

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 details of relevant publications on the topic.

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| • Artificial gametes | |
| • Food: ethical issues (looking at questions of ‘artificial’ vs ‘natural’ food, and at the exporting of western models of food) | |
| • Sharing genetic information in primary care (not necessarily focussing specifically on confidential/circumstances in which information may be shared, but also about the practicalities of health professionals holding/storing information that cannot be shared until later) | |
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Biotechnology and globalisation

Overview

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. The industries associated with biotechnology include agriculture, pharmacology and bioengineering. The effects of the mechanisms of globalisation on such industries raise significant ethical and policy issues. 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. At the same time, the increase in global competence in biotechnology raises the possibility of internationally directed projects such as large scale geo-engineering.

Ethical issues

Ethical issues to consider with respect to biotechnology and globalisation include: weighing the potential harms and benefits from biotechnology; ensuring fair access; ensuring just treatment of workers in biotechnological industries; protecting cultural integrity and national sovereignty; and determining the appropriate role for private companies and market forces in public health and biotechnology. Using populations in less economically developed countries as sources of inexpensive labour and as clinically naive patient populations raises important questions to do with both consent and exploitation. Countries may find themselves losing a skilled workforce to international biotechnology companies, without receiving the benefits of research. Furthermore, the aggressive expansion of multinationals within a country may skew the educational priorities of the native population. Lesser developed countries may find that these processes leave them dependent on continued investment by foreign-controlled companies and thus economically vulnerable. Large-scale cooperative biotechnology projects raise questions of our relationship to the natural world. Should we make permanent and radical changes to the environment in order to meet human needs, or to satisfy non-essential preferences? If so, when are such changes warranted? Ethical issues arise as to the equitable distribution of risks and benefits arising from such practices. Globalised biotechnology challenges our notion of solidarity.

Policy implications

Effective policy may require a better understanding of the process of globalisation, the mechanisms by which it works and its likely or possible outcomes. Allowing market forces solely to dictate the shape of biotechnological industries is neither feasible nor desirable. Policy is concerned with; quality assurance and regulation, guiding and fostering research and ensuring equitable benefit sharing of the results of biotechnology. This will require mechanisms for effective coordination between national and international governments and corporations. Issues with generic and counterfeit prescription medicines highlight difficulties in ensuring quality control, and in seeking redress for breaches of national or international regulations. Policymakers must also address the role of intellectual property rights in biotechnology, in order to constrain biopiracy without restricting innovation. Global cooperation must not constrain democratic accountability.

Recent literature

International Assessment of Agricultural Knowledge, Science and Technology for Development (2008) [Agriculture at a crossroads](#).
Council of Europe (1999) *International conference on ethical issues arising from the application of biotechnology* (Oviedo: Spain).
Falkner R (2013) *The handbook of global climate and environment policy* (London: Wiley-Blackwell).
Glasner P and Rothman H (2001) New genetics, new ethics? Globalisation and its discontents *Health, Risk & Society* **3(3)**: 245-59.
Newell P (2003) Globalization and the Governance of Biotechnology *Global Environmental Politics* **3(2)**: 56-71.

Complementary medicines and therapies

Overview

Complementary therapies (CT) are treatments intended to cure illness or promote well-being, which have not been endorsed by scientific medical practice. Examples of CT include: aromatherapy; homeopathy; hypnotherapy; massage therapy; acupuncture; naturopathy; nutritional therapy; reflexology; reiki; shiatsu; traditional Chinese medicine and yoga therapy. The promotion and use of CT is highly contentious due to the questionable or non-existent evidence bases for their claims. In defence of CT, practitioners point to the value of tradition and mostly anecdotal evidence of interventions promoting an individual's well-being. It has been argued that traditional medicine can be too mechanistic; the benefits of CT are thought to be holistic, giving psychological, social and spiritual benefits. In response, sceptics argue that CT is inconsistent with the principles of evidence based medicine and that its toleration is dangerous or misleading. When making decisions about CT it is important to judge each therapy on its own merits.

