The following topics have been suggested as possible project areas for further investigation by the Council. These topic summaries do not aim for comprehensiveness; rather, they are intended to sign-post some of the key considerations and to provide a starting point for discussion. Each summary includes links to relevant publications on the topic.

This list is regularly updated as topics are selected and/or revised following discussions among members of the Future Work Sub-Group and the Council. This list was updated in October 2015.

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Autism

Recent research into the genetics of autism has raised speculative questions about the prospect of prenatal testing for the condition and the development of preventative interventions and treatments in the future. This research also has wider implications for our perception of behavioural disorders in general.

Are there recent scientific, legal or social developments?
The Autism Genome Project was established in 2004 and is currently planning a third phase of activities. Recently, researchers identified a likely genetic mutation linked to autism, which could be a potential target for drug treatments. MRI scans of autistic patients have revealed abnormalities in the white matter of the brain, leading to the theory that neuroinflammation may be a causative factor. If so, drug treatments involving anti-inflammatories could be developed. In 2013, scientists reported a trial to use deep brain stimulation (DBS) to alleviate symptoms in a boy with severe autism, which showed promising results.

Are there complex ethical issues?
Some have raised concerns that these developments represent the increasing pathologisation of behaviours and question the permissibility of neurological treatments that aim to normalise individuals with these conditions. Advocates of the neurodiversity movement argue that autism is just a particular type of cognitive style, rather than a disorder to be treated, and that part of the problem stems from society's inability to respond to the needs of people with autism. Supporters of this view are worried that increased genetic testing and intervention will further stigmatise those with the condition, and that resources will be directed towards the eradication of the disorder, rather than focusing on improving the lives of those already living with autism. However, other commentators stress that autism exists as a spectrum, and that for some it can have a profound effect on their quality of life. For these individuals and their families, research into the genetics of the condition could result in significant improvements in diagnosis and treatment.

Is there a potential policy impact?
If a genetic test for autism were to become clinically feasible, regulators would need to decide whether such a test should be made available, and if so, the criteria for eligibility. In making this decision, policy-makers will need to take account of the wider implications that permitting genetic testing for autism would have on our conceptualisation of behavioural disorders.

Is it a subject of public concern?
The sharp increase in the number of children diagnosed with autism over the past two decades and the controversy surrounding the proposed link between the condition and the MMR vaccine has resulted in autism being a subject of significant public concern. This is perhaps reflected in the Autism Act 2009, the first condition-specific legislation of its type in England, which places a duty on the Secretary of State for Health to introduce a strategy for meeting the needs of adults with autism.

Is consideration timely?
The development of a diagnostic test for autism is still likely to be some years away. Similarly, the use of DBS to treat the condition is still in the early trial stages. However, considering that the research is currently being conducted, it might be timely to discuss some of the ethical and policy implications now.

Can the Council offer a distinctive contribution?
The Progress Educational Trust is currently running a project on autism supported by the Wellcome Trust, which is focussing on the interplay between genetics and psychology, and the public’s understanding of spectrum disorders. An alternative approach for the Council could be to look at the wider issue of behavioural disorders more generally using case studies on a range of conditions (e.g. autism and addiction). There is likely to be some overlap with the Council’s previous work on Novel Neurotechnologies and the future topic on non-invasive prenatal testing currently under consideration.
Biotechnology and globalisation

Biotechnology refers to any technological application that uses biological systems, living organisms or derivatives thereof, to make or modify products and processes for specific uses, for example in the fields of agriculture, pharmacology and bioengineering. The effects of the mechanisms of globalisation on such industries raise significant ethical and policy issues.

Are there recent scientific, legal or social developments?
The costs of international transportation and communication are declining, and there is a progressive dismantling of barriers to trade and capital mobility. These make possible the outsourcing and relocating of research and development, and foreign investment in national biotechnology concerns.

Are there complex ethical issues?
Concerns have been raised that the benefits and opportunities of globalisation have been largely limited to a relatively small number of wealthier countries, whilst the costs have largely been borne by developing and poorer countries. Using populations in less economically developed countries as sources of inexpensive labour and as clinically naive patient populations raises important questions surrounding both consent and exploitation. A key question in this area relates to the responsibilities of biotechnology corporations that operate globally. These corporations may affect a local population in a number of ways, including: the loss of a workforce; the distortion of social and educational priorities; and increased economic instability. As a result, less developed countries may find themselves dependent on continued investment by foreign-controlled companies.

