NUFFIELD COUNCIL[™] BIOETHICS

Long list of topics for 2023 'What's on the horizon?' infographic

Contents

	Prioritisation in the NHS	10
	Racial inequalities in health	10
	Medical tourism	10
	Gender identity	10
	Disagreements in patient care	11
	Experimental medical treatments	11
	Assisted dying	11
	Treatments for biological ageing	12
	Microbiome research	12
	Epigenetics	12
	Polygenic risk scores	13
	The science of learning	13
	Sports enhancement	13
	Xenotransplantation	13
	Cryonic freezing after death	14
Data and technology		
	Artificial intelligence (AI)	14
	Artificial intelligence in healthcare	14
	Virtual and augmented reality in healthcare	15
	Health data and research	15
	Digital twins	15
	Robotics in healthcare	15
	Wearable technology	16
	Medical implants	16
	Technology in mental healthcare	16
	Technology in social care	17
	Novel neurotechnologies	17
	Bioengineering	17
	Nanotechnology	18
	Identification biometrics	18
	Forensic DNA phenotyping	18
	Dual use technologies	18
A	nimals, food and environment	19
	Environment and health	19
	Biosafety	19

Cultured human milk	19
Gene drives	20
Animal research	20
Genome editing in farmed animals	20
De-extinction	21
Research ethics	21
Participant-led research	21
Culture of research	21
Research in areas of controversy	21
Equity in the development of medicines and therapies	22
Brain surrogates	22
Fetal tissue research	22
Embryo research	22
Synthesizing entire human genomes	23
Clinical research in pregnancy	23
Military biomedical research	23
Biotechnological patents	23

Beginning of life

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 in the NHS and private sector. Should there be limits on what people can test for? How should commercial screening be regulated? And could extended genetic screening become a requirement for gamete donors?

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. 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. The emergence of private sector companies offering egg freezing has sparked debate about the cost and accessibility of this 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, raising questions about informed consent. If egg freezing success rates improve, it might enable more people to become parents at an older age, with possible consequences for their and their children's health and for the social and cultural meanings of motherhood, parenthood and ageing. Read our briefing note on egg freezing.

In vitro derived gametes

Mouse sperm and eggs 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 in vitro could offer a route to parenthood for infertile couples or individuals, same-sex and single parents and older women who want to have children who are genetically related to them. It could also hold potential to increase the supply of gametes for research. 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. Therefore, raising questions about the status and significance of genetic relatedness and parenthood.

Genome editing in human reproduction

Heritable (or germline) genome editing, where DNA is edited in a way that can be inherited by the patients' descendants, has provoked intense ethical deliberation amongst scientists and the public. This was catalysed when a scientist in China edited the genome of twin girls without proper ethical or safety oversight. He was imprisoned for three years and released in 2022. At the Third International Summit on Human Genome Editing in 2023, scientists agreed that heritable genome editing is not ready for use in humans and should only be used after rigorous testing with sufficient regulatory oversight. Whilst genome editing of human embryos for research has been permitted in the UK since 2009, it is currently illegal to use genome editing in human embryos with the aim of establishing a pregnancy. There are currently no plans for this to change, but the Human Fertilisation and Embryology Authority (HFEA) is considering how the HFE Act might apply to this technology in the future. Read our report on genome editing and human reproduction.

Whole genome sequencing of embryos and fetuses

The NHS has recently started offering rapid prenatal whole exome sequencing (RP-WES), to detect certain genetic conditions by reading the fetus's DNA and comparing it with the parents'. As with the genome sequencing of newborn babies, key ethical issues include informed consent and the difficulty of dealing with uncertain or potentially inaccurate results, as well as the current capacity of health professionals to guide and support patients. As with other forms of screening, this could identify opportunities to treat or prevent serious conditions, but also raises questions about what should be screened for, and society's view of disability.

Artificial wombs

Researchers have been able to keep premature lambs alive in artificial wombs for several weeks. If applied successfully in humans, this could help support infants born prematurely, and raise questions about when a fetus might be considered viable. There is also speculation that '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. Yet, they could also make it possible for gay or single men to have genetically related children without the need for surrogacy. Some think it could also have significant effects on the balance of childcare between men and women and potentially increase gender equality.

Womb transplants

Womb transplants are a possible option for people who are unable to get pregnant because their uterus is not present or not functioning, potentially contributing to reproductive autonomy. Concerns have been raised about health risks for donors and recipient women, as well as long term health risks for the resulting children, e.g. arising from the use of immune-suppressing drugs, though clinical trials have not detected specific risks for children so far. As an experimental procedure, ethical issues centre around consent to the procedure and to donation. Recently, researchers have considered whether trans women might receive womb transplants. Although this poses surgical challenges, it has been argued that it would make this treatment, and pregnancy, accessible to a more diverse group of people.

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 biogenetically related to at least one parent through the use of their egg or sperm. 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. <u>Read our policy briefing on</u> <u>surrogacy law here.</u>

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. 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 the existing law in the UK, 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.

Fetal intervention

Surgical interventions can be performed on fetuses *in utero* to manage lifethreatening conditions and prevent disability, for example to repair heart valves, drain blocked bladders, and correct diaphragmatic hernia. These interventions 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 concerning conditions for which fetal interventions might be a treatment option?

