

# Submission from the Nuffield Council on Bioethics to the NIHR Futures of Health Project

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## Introduction

- 1 This submission sets out a response from the Nuffield Council on Bioethics in answer to the NIHR's call for views on the following questions:
  - In relation to your area of interest (discipline or geography), what differences do you foresee in the state of health and provision of healthcare in England in 20-30 years' time? In your answer, please consider if/how these changes might affect some populations (within England) differently to others, i.e. socioeconomic, ethnic groups and/or geographic groups.
  - What do you think will be the key drivers of the changes you have described?
- 2 The Nuffield Council on Bioethics considers the ethical questions raised by recent developments in biological and medical research that concern, or are likely to concern, the public interest. The Council continually monitors the research literature and talks regularly to those working in biological and medical research fields to keep abreast of developments that might raise ethical questions. Many such developments are likely to impact on the state of health and the provision of healthcare in England both now and in the future. This submission draws upon the Council's recent inquiries and on its horizon scanning activities to highlight areas of research that might have such an impact.

## Fertility and parenthood

- 3 The number of women seeking fertility treatment has increased each year since 1991, and increasing numbers of women are choosing to harvest and store their eggs in anticipation of infertility.<sup>1</sup> This may be driven both by advances in science and an increase in the average age for first time mothers<sup>2</sup> – a trend that is likely to continue. However, the live birth rate for IVF treatment is around 25 per cent on average (and much lower for older women),<sup>3</sup> motivating researchers to explore new and innovative ways of enhancing fertility.
- 4 Recently, for example, sperm and egg-like cells were derived from mouse stem cells, which went on to produce viable and fertile offspring.<sup>4</sup> The development of *in vitro* derived human gametes has been partway successful, and the beginnings of creating ‘embryos in a dish’, without the need for distinct gametes, has also been reported.<sup>5</sup> Artificial parts of wombs that enable embryos to stay alive outside the mother – ‘ectogenesis’ – are being developed primarily for embryo research purposes and to improve the survival of extremely premature babies. In the future this may lead to full ectogenesis, where the entire reproductive process occurs outside of the female human body in an artificial womb.
- 5 Technologies or treatments that enhance fertility in new and different ways raise important questions about how we view pregnancy and parenthood. The use of donor gametes in fertility treatment has already shown how developments in science can confront notions of family and kinship, on which there is a diversity of opinion.<sup>6</sup>
- 6 In future, *in vitro* derived gametes might make it possible for same-sex couples to have fully genetically related children, or enable children to be created from the genetic material of one person. Artificial wombs may lead to ‘natural’ pregnancy and birth being considered as risky and stigmatised, and could remove women as the sole bearers of the risks and burdens of pregnancy.

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<sup>1</sup> Human Fertilisation and Embryology Authority (2016) *Fertility treatment 2014. Trends and figures*, available at: [http://www.hfea.gov.uk/docs/HFEA\\_Fertility\\_treatment\\_Trends\\_and\\_figures\\_2014.pdf](http://www.hfea.gov.uk/docs/HFEA_Fertility_treatment_Trends_and_figures_2014.pdf)

<sup>2</sup> Office for National Statistics (2016) *Births by parents' characteristics in England and Wales: 2015*, available at:

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthsbyparentscharacteristicsinenglandandwales/2015#main-points>

<sup>3</sup> Human Fertilisation and Embryology Authority (2016) *Fertility treatment 2014. Trends and figures*, available at: [http://www.hfea.gov.uk/docs/HFEA\\_Fertility\\_treatment\\_Trends\\_and\\_figures\\_2014.pdf](http://www.hfea.gov.uk/docs/HFEA_Fertility_treatment_Trends_and_figures_2014.pdf)