Is there a potential policy impact?
At the UN Millennium Summit in 2002, ensuring that globalisation becomes a positive force for all was declared a central challenge. A potential focus for policy impact in this area is in respect to the global responsibilities of corporations developing new biotechnologies, such as encouraging private companies to incorporate an ethical approach to their activities. For example, the UN Global Compact is a voluntary initiative that seeks to promote responsible corporate citizenship so that businesses help to respond to the challenges of globalisation. Some question how effective these voluntary ethical codes can be, and whether more regulatory control is needed.

Is it a subject of public concern?
The impact of globalisation is increasingly becoming a subject of public concern, particularly in regards to the actions of large, multinational corporations, and the perception that the benefits and burdens have been unfairly shared in the past.

Is consideration timely?
The UN Global Compact Leaders Summit is a meeting of Global Compact participants and other stakeholders from government, civil society, academia, and the UN, which aims to continue to develop the Global Compact’s strategic guidance. The Leaders Summit is held every three years with the next meeting presumably planned for 2016 (the last one was held in 2013).

Can the Council offer a distinctive contribution?
This is a huge topic involving an array of issues related to globalisation and economics, and so any contribution by the Council would need to be carefully focused. One possible avenue of work could be a follow-up activity linked to the Emerging Biotechnology report, with a focus on the global responsibilities of biotechnology corporations.
Citizen science

Citizen science is the term given to research that involves amateurs or non-professionals. These projects can vary in the level of public participation, from contributory and collaborative ventures to projects entirely devised by communities of individuals and directed towards local priorities.

Are there recent scientific, legal or social developments?
Citizen science is increasingly being utilised in environmental science to aid in the collection and classification of vast amounts of raw data. The proliferation in personal health monitoring devices and social networks has facilitated the formation of online health data sharing platforms, such as PatientsLikeMe, which enable patient groups to conduct their own research, including informal drug trials and analyses of genomic data. Cancer Research UK has developed apps and online games for the public to use which help scientists to map genetic faults in cancer data.

Are there complex ethical issues?
Some view citizen science as a way to promote public engagement with science, and empower individuals and communities by providing a mechanism by which the wider public can steer priority setting in research. These projects can also potentially increase productivity and be cost-effective. However, citizen science also raises a number of challenges, particularly in the context of medical or health research. One potential issue concerns how the risk-benefit analysis of a proposed study should be conducted and who should be responsible for this. One option may be to allow the participant-researchers themselves to assess the level of risk involved and determine whether this is acceptable, placing a strong emphasis on the respect for individual autonomy. However, there may be limits to how much risk individuals should be allowed to expose themselves to. Furthermore, patients involved in self-experimentation may conduct a distorted risk assessment leading to unacceptable risk-taking, or they may be subjected to coercion and peer pressure by fellow participant-researchers who are keen to recruit more people. Related to this is the question of how to ensure that participants have given their informed consent, or whether the doctrine of consent is even appropriate in the context of participant-led research. There is also the issue of the security of personal information shared online and how this equates with the capacity for people to control their own health data to whatever end they see fit.

Is there a potential policy impact?
One of the key questions for policymakers is how to ensure regulatory oversight, and who should be responsible for this. Any research governance framework would need to strike a balance between protecting potential participant-researchers and empowering individuals who wish to pursue this research. In some instances, citizen science organisations have produced their own code of ethics to guide their members.

Is it a subject of public concern?
The citizen science web portal, Zooniverse, which is operated by the Citizen Science Alliance, has reportedly more than 1 million registered volunteers.

Is consideration timely?
In the EU Green Paper on Citizen Science for Europe, citizen science was identified as an important tool for achieving the goals of the Europe 2020 strategy and relevant to many of the topics of the Horizon 2020 programme. The subsequent White Paper was released in September 2014 by the EU-funded Socientize project, which highlighted a number of challenges, including the need to have a stronger focus on social values and greater openness and diversity among the various actors.