Whole genome sequencing of newborn babies

Genomics England has established a Newborn Genomes Programme, to study the benefits, challenges and feasibility of sequencing all babies at birth within the NHS. If rolled out to all newborns and their parents, this will create an enormous dataset of genetic information. Whole genome sequencing of seriously ill babies can have immediate benefits in terms of diagnosis and treatment. But with a programme aimed at all babies, uncertain results, false positives or markers for adult-onset diseases which are currently untreatable may cause confusion and anxiety for parents and children. Questions have also been raised about the capacity of children to consent to sequencing and the retention of data, which may shift as they grow older. As with any screening programme, it may also have effects on how society views difference and disability. Read our briefing note on whole genome sequencing of babies.

Surgery in intersex infants

People born with variations in sex characteristics may undergo surgery during infancy, before being able to consent to medical treatment. While, on some occasions, surgical procedures are necessary to avoid long-term risks to an individual's health, a significant number of interventions are performed primarily for cosmetic reasons, for example to normalise the appearance of genitals. Should

cosmetic surgery for intersex infants be delayed until they are able to decide for themselves, and what would be the implications of that for the child?

Mitochondrial transfer treatment

Mitochondrial transfer treatment is being trialled as an option to prevent severe diseases of the mitochondria, which are part of the cell, being passed on to children. In this technique, an egg from a donor with healthy mitochondria, or an embryo created with a healthy donor egg, has its nuclear genetic material removed and replaced with that of the intended mother or parents, before being fertilised and implanted in the intended mother's womb. This treatment has been legal, under strict guidelines, in the UK since 2015, but it is not yet known how many children have been born following mitochondrial transfer treatment in the UK, and whether the treatment has been effective in these cases. Researchers are also exploring whether this treatment might be helpful as a treatment for infertility, including especially for older women.

Ovarian tissue cryopreservation and transplantation

Ovarian tissue can be excised through laparoscopy, then transplanted later. This was originally developed as a method of fertility preservation for cancer patients. A few commercial companies are offering ovarian tissue cryopreservation and transplantation (OTCT) as an elective procedure to delay menopause, aiming to postpone symptoms and potentially extend fertility. However, this is an expensive intervention, there is a lack of research into the efficacy and safety of this intervention for 'treating' menopause, and there is no evidence that it is more effective than other, less invasive, alternatives such as hormone replacement therapy (HRT). Promises to extend fertility also overlook the greater likelihood of complications in pregnancy later in life and the social and relational reasons why someone may not have had a child younger.

Health and society

Public health emergencies

In a public health emergency, interventions should aim to prevent suffering, protect people's rights to respect and fairness, and be proportionate to the threat involved. Governments and policymakers need to be careful about preventing misinformation about diseases and their treatment and negative associations between specific diseases and communities. Questions of equity also arise when decisions are made about distribution of resources and the longer-term effects of dealing with emergencies on the healthcare system. The World Health Organization (WHO) has declared the COVID-19 pandemic to no longer be a global health emergency. Further pandemics are expected and agencies are monitoring new threats such as mpox and avian flu. Preparedness is crucial for the short-term response and longer-term recovery; this should include 'ethical preparedness' to help guide the difficult decisions that emergencies necessarily entail. Read more about our work on COVID-19.

Zoonotic diseases

Zoonotic diseases jump from other vertebrate species to humans and represent a major public health problem. For example, rabies kills 60,000 people a year, while others have caused global pandemics, like HIV and COVID-19. As well as the health impact on humans and other animals, zoonotic diseases can negatively affect livelihoods through the disruption of food production and countries' economies. Zoonotic diseases can spread to humans through any contact with infected animals; this is complicated by the use of antibiotics in farming, which increases exposure to pathogens that are resistant to antibiotics. Urbanisation and the associated destruction of wild habitats increases contact between humans and animals and therefore the risk of infection. 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 the environment, though some point out that, in reality, human health tends to be prioritised, leading, for example, to mass culls of healthy animals.

Vaccinations

The highly successful roll-out of COVID-19 vaccination demonstrates the importance of making vaccination simple and convenient to access, as well as the promise of mRNA vaccinations and other nucleic acid technologies. Vaccination programmes depend on agencies working together, striving to reach those who find it harder to access healthcare or who are hesitant about vaccinations. They also show the ethical dilemmas that vaccination can bring about, in terms of balancing the rights of an individual versus the benefits to public health. In 2021, the WHO approved roll-out of the first malaria vaccine in Africa, and in October 2023, a second malaria vaccine received WHO approval. However, large-scale distribution of these vaccines depends on them being effective and cheap. Globally, vaccines are still not reaching those who need them and the WHO has announced The Big Catch-Up, to try and reach children who missed immunisations during the coronavirus pandemic. Read more about our work on vaccination.

Health screening

Whole populations are offered health screening throughout life for diseases such as cystic fibrosis and cancer. Early diagnosis can enable earlier intervention, reducing morbidity and mortality. For individuals, ethical issues centre around informed consent and the potential for over-diagnosis, over-treatment, anxiety, stigma, and false negatives. On a population level, issues include resource allocation, fairness and equity of access. The UK government recommends caution about private screening and has a regularly updated list of recommendations for people seeking tests. People who have tests in the private sector may then present in the NHS, sometimes on the basis of uncertain results. Private screening can also exacerbate health inequalities. The potential for genome sequencing to be utilised in more screening programmes in future raises questions about what results and information should be returned or withheld, how much uncertainty people are willing to accept, and whether screening should be motivated solely by the benefit of the screened individual or also their family, the NHS and wider society.-Read more about our work on screening.