Ethical issues

The ethical issues relating to CT include: patient autonomy; paternalism; overall risks of harm/benefit to the individual, to third parties and to society; consent and vulnerability; the doctor-patient relationship; respect for cultural practices and their limits; and the role of profit-making enterprise in healthcare contexts. Certain CT may have positive effects via the placebo effect. Whether this is sufficient grounds for allowing their prescription is contentious. In order for such treatment to be ethical, the patient must understand and consent to the treatment; this would require that they be told the prescription was a placebo, presumably weakening or nullifying its effect. Since a placebo only treats the symptoms of a condition, not its underlying causes, it has the potential to mislead an individual about their overall health. An assessment of the ethical implications of CT will have to balance individual autonomy against the State's duty to safeguard public health and a doctor's duty to provide their patients with the best available treatments. Furthermore, there are concerns regarding how far CT practitioners adhere (or should adhere) to conventional medical ethical standards, such as respecting informed consent, assessing capacity, and ensuring the just distribution of care. The variation in training amongst CT practitioners varies widely, as does their membership of professional bodies; this raises important questions about how to safeguard patients, and processes of accountability should patients come to harm.

Policy implications

There are a number of possible positions that can be taken with respect to the State's relation to CT. These range from banning such practices entirely, to publically funding research into, and prescription of, CT. Alternatively, the government may consider CT a matter of personal choice, and determine that it is not appropriate for the State either to promote or prevent its use. In the latter scenario, it remains an open question whether (and, if so, to what extent) the provision of CT ought to be regulated. Should regulation be deemed desirable, it must be determined who is to provide such regulation and on what grounds. The regulation of some CT (e.g. homeopathy) is required by European directive, which states that homeopathic treatments should be available for sale so long as they do not make misleading therapeutic claims and are safe for human consumption. Despite this, there is much variation in the quality and extent of regulation of complementary therapies across the EU. Licensing CT may protect patients from rogue and unscrupulous practitioners. On the other hand, sceptics contend that licensing provides an air of false legitimacy to unproven practices. Poorly understood or under-researched areas of CT might be useful subjects for research and provide legitimate advances to evidence based medicine in the future.

Recent literature

Department of Health (2010) *Government response to the Science and Technology Committee report 'evidence check 2: homeopathy'* (London: The Stationery Office).

Ernst E, Cohen MH and Stone J (2004) Ethical problems arising in evidence based complementary and alternative medicine *Journal of Medical Ethics* **20**: 156-9.

The Royal Society (1999) [Complementary and alternative medicine: response to the House of Lords inquiry into complementary and alternative medicine.](#)

World Health Organization (2005) [National policy on traditional medicine and regulation of herbal medicines: report of the WHO global survey.](#)

Dual-use technologies

Overview

Dual-use technology (DUT) refers to scientific research and its products which can be used for both good and bad purposes. The danger that scientific advances might be used for bad ends first entered modern consciousness with the role of atomic research in the creation of nuclear weapons. Recent advances in genetics, neuroscience and synthetic biology have heightened these issues. The combination of a globalised world, the availability of scientific equipment and knowledge and the threat of global terrorism, make the dangers inherent in DUTs more pressing than ever. On the flipside, many beneficial technologies arise (either directly or indirectly) from morally bad (or questionable) research projects.

Ethical issues

The chief ethical issues to do with DUTs turn around the values of scientific knowledge on the one hand, and global security on the other. It is an open question whether either security, or the pursuit and dissemination of scientific knowledge, are intrinsically (rather than merely instrumentally) valuable. Supposing each to be valuable in their own right, there remains substantial disagreement over how to resolve conflicts between them. Is there a right to security, and, if so, what degree of risk is consistent with its observance? To what extent can scientists disclaim responsibility for the potentially harmful uses of their research? On the other hand, can unforeseen or unintended beneficial consequences of research justify an otherwise ethically dubious research programme? How far ought individual scientists, or the scientific community as a whole, consider the potential social ramifications of their work when deciding how to proceed? Insofar as DUTs involve foreseen but unintended consequences of an activity, there are clear parallels with the disputed 'doctrine of double effect'.

Policy implications

It is generally agreed that we should aim for policy that strikes a balance between the goal of promoting scientific progress (and the goods that this entails) and the goal of protecting security. Given the globalised nature of scientific enterprise, and the potentially global ramifications of the weaponisation of biotechnology, international coordination is necessary. However, there is no consensus over the shape that policy should take; in particular, the degree to which governments should interfere in scientific practice. Regulators may choose to affect the content of a publication, its timing or its distribution. Control over the areas of research and the dissemination of its products may occur at any of a number of different levels. These include regulation by individuals, professional associations, publishers, research committees, funding boards, governments, or extra-governmental organisations. The scientific community is generally in favour of voluntary self-governance, arguing that autonomy is essential to scientific progress and that governmental interference would be both unethical and counterproductive. Against this, it has been argued that scientists lack both the independence and the knowledge required to make decisions about the security implications of their research.