<sup>4</sup> Hikabe O, Hamazaki N, Nagamatsu G *et al.* (2016) Reconstitution in vitro of the entire cycle of the mouse female germ line *Nature* **539**: 299-303; Zhou Q, Wang M, Yuan Y *et al.* (2016) Complete Meiosis from Embryonic Stem Cell-Derived Germ Cells In Vitro *Cell Stem Cell* **18**: 330-40

<sup>5</sup> These kinds of developments may also enable gametes to be genetically modified in order to avoid inherited diseases in future offspring. See the next section on [Genetics – avoiding, diagnosing and treating disease and disability](#)

<sup>6</sup> For more on this see: Nuffield Council on Bioethics (2013) *Donor conception: ethical aspects of information sharing*, available at: [www.nuffieldbioethics.org/donor-conception](http://www.nuffieldbioethics.org/donor-conception)

- 7 Questions will continue to be asked about the appropriate use of public resources in this field. It could be argued that society has a duty to help its citizens to fulfil their desire for their own genetic children, but this may not be prioritised as pressure on NHS resources mounts. The private sector in this field is likely to grow however, enabling the full range of new treatments to be accessed by those who can afford them. More companies may offer fertility services as an employee benefit, as Apple and Facebook have done in the US. Disparities between who can and cannot access fertility treatments are likely to increase in future, raising issues of equity. Consumer protection issues might become relevant if people are encouraged to spend substantial amounts of money on new techniques that have not been proven to meet high standards of safety and efficacy. Concerns have already been raised about women being given exaggerated claims about egg freezing, and whether women who donate their eggs in return for fertility treatment are doing so entirely voluntarily.<sup>7</sup> Questions might also need to be asked about whether it is ethically acceptable for any health provider, which would be subject to professional standards, to market services for which a solid evidence base is lacking.<sup>8</sup>
- 8 Although the increasing use of technology that influences fertility is often presented as liberating and choice-enhancing, it might in practice reduce the choices of some. For example, women who work in or wish to succeed in companies and professions which routinely offer egg freezing might feel obligated to delay pregnancy. If this becomes common it might become expected that women who are serious about career success routinely freeze eggs. These issues will require careful consideration as research and clinical practice in this field develops.

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<sup>7</sup> For further discussion of the ethical issues raised by the donation of gametes see: Nuffield Bioethics (2011) *Human bodies: donation for medicine and research*, available at: [www.nuffieldbioethics.org/donation](http://www.nuffieldbioethics.org/donation). See also Daily Mail (2 May 2017) *IVF clinics peddling false hope over egg freezing*, available at: <http://www.dailymail.co.uk/news/article-4467352/Desperate-women-duped-freezing-eggs.html>

<sup>8</sup> This issue is discussed in the Council's forthcoming report: Nuffield Council on Bioethics (2017) *Cosmetic procedures: ethical issues* (in print), see [www.nuffieldbioethics.org/cosmetic-procedures](http://www.nuffieldbioethics.org/cosmetic-procedures)

## Genetics – avoiding, diagnosing and treating disease

- 9 Today, couples planning a baby can have preconception testing to find out if they are carriers of a gene for a genetic disorder. Pre-implantation genetic diagnosis enables couples undergoing IVF to avoid their children inheriting specific genetic conditions, and mitochondrial donation was recently approved as a treatment for people at risk of having a child with mitochondrial disease. Non-invasive prenatal testing, chromosomal microarray and other prenatal testing techniques can identify genetic conditions in a fetus early in pregnancy, giving women and couples choices about whether to continue the pregnancy or have an abortion.<sup>9</sup> Genetic testing is also available after birth, to ascertain the risk of developing disease in future, such as breast cancer, and to diagnose suspected conditions and guide therapy.
- 10 Although we should be careful about over-hyping the potential impact of genetics and epigenetics research on healthcare, in future we are likely to be able to diagnose and treat, effectively and safely, a wider range of genetic conditions. Initiatives such as the 100,000 Genomes Project could underpin the development of precision medicine, where treatments are tailored for particular individuals to increase effectiveness. Whole genome or exome sequencing of adults might become cheap and commonplace, and parents might be able to sequence the whole genomes of their children, before or after birth. Gene editing techniques such as CRISPR-Cas9 are opening up new possibilities for carrying out research on human disease, for ‘fixing’ genetic mutations in embryos, and for developing therapies, such as engineering cell lines for cancer treatment.<sup>10</sup> Gene editing has also led to advances in research on growing organs in animals, which could help meet demand for organs for transplantation.<sup>11</sup> It may even become possible to create genomes from scratch, with potential applications including growing in the laboratory cell lines for cancer or virus resistance, or transplantable organs.<sup>12</sup>
- 11 These developments could offer benefits to individuals and families living with or at risk of serious disability or disease. They also raise a number of ethical issues that will require careful consideration. Prenatal testing and treatment of genetic