Non-communicable diseases

Non-communicable diseases (NCDs) like cardiovascular disease, cancer and diabetes represent 71% of all deaths globally. 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 more likely to suffer from NCDs. In England, where 6.8 million people have cardiovascular disease, this condition seems to be contributing to a slowing down of improvements in life expectancy. The UK government's Global Health Framework includes tackling NCDs through investing in research and development and strengthening health systems. NCDs raise complex questions about the relationship between the state and its citizens and the responsibilities of individuals towards each other. In designing interventions, 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 of NCDs. <u>Read our work on public health ethics.</u>

Antimicrobial resistance

The emergence and spread of drug-resistant pathogens (bacteria, viruses, fungi, and parasites) threatens our ability to treat common infections. The drivers of antimicrobial resistance (AMR) cited by the WHO include the misuse and overuse of antimicrobials, poor infection and disease prevention and control in health-care facilities and farms, lack of awareness and knowledge, and lack of enforcement of legislation. AMR raises ethical questions such as who should have access to antibiotics, whether the physician's moral duty is towards the patient's current need or toward potential future patients, and whether our current use of antibiotics should be restricted out of consideration of future generations.

Mental health and wellbeing

There is increasing attention on the need to promote wellbeing, build resilience and prevent mental health problems. A person's mental health can change over time, with periods where they may struggle and other times when they feel well. Environmental factors such as trauma, isolation, poverty and discrimination are risk factors for poor mental health. Public mental health interventions that seek to mitigate these factors can play a role in improving mental health. In addition, researchers are working on ways to prevent and manage mental health issues. Areas of exploration include identifying genetic and environmental risk factors for mental health problems; machine learning algorithms to analyse brain scans and identify abnormalities; digital technologies to deliver psychological therapy; and psilocybin therapy to treat depression, anxiety and a range of other mental health issues. There are questions around the efficacy of these approaches, challenges in ensuring privacy and security of large amounts of sensitive data, the potential implications of increasing individual responsibility for one's own health and the extent to which we are taking an overly medicalised approach to mental health. Read more about our work on mental health.

Behavioural sciences and policymaking

Behavioural science units have been established to inform innovations in a variety of policy fields. Concerns have been raised about how behavioural research is defined

and conducted, relating to the use of small sample sizes, non-diverse datasets, and unvalidated measures. Nudge theory proposes interventions to steer people towards beneficial choices and behaviours. Examples include adding specific phrases to correspondence to encourage people to file their taxes and informing individual GPs that they prescribe an abnormally high number of antibiotics to encourage them to hold back. As well as ethical questions about the evidence base for such 'nudges', we should also consider what aggregate effects such apparently benign interventions might have, as well as who has the power to design and administer nudges and who benefits from them.

Prioritisation in the NHS

NHS waiting lists have ballooned following the COVID-19 pandemic, with over 7.7 million people waiting for treatment in England alone. The NHS regularly identifies priorities for the whole service. Post-pandemic, these include delivering more elective care and improving the responsiveness of emergency care. An overarching aim is to tackle inequalities in healthcare, which were laid bare during the pandemic. These are currently framed around socioeconomic and racial inequalities, but some have also argued for more specific consideration of the needs of children.

Racial inequalities in health

In the UK, there are health inequalities between ethnic minorities and white populations and between different racialised minorities. The COVID-19 pandemic had disproportionate effects on people from ethnic minority backgrounds, for example, in terms of infection and mortality rates. Black women are four times more likely to die in childbirth than white women and women from Asian ethnic backgrounds twice as likely to die in childbirth. Economic deprivation, poor housing, unemployment and lower levels of education are all associated with poorer health and are more common amongst racialised minorities. However, structural racism is also thought to play a part. For example, the 'weathering' hypothesis posits that the stress of living in a racist society has a biological effect. These disparities raise questions about how medical research is conducted, how healthcare is delivered, how policy is formed and whether the perspectives of affected groups are properly represented in these contexts.

Medical tourism

Medical tourism is the practice of people travelling across international borders to access healthcare. British patients can access healthcare in the EU and Switzerland with NHS funding, but this is very limited, and patients must complete all necessary administration themselves to be reimbursed. The Office for National Statistics estimates that 248,000 UK residents went abroad for medical treatment in 2019, more than twice those in 2015. Increasingly, with the backlog in the NHS, this is for core medical treatment. Medical tourism can enable people to access treatments that are unavailable or prohibitively expensive in their home country, but raises issues of safety, continuity of care and fair distribution of medical resources.

Gender identity

Since 2019, the WHO no longer categorises 'gender incongruence' as a mental and behavioural disorder. Following the interim report of the Cass Review, which found

long waiting lists for children and young people with gender dysphoria, England's only specialist clinic is being closed and replaced by two regional clinics in 2024. The NHS has recently announced that puberty-suppressing hormones should not be routinely commissioned for children and adolescents outside of clinical research settings. With greater visibility and acceptance of people with divergent gender identities, there are ongoing intense 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. These reflect the significance of diversity in society and biology, appropriate medical intervention, and acceptance of diversity in society and healthcare settings.

Disagreements in patient care

Disagreements about appropriate treatment for patients can arise within healthcare teams, between doctors and patients, and within families. These are complicated when the patient cannot make the decision for themselves, for example if they are unconscious or lack capacity. If relations and trust between families and healthcare professionals break down, this can lead families to turn to external sources of information and support on social media and the internet and to experimental treatments. Disagreements in patient care raise deep moral questions about the responsibilities of healthcare providers, patients, families and carers and the role of the state and the status of moral and religious values in healthcare and family life. As well as patients, families and healthcare professionals, such disagreements can have negative impacts on the NHS and broader society, fuelling a climate of mistrust in medical authority. Read our report on disagreements in the care of critically ill children.