Can the Council offer a distinctive contribution?
The UK Environmental Observation Framework (UKEOF) commissioned the NERC’s Centre for Ecology and Hydrology to produce a best practice guide to running citizen science projects, which was further supplemented with a guide regarding the implementation of these types of project in 2014. The UKEOF has also established a Citizen Science Working Group to provide a forum for sharing good practice. This work has mainly concentrated on the role of citizen science in environmental projects. The Council could potentially contribute in this area, therefore, by focussing on the issues that might be raised in the context of medical research.
Dignity

Dignity is a term that is used in moral, legal, and political discussions to express the idea that a being has the right to be valued, respected and receive ethical treatment. The term is often invoked in the context of medical research or practice and is assumed to carry significant moral force. However, it is often used in competing or opposing ways, and it is not always apparent what is meant when the term is used.

Are there recent scientific, legal or social developments?
The concept of human dignity is increasingly being utilised in public discourse to advocate or oppose a scientific or legal development. For example, in the ongoing debate about the legalisation of assisted dying in the UK, both sides of the debate use the word dignity for competing interests (see: ‘Dignity in Dying’ versus ‘Right to Life’).

Are there complex ethical issues?
Respect for human dignity is a powerful construct in bioethics, and opposition to a particular area of medical research or practice is often based on the claim that it threatens or violates human dignity. However, the use of the term is sometimes viewed as contentious because of the different meanings that can be implied by its use. Some bioethicists have denounced the term as meaningless, or argued that it is completely reducible to respect for autonomy, whilst others consider it a distinct property possessed by all and only human beings, and which serves as the foundation for human rights. Dignity is sometimes viewed as the basis of freedom to pursue one’s chosen goals. In contrast, it is also viewed as the basis of legal barriers to pursuing certain goals that are considered contrary to dignity. These different readings of dignity can create problems when the term is used inconsistently in debates by both sides, resulting in a loss of clarity and misunderstanding.

Is there a potential policy impact?
The concept of dignity is used frequently in bioethics conventions and legal instruments, such as the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, the UN Universal Declaration of Human Rights, and the European Convention on Human Rights. It is also relied upon in policy documents and best practice guidelines for healthcare professionals (for example, see: Delivering Dignity).

Is it a subject of public concern?
Many of the subjects in which dignity is frequently used, such as assisted dying, care of older people, reproductive technologies, and genetics, are of huge public concern.

Is consideration timely?
The Assisted Dying (No.2) Bill, a Private Member’s Bill that would allow terminally ill adults to end their life with medical assistance (adopting Lord Falconer’s draft regulations), is currently under debate in the House of Commons and is expected to have its second reading on 11 September 2015.

Can the Council offer a distinctive contribution?
There is already a considerable body of work on the concept of dignity. However, this is mainly academic in nature. The Council could potentially contribute in this area by providing clarity and guidance for politicians, policy-makers, campaign groups and other interested parties on the use of the term (in a similar vein to the current project on Naturalness). A possible approach could be to identify a number of case-studies where the term is often used (e.g. assisted dying, sex selection, stem cell research) and explore the range of associated meanings.
Global health inequalities

Global health inequalities refer to the disparity in health outcomes and access to healthcare services across the world’s populations. For example, there are often significant differences in life expectancy and maternal and infant mortality rates between richer, more developed countries and poorer ones.

Are there recent scientific, legal or social developments?
In May 2012, the WHO Member States adopted a resolution endorsing the Rio Political Declaration on Social Determinants of Health at the 65th World Health Assembly (WHA), with the aim of improving public health and reducing health inequities through action on the social determinants of health. Universal health coverage was also a key topic at the World Innovation Summit for Health (WISH) in 2015.

Are there complex ethical issues?
A key question in this area relates to the roles of the various agents that operate within the broad sphere of global health, and where responsibility should lie for reducing inequalities. The number and diversity of sectors involved, including states, NGOs, philanthropic foundations and charities, medical and research institutions, and global industries, makes effective coordination between these agents problematic. Any intervention to address global health inequalities must also be mindful of the cultural and social contexts in which it occurs, and actors (both state and non-state) will need to be aware of the potential for global efforts to distort local priorities in ways that are counterproductive. This could include a wider discussion on the motivations for philanthropic acts and corporate social responsibility; are these acts always motivated by altruism, and does it matter what the intentions are if some good is achieved?

