. Microbiome research

Our microbiome contains bacteria, viruses and fungi that live on and in us, making up to 1-3% of our body mass. Microbiome research is a thriving area which aims to understand the microbiome's role in the immune system, infant development,¹⁸¹ and the mechanisms of multiple diseases from Parkinson's disease to inflammatory bowel disease and cancer.¹⁸²

Research into the microbiome-gut-brain axis for example, aims to understand how gut microbiota might impact our mental health, behaviour and mood.¹⁸³ Growing interest in this field has been accompanied by the proliferation of direct-to-consumer microbiome tests and

¹⁷⁹ Imperial College London (7 February 2024) [Unveiling the Impact of Digital Technologies on Adolescent Mental Health](#) and King's College London (22 May 2024) [Self-harm and digital technology overuse in young people with lived mental health experience](#).

¹⁸⁰ House of Commons Education Committee (2024) [Screen time: impacts on education and wellbeing](#).

¹⁸¹ Shao Y *et al.* (2024) Primary succession of Bifidobacteria drives pathogen resistance in neonatal microbiota assembly *Nat Microbiol* **9**: 2570–82.

¹⁸² Wallen ZD *et al.* (2022) Metagenomics of Parkinson's disease implicates the gut microbiome in multiple disease mechanisms *Nat Commun* **13**: 1-20.

¹⁸³ Baske MM *et al.* (2024) Fecal microbiota transplant on Escherichia-Shigella gut composition and its potential role in the treatment of generalized anxiety disorder: A systematic review *J Affect Disord* **354**: 309-17.

the development of microbiome-based therapeutics.¹⁸⁴ Treatments already in use include dietary supplements and faecal transplants, which may offer an alternative to antibiotics in treating some bacterial infections.¹⁸⁵

Microbiome research reframes the human body as an ecosystem and raises questions about individuality, our place in our environments and our relationships with other species.¹⁸⁶ Ethical issues include how we manage identity, privacy and ownership in relation to microbiome data and commercial products. Regulatory challenges arise around standardisation, consumer safety and the evidence base for health-related claims made by commercial companies marketing microbiome products.¹⁸⁷

Timeframe: <5yrs

Evidence:

- **Commercial:** There is a huge amount of financial market interest in microbiome research after it has been touted as a way for scientists to find solutions to AMR and develop personalised medicines / therapies / diagnostics.
- **Political:** There is also global health interest with the UN Assembly doing a huge showcase on the potential for this research to combat malnutrition. Professor Jeffrey I. Gordon received the 2024 Nierenberg Prize for Science in the Public Interest and presented how his work can move from a proof of concept into a clinical application ‘in the coming years’.
- **Public / Commercial:** Some of the recent research investigating the links between microbiome and health is open access and source coding means it could be picked up and used by (nearly) anyone. There is no doubt that the boom linking microbes to health is making it into the public domain with people choosing to pay and test their microbiomes / invest in diet and lifestyle to improve it as a preventative measure. There is no state-paid way of testing and improving, which opens up equity issues and also suggest data collected could be limited in its diversity.
- <https://www.prnewswire.co.uk/news-releases/human-microbiome-market-to-hit-usd-4-206-million-by-2030-with-31-5-cagr--marketsandmarkets-302248855.html>
- <https://www.bbc.co.uk/future/article/20240913-the-hidden-kingdom-of-viruses-living-in-your-gut>
- <https://www.msn.com/en-gb/health/other/microbiome-science-could-revolutionize-fight-against-malnutrition/ar-AA1qyNXD?ocid=BingNewsVerp>
- <https://scripps.ucsd.edu/news/scripps-oceanography-selects-microbiome-researcher-jeffrey-i-gordon-2024-nierenberg-prize>

¹⁸⁴ The Lancet Gastroenterology Hepatology (2024) Direct-to-consumer microbiome testing needs regulation *Lancet Gastroenterol Hepatol* **9(7)**: 583.

¹⁸⁵ European Pharmaceutical Review (12 June 2024) [Developing the EU's first intestinal microbiota-based biologic](#).

¹⁸⁶ Ma Y *et al.* (2018) Help, hope and hype: ethical considerations of human microbiome research and applications *Protein Cell* **9(5)**: 404-415.

¹⁸⁷ Diane E. Hoffmann *et al.* (2024) The DTC microbiome testing industry needs more regulation *Science* **383(6688)**:1176-9 and The Lancet Gastroenterology Hepatology (2024) Direct-to-consumer microbiome testing needs regulation *Lancet Gastroenterol Hepatol* **9(7)**: 583.

- <https://www.nature.com/articles/s41467-024-51651-9>

36. Mitochondrial donation treatment

Mitochondria reside outside the cell's nucleus and carry their own DNA (mtDNA), which is inherited maternally. Mitochondria provide cells with energy they need to function properly, and errors in mtDNA can lead to serious, life-shortening disorders. Pioneering IVF techniques, developed in the UK can facilitate the replacement of faulty mtDNA with healthy mtDNA by isolating the nucleus of a patient's egg or embryo and transferring it into an enucleated donor egg, which contains healthy mitochondria, often referred to as mitochondrial replacement therapy (MRT).

In October 2015, UK parliament passed the Human Fertilisation and Embryology (Mitochondrial Donation) Regulations, making human mitochondrial donation treatment legal in the UK.¹⁸⁸

The HFEA has only granted a licence to one centre, Newcastle Fertility Centre and if a patient contacts the Centre for treatment, the Centre then need to apply to the HFEA for permission to treat.¹⁸⁹ In 2023, it was reported that at least one baby has been born using this technique.¹⁹⁰ The clinical research paper is yet to be published, meaning questions around the efficacy and follow-up of the procedure, as well as treatment and future-use remain. Researchers are also exploring whether this treatment might be helpful as a treatment for infertility, especially for older women.

The UK and Australia are the only countries with laws governing IVF that have legalised this procedure. Australia have not yet started to do it clinically but are gearing up to do so.¹⁹¹

[Read our work on mitochondria donation treatment.](#)

Timeframe: <5 years

Evidence:

- **Political:** This is a topic that has previously attracted huge political and regulatory interest. It is also an area where the UK leads with regards to its permissions and set-up for allowance of the technique to be used in a way the public suggested they were happy with.

¹⁸⁸ The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015 No. 572 (2015) [The Human Fertilisation and Embryology \(Mitochondrial Donation\) Regulations 2015 \(legislation.gov.uk\)](#).

¹⁸⁹ HFEA (n.d.) [Mitochondrial donation treatment](#).

¹⁹⁰ BBC news (9 May 2023) [Baby born from three people's DNA in UK first](#).

¹⁹¹ Monash University (2024) [The MitoHOPE Program](#).

- A research paper is imminent, and this will be of high interest to policy, government, research and public audiences. What it says will have implications for the tech going forward and highlight whether any further assessment is needed in its use / application.
- **Regulatory:** There is high regulatory interest with mitochondrial donation treatment featuring prominently in the most recent HFEA Scientific and Clinical Advances Advisory Group meeting - [Scientific and Clinical Advances Advisory Committee \(SCAAC\) - Matters arising - 7th October 2024 \(hfea.gov.uk\)](#)

37. Neural organoids

Neural organoids (NO) are small, lab-grown 3D structures that are made from stem cells to model different aspects of the developing brain. They offer researchers the opportunity to study human brain development and activity without the ethical and practical complications of experimenting on living brains inside human bodies.