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<sup>9</sup> The Council published a report on the ethical issues raised by non-invasive prenatal testing in March 2017, available at: [www.nuffieldbioethics.org/NIPT](http://www.nuffieldbioethics.org/NIPT)

<sup>10</sup> The Council published an ethical review of genome editing in 2016 and is currently considering the specific issues raised by genome editing in human reproduction contexts, see [www.nuffieldbioethics.org/genome-editing](http://www.nuffieldbioethics.org/genome-editing). See also: Cai L, Fisher AL, Huang H and Xie Z (2016) CRISPR-mediated genome editing and human diseases *Genes & Diseases* **3**: 244-51

<sup>11</sup> Research on xenotransplantation has been ongoing for some years and was the subject of one of the Council’s first reports: Nuffield Council on Bioethics (1996) *Animal-to-human transplants: the ethics of xenotransplantation*, available at: [www.nuffieldbioethics.org/xenotransplantation](http://www.nuffieldbioethics.org/xenotransplantation)

<sup>12</sup> In 2002 scientists described the de novo synthesis of infectious poliovirus using a synthetic genome built from scratch, see: Cello J, Paul AV and Wimmer E (2002) Chemical Synthesis of Poliovirus cDNA: Generation of Infectious Virus in the Absence of Natural Template *Science* **297**: 1016-8. This was followed in 2010 by the successful construction of the first self-replicating, synthetic bacterial cell, see: Gibson DG, Glass JI, Lartigue C *et al.* (2010) Creation of a Bacterial Cell Controlled by a Chemically Synthesized Genome *Science* **329**: 52-6.

conditions, for example, raise questions about which conditions constitute a sufficient reason for intervention and which, on the other hand, are mere differences that make up our diverse society. For some genetic conditions, particularly those which have highly variable manifestations, this is not clear cut. Attitudes towards disability have changed significantly over the past 50 years, and there is now widespread acceptance that social and environmental factors, in combination with physical impairments, give rise to disability. There is a view that removing disability by genetic means is expressive of a discriminatory attitude towards disabled people.<sup>13</sup>

- 12 Gene editing may in future, if the law allows, enable changes to be made in the genome that can be passed on to future generations. The long-term consequences of this kind of modification are unknown. In 2017, the Council will be publishing a report on the application of gene editing techniques in human reproduction which will consider the acceptability and future use of so-called germline therapies.<sup>14</sup>
- 13 Even if treatment is not the aim, genetic technologies that enable people to find out about their genes raise questions about whether they will be disadvantaged or harmed in any way by having had their genome sequenced – either by their own choice or that of their parents. There is the potential for people to experience discrimination on the basis of their genes, in insurance and employment contexts for example. The Council recommends that whole genome sequencing of fetuses should not be offered to parents unless there is a clear clinical need, in order that the future person can make his or her own choices about accessing their genetic information.<sup>15</sup>
- 14 Technological development may, in future, move away from information-giving, diagnosis and treatment, and towards enhancement. Gene editing raises the possibility of ‘engineering’ humans to introduce protection against disease or other desirable genetic traits. Genetic technologies may also provide new avenues for enhancing appearance, which may further feed the ever-increasing development and promotion of cosmetic procedures. In response to this, we suggest in our forthcoming report on cosmetic procedures that the promotion of potentially damaging appearance ideals should be challenged, and that high standards of governance for the industry are required to ensure a more ethical encounter between users and practitioners.<sup>16</sup>