Is there a potential policy impact?
A key issue in this area relates to global health governance and the responsibilities of the various actors involved, particularly non-state actors, such as philanthropic organisations and other funding bodies. These large private foundations can often dictate global health strategies in terms of agenda and priority setting, yet are often not subject to the same level of democratic scrutiny and accountability as state actors.

Is it a subject of public concern?
The issue of global health is a subject of public concern, with a number of large grassroots organisations, such as the People’s Health Movement, campaigning for better health equity among the world’s populations.

Is consideration timely?
The UN Sustainable Development Summit will be held in September 2015. During this summit, member states will discuss the adoption of the Sustainable Development Goals, a set of targets that follow and expand on the Millennium Development Goals, which were agreed by governments in 2000 and are due to expire at the end of 2015. These Sustainable Development Goals aim to improve the lives of poorer people around the world, including ensuring the health and wellbeing of all, and will be used by UN member states to frame their political policies over the next 15 years. However, these initiatives focus on the responsibilities of member states, and provide little guidance as to the role of non-state actors.

Can the Council offer a distinctive contribution?
The issue of global health inequalities encompasses a diverse range of complex challenges, involving numerous actors, from individuals and NGOs, to governments and international organisations. This would make it difficult for the Council to address in a single inquiry. Therefore, the key question for the Council is whether it can define a particular aspect that is both manageable and offers the opportunity to contribute something distinctive. In 2011, the Nuffield Council held a global health symposium, which identified a number of areas in which the Council might contribute. One of the key themes that emerged from this was global health governance with a focus on private philanthropy. Such foundations are often powerful and difficult to oppose or criticise, and universities and organisations might feel unable to challenge these foundations as they might rely on them for funding. In this respect, the Council, considering its relative independence and authority, might be able to provide a significant and distinctive contribution. It was also suggested that a stream of work could be dedicated to global health inequalities, which would allow the Council to pursue a range of topics within this very broad field, and that the Council could engage with other bioethics committees on this subject.
An innovative therapy (IT) is a newly introduced or modified therapy with unproven effects. Unlike research, which follows a predetermined course of action set out in a protocol, experimental or innovative therapy involves a more speculative approach to the patient's care and may be adapted to the individual's response. However, such innovations may blur the distinction between treatment and research.

Are there recent scientific, legal or social developments?
The use of ITs has emerged as an important and difficult issue in recent Council reports, such as *Children in Clinical Research* and *Novel Neurotechnologies*. The ethical and policy issues that arise with the use of ITs were also the subject of debate during the recent Ebola outbreak and the discussion surrounding the acceptability of giving experimental drugs or vaccines to sufferers of the disease outside the confines of a traditional research trial.

Are there complex ethical issues?
The use of ITs raises a number of ethical issues because the border between research and treatment is less clearly defined. Physicians involved in IT will need to be aware of the potential conflict that might arise between the goal of furthering medical knowledge and ensuring the welfare of the individual patient, and the potential for this conflict to undermine trust in the doctor-patient relationship. Patients may feel objectified if doctors view their condition as a subject for experimentation or for professional development via publication. Other patients may view the ability to participate in experimental therapies in a positive light if they view the treatment as their only chance of getting better. However, the ability to give informed consent in this context may be compromised by the emotional pressures of suffering from an incurable and potentially life-threatening condition. Furthermore, implicit trust in the medical profession and in the efficacy of modern medicine may cause both patients and doctors to overlook or downplay the risks inherent in a procedure. Finally, there is the question of whether clinicians involved in IT should have a duty to record and share any insight gained regarding the benefits or negative outcomes of the intervention, and if so, how this could best be achieved. This information might be of use to enable other patients to benefit from the same treatments or to avoid suffering the same adverse effects, as well as to guide potential future research strategies. However, this may further blur the distinction between what is considered treatment and what is considered research.

Is there a potential policy impact?
In contrast to conventional research protocols, which are subject to strict regulatory mechanisms, there is a distinct lack of clear governance in relation to ITs, and therefore relatively little guidance and protection available for those involved. A key question is whether existing models used for research governance, such as research ethics committees, are appropriate in this context, or whether a new form of assessment is required. Unlike research, IT is aimed primarily at treating particular individuals, and so any proposed regulation would ideally need to maintain sufficient flexibility to allow for variations in individual circumstances. The biggest challenge for policy makers may be in defining exactly what constitutes treatment and what constitutes research, and how to regulate the spectrum of interventions that may fall under the umbrella term of IT. Lastly, there is the question of whether national or international databases would be required to capture the learning gained from the use of ITs, and how these might be structured.