Experimental medical treatments

Patients, or parents and carers of patients, with limited options might wish to try experimental treatments despite uncertainties about safety and efficacy. Now that patients can easily find out about experimental treatments online, and if necessary, crowdfund to pay for them, a key challenge is respecting the interests and autonomy of patients while ensuring they are protected from harm. The professional and ethical responsibilities of those developing, promoting and prescribing experimental treatments are also important. For example, many fertility treatment 'add-ons' have little or no evidence to show they are safe and effective. There can be blurred lines between treatments that are considered to be experimental and those that are used 'off-label' or through exemption schemes, raising questions about what kind of evidence is enough evidence in good clinical practice and how treatment decisions should be made in the face of imperfect evidence. <u>Read our briefing note on</u> experimental treatments.

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 and states in the USA have been 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. The Health and Social Care

Committee has launched a public inquiry into assisted dying and an assisted dying bill for terminally ill adults is being introduced to the Scottish Parliament. An assisted dying bill was put forward and debated in the House of Lords in 2021, but ran out of time in the parliamentary session. Read about our project exploring public views on assisted dying.

Treatments for biological ageing

Ageing is not a disease, but is associated with many major chronic diseases, and this is a particular issue in ageing societies. Researchers are exploring potential treatments 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. 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. What effect would these treatments have for people's longevity and for demography? Is it helpful to medicalise ageing, rather than accepting and valuing it as a stage in life? Given the commercial anti-ageing market, how can we ensure that treatments are evidence-based as well as accessible to a wide range of people? <u>Read our report on the future of ageing</u>.

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 causes and mechanisms of multiple diseases from Alzheimer's disease to inflammatory bowel disease to cancer. Research into the microbiome-gutbrain axis aims, for example, is leading to new insights into the impact that our gut microbiome might have on our mental health, with possible implications for our understanding of mental health as related exclusively to the brain. Treatments already in use include faecal transplants and dietary supplements. Microbiome analysis can reveal information about a person's behaviour, and new research findings reveal how microbiome composition might affect our mood and behaviour. As well as classic bioethical questions, microbiome research raises questions about individuality and individualism, humans' place in our environments and our relationships with other species.

Epigenetics

Epigenetic research, which is in its early stages, studies changes in gene expression caused by environmental effects, such as diet, stress, smoking, and childhood trauma. Key ethical issues in this field include the handling and storage of patient data, discrimination and stigmatisation related to environmental and 'lifestyle' factors, and questions about personal and societal responsibility. Emphasising epigenetic effects in fetal development may also unfairly increase the burden on women to take responsibility for their children's future health. Research is ongoing into the potential for epigenetic editing, raising questions about traits that might be targeted, such as those associated with disability, sex, gender and sexuality, which could reinforce stereotypes. Read about a workshop we held to the explore the issues raised by epigenetics.

Polygenic risk scores

Polygenic risk scores (PRS) are intended to assess a person's heritable risk of developing diseases that are influenced by multiple genes, such as coronary artery disease, type 2 diabetes and common cancers. PRS is still an uncertain science, but might have applications in sectors such as education and crime prevention. Research has accelerated thanks to the availability of large datasets, new statistical methods, and advances in genome sequencing technology. Our Future Health is the UK's largest ever health research programme. It is recruiting 5 million volunteers to donate blood samples to better understand and predict ill health, including through PRS. If someone has a high PRS for a certain disease which cannot be prevented, this may cause anxiety, but could also help future research and treatment. PRS are largely calculated from European genome sequences, which can limit understanding of genetic variants in communities with different backgrounds and exacerbate inequalities.

The science of learning

Several scientific disciplines, such as cognitive and developmental psychology, cognitive and developmental neuroscience and behavioural genetics, have considered the mechanisms by which children, and adults, learn. One focus of this research is understanding the relationship between genetic and environmental factors in people's ability to learn. These approaches raise questions about the medicalisation of education and relying on technologies to solve social problems. Much research has focused on interventions for people with learning-related difficulties, which could support greater inclusivity, but this would have to be handled carefully in relation to wider issues in education such as equity and equality of opportunity, timing of specialisation and the respective roles of home and educational providers in the early years.

Sports enhancement

Sports performance can be improved through biomechanics, genetics, materials science, nutrition, pharmaceuticals, physiology, psychology, and surgery. Although genetic variants associated with high performance have been identified, it is unclear if this could predict or improve performance. Over time, sports often accept new technologies if they are equally available to all competitors and not in danger of fundamentally changing the nature of the sport. Some have described the use of high-tech equipment as 'technological doping' - how are these lines drawn and do they become less clear over time? As well as questions of fairness and natural talent, some enhancements such as steroids also have negative health effects – allowing these drugs could put pressure on all athletes to use them and thus increase risk.