Although today's neural organoids are evolving and becoming more complex, there are still substantial differences between them and the living human brain, and it is uncertain how well these organoids can model human brain function.¹⁹²

Current research applications include modelling fetal neurodevelopment, studying neurodegenerative conditions, exploring human brain evolution and pre-clinical drug testing. In the future, neural organoids may be used for personalised drug screening and modelling of an individual's disease progression, transplantation and regenerative medicine, and developing biocomputing technology.

As neural organoids become increasingly complex, ethical considerations relate to their ability to develop consciousness and sentience - and how we would monitor this, their moral and legal status, their potential to replace non-human animals in research, and informed consent for tissue donors.¹⁹³

[Read about our ongoing work in this area, including a briefing note, here.](#)

Timeframe: 5-10yrs

Evidence:

- **Expert:** Our published briefing note highlights key ethical concerns in this area, some of which are not too dissimilar from that of stem cell-based embryo models (SCBEMs). However, the similarity between a NO and a brain is much further away than that of a SCBEM and a gamete derived embryo.
- **Regulatory:** Those using them in research and funding are awake to the regulatory loophole and they have approached NCOB about guidance in this area. We will publish our recommendations in 2025.

38. Non-communicable diseases

¹⁹² NCOB (2024) [Neural organoids in research: ethical considerations.](#)

¹⁹³ *Ibid.*

Non-communicable diseases (NCDs) like cardiovascular disease, cancer and diabetes are responsible for 74% of all deaths globally.¹⁹⁴ Tobacco use, physical inactivity, air pollution, harmful alcohol use and unhealthy diets are all associated with a higher risk of NCDs.

In the UK, people from more deprived backgrounds are also more likely to suffer from NCDs.¹⁹⁵ Research suggests that many of these health inequalities will persist to 2040, based on current trends.¹⁹⁶ Interventions to reduce NCDs include the 'sugar tax', a levy applied to soft drinks to reduce sugar consumption and the prevalence of childhood obesity,¹⁹⁷ and the tobacco and vapes bill, which proposes prohibition of the sale of tobacco to people born on or after 1st January 2009 (alongside other restrictions).¹⁹⁸

These interventions highlight potential conflicts between individual freedoms and public health, and the complex relationship between the state and its citizens. In designing public health measures to reduce NCDs, tensions can arise between emphasising individual-level action and a systems approach that focuses on broader structural factors, global and national inequalities, health system drivers, and social determinants.

[Read more about our work on public health ethics here.](#)

Timeframe: <5yrs

Evidence:

- **Political:** The Government has been very clear, both before its election success and since that prevention is the cornerstone of their health policies.
[Labour's health mission must be radical – and much wider than the NHS – LabourList](#)
[How can a preventative approach to health and care help Labour deliver for patients? - New Statesman](#)
- The UK's life sciences vision (2024) healthcare missions focus on NCDs - dementia, cancer, obesity - [Life Sciences Vision Missions - GOV.UK \(www.gov.uk\)](#)
- Whereas the Conservative Government was sometimes unwilling to increase sugar taxes and reformulate manufacturing to reduce salt consumption as they felt this impinging on personal choice, the new Labour Government have not taken the same view. [Keir Starmer ready to face down 'nanny state' jibes in radical public health drive | Health policy | The Guardian](#)
- They have also stated that the NHS is broken and that reform / a shift to prevention is needed to mend it. They have suggested investment in digital, AI and other advancing technologies will help to achieve it.

39. Polygenic scores and indexes

¹⁹⁴ World Health Organization (16 September 2023) [Noncommunicable diseases](#).

¹⁹⁵ Office for Health Improvement & Disparities (2021) [Annex C: data on the distribution, determinants and burden of non-communicable diseases in England](#).

¹⁹⁶ The Health Foundation (2024) [Health inequalities in 2040: current and projected patterns of illness by deprivation in England](#).

¹⁹⁷ Gov.uk press release (5 April 2018) [Soft Drinks Industry Levy comes into effect](#).

¹⁹⁸ House of Commons (2023-24) [Tobacco and Vapes Bill 220](#).

There is growing interest in the application of Polygenic scores (PGS)* to predict a person's genomic likelihood of developing a certain condition or outcome compared to others in the population. Common health conditions (such as coronary artery disease and type 2 diabetes), behaviours (such as cognitive abilities and mental health) and social measures (such as educational achievement) do not have a single cause – they are associated with multiple genetic variants as well as environmental factors.¹⁹⁹

PGSs can capture a portion of this polygenic contribution by indexing the cumulative effect of multiple, individually low-impact genetic variants.²⁰⁰ While PGS can be good at detecting group-level differences, they – like all predictors – are probabilistic and not accurate for predicting individual-level risk (or resilience). This is because PGS do not index all genomic influences on a condition or outcome, and do not account for the effects of environment or lifestyle – that may modify or override genomic propensities.²⁰¹

Further, genomic research is biased toward participants of European genetic ancestry, and PGSs are currently less predictive (and so less accurate) for other genetic ancestries.²⁰² Research shows that even within a genetic ancestry, PGS accuracy can vary depending on sex, age or socioeconomic status.²⁰³ As a result, extrapolating PGSs from one population to another – whether in terms of environmental and social conditions or genetic ancestry – could lead to ineffective or even harmful interventions, with these risks disproportionately affecting already marginalised groups and individuals.

Despite these limitations, PGSs have received significant attention for their potential to drive a new era of “genomic prevention” and targeted interventions in healthcare, by informing screening and lifestyle recommendations,²⁰⁴ and may have future applications across social care,²⁰⁵ education and crime prevention.²⁰⁶ However, PGSs are only useful for individual-level prediction if the information can be translated into effective and equitable actions. In many cases, particularly for PGSs related to educational and mental health conditions, the processes linking polygenic liability to specific outcomes – and what actions can be taken to modify that risk – might be unknown.²⁰⁷

Research and development continues at pace, and the predictive accuracy and portability of PGSs might increase, especially when considered with other indicators. For instance, convergence with AI has also led to growing interest and investment in AI-powered genomic

¹⁹⁹ Polderman T *et al.* (2015) Meta-analysis of the heritability of human traits based on fifty years of twin studies *Nat Genet* **47**: 702–9.

²⁰⁰ National Human Genome Research Institute (n.d.) [Polygenic Risk Scores](#).

²⁰¹ Sud A *et al.* (2023) Realistic expectations are key to realising the benefits of polygenic scores *BMJ (Clinical research ed.)* **380**: e073149.

²⁰² Ding Y *et al.* (2023) Polygenic scoring accuracy varies across the genetic ancestry continuum *Nature* **618**: 774–81.

²⁰³ Mostafavi H *et al.* (2020) Variable prediction accuracy of polygenic scores within an ancestry group *Elife* **9**: e48376.

²⁰⁴ HM Government (2020) [Genome UK The future of healthcare](#), at page 29.

²⁰⁵ Kullo IJ *et al.* (2022) Polygenic scores in biomedical research *Nat Rev Genet* **23**: 524–32.

²⁰⁶ GOV.UK (2022) [Genomics beyond health: Full report](#).

²⁰⁷ Lewis ACF *et al.* (2021) Polygenic risk scores in the clinic: Translating risk into action *HGG Adv.* **2(4)**: 100047.

health prediction systems, and the potential for AI technologies to accelerate advances in polygenic scoring.²⁰⁸

As part of Our Future Health, the UK's largest health research programme, the NHS will offer 5 million people polygenic score reports. This work will generate vital evidence around the psychological, behavioural, and social impacts, and the potential clinical utility, of polygenic screening and personalised risk information.²⁰⁹

Lastly, the emergence of direct-to-consumer (DTC) PGS reports raises challenges related to regulation and standards, the commercialisation of genomic data, and new pressures on systems e.g. education if consumers seek professional support based on commercial tests results.²¹⁰

*also referred to as polygenic indexes (PGIs) for social and behavioural traits such as educational attainment and intelligence.