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<sup>13</sup> For further discussion of the ‘expressivist’ objection to prenatal genetic screening, see: Nuffield Council on Bioethics (2017) *Non-invasive prenatal testing: ethical issues*, available at: [www.nuffieldbioethics.org/NIPT](http://www.nuffieldbioethics.org/NIPT)

<sup>14</sup> For more on this see [www.nuffieldbioethics.org/genome-editing](http://www.nuffieldbioethics.org/genome-editing)

<sup>15</sup> Nuffield Council on Bioethics (2017) *Non-invasive prenatal testing: ethical issues*, available at: [www.nuffieldbioethics.org/NIPT](http://www.nuffieldbioethics.org/NIPT)

<sup>16</sup> Nuffield Council on Bioethics (2017) *Cosmetic procedures: ethical issues* (in print), see [www.nuffieldbioethics.org/cosmetic-procedures](http://www.nuffieldbioethics.org/cosmetic-procedures)

## Technology and health

- 15 There has been a recent influx of medical technologies capable of diagnosing, managing and preventing health problems. These include mobile phone health apps, complex networks of sensors capable of monitoring physiological parameters and behaviours, technology that reminds people to take their medicine, and telemedicine that allows patients to meet with a doctor remotely and relay information back to them from home diagnostic devices. Robotic technology has been used to deliver targeted radiation treatments and to assist surgeons with prostatic surgery, and electrodes inserted into the brain are used to treat Parkinson's disease and movement disorders such as dystonia (also see [Mental health](#)).
- 16 We are likely to see significant developments in this field in future. The next generation of robots may be able to perform surgical procedures or antenatal scans independently, or provide day-to-day care for dementia patients and others with caring needs. Developments in nanotechnology present many potential uses in medicine, including nanoparticles for personalised medicine delivery, nano-devices to monitor health from inside a patient or nano-robots to perform intra-cellular surgery. Tools that use machine learning and AI, which apply algorithms to large data sets, are being developed to recognise patterns and make predictions related to symptoms and optimum treatments.<sup>17</sup>
- 17 Central questions in this area concern personal autonomy, the doctor-patient relationship and privacy. Some of these technologies may threaten patient autonomy if devices are programmed to encourage or coerce users to make healthier life choices, to control their adherence to medications or to monitor their behaviours. Who is responsible for the actions and decisions made by health technologies, and how such technologies could affect individuals' sense of responsibility for their health will need to be considered.
- 18 There are arguably some fundamentally human qualities which are important in medical treatment and counselling, and the subtleties of the 'human' doctor-patient relationship may be unduly threatened by technological advancements that encroach into human roles. Related issues are raised by the potential of these technologies to enhance individual independence, but also to exacerbate the social isolation of some members of society.
- 19 Technological advance means it is becoming easier and cheaper to gather, transfer, link, store and analyse biological and health data. This offers opportunities both now and in the future to generate new knowledge, improve medical practice, increase service efficiency and drive innovation in the public interest. The drive to link and re-use data is, however, putting pressure on conventional governance approaches, making it hard to meet in practice

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<sup>17</sup> For more on this see: Marr B (2016) How Machine Learning, Big Data And AI Are Changing Healthcare Forever, available at: <https://www.forbes.com/sites/bernardmarr/2016/09/23/how-machine-learning-big-data-and-ai-are-changing-healthcare-forever/#1bafdfb1a1c>

standards of informed consent and anonymisation. In the world of Big Data, where selling and owning data sets is already a huge business, preserving anonymity might become impossible. There is a need to develop effective governance arrangements to ensure the use of data respects individuals' privacy, dignity and human rights and reflects the expectations of patients and participants. In the future, the Council recommends this should be backed up by accountability arrangements and robust penalties for the deliberate misuse of data.<sup>18</sup>