Xenotransplantation

In 2022, the first operation in which a patient received a heart transplant from a pig took place The pig which provided the heart was genetically engineered to prevent the patient's body rejecting it. The man died two months later, although, it is unclear what caused his death. A recent *Nature* study showed a monkey was kept alive by a genome-edited pig kidney for more than the two years, the survival time is the longest of any interspecies transplant. Xenotransplantation could extend the supply

of donor organs. However, it may be that other technologies, such as regenerative medicine, will make transplants obsolete. Key ethical objections to xenotransplantation include concerns about animal welfare, opposition to (and legal regulation of) genetic engineering and 'yuk factor'. The fact that pigs are the animals most likely to be donors also poses problems for some religious groups. If people reject animal-derived organs on religious or political grounds, should this affect their eligibility for a human organ transplant?

Cryonic freezing after death

Cryogenic freezing of humans in an attempt to avoid permanent death is commercially available, but the likelihood of ever being revived is vanishingly low. Cryonic freezing services are not regulated in the UK, and there are concerns about companies making misleading claims and false promises. However, some people are opting to pay large sums of money to be cryogenically preserved after death. This can create intense challenges for families who disagree with their relative's wishes and raises questions about the morality of attempting to avoid death.

Data and technology

Artificial intelligence (AI)

Artificial Intelligence has become more advanced in recent years. This includes machine learning techniques, where computer systems can 'learn' patterns through processing data. In 2022, the ability of systems to generate new content improved dramatically, receiving widespread media attention, as well as warnings from scientists about the potential weaponisation of AI. Survey data shows that people feel that AI should be transparent and explainable and that room should still be retained for humans to make decisions and judgements. Attitudes differ according to the specific technology or application, which shows the complexity of making ethical judgements about AI at a more general level. However, focusing on specific topics, rather than on the ecosystem of AI, limits understanding of its full ethical consequences.

Artificial intelligence in healthcare

A wide range of applications of AI are being explored in the healthcare sector, including detection and diagnosis of disease, management of chronic conditions, delivery of health services, and drug discovery. The WHO recommends that ethics be at the heart of design, deployment and use of AI in healthcare. AI could empower patients and bridge gaps in care in low-resource settings, but challenges include data collection and usage, the encoding of biases in algorithms and risks to patient safety, cybersecurity and the environment. Increased explainability – transparency about the assumptions, and therefore biases, that may be encoded in AI systems – could help enable safer and more widespread usage in sensitive areas like healthcare. Read our briefing note on AI in healthcare and research. And our joint interim report with the Ada Lovelace Institute on <u>AI and Genomics</u>.

Virtual and augmented reality in healthcare

Virtual reality (VR) and augmented reality (AR) can be used in several ways, from 'trying on' glasses, to rehabilitation exercises at home, to paediatric diagnostics, mental health treatment and to prepare surgeons and patients for operations. In NHS trials, nurses on home-visits have used headsets which transcribe notes, record video to share with colleagues for second opinions, and use thermal imaging to assess wound healing, aiming to improve care by freeing up more time for clinical tasks. Expensive technologies like these raise questions about cost and resource allocation, but also have the potential to facilitate better healthcare for vulnerable, disabled and elderly people in their own homes, making treatment more accessible for some. Ethical concerns include cybersecurity and privacy risks, and a lack of transparency leading to patients being misled about effectiveness. The fact that VR may be applied in vulnerable patients underlines the need for caution.

Health data and research

The digitisation of health data and research, from bioinformatics to wearables, molecular medicine, synthetic biology and biotechnology, has increased the amount of health data and different means for it to be collected and stored. This brings with it ethical problems regarding privacy, trust, accountability, fairness, and justice. Some have also drawn attention to a 'digital divide', in terms of whose data is collected and who benefits from data-driven approaches. Genomic data raises issues in terms of identifiability – both for the patient and their relatives, raising questions about consent and the right to know, or not to know. 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. There are questions about what kind of consent is required in these situations, how data should be controlled and used, and whether individuals should have a share in any profits made from its use.

Digital twins

A digital twin (DT) is used to simulate the effect of different conditions by continuously collecting and analysing data, with the aim of optimising and maintaining systems and processes. The use of DTs is being explored across healthcare, from personalised medicine, where a clinical intervention is tested on a specific patient's DT, to using a DT of a hospital to help with operational planning. DTs have potential in prevention and treatment of disease, cost reduction, patient autonomy and freedom and equal treatment, but also present ethical risks in relation to privacy and data ownership, disruption of existing societal structures, inequality and injustice. DTs could also undermine the decision-making status of physicians. DTs rely on different technologies, including AI, Internet of Things, big data and robotics, which means that each application will have slightly different ethical implications, but also that any changes they bring about will likely accelerate pre-existing trends rather than present novel issues.

Robotics in healthcare

Robots are currently used for rehabilitation and mobility, assessing patients, surgical assistance, remote communication, pharmacy services, social care tasks, interventional procedures and imaging. They can also be used for disinfection,

radiotherapy, delivery and transport, training, health promotion, research and early detection. Robots could be particularly helpful with remote assistance and carrying out healthcare in challenging environments, but this will require infrastructure and enhanced network capabilities. Robots could support nursing and caring work, improving efficiency and reducing workers' exposure to infections or back pain from lifting and moving patients. Challenges include lack of emotional interaction, social acceptance, security and privacy, inefficient power use and power sources, user-friendliness, lack of functional capabilities beyond highly restrictive environments and the possible expansion of 'value-added' work. <u>Read our report on the future of ageing</u>.