[Read our joint report on AI-powered genomic health prediction](#) and the interim report [DNAi](#).

Timeframe: 5-10 years

Evidence:

- **Commercial:** Polygenic embryo screening (PES) or PGT-P has been subject to significant commercial interest and a number of start-ups have been established in this space e.g. [Orchid | Whole Genome Embryo Report](#)
- **Regulatory:** PES is currently illegal in the UK and HFEA has shown no sign of changing regulations around this. They highlight the fact that PGT-P could also reduce chances of a healthy baby, as embryos that would be health may be deselected for use. [Embryo testing and treatments for disease | HFEA](#)
- Professor Anneke Lucassen gave a presentation on the use of polygenic scores at the third UK National Screening Committee (UK NSC) online seminar (2024) – this shows an awareness/interest by regulators. [Fascinating insight into potential benefits and limitations of using polygenic scores – UK National Screening Committee](#)
- **Public:** This has also caught the attention of media.
- [US startup charging couples to 'screen embryos for IQ' | Genetics | The Guardian](#)
- [How to make a superbaby — start by screening your embryos](#)
- PET dialogue with patients to find out their views on PES [Polygenic embryo screening – Patient perspectives and concerns](#). Concerns about anxiety, the illusion of control of child's health etc. raised.
- Recent public engagement conducted in the US (where polygenic embryo screening is largely unregulated) shows that a significant proportion of the public are concerned about the potential risks and impacts in society. [Study Reveals Public Opinion on Polygenic Embryo Screening for IVF | Harvard Medical School](#)

²⁰⁸ Ada Lovelace Institute and NCOB (2024) [Predicting: The future of health? Assessing the potential, risks and appropriate role of AI-powered genomic health prediction in the UK health system](#).

²⁰⁹ Our Future Health (31 March 2022) [Our Future Health supports Genome UK plan](#).

²¹⁰ Park JK and Lu CY (2023) Polygenic Scores in the Direct-to-Consumer Setting: Challenges and Opportunities for a New Era in Consumer Genetic Testing *J Pers Med.* **13(4)**: 573.

- **Expert:** Qualitative insights from our team working on PGS and AI-powered genomic health predictions.

40. Precision medicine

Precision medicine uses molecular information (genomic, transcriptomic, proteomic, metabolic) as well as phenotypic and environmental data about individuals to more accurately prevent, diagnose and treat diseases.²¹¹ It aims to shift from a traditional one-size-fits-all model of medicine to a more tailored, data-driven and effective approach.²¹² Precision medicine promises more efficient use of healthcare resources and better outcomes for patients - targeting screening, treatments and preventive actions to the populations who will benefit, whilst minimising unnecessary interventions for those who won't.²¹³ Other similar terms that are used for this approach include personalised medicine, individualised medicine, stratified medicine and P4 medicine (predictive, preventive, personalised and participatory).

Precision medicine encompasses gene and stem cell therapies, targeted genetic testing for at risk populations, biomarker testing, tumour profiling and tailored cancer treatments. For example, personalised mRNA cancer vaccines are being trialled across the UK with the aim of providing treatment for 10,000 patients by 2030.²¹⁴ Although most established in oncology, precision approaches are being explored across medicine for conditions such as asthma, cystic fibrosis and sepsis,²¹⁵ as well as a range of infectious diseases. Advances in high-throughput screening, genomics, AI and health data collection and storage are expected to enable further shifts towards precision medicine. The introduction of a regulatory framework tailored to point-of-care manufactured products is aimed at facilitating access to a range of personalised medicines, such as cell and gene therapies, across the UK.²¹⁶

Despite growing enthusiasm for precision medicine, there are concerns around equitable access, the evidence base for their widespread benefit and their broader societal impact.²¹⁷ A report on Fairness in Precision Medicines by Data&Society highlights two emergent biases: 1) "Bias in the building and analysis of datasets" - leading to poorer outcomes for populations historically underrepresented in biomedical research datasets, and 2) "Bias as the result of precision medicine research" – including an overemphasis on individual responsibility for health rather than structural interventions and the marginalisation of populations with poorer health literacy or who live in resource-poor areas.²¹⁸ Casgev, the first CRISPR gene-editing therapy to be licensed in the UK, shows the tensions between

²¹¹ European Commission (2017) [Personalised Medicine: Focusing on citizen's health](#).

²¹² NHSx (2019) [Artificial Intelligence: How to get it right](#), at page 76.

²¹³ Association of British Pharmaceutical In (2014) [Stratified medicine in the NHS](#).

²¹⁴ NHS England (31 May 2024) [Thousands of NHS patients to access trials of personalised cancer 'vaccines'](#).

²¹⁵ Wellcome Sanger Institute (18 June 2024) [Sepsis patients could get the right treatment faster, based on their genes](#).

²¹⁶ GOV.UK (25 January 2023) [UK to introduce first-of-its-kind framework to make it easier to manufacture innovative medicines at the point of care](#).

²¹⁷ The Health Foundation (11 September 2024) [Personalised prevention in England](#).

²¹⁸ Data&Society (2018) [Fairness in Precision Medicine](#).

cost and access to precision medicine.²¹⁹ The treatment, which is the only cure other than a bone-marrow transplant for sickle cell disease, costs over £1.65 million per patient. This has raised concerns about the likelihood of the treatment being available to the majority of people with the disease (75%) who are born in sub-Saharan Africa and India.²²⁰

a. Pharmacogenomics

Pharmacogenomics brings together pharmacology and genomics to study how a person's genome affects their response to medicines.

Adverse side effects pose serious risks to patients and place a significant burden on the NHS, accounting for one in 16 hospital admissions and costing £530 million per year.²²¹ Furthermore, it is estimated that standard drug intervention for patients with the same condition are only 30 – 60% effective due to individual differences in drug response.²²²

Pharmacogenomic testing offers an opportunity to optimise therapeutic interventions by identifying which variants of certain genes a person carries, and how this will influence their body's response to medication. If done at birth, an individual's pharmacogenomic profile could inform the drugs and dosages prescribed throughout their life, increasing the chance of effective treatment and reducing side effects.

Currently, outside of a few specific drug-gene pairings, pharmacogenomic testing is not widely utilised in the NHS. A 2022 report, '*Personalised prescribing: using pharmacogenomics to improve patient outcomes*', published by the British Pharmacological Society and the Royal College of Physicians calls for testing to be rolled out across the NHS, alongside necessary training and support for clinicians.²²³

The widespread implementation of pharmacogenomic testing raises ethical challenges around data storage and privacy, the fair distribution of limited public health resources and equitable outcomes.²²⁴ A recent study, examining the roll out of pharmacogenomic testing prior to treatment with chemotherapy fluoropyrimidine, showed that the test screens for four genetic variants more prominently found in Europeans, but not a fifth variant often found in African populations.²²⁵

Timeframe: 5-10 years

Evidence:

²¹⁹ The Pharmaceutical Journal (14 March 2024) [Gene-editing sickle cell drug not approved for NHS use in draft NICE guidance.](#)

²²⁰ Nature (17 July 2024) [Make gene therapies more available by manufacturing them in lower-income nations.](#)

²²¹ GOV.UK (13 February 2024) [Pioneering genetic biobank to start recruiting patients on stroke prevention medicines.](#)

²²² NHS England (2016) [Improving outcomes through personalised medicine.](#)

²²³ Royal College of Physicians and British Pharmacological Society (2022) [Personalised prescribing: using pharmacogenomics to improve patient outcomes. Report of a working party.](#)

²²⁴ *Ibid.*

²²⁵ Chan TH *et al.* (2024) DPYD genetic polymorphisms in non-European patients with severe fluoropyrimidine-related toxicity: a systematic review *Br J Cancer* **131**: 498–514.