Is it a subject of public concern?
ITs are often used in the context of a life-threatening condition when all other treatments have failed, and so are likely to be of significant concern for the public.

Is consideration timely?
Considering that this issue has emerged in recent Council reports and the recent Ebola outbreak, and the obvious gap in governance that currently exists, it would appear that this topic would be appropriate for discussion in the near future.

Can the Council offer a distinctive contribution?
There is an opportunity for the Council to contribute in this area by conducting an in-depth analysis of the complex ethical issues involved and providing much needed guidance for both policy-makers and physicians.
The Nagoya Protocol on Access to Genetic Resources and the Fair and Equitable Sharing of Benefits Arising from their Utilization to the Convention on Biological Diversity (Nagoya Protocol), which was adopted in 2010 and entered into force on 12 October 2014, is a supplementary agreement to the Convention on Biological Diversity (CBD). It provides a legal framework that governs access to non-human genetic resources and traditional knowledge.

Are there recent scientific, legal or social developments?
The Nagoya Protocol was brought into EU law by the adoption of Regulation EU No 511/2014 on 16 April 2014, although some of the key provisions will only become applicable on 12 October 2015. In the UK, this EU regulation will be implemented by the Nagoya Protocol (Compliance) Regulations 2015. In particular, the Nagoya Protocol details information that must be included in the prior informed consent given by the provider country, and a general obligation to establish a benefit sharing agreement between the provider and user.

Are there complex ethical issues?
One of the fundamental elements underpinning the Protocol is the equitable sharing of benefits. In practice, the majority of the agreements are expected to be signed between biodiversity-rich, and often developing, countries, and users from more developed countries. Access and benefit sharing for the utilisation of genetic resources has been a controversial issue in the past, and it was felt that the CBD did not offer sufficient legal clarity to protect the rights of states and indigenous communities over their local resources. Companies and scientists sometimes developed and patented commercial products based on genetic resources, resulting in accusations of biopiracy. The Nagoya Protocol aims to combat this by ensuring that developing states benefit from the use of their genetic resources by foreign institutions. Some institutions, including the Wellcome Trust, have raised concerns about the potential negative impact on international research efforts (e.g. monitoring of drug resistance and responding to disease outbreaks), which rely on open and comprehensive databases that source information from many countries. The concern is that the requirements contained within the protocol will restrict the efficient sharing of information, or that research institutions might migrate to countries that have not ratified the Protocol, such as the USA or China.

Is there a potential policy impact?
A number of aspects of the EU Regulation still remain unclear, including what constitutes due diligence (what users must exercise when ascertaining whether a genetic resource has been accessed in accordance with regulatory requirements), whether the Protocol applies to derived materials (e.g. DNA sequences), and how to collaborate with organisations from countries that are not signatories. As yet, no detailed guidance has been produced by either the European Commission or the UK government (DEFRA has responsibility for the implementation of the EU Regulation, and the National Measurement and Regulation Office (NMRO) will be responsible for enforcing it).

Is it a subject of public concern?
It would appear that the existence of the Nagoya Protocol has remained largely outside of the public’s awareness thus far. However, the ability of the international community to prevent and respond to potential epidemics or pandemics is likely to be a subject of significant public concern.

Is consideration timely?
The European Commission is planning to develop guidance documents following a Consultation Forum, which will likely be convened in the third quarter of 2015 after the Implementing Regulation has been adopted. The UK government will conduct a review within the next five years to address any concerns that arise from the implementation of the EU Regulation. In addition, the EU Regulation requires Member States to provide a report on its application by 11 June 2017, and so a review of some type is likely to be carried out before this date.