Wearable technology

Wearables could be used for monitoring, screening, detection, and prediction in healthcare. Product testing raises questions about research ethics using human subjects. Other ethical issues include power relationships between doctors and patients, the sensitivity of the data collected and its potential for being hacked. Mounted and transdermal devices also present risks of chemical exposure or infection. There is potential for wearables to reproduce and exacerbate existing disparities. There is also a current lack of legal regulation of the products and oversight of the companies producing them, including how they trade personal data.

Medical implants

Medical implants are used to replace body parts such as hips or knees, deliver medication such as pain relief, and monitor and regulate body functions such as heart rate. The Cumberledge Review (2020) pointed out the problems that come when technologies and treatments are not given comprehensive pre-market testing, and when such tools are not monitored in the long term. It also highlighted a tendency for patient voices to be marginalised and dismissed and fear of criticism and litigation preventing reporting. It led to the Medicines and Medical Devices Act 2021, which aims to strengthen regulation and to establish a Commissioner for Patient Safety. Post-Brexit, the Medicines and Healthcare products Regulatory Agency is reviewing the regulation of medical devices in the UK. <u>Read our policy briefing on medical implants</u>.

Technology in mental healthcare

Emerging mental health technologies include mental health apps - which could be anything from providing clinical support for people with mental health conditions to mindfulness and meditation, portable brain stimulation devices, and digital phenotyping. 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. At the same time, mental health technologies raise ethical concerns relating to reductions in face-toface contact, the effectiveness, quality, and safety of care, potential exacerbation of health inequalities, and data privacy and security. <u>Read about our work on the role of</u> technology in the future of mental healthcare.

Technology in social care

A wide range of technologies could play a role in social care. Existing uses of technology by patients and carers include using reminders and alarms on phones to keep track of medication, smart personal alarms, e-rostering amongst careworkers and electronic record-keeping. The UK government has pledged £150 million to support greater adoption of technology and digitisation across social care. In the NHS, digitisation is aimed to cover record-keeping and clinical planning, technologies for assisted living, connecting care homes and upskilling staff in digital skills. 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. Concerns have also been raised about whether these technologies might exacerbate loneliness and social isolation. When thinking about technologies in social care, we should consider how individual lives, caring practices and societies and communities might be (re)configured through their use. <u>Read our report on the future of ageing</u>.

Novel neurotechnologies

Neurotechnologies including genome editing and stem cell techniques could be applied in healthcare, business, education, military and sport to enhance cognitive and motor abilities, or to treat conditions like obesity, autism or depression. Human trials of neurotechnologies such as brain-computer interfaces (BCIs) to treat conditions like Parkinson's disease, spinal injuries and epilepsy are commencing. Some have even discussed using neurotechnologies for moral enhancement, to help tackle major societal challenges. As well as questions about safety, regulation, privacy and consent, BCIs prompt concerns about unequal access to technologies and the nightmare scenario of brain hacking. The unique status of the brain as the organ of the mind raises ethical and social concerns around personal identity and autonomy, moral responsibility, and free will. The potential for non-therapeutic applications give rise to further questions about the ethics of cognitive enhancement and dual use, while the emergence of the field of 'neurorights'. <u>Read our work on novel neurotechnologies</u>.

Bioengineering

Bioengineering refers to the application of engineering principles and techniques to biological processes and systems, including medicine, agriculture, and food. The concept is not new, but many potential future applications present new ethical challenges: for example, 'bioelectronic medicine' (the use of implanted devices to read and modulate electrical activity in the body, for the purposes of diagnosis or treatment - or possibly regeneration and enhancement); the use of 3D printing to create complete replicas of organs and cells; and the use of nano-materials for diagnostic or therapeutic purposes. Questions around human enhancement, identity, regulation and access, and the potential for dual use should be considered alongside research and development in this area.

Nanotechnology

Nanomaterials could help fight antibiotic resistance, improve detection and treatment of cancers, and make drug delivery more effective. Further developments in vaccine

nanotechnology could enable thermostability, needle-free single dose application and increased safety and efficacy – all of which would be particularly helpful in lowand middle-income settings. However, there are also concerns that the Global South may also become a 'dumping ground' for low quality nanoproducts. Healthcare workers may be exposed to toxic nanomaterials or lose their jobs to nanodevices. The interactions of nanomaterials with cells and environments are still poorly understood. This raises questions about the potential impacts of nanotechnology on the health and safety of humans, animals and ecosystems.

Identification biometrics

In addition to traditional physiological biometrics such as fingerprints and behavioural ones such as gait, new modalities are emerging based in involuntary biological processes like heartbeats, and using machine learning to improve reliability. Live facial recognition is an example of a biometric technology that has caused ethical concerns. It could be used for surveillance and oppression and it raises questions about accuracy, bias and reliability when it comes to ethnic and gender diversity, as well as about the extent to which data is collected without consent, or for purposes which might include commercial or military surveillance algorithms. The Biometrics and Forensics Ethics Group is a non-departmental public body that advises government on ethical issues in relation to biometrics and forensic data. Its governing principles include that procedure should enhance public good, respect dignity, not discriminate, respect personal data, promote the use of technology for delivery of justice, publicly accessible and explainable, based on robust science and subject to review by independent bodies.

Forensic DNA phenotyping

Although progress has been made in accuracy and reliability for many traits, including biogeographic ancestry, more research is needed to make FDP routinely useful in forensic science and investigations. One technique that could help is massive parallel sequencing. FDP has been adopted cautiously because of the lack of reliable data about some traits and the ethical questions that accompany this, as well as legal barriers to its wider use. It has mostly been used for 'cold cases', but many predict that as the data and analysis improve (and with requisite financial investment), it will be increasingly applied in live forensic cases. Key ethical issues with implementing and expanding this technique's use are risks to privacy and racial discrimination, as well as transparency and proportionality.