- **Political:** Government has been clear in its focus on preventive healthcare, shifting the NHS from 'sickness to prevention'. Initial efforts seem to be focussed on widespread public health interventions and community care (e.g. tobacco and vapes bill).
- However, Wes Streeting highlighted precision medicine at labour party conference: "Advances in genomics and data mean the healthcare of the future will be more predictive, more preventative and more personalised than ever before. Detecting from birth a child's risk of disease so we can act to keep them well; spotting cancer earlier, saving countless lives; treating patients with targeted medicines."
- **Regulatory:** MHRA - Yellow card biobank – gathering genetic and patient samples to better understand adverse reactions to medication – was launched in 2023. [Pioneering genetic biobank to start recruiting patients on stroke prevention medicines - GOV.UK \(www.gov.uk\)](#)
- Regulatory framework for point-of-care manufactured therapeutics – including gene/stem cell therapies.
- Calls for NICE to reduce its discount rate from 3.5% to better evaluate long-term benefits of cell and gene therapies. [nice-methods-process-review-post-consultation-key-messages-february-2022 final.pdf \(abpi.org.uk\)](#)
- **Funding:** NHS England / DHSC have committed to investing in predictive genomic-based medicine [NHS England » Accelerating genomic medicine in the NHS](#)
- Genome UK: 2022 to 2025 implementation plan for England - [GOV.UK \(www.gov.uk\)](#)
- DHSC's rare diseases action plan highlights efforts to improve early genetic diagnosis, including the Generation Study – pilot WGS of 100,000 newborns to enable diagnosis of rare conditions started Oct 2024, and improved access to specialist care and advanced therapeutics.
- [Babies tested for over 200 genetic conditions as Trust joins world-leading study | Imperial College Healthcare NHS Trust](#)

41. Preconception screening

Prospective parents, particularly those with a family history of inherited medical conditions such as cystic fibrosis, sickle cell anaemia or thalassaemia, can have genetic testing before they conceive to find out if they are carriers. Testing is likely to become cheaper and more accessible, allowing anyone to test for a wider range of genetic conditions and features relatively cheaply – both on the NHS and private sector.²²⁶

Preconception expanded carrier screening (ECS) is a more comprehensive genetic screening for a broader range of conditions, targeted at 'healthy' individuals as opposed to known carriers. In the UK, this test is being offered in a direct-to consumer format,²²⁷ as well as through fertility clinics.²²⁸ The government's current position is that screening of this nature should only be mandatory in regulated cases such as particular assisted reproductive

²²⁶ HFEA (n.d.) [Pre-implantation genetic testing for monogenic disorders \(PGT-M\) and Pre-implantation genetic testing for chromosomal structural rearrangements \(PGT-SR\)](#) and Paternity for Life (n.d.) [Extended Carrier Screening - DNA Paternity Testing UK.](#)

²²⁷ Fertility Genetics (3 August 2020) [Pre-conception Extended Carrier Screening from home.](#)

²²⁸ PRECAS De Montfort University (2023) [The Research.](#)

techniques and surrogacy. Should there be limits on what people can test for? How should commercial screening be regulated?²²⁹ And could extended genetic screening become a requirement for gamete donors?²³⁰

Timeframe: 5-10 years

Evidence:

- **Political:** No recent Government or regulatory statements on this being an area of large concern. There does not appear to be any plans to encourage preconception screening to be done differently.
- **Regulatory:** The HFEA provides guidance to UK fertility clinics about donor screening however there is currently no national guidance in the UK specific to ECS, and no requirements for UK fertility clinics or gamete donors to carry out ECS.
- **Public:** There is public reaction to direct-to-consumer testing being increased and some claims for what can be tested for if you are willing to pay. If these pick-up pace / evidence emerges on damages or inequalities being increased, there could be calls for action.
- **Sector:** The Royal College of Obstetricians & Gynaecologists produced a scientific impact paper on ECS in 2024. They recognise that ECS is growing in use among patients seeking fertility treatment and gamete donors, therefore there is a need for clinicians to be aware of ECS, including the ethical risks. [The Use of Expanded Carrier Screening in Reproductive Medicine - Elson - 2024 - BJOG: An International Journal of Obstetrics & Gynaecology - Wiley Online Library](#)

42. Quantum technologies

Quantum technologies, defined as devices and systems which rely on quantum mechanics, to provide capabilities that 'classical' machines cannot, were identified as one of the critical technologies in the 2023 UK Science and Technology Framework.²³¹ Quantum computing has potential in the drug discovery space, by accurately modelling protein folding, molecular dynamics and drug interactions, for example, quantum computers could reduce the time and cost required for drug discovery.²³² The potential of quantum computing to analyse large scale genome data – more efficiently than traditional methods - means there are also potential implications for genomics and thus, personalised medicine.²³³

In order to deliver the 2023, National Quantum Strategy, the previous UK government introduced 5 missions. Mission 3 states that, 'by 2030, every NHS Trust will benefit from quantum sensing-enabled solutions, helping those with chronic illness live healthier, longer

²²⁹ NCOB (2017) [Non-invasive prenatal testing: ethical issues](#).

²³⁰ Capalbo A *et al.* (2024) Should we use expanded carrier screening in gamete donation? *Fertility and Sterility* **122(2)**: 220-7.

²³¹ Department for Science, Innovation and Technology (2023) [UK Science and Technology Framework](#).

²³² Gircha AI *et al.* (2023) Hybrid quantum-classical machine learning for generative chemistry and drug design *Scientific Reports*.

²³³ Durant TJS *et al.* (2024) A primer for quantum computing and its applications to healthcare and biomedical research, *Journal of the American Medical Informatics Association* **31(8)**: 1774–84.

lives through early diagnosis and treatment'.²³⁴ In their independent review of quantum infrastructure, the Royal Academy of Engineering recommended that 'for successful operation of infrastructure, government needs to consider key enablers such as sufficient provision of skills, appropriate development of standards and adequate regulation to ensure responsible and ethical innovation, including environmental impacts.'²³⁵ Given the possibility that quantum technologies will have very substantial processing power and data applications, e.g. for analysing genomic data, there is a need for evolving cybersecurity measures and securing health data will be crucial. The use of quantum technologies holds great promise. However, they are - and will likely continue to be - expensive and require specialised knowledge. This could lead to unequal access nationally and internationally, with wealthier countries that have the required infrastructure able to utilise the benefits and poorer countries at a disadvantage. There are also concerns around the energy requirements of quantum computing and its implications for the environment.²³⁶

Timeframe: 5-10 years

Evidence:

- **Political / Funding:** Quantum technologies have very clear political and funder interest. The UK government has unveiled a National Quantum Strategy with five ambitious quantum missions. However, much of the research and implementation for these technologies is very early stage and not ready for deployment.
- National Quantum Strategy: [National quantum strategy - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/consultations/national-quantum-strategy) Five new quantum research hubs backed by £100 million of government funding: [Over £100 million boost to quantum hubs to develop life-saving blood tests and resilient security systems - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/news/over-100-million-boost-to-quantum-hubs-to-develop-life-saving-blood-tests-and-resilient-security-systems)
- **Public:** Media coverage is largely focused on trying to explain the tech, suggesting the level of public awareness is low. E.g. What is quantum computing? Our science editor tries to explain: <https://www.thetimes.com/article/6e00a831-29e5-4674-8ecc-bd23f0355ac6?shareToken=b601c001ce0ae7ca5dc202d3b56b8759>
- **Sector:** The National Cyber Security Centre (NCSC) published a 2023 white paper calling for government, businesses and organisations to prepare for the quantum threat e.g. by transitioning to quantum-resistant algorithms. [Next steps in preparing for post-quantum cryptography - NCSC.GOV.UK](https://www.ncsc.gov.uk/next-steps-in-preparing-for-post-quantum-cryptography)
- [Announcement of Quantum Missions in the Autumn Statement pushes the UK towards real-world deployment of quantum technologies \(techuk.org\)](https://techuk.org/news/announcement-of-quantum-missions-in-the-autumn-statement-pushes-the-uk-towards-real-world-deployment-of-quantum-technologies)

43. Research culture

²³⁴ Royal Academy of Engineering (2024) [Quantum Infrastructure Review](#).