Can the Council offer a distinctive contribution?
The Nagoya Protocol is essentially a legal development, albeit one with important implications for future biological and medical research. However, it may be that the Council can offer a neutral perspective on some of the raised concerns, or provide a platform for involved parties to debate the potential impact of this Protocol on research. In addition, this topic might provide the opportunity to explore some of the ethical challenges that were highlighted in the previous background paper on pandemics and the global response to disease outbreaks.
Non-human technologies in health and social care

This topic is focused on the use of non-human technologies for health monitoring, care provision, and automated decision-making, including personal mobile health monitoring devices, robotics, and artificial intelligence.

Are there recent scientific, legal or social developments?
Smart phone applications for personal health monitoring are now being used in conjunction with clothing capable of measuring vital signs (for example, see: OMsignal and Footfalls and Heartbeats). Google is also currently developing a contact lens that could measure glucose levels, and exploring the possibility of ingestible nanoparticles that detect the presence of biomarkers in the body. In February 2015, an EU-funded project, MARIO, was launched to address the challenges of dementia with the use of service robots, involving three pilot studies in the UK, Ireland and Italy. A significant amount of research is also being conducted on machine learning with potential applications in medical diagnostics and treatment decision-making (for example, see IBM Watson).

Are there complex ethical issues?
A key question in this area concerns trust, and whether healthcare professionals and patients would accept the use of these machines. Even if the technology was shown to be safe and accurate, people still might feel a general uneasiness, at least initially, to the idea of robots being responsible for their care. These technologies could potentially allow more people to remain independent in their own home, but might lead to dependency on the technology or create anxiety amongst users regarding their health from continuous monitoring. Devices could be designed to prompt users to make healthier lifestyle choices, raising questions about the permissibility for technology to modify behaviour. Health monitoring devices that automatically alert medical staff would reduce an individual’s capacity to make their own decisions, potentially resulting in a loss of self-determination or a sense of reduced responsibility for one’s own health. Concerns have also been raised that these technologies might lead to the social isolation of vulnerable members of society, and the loss of collective responsibility to care for others. Advances in AI in the future could raise a number of fundamental questions about our notions of intelligence and consciousness, and even the very question of what it means to be human.

Is there a potential policy impact?
There a number of questions for policymakers to address in this area, including the issue of liability if something goes wrong, and the impact on the current workforce. A significant issue in this area pertains to the privacy of the information collected. Who would be able to access this information and how could it be used? For example, some companies have initiated corporate wellness programmes where employees are rewarded for making healthier lifestyle choices. Could a healthcare provider (private or state-funded) impose lifestyle choices on people based on the data that is gathered? Lastly, there is the need for guidance regarding responsible research and innovation. For example, the EPSRC and ARC have drafted a set of ethical principles for robot designers.

Is it a subject of public concern?
Non-human technologies are set to pervade many aspects of our daily lives in the near future, including the very personal and human experience of health and social care. Therefore, this subject is likely to generate significant concern among the public as these technologies become more widely adopted.

Is consideration timely?
There is a growing recognition of the role that robotics and autonomous systems are going to play in the very near future (for example, see the UK Government's commitment to invest in these technologies and the launch of the EPSRC UK Robotics and Autonomous Systems Network). The Royal Society recently held a conference on machine learning, and participated in a roundtable discussion with the Government Office for Science and the AHRC on ethics and trust in the human-machine relationship.

Can the Council offer a distinctive contribution?
The Council could potentially contribute in this area by providing an independent platform upon which a wide group of interested stakeholders could be brought together to discuss the ethical and policy issues that might arise.
Relational autonomy

Relational autonomy is a term that is used to convey the idea that cultural norms, social environments, and interpersonal relationships can all play a role in an individual’s sense of self and self-expression. This idea challenges some areas of current healthcare practice and policy, which are based on a very individualistic approach to autonomy.

Are there recent scientific, legal or social developments?
The challenges that can arise from an individualistic account of autonomy were highlighted in the Council’s report on Dementia, and more recently in the report on Children and Clinical Research.

Are there complex ethical issues?
Respect for autonomy is one of the leading guiding principles in medical ethics and underpins the doctrine of consent in research and medical practice. However, the traditional account of autonomy has been criticised for an oversimplified interpretation that places too much value on moral independence and the self, and that this interpretation is problematic in some areas of healthcare, particularly in mental health. In response to this, the notion of relational autonomy has been proposed. This recognises that people do not live in isolation, but rather exist within the context of interpersonal relationships and social networks, and encourages consideration of the obligations and sources of support that arise from these interconnections. This concept of relational autonomy has important implications for our understanding of a number of areas in healthcare, such as person-centred care, personal identity, and decision-making. It is also likely to be of relevance in the context of genetic privacy, in which the inherently shared nature of genetic information challenges our current individualistic model of confidentiality.