Dual use technologies

Dual use refers to the fact that many technologies can be used for both peaceful and hostile ends. Rapidly expanding technologies including life science techniques could be harnessed maliciously for bioterrorism, genocidal or ecocidal purposes. Historically, dual use technologies have had some kind of physical substance, but with increasingly digitisation, the definition and regulation of dual use is even more complex. Recently, it has been shown that AI can be used to generate toxins such as nerve agents *in silico*, with alarming potential consequences. While this was done by researchers aiming to raise awareness of the potential harmful effects of such technologies, it also raises questions about the security of the data yielded and the relative ease with which they were able to generate these results.

Animals, food and environment

Environment and health

Nearly one quarter of global deaths are linked with environmental conditions. Between 2030 and 2050, climate change is expected to cause approximately 250,000 additional annual deaths globally, affecting people in countries with weaker health infrastructures worst. Biodiversity loss impacts food security, drug discovery and the spread of infectious diseases. In the UK, air pollution represents the biggest environmental threat to health. It is distributed unequally, exacerbating existing inequalities. Children, the elderly and those with pre-existing conditions are most vulnerable to its effects. Environmental conditions are also linked with mental health issues, for example in the after-effects of flooding and climate anxiety. Greater access to nature and healthy environments have proven beneficial effects on human health and could be taken into account in planning and policy decisions. The One Health approach advocates sustainable healthcare policies where protecting the environment is considered an integral part of protecting human health. Read <u>our</u> <u>overview paper about health, climate change and ethics</u>.

Biosafety

Biosafety laboratories characterise human and animal pathogens, assist in disease surveillance, and conduct pre-clinical research that sustains the pipeline for development of diagnostics, therapeutics and vaccines. High-risk research of this kind poses challenges around safety compliance and dual use; this can be exacerbated by secrecy around breaches of safety protocols. Efforts are developing to integrate material science and nanotechnology with biotechnology for biosafety, through improved testing and diagnosis kits, PPE, vaccines and drug development. While synthetic biology is associated with biosafety concerns and should be carefully regulated and overseen, it also has the potential to contribute to solutions to these problems, through the development of vaccines and other treatments for pathogens.

Alternative proteins

Plant-based foods have become popular in recent years, but the industry is experiencing a slow-down, partly due to the cost-of-living crisis. Cellular agriculture has the potential to benefit people, non-human animals and the environment by eliminating intensive agriculture and reducing antibiotic use, but some worry about the use of genetic modification. Scaling-up may lead companies to replicate existing modes of production, undermining their capacity to transform the way we produce and consume food. Alternative proteins also present philosophical questions about the nature of alternative food products and whether they challenge the ethical problems of the thing they are substituting for, including the speciesism that may go with that. Therefore, we should not lose sight of other alternatives. <u>Read our briefing note on meat alternatives</u>.

Cultured human milk

Some companies are using cellular agriculture to develop human milk for babies. This could support premature infants and parents who cannot breastfeed their children, as well as extending the number of people who can feed an infant, with potential positive effects for gender equality. Cultured milk might be more suitable than formula milk, as it uses human rather than bovine cells, and could be safer than buying breastmilk online. It could also have environmental and animal welfare benefits by replacing the intensive agriculture used to produce cow-based formula. However, the products are likely to be expensive and it would be energy-intensive to scale-up production. Cultured milk could also be used beyond infant feeding, as a health supplement for adults, raising questions about the ethics of eating humanderived products.

Gene drives

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. 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.

Animal research

Many argue that the use of animals, such as genetically modified mice, is essential for research that benefits human health. Nonetheless, major funding bodies are supporting moves to institute the principles of replacement, refinement and reduction (the 3Rs) towards animal use in research and testing. Scientists are encouraged to use the ARRIVE guidelines in preparing research and publications, to maintain scrutiny, rigour and reproducibility in research using animals. The UK's Animal Sentience Committee, established in 2023, advises the government in relation to matters relating to animal welfare, and specifically sentience. 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. Read more about our work on animal research.

Genome editing in farmed animals

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 of the challenges of our current agricultural system, such as making animals resistant to diseases or more productive. But it might also be used to circumvent animal welfare considerations, for example by breeding animals that are able to withstand poor living conditions rather than improving their conditions. What would the implications of these developments be for animal welfare, product safety, and human health, and would meat and dairy products from genome edited animals be widely accepted by farmers and consumers? Genome editing should be assessed alongside other alternative food production techniques in terms of accessibility, animal welfare, food sustainability, biodiversity loss and environmental degradation. Read about our report on genome editing in farmed animals.

De-extinction

Genetic technologies are being tested to revive extinct and save endangered animals. Such animals will never be the same as the originals, partly due to the interaction between genes and environment and partly because DNA disintegrates over time. This raises questions about how we would treat them legally and morally. De-extinction might contribute to halting or reversing biodiversity loss at a time of mass extinction, but where would these animals live and what kinds of support they would need, especially if the reasons for their extinction have not been addressed? It is important to consider welfare concerns for animals used in these experiments and whether it might be better to invest in cheaper, low-tech conservation efforts. Some anticipate that commercial companies will ultimately focus on resurrecting beloved pets or even dead humans rather than saving endangered or extinct species.