²³⁵ *Ibid.*

²³⁶ Gupta M and Lekkas A (2021) Energy use in quantum data centers: Scaling the impact of computer architecture, qubit performance, size, and thermal parameters *arXiv*.

The Royal Society defines research culture as ‘the behaviours, values, expectations, attitudes and norms of our research communities’, it shapes who is involved in research, what is researched, and how it is conducted and communicated.²³⁷

Concerns relating to research culture centre around inclusivity and equity, research integrity, barriers to collaboration and career longevity. Transparency, regarding what research is being conducted, how it is funded, and what the benefits are, is also key to accountability and building trust within the research community.²³⁸ Improving research cultures requires clear management systems, access to training and development, pathways to identify and address issues in working environments and support for collaborative working.

a. Research assessment

Calls to reform how academic research is ranked highlight a need to better recognise diverse outputs, include assessments of research culture and reduce harmful pressure on researchers.²³⁹ International collaborations, such as the Coalition for Advancing Research Assessment (CoARA) and the Declaration on Research Assessment (DORA), have established shared commitments and strategies for reform.²⁴⁰

The Research Excellence Framework (REF), which aims to assess the quality of research within UK higher education, has increased the weighting of ‘people, culture and environment’ for its next round in 2029.²⁴¹

b. Research equity and access

In an effort to widen access to research careers, UKRI, the UK’s largest public funder of research, has implemented narrative CVs in its funding applications. The narrative CV format encourages individuals to describe a wider range of relevant experience and skills than traditional CVs and is intended to support people with diverse backgrounds and career pathways.²⁴² Several other major funders, such as the NIHR and Wellcome, have launched strategies for research inclusion and greater diversity in their funding recipients.²⁴³

Recent proposals to update legislation for clinical trials have also commented on the importance of patient and public involvement throughout the design and management of trials.²⁴⁴ By involving patients and carers with lived experience in clinical research design and management, researchers can ensure research is relevant, improve participant recruitment and retention and address barriers to participation as early as possible. In relation to international research, there is an increasing emphasis on equitable

²³⁷ The Royal Society (2019) [Research culture: changing expectations – conference report](#).

²³⁸ Campaign for Science and Engineering (2024) [People’s Vision for R&D](#).

²³⁹ Nature (09 September 2024) [The human costs of the research-assessment culture](#).

²⁴⁰ CoARA (2022) [Agreement on Reforming Research Assessment](#) and DORA (n.d.) [San Francisco Declaration on Research Assessment](#).

²⁴¹ Research Professional News (27 March 2024) [Language of the REF reveals shifting expectations](#).

²⁴² UK Research and Innovation (3 June 2024) [Narrative CVs: what they are and why use them](#).

²⁴³ National Institute for Health and Care Research (14 December 2022) [Equality, diversity and inclusion strategy 2022-27 action plan](#) and Wellcome (n.d.) [Diversity and inclusion programme strategy](#).

²⁴⁴ Medicines & Healthcare products Regulatory Agency (2023) [Government response: Consultation on legislative proposals for clinical trials](#).

collaborations, overcoming barriers to research in resource-constrained settings (e.g. flexible fees and funding opportunities), decolonising research practices, and engaging with local knowledge.²⁴⁵

Despite promises of making research freely available, open-access publishing models, where the author pays an upfront publishing fee, risk creating prohibitive barriers to publication for researchers from less well-funded institutions, particularly in low- and middle-income countries (LMICs).²⁴⁶ In response to this, some journals offer waivers to researchers from LMICs and alternative not-for-profit models of publishing,²⁴⁷ such as ‘diamond’ open access where neither the readers nor authors are charged, are gaining interest.²⁴⁸

c. Research credibility

‘Publish or perish’ culture and a preference for novel positive results have been cited as drivers of questionable research practices.²⁴⁹ Recent concerns have centred around ‘paper mills’ and increasing numbers of fabricated research papers, retractions and fake citations in published work.²⁵⁰ In particular, the potential for generative AI to produce seemingly authentic scientific papers presents new challenges for peer review processes and trust in published research.²⁵¹ For clinical and biomedical research, this also has implications for patient health risks and treatment development.²⁵²

Timeframe: <5 years

Evidence:

- **Public:** REF reforms and potential changes attracted a huge amount of social coverage / debate from academics, universities and publishers. More news is expected on this within 5yrs.
- **Political:** It is hard to find specific mentions / plans across these three areas individually, but there is a lot of political conversation about how the UK’s research community and profession can be strengthened to keep the country ahead and to drive economic benefit. So, stands to reason that policies, approaches and guidance in all three of these areas could be expected alongside funding decisions, speciality support (e.g. seeking out more social scientists for responsible innovation) and Government research focus.

²⁴⁵ ESSENCE and UKCDR (2022) [Four approaches to supporting equitable research partnerships.](#)

²⁴⁶ Nabyonga-Orem J *et al.* (2020) Article processing charges are stalling the progress of African researchers: a call for urgent reforms *BMJ Global Health* **5**: e003650.

²⁴⁷ The Royal Society blog (31 August 2023) [The road to open access.](#)

²⁴⁸ The Guardian (16 July 2024) [Academic journals are a lucrative scam – and we’re determined to change that.](#)

²⁴⁹ Tukanova M *et al.* (2023) How can we overcome the barriers to researchers producing high quality, open research? *Octopus.ac* 1-16.

²⁵⁰ Committee on Publication Ethics and The International Association of Scientific, Technical and Medical Publishers (2022) [Paper mills research report with recommendations.](#)

²⁵¹ Májovský M *et al.* (2023) Artificial Intelligence Can Generate Fraudulent but Authentic-Looking Scientific Medical Articles: Pandora’s Box Has Been Opened *J Med Internet Res* **25**:e46924.

²⁵² Nature (18 July 2023) [Medicine is plagued by untrustworthy clinical trials. How many studies are faked or flawed?.](#)

44. Sports performance and competitive advantage

Sports performance can be affected by biomechanics, genomics, materials science, nutrition, pharmaceuticals, physiology, psychology, and surgery. Research has identified genomic variants associated with high performance; however, it is unclear how significantly these impact an individual's performance and if genotyping could be used to predict athletic ability or improve training.²⁵³

The World Anti-Doping Agency and other sports regulators have responded to the potential for 'gene doping', genome editing to enhance performance, by researching the development of 'gene doping' detection methods.²⁵⁴ Enhancements, such as genome-editing or steroids, also pose negative health risks – allowing them could increase pressure to use them and thus impact athletes' safety.