Is there a potential policy impact?
This account of autonomy has implications for current policy in a number of areas of health and social care, particularly in relation to mental health and long-term care provision, guidance on confidentiality, and best practice guidelines regarding the relationship between healthcare professionals and carers. For example, the Council’s Dementia report recommended a review of the guidance on confidentiality in the MCA Code of Practice and for there to be greater recognition of the reasons why carers may need access to confidential information.

Is it a subject of public concern?
The demographic shift towards a predominantly older population has resulted in an ever increasing need for informal carers, which are often fulfilled by family members. This has meant that the role of family carers has become a topic of significant political and public concern (see: UK Government’s Carers Strategy).

Is consideration timely?
In March 2014, the House of Lords Select Committee published their post-legislative scrutiny report on the Mental Capacity Act 2005, which was highly critical of its implementation. In response to the Lord’s recommendation to establish an independent body to oversee MCA implementation, the Government has announced their intention to create a National Mental Capacity Forum with an independent chair, which will coordinate efforts to increase awareness of the Act. The appointment of the Chair is expected to be announced after the summer recess with the first meeting of the forum to be held in November 2015. Such a forum might be well placed to discuss the implications of a more rational approach to autonomy.

Can the Council offer a distinctive contribution?
Much of the discussion to date concerning the notion of relational autonomy has been academic in nature. The Council could potentially contribute in this area by reflecting on how this notion of autonomy impacts on current policy, or use a range of case studies to illustrate how the traditional account of autonomy can present problems in certain contexts.
Suppressing the extra chromosome in Down’s syndrome

Research on the silencing of the extra copy of chromosome 21 has led to speculations that a chromosomal therapy for Down’s syndrome could be developed in the future.

Are there recent scientific, legal or social developments?
In July 2013, a team of scientists from the University of Massachusetts Medical School published research detailing a method of silencing the third copy of chromosome 21. Normally, an RNA gene called XIST (X-active specific transcript) silences one of the 2 X-chromosomes in female cells in early development. The team mimicked this process by inserting the XIST gene into affected cells in vitro.

Are there complex ethical issues?
Individuals with Down’s syndrome are more at risk of developing a number of health complications and all will have some degree of learning disability. Some argue, therefore, that a chromosomal therapy could benefit these individuals, and that if such treatments are available, then people have a right to access them. However, parents in particular may feel that they have a duty to reduce genetic harm to their offspring. Some have criticised the focus on curing Down’s syndrome, rather than aiming to facilitate and support individuals with the condition in their daily lives. Some view disability as an important aspect of an individual’s identity, and are concerned that the idea of a cure further perpetuates the notion that a life with Down’s syndrome is worth less, leading to increased stigma and discrimination towards those living with the condition.

Is there a potential policy impact?
This research has the potential to produce a number of developments in the future, from an enhanced ability to study the genetic factors involved in Down’s syndrome, to potential treatments for the syndrome itself. A key question for policymakers is whether any potential chromosomal therapy for Down’s syndrome should be made available if it were to ever become a possibility in the future. Furthermore, this research is likely to have implications for other chromosomal and genetic disorders aside from Down’s syndrome.

Is it a subject of public concern?
About 750 babies are born with Down’s syndrome each year in the UK, and all pregnant women are routinely offered prenatal screening for Down’s syndrome. If a chromosomal therapy for Down’s syndrome ever became a possibility in the future, it would likely be a subject of significant public concern, especially considering the relevance of the ethical and policy issues involved to a wide range of conditions, and our notions of disability in general.

Is consideration timely?
The research into a chromosomal therapy for Down’s syndrome is still at a very early stage, and may not be available for many years, if at all. However, considering that the research is currently underway, it may be timely to discuss the future implications of this research and question whether limited funding is being appropriately prioritised.

Can the Council offer a distinctive contribution?
It is likely that the issues outlined above would be included within the broader context of non-invasive prenatal testing or genome editing, two areas that the Council is already actively considering and working on, respectively.