Research ethics

Participant-led research

Participant-led research goes beyond involving patients in research, instead giving them a leading role. In health research, this might mean that the researchers are also people with the condition being studied. It goes beyond traditional research ethics, which focuses on protecting participants from exploitation, by aiming to democratise science, technology and data. Participant-led research can be ethically reviewed much as other research, with participant-researchers evaluating transparency, data use and storage, and the risks and benefits of different approaches. Questions arise about whether participant-led research generates generalisable health knowledge, which requires formal ethical review, or personal health knowledge, which does not.

Culture of research

Aspects of working culture have been found to encourage poor research practices and hinder the production of high-quality science. Wellcome, a major research funder, has criticised the emphasis on excellence for stifling diverse thinking and positive behaviours. Another key funding body, UKRI, is promoting a switch towards narrative CVs in funding applications, to support people with diverse career paths. There have also been calls to change how academic research is ranked to include assessments of research culture. Improving research cultures requires clear management systems, access to training and development, and support for researchers and pathways to identify and address issues in working environments and management. There is also an increasing emphasis on equitable collaborations, particularly in international research.

Research in areas of controversy

Some areas of research are surrounded by broader political and social debates. Public perceptions of research, science and technology, which shift over time, can be important factors in such debates. Examples of controversial topics include gender identity, tobacco use, chronic fatigue syndrome, climate change and research involving animals. Researchers working in these areas have experienced verbal and physical abuse, misuse and discrediting of their work, and difficulty in attracting funding. This could have a chilling effect, leading researchers to avoid these areas of research, to reframe their research to avoid potential controversy, or even to leave research altogether.

Equity in the development of medicines and therapies

Essential medicines are inaccessible to a quarter of the world's population. There are concerns that the current system of medical research and development does not benefit patients equitably and the development of drugs and vaccinations may be unduly influenced by factors beyond patient need, such as profit. 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 from racialised minorities. Making treatments available on a non-profit basis or making treatments open access can save money and ensure that resources are available to those most in need. <u>Read our briefing note on equitable access to COVID-19 treatments and vaccines.</u>

Brain surrogates

Brain surrogates are one solution to the ethical problem of experimenting on living human brains. How well will organoids be able to model human brain function? One approach under development is neural organoids grown from stem cells, which could facilitate research into brain conditions and mental health issues. Could such organoids develop consciousness and therefore experience suffering? Would we be able to recognise or monitor such suffering when there is no body? While this possibility is remote, it is still worth considering as these models become increasingly complex.

Fetal tissue research

Cell lines from fetal tissue have been used to develop vitally important vaccines and drugs since the 1960s. Current fetal tissue research focuses on conditions like HIV/AIDS, developmental biology and eye diseases. As the tissue usually results from elective terminations of pregnancy, the overturning of *Roe v Wade* in 2022 is expected to affect access to fetal tissue and divert research funding and resources away from those states that ban or restrict abortion in the USA. Alternatives that replace the need for fetal tissue in some research areas may arise, yet it will remain crucial for research into problems that occur in fetal development and some heritable diseases.

Embryo research

Embryo research raises questions about the beginning of life and the moral status of embryos. 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, signifying individuation, but some argue that this is hinderingresearch, and the law is currently under review. Embryo models grown from stem cells have the potential to complement embryo research. The International Society for Stem Cell Research (ISSCR) has issued guidance on the use of such models in research, however the extent to which the use of these models is covered by regulations is not clear. Potential applications for model embryos 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.

Synthesizing entire human genomes

Researchers have synthesized entire bacteria in the lab, and technologies that might in the future make it possible to better understand and potentially create human cells from scratch is now being explored. In future, the cells could be 're-written' built to resist viruses, radiation, freezing, ageing and cancer, and would be a valuable resource for research. Such a development would raise significant ethical and philosophical questions about the nature of life, parenthood, and scientific hubris.

Clinical research in pregnancy

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 reticinet to partake in trials because of concerns about this. Yet, this can inhibit research that may directly benefit them. People still need access to medical treatments while pregnant, and it is best that we know drugs and vaccines are safe and effective and that the dosage is appropriate given the physiological changes pregnancy brings about. 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. Classing pregnant people as vulnerable also undermines their capacity for informed decision-making. Machine learning has been used to map and predict complications in pregnancy and birth and could be a powerful, non-invasive complement to clinical research.

Military biomedical research

Military biomedical research has historically driven technological progress and medical advances, with important broader applications such as vaccine development and advances in surgery. Military biomedical research is increasingly looking at genetic engineering, neuroscience, AI and supercomputing, to enhance ability and performance. Enhancement raises safety concerns, especially if its use is mandated. What might be an enhancement during deployment could cause problems for the individual and society when they are demobilised. What is the military's duty of care towards its staff and to society? Military conditions can make it difficult to obtain informed consent and conduct controlled clinical trials of new therapies. Another emerging question is the extent of mental health conditions in military veterans and how this might be studied in an ethical manner.

Biotechnological patents

Biotechnological patents can incentivise innovation in research fields including medicine, energy, and agriculture. However, the patenting of biotechnological innovations can also have negative consequences, such as disincentivising innovation for products that are likely to return lower profits, excessive development of similar products, and a focus on drugs and therapies for diseases that affect people in wealthy countries. There is an ongoing campaign to temporarily waive intellectual property protection on coronavirus vaccines as a step towards more equitable distribution. Read our policy briefing on fair and equitable access to COVID-19 treatments and vaccines.