During the 2024 Olympics, questions around natural biological difference and what constitutes fair advantage were placed under the spotlight. Sex testing and regulations imposed on transgender athletes and those with differences of sexual development have implications for societal views of sex and gender and raise concerns around athletes' privacy and potential discrimination²⁵⁵.

Access to new technologies and what some term 'technological doping' also raises questions of fairness in relation to resources and funding.²⁵⁶ AI tools developed for talent identification aim to expand the reach of scouts and reduce geographical barriers, however, AI recruitment based on prediction of future potential and the subsequent allocation of opportunities also raise further ethical challenges.²⁵⁷

Timeframe: >10 years

Evidence:

- **Public:** The public reaction / media coverage to doping appears to be limited to pockets of time where there is a big sports event.
- **Regulatory:** International regulators (ITA) have referenced how testing needs to advanced and how they will keep samples for retesting:
<https://www.cbc.ca/sports/olympics/paris-olympics-doping-september-19-1.7327771>
- DCMS has an anti-doping framework from 2023-2026 (nothing under new Government) which makes no mention of gender or performative enhancement:

²⁵³ Psatha A *et al.* (2024) Meta-analysis of genomic variants in power and endurance sports to decode the impact of genomics on athletic performance and success *Hum Genomics* **18**: 47.

²⁵⁴ WADA press release (15 February 2023) [WADA invites applications for research projects on the development of gene doping detection methods.](#)

²⁵⁵ The Conversation (7 August 2024) [Imane Khelif's gold medal run shows how sex testing in women's sports puts regulators in an impossible bind](#) and Bowman-Smart H *et al.* (2024) World Athletics regulations unfairly affect female athletes with differences in sex development *Journal of the Philosophy of Sport* **51(1)**: 29-53.

²⁵⁶ The Conversation (18 July 2024) [Are running shoes getting too good? Why 'technological doping' is a growing concern for professional sports.](#)

²⁵⁷ Intel (29 July 2024) [Intel-Powered AI Platform Technology Might Spot Next Olympic Hopeful](#) and BBC News (9 August 2024) [The AI tech aiming to identify future Olympians.](#)

<https://www.gov.uk/government/publications/uk-anti-doping-framework-document-2023-2026/uk-anti-doping-framework-document-2023-2026>

- In the Labour manifesto they mentioned a commitment to widening access to sport, no mention of doping, gender impact or AI: <https://labour.org.uk/wp-content/uploads/2024/06/Labour-Party-manifesto-2024.pdf>
- UK Sport published a new strategy in 2024, which linked sports to our economy, but it has no mention of an approach to curb doping or regulate gender differences: <https://www.uk sport.gov.uk/news/2024/03/05/making-live-sport-matter---a-new-major-event-strategic-framework>

45. Surrogacy

Surrogacy is when a person becomes pregnant and bears a child on behalf of another person or couple, who then raise the child. It is used by some who are unable to carry a pregnancy to term (for clinical or other reasons) and offers the option to have a child that is genetically related to at least one parent through the use of their egg or sperm.

In the UK, surrogacy is only permitted if the surrogate mother is not paid, or only paid reasonable expenses. Only 400-500 cases are known to occur in the UK each year, but more people are going abroad and using the internet to make surrogacy arrangements, which creates legal uncertainties. The Law Commission recently published proposals to reform the law, including clarifying rules on payments to surrogates, safeguarding children born through international arrangements and establishing the intended parents' parental rights at birth.²⁵⁸ It will now be the decision of the Government to decide whether to adopt – in some form – these proposals.

[See our work on surrogacy.](#)

Timeframe: <5 years

Evidence:

- **Public:** There continues to be media attention on this topic suggesting a high amount of public awareness and interest. E.g. [‘The whole thing is a scandal’: The looming war over surrogacy](#)
- **Political:** Insights we have gathered through our stakeholder engagement indicate law reforms are likely to come up again in the next 5 years. [Surrogacy laws to be overhauled under new reforms – benefitting the child, surrogate and intended parents - Law Commission](#)
- [Surrogacy law reforms – “timid tinkering” or “nothing short of revolutionary?” - The Nuffield Council on Bioethics](#)

²⁵⁸ Law Commission (2023) [Building families through surrogacy: a new law.](#)

46. Sustainability of research, healthcare and systems

'Net zero' means our total emissions are equal to or less than the emissions we remove from the environment. The UK has a legally binding net zero target by 2050 and new interim targets to reduce emissions by 78% by 2035.²⁵⁹

The British Academy's *Governance for Net Zero* report cautions that achieving net zero will require a focus on governance to facilitate the urgent and decisive action needed for the UK to reach its target.²⁶⁰ In doing so, it highlights how the transition will require socio- and economic transformation, not just technological change, and the range of challenges faced by leadership to govern and sufficiently engage people in net zero.

It was clear from a recent NCOB policy workshop with key stakeholders, that there is a consensus that net zero targets are a positive but as organisations such as the NHS work to meet them, they *must* embed ethics as part of this pursuit.

a. The NHS

The NHS is well respected globally and should continue to utilise its reputation to illustrate good practice in terms of how to address climate change within the health sector. This includes through both mitigation (based on reducing related greenhouse gas emission) and adaptation (to ensure a resilient health system). Wider issues of overprescription may be compounded by a lack of information available at the point of prescription about environmental impact of specific drugs/interventions - this information exists, and might encourage more responsible prescribing decisions, but is not integrated systemically to facilitate it.

b. Supply chains

Sustainable procurement and sustainability within supply chains are seen as a significant area to target in the quest to tackle climate change. In 2021, the World Economic Forum, identified that a substantial number of companies can reduce their climate impact by decarbonising supply chains.

c. Laboratory research

Wet labs, computational research and clinical trials have a significant carbon footprint. Wet labs for example, can rely on energy-intensive equipment like incubators, fume hoods and freezers. A Wellcome and RAND Europe report identifies 146 tools to measure and mitigate these types of impacts.²⁶¹

Timeframe: <5 years

Evidence:

²⁵⁹ House of Commons (12 November 2021) [Global net zero commitments](#).

²⁶⁰ The British Academy (2024) [Governance for Net Zero](#).

²⁶¹ RAND Europe, Prepared for Wellcome (2023) [Advancing Environmentally Sustainable Health Research](#).

- **Political:** Target deadlines are fast approaching with policy and political figures being vocal about the difficult decisions needed to meet them.

[Greener NHS » Delivering a net zero NHS](#)

[Greener NHS » Delivering a 'Net Zero' National Health Service](#)

- **Public:** Patient and public concern are captured in the media as people consider how to best access the care and support they need. [Reform UK criticised for claiming funding NHS and reaching net zero are at odds | Reform UK | The Guardian](#)
[Going green: what do the public think about the NHS and climate change? - The Health Foundation](#)

47. The built environment

The built environment refers to all the human made parts of where we live. The UK built environment is responsible for approximately 25% of total UK greenhouse gas emissions.²⁶²

A 2022 Environmental Audit Committee report argued 'whole-life carbon assessments' are a potential solution and are widely supported as a way to transition to a low-carbon built environment.²⁶³

Nature based solutions, such as increasing accessible green spaces also have health benefits such as improving air quality, reducing temperatures from global warming and promoting physical and mental health.²⁶⁴ However, in the UK there are clear inequalities in access to green spaces, especially within socioeconomically deprived areas²⁶⁵.

Green and blue corridors are another initiative. Green corridors are segments of natural vegetation that run through urban areas. Blue corridors seek to enable water to act in natural ways in urban settings. Whilst they have not been made legally binding, they are increasingly being integrated into urban planning frameworks.