20 Technology is having a profound effect on how people access information about their health. People increasingly use the internet to search for, exchange and post health information on various types of websites and social media. Social media allows patients to discuss their health and their doctors, and to crowd-fund medical treatment.<sup>19</sup> This allows for more convenient 'consumer-like' or patient-led access to or discussion of information, with patients feeling more involved in their own health. Potential harm arises from misleading or poor-quality information, potential breaches of privacy, an undermining of the traditional doctor-patient relationship, and a lack of recognisable quality standards. The Council recommends that professional medical practice should be adapted to the modern information age, by ensuring doctors receive training on caring for patients who increasingly use the internet to access or discuss health information.<sup>20</sup>

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<sup>18</sup> For more on this see: Nuffield Council on Bioethics (2015) *The collection, linking and use of data in biomedical research and health care: ethical issues*, available at:

[www.nuffieldbioethics.org/biological-health-data](http://www.nuffieldbioethics.org/biological-health-data)

<sup>19</sup> For example, the parents of Charlie Gard raised over £1 million to fund experimental treatment in the US, see: <https://www.gofundme.com/please-help-to-save-charlies-life>

<sup>20</sup> See Nuffield Council on Bioethics (2010) *Medical profiling and online medicine: the ethics of 'personalised healthcare' in a consumer age*, available at: <http://nuffieldbioethics.org/project/personalised-healthcare-0>



## Ageing and health

- 22 Our population is growing older. A major challenge of population ageing is an increase in the old-age dependency ratio, and a projected rise in spending for healthcare and nursing care. A broader policy debate will need to be had about how health care resources are distributed across different age cohorts in the coming decades.
- 23 Biomedical research will increasingly contribute to challenges posed by an ageing society. Researchers are exploring interventions that could extend the human 'health span' by maintaining health and increasing quality of life in old age. Although it is widely accepted that biological ageing cannot be halted altogether, animal studies have shown that it is possible to intervene in the process.<sup>21</sup> In mice, life span can be increased by 30-50 per cent.<sup>22</sup> The TAME (Targeting Ageing with Metformin) clinical trial will test the effects of a drug on the metabolic and cellular processes associated with the development of age-related conditions in people aged over 60 years.<sup>23</sup> More clinical trials are likely to follow. Although at an early stage, research on epigenetic changes that occur within cells during ageing is also providing potential avenues for the development of therapeutic interventions for ageing.<sup>24</sup>
- 24 It is hard to predict what the health effects of intervening in biological ageing would be for individuals, and further research on the possible consequences will be important. Ageing interventions may result in compressed morbidity, with people remaining healthy until the last few months of their life. Alternatively, the number of much older people with multiple co-morbidities may increase, putting further pressure on the NHS and on the individuals themselves and their families.
- 25 In a world where treatments or interventions for biological ageing existed, people's aspirations and expectations of old age might change. People may feel judged or guilty if they choose not to take ageing interventions. Any benefits of such interventions would be likely to be felt unevenly within and across societies because of existing intra- and inter-societal inequalities. Developments in genetics and neuroscience that are moving towards the prediction of conditions that may develop later in life, such as dementia, might add to the anxiety that many people already feel about old age. If people with such predictions did not take up preventative interventions, their entitlement to state care later on might be questioned.<sup>25</sup>

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<sup>21</sup> For example see: Li J, Bonkowski MS, Moniot S *et al.* (2017) A conserved NAD<sup>+</sup>-binding pocket that regulates protein-protein interactions during aging *Science* **355**: 1312-7

<sup>22</sup> Fontana L, Partridge L and Longo VD (2010) Extending Healthy Life Span: From Yeast to Humans *Science* **328**: 321-6