Timeframe: <5 years

Evidence:

- Policies, funding, regulations and public interest are converging around the need for sustainable transformation for urban design and housing. Some policies have a focus on whole-life carbon reductions, energy efficiency and the integration of green spaces in urban planning.
- **Political / Regulator:** The government's Future Homes Standard will require new build homes to be future-proofed with low carbon heating and world-leading levels of energy efficiency - it will be introduced by 2025: [The Future Homes Standard: changes to Part L and Part F of the Building Regulations for new dwellings - GOV.UK \(www.gov.uk\)](#)
- The London Plan Policy S2 (Whole life-cycle carbon assessments): The London Plan already mandates WLC assessments for major projects. This regulation requires

²⁶² House of Commons Environmental Audit Committee (2022) [Building to net zero: costing carbon in construction](#).

²⁶³ *Ibid.*

²⁶⁴ Lancet Countdown on Health and Climate Change (2023) [Policy Brief for the UK](#).

²⁶⁵ [Inequalities in access to green space - The Health Foundation](#)

developers to assess the carbon impacts of a building across its lifecycle, from construction through to demolition:

london.gov.uk/sites/default/files/the_london_plan_2021.pdf#page=357

- **Funding:** E.g. Great British Insulation Scheme (GBIS): Launched in July 2023, GBIS is a £1 billion initiative running until March 2026. It aims to improve energy efficiency in homes through various insulation measures: [Great British Insulation Scheme | Ofgem](#).

48. The Wellness Agenda

The Global Wellness Institute defines wellness as “the active pursuit of activities, choices and lifestyles that lead to a state of holistic health”.²⁶⁶ This is a rapidly growing area; the wellness industry is estimated to be worth \$6.3 trillion this year and forecast to grow to \$8.5 trillion in 2027.²⁶⁷

The industry encompasses everything from meditation retreats and spas to dietary supplements and mindfulness apps. A significant aspect of the wellness agenda involves self-tracking and the collection of data on various aspects of everyday life, including sleep, steps, exercise, diet, menstruation and mood, in order to better understand and optimise wellbeing. Digital self-tracking is facilitated by mobile apps and wearable technologies such as smart watches, which can monitor step count and heart rate, and biosensors that can measure optimal hydration levels by identifying molecular markers in sweat.²⁶⁸

The wellness agenda intersects with advances in biomedical research and understandings of what contributes to health and longevity. This can be seen in fasting diets to reduce ageing and the proliferation of direct-to-consumer (DTC) wellness tests that promise to inform customers’ lifestyle choices based on their genome, microbiome, metabolism or hormones. Wellness products, such as wearables, mobile apps and DTC tests, offer an opportunity to empower users with information about themselves and interventions to improve their health and wellbeing. However, these technologies are not classed as medical devices and are not subject to the same regulations and oversight. Concerns have been raised about accuracy,²⁶⁹ the evidence base of wellness claims,²⁷⁰ and how companies trade and safeguard personal data, particularly in the cases of genomic data and the intimate reproductive data collected by female mobile health apps.²⁷¹ Wearable technologies also risk reproducing existing inequalities for example, they are less commonly used by low-income

²⁶⁶ Global Wellness Institute (n.d.) [What is Wellness?](#)

²⁶⁷ Forbes (20 November 2023) [The Future Of Wellness: New Data On Wellness Travel, Mental Wellness](#).

²⁶⁸ Brunel University of London (26 February 2024) [Your smart watch isn't a medical device – but it is tracking all your health data](#).

²⁶⁹ Science and Technology Committee (22 June 2021) [MPs urge Government to review regulations for direct-to-consumer genetic testing](#) and The Lancet (2024) Direct-to-consumer medical testing: an industry built on fear *The Lancet* **404(10457)**: 991.

²⁷⁰ The Guardian (18 May 2024) [‘Personalising stuff that doesn’t matter’: the trouble with the Zoe nutrition app](#).

²⁷¹ LSE blog (14 December 2022) [Rethinking Explicit Consent and Intimate Data Collection: The Looming Digital Privacy Concern With Roe v. Wade Overturned](#).

and other marginalised communities, and features such as heart rate monitoring have been shown to be less effective on darker skin.²⁷²

Timeframe: 5-10 years

Evidence:

- **Political:** Limited political interest, perhaps in terms of shift from ‘hospitals to community’ and how remote monitoring / wearable technologies can facilitate this. Labour manifesto also mentions improving/protecting access to sports for school children, although this relates more to PE etc.
- **Regulatory:** Limited regulatory interest.
- **Commercial:** Huge commercial interest in this area – the wellness industry is growing rapidly.
- **Public:** Wearables/mHealth apps are widespread in the UK and wellness innovation and claims receive significant media attention / often make headlines.
- [Wearable fitness trackers are making us anxious—here’s how to stop it \(nationalgeographic.com\)](#).
- [Breast milk for adults: wellness elixir or unscientific fascination? | Well actually | The Guardian](#)

49. Whole population mental health services

Mental health is the expression of a complex interplay of biological, psychological and environmental factors. Poor physical health, stress, trauma, poverty, isolation and discrimination are all risk factors for mental illness.²⁷³

In the UK, demand for mental health support has grown significantly over the past decade. Since 2016, the number of people in contact with NHS mental health services has grown from 2.6 to 3.6 million people.²⁷⁴

Attention has also been drawn to population-wide inequalities in mental health. Some groups, such as women, LGBTQ+ people and those not in employment, are more likely to have a mental health condition.²⁷⁵ Inequalities in access to and provision of care also means that some demographics, such as ethnic minority groups, are less likely to access early-stage treatment and more likely to experience acute, high security care.²⁷⁶

In 2023, NHS England launched its first anti-racism framework, the Patient and Carer Race Equality Framework, to reduce racial inequality in mental health services.²⁷⁷ Recently, reforms to the Mental Health Act, which was created over 40 years ago, have also been

²⁷² Colvonen PJ *et al.* (2020) Limiting racial disparities and bias for wearable devices in health science research *Sleep* **43**(10).

²⁷³ Public Health England (2019) [Mental health: environmental factors](#).

²⁷⁴ Darzi A (2024) [Independent investigation of the National Health Service in England](#).

²⁷⁵ The King's Fund (21 February 2024) [Mental health 360: inequalities](#).

²⁷⁶ Centre for Mental Health (2020) [Mental health for all? The final report of the Commission for Equality in Mental Health](#).

²⁷⁷ NHS England (2023) [Patient and carer race equality framework](#).

proposed. The government has committed to modernising the act, aiming to address concerns around the increased detention of people with autism or a learning disability and the disproportionate detention of black people.²⁷⁸

Timeframe: <5yrs

Evidence:

- **Political:** There is a huge amount of focus coming from the Government, patient groups and health care professionals on what needs to change to make population-level access to mental health services and treatment within them more equitable. News is saturated with it and the tone is one of alarm and urgency.
- King’s speech announcements from new Government have been well received by key stakeholders (e.g. Dr Sarah Hughes, chief executive of Mind, hailed the reforms as a “once-in-a-generation opportunity”) suggesting that the alterations being proposed are supported by those closest to those impacted
<https://www.independent.co.uk/news/uk/people-theresa-may-bill-labour-conservative-b2581249.html>
- Health leaders are calling for fast action, suggesting pressure on the Government is not going to reduce and there is professional concern as well as from patient groups.
[New Mental Health Act statistics show urgent need for reform | UK Healthcare News \(nationalhealthexecutive.com\)](https://www.nationalhealthexecutive.com/news/new-mental-health-act-statistics-show-urgent-need-for-reform-uk-healthcare-news)
- **Funding:** Reporting on the effectiveness of NHS England’s 2023 plans will pick up pace soon and depending on what it shows, there could be calls for mental health provision to be one of the areas for funding reform.

50. Xenotransplantation

In 2024, a genome-edited pig liver was transplanted into a human patient for the first time.²⁷⁹ This follows the transplantation of two pig kidneys and two pig hearts into human recipients since 2022.²⁸⁰ These procedures have utilised advancing genome editing technologies to improve compatibility with humans and to reduce the risk of infection,²⁸¹ however, all four recipients died within 8 weeks of their surgeries.²⁸²

Xenotransplantation could address ongoing shortages of donor organs,²⁸³ particularly for ethnic minority patients who are less likely to find well-matched donors on organ donor registers.²⁸⁴ However, this raises ethical questions around who is recruited to participate in

²⁷⁸ House of Commons (2024) [Reforming the Mental Health Act](#).

²⁷⁹ PET BioNews (3 June 2024) [World's first successful pig-to-human liver transplant](#).

²⁸⁰ The New York Times (9 July 2024) [Second Patient to Receive a Genetically Modified Pig Kidney Has Died](#).

²⁸¹ Harvard Medical School (21 March 2024) [In a First, Genetically Edited Pig Kidney Is Transplanted Into Human](#).

²⁸² PET BioNews (3 June 2024) [World's first successful pig-to-human liver transplant](#).

²⁸³ House of Lords (6 December 2023) [Organ donation in England and the UK: Statistics and law changes](#).

²⁸⁴ All-Party Parliamentary Group: Ethnicity Transplantation and Transfusion (2023) [Where are our nations donors?](#).

xenotransplantation trials and the vulnerability of patients with limited treatment options.²⁸⁵ Ethical considerations also relate to concerns about animal welfare, opposition to (and legal regulation of) genetic engineering, public perception and environmental impact.²⁸⁶ The fact that pigs are the animals most likely to be donors also poses problems for some religious groups.²⁸⁷

Timeframe: 5-10 years

Evidence:

- **Political:** No government department has (recently) hailed it as a way to assist in medical options for marginalised groups or those awaiting transplants.
- **Funding:** There is no active funding pipeline. Conversations focus on whether people would accept this as a way to save lives and whether those with animal organs would be treated differently.
- **Regulatory:** The regulator in this space was disbanded in the early 2000s, with responsibility transferred to the HTA, but the move was not accepted by all. We know through speaking to HTA and others that there is regulatory and Government interest in refreshing their understanding and knowing where the science stands now, and what its potential looks to be (including bioethical implications).
- **Expert:** The scientific community appears somewhat divided on how quickly xenotransplantation will be viable and at what pace we should be moving for human-based trials. However, there is a lot of excitement and interest in the area.
- There is more consensus in models placed in 'in vivo' environments having substantial benefit for research and less belief that we can successfully mitigate the immunology risks of whole organ transplants.
- **Expert:** In 2022, there was a symposium on the science and ethics of xenotransplantation (first of its kind in the UK for 20 years) - <https://jme.bmj.com/content/50/9/585>

51. Zoonotic diseases

Zoonotic diseases can be transmitted between animals and humans, either by direct contact or via a vector (such as ticks and mosquitoes), and represent a major global health challenge. For example, rabies, Ebola and HIV all began as zoonosis, and it is estimated that 75% of emerging diseases have zoonotic origins.²⁸⁸

²⁸⁵ Chisholm-Burns M *et al.* (2024) Xenotransplantation could either be a friend or foe of healthcare equity *Commun Med* 4: 1-3.

²⁸⁶ Haddow G (2021) 'Dirty pigs' and the xenotransplantation paradox *Med Humanit* 47: 417-24 and Fedson S *et al.* (2024) Ethical considerations in xenotransplantation of thoracic organs – a call for a debate on value based decisions *The Journal of Heart and Lung Transplantation* 43(7): 1033-8.

²⁸⁷ BBC News (11 January 2022) [Three ethical issues around pig heart transplants.](#)

²⁸⁸ Animal and Plant Health Agency blog (6 July 2024) [World Zoonoses Day: Tackling the challenge of vector-borne diseases.](#)

Zoonotic disease outbreaks are linked to human activities such as urbanisation, deforestation, hunting and wildmeat consumption.²⁸⁹ Some research suggests that a three-way interaction between humans, animals and growing volumes of plastic pollution may be worsening the spread of zoonotic pathogens.²⁹⁰

The impacts of climate change are also being explored. A 2023 UK Health Security Agency report on *Health effects of climate change in the UK* highlights the growing risk of vector-borne zoonoses such as West Nile virus, Zika virus and dengue fever in the UK as temperatures rise.²⁹¹ Warmer climates prolong the transmission season and expand the geographic spread of vector-borne diseases that have previously been confined to tropical or sub-tropical areas. Inconsistent rainfall and droughts increase the prevalence of standing water providing more breeding sites for vectors, and flooding is related to increased spread of waterborne zoonoses.²⁹²

One Health has been adopted as a key approach in managing zoonotic disease. It aims to combine disciplines and agencies to promote the health of humans, animals and our shared environment, recognising that they are all closely linked and interdependent.²⁹³ Major pandemics, such as COVID-19, underscore the need for global efforts towards data-driven pathogen surveillance, detection and preparedness.²⁹⁴ As well as the health impacts on humans and non-human animals, zoonotic diseases can negatively affect livelihoods through the disruption of food production and countries' economies.

Timeframe: <5 years

Evidence:

- **Public:** Recent outbreaks of mpox and avian flu have been extensively covered in media – significant public awareness, especially as cases spread to Europe.
- First case of mpox confirmed in UK - [UK confirms first case of clade Ib mpox | The BMJ](#)
- **Regulator:** UKHSA highlights increasing risk of certain zoonotic diseases due to climate change and increased temperatures.
- There is also a lot of talk from UKHSA scientists (and related international agencies) about prep work on dealing with 'disease X' which could be zoonotic and could cause the

²⁸⁹ Food and Agriculture Organization of the United Nations (2020) [Global emergence of infectious diseases: links with wild meat consumption, ecosystem disruption, habitat degradation and biodiversity loss](#).

²⁹⁰ Maquart P *et al.* (2022) Plastic pollution and infectious diseases *The Lancet Planetary Health* **6(10)**: E842-5 and Ormsby *et al.* (2024) Can plastic pollution drive the emergence and dissemination of novel zoonotic diseases? *Environmental Research* **246**: 1-7.

²⁹¹ UK Health Security Agency (2023) [Health effects of climate change \(HECC\) in the UK: 2023 report. Chapter 8: Direct and indirect effects of climate change on vectors and vector-borne diseases in the UK](#).

²⁹² Rupasinghe R *et al.* (2022) Climate change and zoonoses: A review of the current status, knowledge gaps, and future trends *Acta Tropica* **226**: 1-13 and Wellcome (14 May 2024) [How climate change affects vector-borne diseases](#).

²⁹³ European Commission (2017) [A European One Health Action Plan against Antimicrobial Resistance \(AMR\)](#), at page 4.

²⁹⁴ Hill R *et al.* (2024) Realising a global One Health disease surveillance approach: insights from wastewater and beyond *Nat Commun* **15**: 1-6.



next pandemic.

[New lung-infecting 'mink' virus poses 'pandemic risk', say scientists warning of 'zoonotic soup' of killer bugs | The Sun](#)

- [UK's next pandemic is already here - and it's keeping scientists up at night \(msn.com\)](#)
- [UK secures more vaccines to help boost resilience against mpox - GOV.UK \(www.gov.uk\)](#)