<sup>23</sup> See <https://clinicaltrials.gov/ct2/show/NCT02432287b>

<sup>24</sup> Pal S and Tyler JK (2016) Epigenetics and aging *Science Advances* **2**: e1600584

<sup>25</sup> This is not a new issue. People who choose to undertake behaviour of any kind that is likely to have consequences for their health might also have their entitlement to healthcare questioned. For a discussion of these issues see Nuffield Council on Bioethics (2007) *Public health: ethical issues*, available at: [www.nuffieldbioethic.org/public-health](http://www.nuffieldbioethic.org/public-health) and Nuffield Council on Bioethics (2010)

- 26 Ageing is multidimensional and complex, and there may be more effective ways of improving health and well-being in old age than developing a drug therapy or other medical intervention. For example, social attitudes towards older people and other aspects of the environment have a major influence on wellbeing in old age. Improving the way in which elderly people receive support and care, and diversifying the options available to people nearing the end of their lives are likely to continue to be important areas for discussion and research in future.
- 27 As we continue to reduce deaths from cancer and cardiovascular disease, the number of people with dementia is predicted to rise in future. Even with the best support, a person with dementia will usually experience significant changes in their life as a result of their declining mental abilities. Dementia needs to become an accepted, visible part of our society. The Council recommends that those who are supporting and caring for people with dementia – family, friends and professionals – need much more support in tackling the ethical problems they meet every day<sup>26</sup> (see also [Mental health](#)).

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*Medical profiling and online medicine: the ethics of 'personalised healthcare' in a consumer age*, available at: <http://nuffieldbioethics.org/project/personalised-healthcare-0>

<sup>26</sup> For more on this see: Nuffield Council on Bioethics (2009) *Dementia: ethical issues*, available at: [www.nuffieldbioethics.org/dementia](http://www.nuffieldbioethics.org/dementia)

## Mental health

- 29 The healthy functioning of the brain plays a central role in our capacity for leading fulfilling lives, and for sustaining our senses of ourselves and our personal relationships. Mental and neurological disorders, such as depression, post-traumatic stress disorder, autism, dementia and schizophrenia, are leading causes of disability.<sup>27</sup> By 2030, it is estimated that there will be approximately two million more adults in the UK with mental health problems than there were in 2013 if prevalence rates stay the same.<sup>28</sup> Social and political change could impact on our mental health further. The population is getting older, for example, and the risk of depression increases with age. Events such as economic recession or terrorist incidents can also have a significant impact on the mental health of people affected.<sup>29</sup>
- 30 Research on the biological and environmental causes of mental health disorders is aiming for the development of new and effective treatments. Strides have been made in determining the links between mental illness, genetics and epigenetics, and the effect of immunosuppression on schizophrenia and autism.<sup>30</sup> The picture is likely to be complicated: scientists have found versions of over 20 different genes that are associated with an altered risk of Alzheimer's disease.<sup>31</sup>
- 31 In future, this kind of research may enable potential parents to find out the chance of their children developing mental illnesses. Given that many mental disorders manifest in extremely variable ways and develop later in life, and that they have been associated with artistic, musical and mathematical talent, this is likely to be controversial and will require careful consideration (see also [Genetics – avoiding, diagnosing and treating disease and disability](#)).
- 32 Technologies that intervene in the brain, such as deep brain stimulation, brain-computer interfaces and neural stem cell therapy, offer the potential to help people with conditions such as Parkinson's disease, dementia, depression and

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<sup>27</sup> National Institute of Mental Health (2010) Grand Challenges in Global Mental Health, available at: <https://www.nimh.nih.gov/about/organization/gmh/grandchallenges/index.shtml>

<sup>28</sup> The Mental Health Foundation (2013) *Starting Today: The future of mental health services*, available at: <https://www.mentalhealth.org.uk/sites/default/files/starting-today.pdf>

<sup>29</sup> For more on this see: Royal College of Psychiatrists (2016) *Responding to large-scale traumatic events and acts of terrorism*, available at: [http://www.rcpsych.ac.uk/pdf/PS03\\_2016.pdf](http://www.rcpsych.ac.uk/pdf/PS03_2016.pdf); Frasilho D, Matos MG, Salonna F *et al.* (2015) Mental health outcomes in times of economic recession: a systematic literature review *BMC Public Health* **16**: 115

<sup>30</sup> See for example the MRC Centre for Neuropsychiatric Genetics and Genomics Research, Cardiff University: <https://www.cardiff.ac.uk/mrc-centre-neuropsychiatric-genetics-genomics>; Abdolmaleky HM, Zhou JR and Thiagalingam S (2015) An update on the epigenetics of psychotic diseases and autism *Epigenomics* **7**: 427-49; Albert PR (2010) Epigenetics in mental illness: Hope or hype? *Journal of Psychiatry & Neuroscience* : *JPN* **35**: 366-8; Zandi MS, Irani SR, Lang B *et al.* (2011) Disease-relevant autoantibodies in first episode schizophrenia *Journal of Neurology* **258**: 686-8; Masi A, Quintana DS, Glozier N *et al.* (2015) Cytokine aberrations in autism spectrum disorder: a systematic review and meta-analysis *Mol Psychiatry* **20**: 440-6

<sup>31</sup> The Alzheimer's Society (2016) *Genes and dementia*, available at: <http://www.alzheimersresearchuk.org/wp-content/uploads/2016/12/Genes-and-dementia-december-2016.pdf>

stroke. It is important to pay attention to the implications of such interventions relating to patient safety, any unintended impacts on privacy, and the promotion of autonomy both in decisions about treatment and in the wider context of patient's lives. This field of research is marked by uncertainty and media hype, and it is vital that regulatory oversight encourages innovation and directs investment and development towards the production of safe and effective products that meet genuine patient needs.<sup>32</sup>

33 Stigmatisation of people with mental health illness can have a range of damaging effects. Stigma attached to dementia, for example, and the fear of being marginalised in society, may serve as a barrier to accessing care, support and treatment. Stigma, rather than the pathology of the disease, can cause feelings of poor self-worth, social exclusion and depression. In future, tackling the stigma attached to mental health problems will be as important as treating the disease itself. Studying the neurobiology of stigma could help measure the effectiveness of stigma-reducing strategies.<sup>33</sup>

34 People with serious mental health illness are over three times more likely to have a physical health problem and may die 10–20 years earlier than others in the general population. There are strong calls for our healthcare services to take an integrated approach to mental and physical health in future, to ensure that people with mental health illness receive the same quality of physical healthcare as those without a mental health problem and appropriate intervention and support to address their much higher rates of health risk behaviour.<sup>34</sup>

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<sup>32</sup> For more on this see: Nuffield Council on Bioethics (2013) *Novel neurotechnologies: intervening in the brain*, available at: [www.nuffieldbioethics.org/neurotechnology](http://www.nuffieldbioethics.org/neurotechnology)

<sup>33</sup> For more on this in the context of dementia see: International Longevity Centre - UK (2014) *A compendium of essays: New perspectives and approaches to understanding dementia and stigma*, available at:

[http://www.ilcuk.org.uk/index.php/publications/publication\\_details/new\\_perspectives\\_and\\_approaches\\_to\\_understanding\\_dementia\\_and\\_stigma](http://www.ilcuk.org.uk/index.php/publications/publication_details/new_perspectives_and_approaches_to_understanding_dementia_and_stigma)

<sup>34</sup> For more on this see: Royal College of Psychiatrists (2016) *Improving the physical health of adults with severe mental illness: essential actions*, available at:

<http://www.rcpsych.ac.uk/files/pdfversion/OP100.pdf>

## Global health challenges

- 36 The implications of outbreaks of infectious diseases, such as influenza, Ebola and Zika, are likely to continue to be felt across the globe, including in England. Research will play an important role in responding to infectious disease and other global health challenges by seeking to develop treatments and vaccines, and improving the evidence base for health-related emergency response. The need for research often to be carried out quickly and within an emergency context raises considerable challenges.
- 37 Research undertaken during global health emergencies ranges from the collection of data and surveillance to more risky and invasive procedures, such as the use of experimental therapeutics or innovative vaccines. Each type of research should be assessed in terms of justification, priority and social value. There needs to be scrutiny of the rationale for carrying out any research in the first place, ensuring that it does not compromise the immediate response to an outbreak, while also recognising the ethical imperative that emergency response should be based on the best possible evidence.<sup>35</sup>
- 38 In global health emergencies, the lines can become blurred between research, which usually is attempting to produce generalisable knowledge, and medical treatment, which is focused on benefiting patients. Many of the traditional core principles of research trials, such as double-blinding, are difficult to apply in such contexts. Yet researchers who want to respond quickly to health emergencies risk being charged with unethical behaviour for not following standard guidelines. Research in emergencies also raises questions relating to trial design, participant selection, and how researchers can respect the sensitivities of the cultural context. A distinct ethics and governance is required to enable this kind of research to take place in future, recognising that interventions during emergencies can be, simultaneously, healthcare, research and public health interventions.<sup>36</sup>
- 39 The threat of infectious disease outbreak is occurring against a backdrop of growing antimicrobial resistance, which is on the verge of becoming a global health emergency itself.<sup>37</sup> If infections become increasingly difficult to treat, previously minor diseases have the potential to turn into epidemics and pandemics, and medical practices such as surgery will be transformed beyond recognition. There is a desperate need for new drugs and vaccines, but research

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<sup>35</sup> For more on this see: The Lancet Series on Health in Humanitarian Crises (8 June 2017), available at: <http://www.thelancet.com/series/health-in-humanitarian-crises>

<sup>36</sup> See Ganguli Mitra A and Sethi N (2016) *Conducting research in the context of global health emergencies: identifying key ethical and governance issues*, available at: <http://nuffieldbioethics.org/wp-content/uploads/Research-in-global-health-emergencies-background-paper.pdf>; and a note of a workshop hosted by the Council in 2016 on the ethical challenges for research and innovation that arise in the context of global health emergencies: <http://nuffieldbioethics.org/project/workshop-research-global-health-emergencies/workshop-2016>

<sup>37</sup> World Health Organization (2014) *Antimicrobial resistance: global report on surveillance*. WHO: Geneva.

has made little headway in this area to date. Changing patient expectations and prescribing behaviours, both in healthcare and agricultural contexts, will be essential for tackling the threat of bacterial infections. Conflicts between the individual interests of patients and the interests of the public in the preservation of antibiotic effectiveness will need to be carefully weighed.<sup>38</sup>

40 We cannot act alone in this context. The future health of England will be ever more connected to the future health and health infrastructure of surrounding nations and to the flow of people in and out of the country. Establishing relationships and supporting global infrastructures will be vital for ensuring we are prepared for health threats and disease that do not respect borders. In particular, there is a need to build research and surveillance capacity in low and middle income countries, where disease outbreaks often occur. The affect on England's international work of political change, such as the UK's decision to leave the European Union, and of conflict between and within countries, will need to be closely monitored.

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<sup>38</sup> For more on this see: HM Government and Wellcome Trust (2014) *Review on antimicrobial resistance*, available at: [https://amr-review.org/sites/default/files/160525\\_Final%20paper\\_with%20cover.pdf](https://amr-review.org/sites/default/files/160525_Final%20paper_with%20cover.pdf); Littmann J, Buyx A and Cars O (2015) Antibiotic resistance: An ethical challenge *International Journal of Antimicrobial Agents* **46**: 359-61.