Recent literature

Baum S and Wilson G (2013) The ethics of global catastrophic risk from dual-use bioengineering *Ethics in Biology, Engineering and Medicine* (forthcoming).

Atlas RM and Dando M (2006) The dual-use dilemma for the life sciences: perspectives, conundrums, and global solutions *Biosecurity and Bioterrorism: Biodefense Strategy, Practice, and Science* 4(3): 276-86.

Fink D (2004) *Biotechnology in an age of terrorism* (Washington DC: National Academies Press).

Miller S, Selgelid MJ and van der Bruggen K (2011) *Report on biosecurity and dual use research: a report for the Dutch Research Council* (The Hague: Dutch Research Council).

Royal Society (2012) [Brain waves 3: neuroscience, conflict and security](#) (London: Royal Society).

Germline gene therapy

Overview

Germline gene therapy refers to any procedure which involves the modification of the genetic material in germ cells for therapeutic purposes. It involves intervening in the reproductive process before conception has taken place. Within such techniques we may distinguish between those which target mitochondrial DNA (mtDNA) and those which target nuclear DNA (nDNA). Germline gene therapies can involve either the manipulation of genetic material (e.g. the insertion of one or a few genes) or its outright replacement. Examples of the former include procedures such as cytoplasmic transfer and gene knockout therapy; of the latter, pronuclear transfer, maternal spindle transfer, somatic cell nuclear transfer and nuclear transfer. Some, but not all, such procedures involve therapeutic human cloning.

Key ethical issues

The key ethical issues to consider with such techniques include the following: the overall balance of potential harms and benefits of the procedure; the identity of individuals affected by gene therapy; the (disputed) right to 'genetic integrity' and its relation to 'human dignity'; respect for the autonomy of the affected individuals; difficulties of establishing informed consent; justice and the possible effects on third parties and society; definitions of parenthood; and the dangers of possible 'slippery slopes' towards reproductive cloning and genetic 'enhancement'. Disability rights campaigners have questioned whether it is ethical to *screen out* certain heritable conditions for a number of reasons; the experience of disability can contribute to a person's sense of identity; difficulty in making value based judgements about which conditions should be targeted for therapy; and making decisions about what is genetically 'undesirable'. This raises questions about what are identity determining characteristics; especially relevant in terms of recent research into the genetic determinants of mental illness.

These ethical issues are heightened by the fact that germline gene therapies affect all future generations of offspring. Given the possibility of unforeseen downstream effects, determining when the overall potential benefits outweigh the harms is problematic. Furthermore, since gene therapies apply to future persons, and arguably alter the identity of the individual who comes into existence, applying concepts of harm and consent to the affected parties is difficult.

Policy implications

From a policy perspective, large questions are raised about what regulatory framework is appropriate. In the UK, such therapies are currently covered by the HFE Act (2008). Questions have been raised about the act's narrow definition of identity, which excludes mtDNA from any role in determining an individual's identity. Furthermore, questions remain as to whether UK legislation should reflect the international concept of 'genetic integrity'. Sweden's Genetic Integrity Act (2006) could act as a template for similar legislation in the UK. Alongside these specific concerns are more general worries to do with the form that regulation should take; whether, for example, legislation ought to be proscriptive and pre-emptive, or rather approach the topic incrementally, taking each new procedure on its individual merits. Recent research involving the successful transfer of donor mtDNA has been backed by the DOH after a public consultation by HFEA (2013). Draft regulations, due to be debated in parliament could pave the way for this therapy being available in the UK.

Recent literature

American Association for the Advancement of Science (2000) [*Human inheritable genetic modifications: assessing scientific, ethical, religious, and policy issues*](#).

Bredenoord AL, Dondorp W, Pennings G and De Wert G (2011) Ethics of modifying the mitochondrial genome *Journal of Medical Ethics* **37(2)**: 97-100.

Human Fertilisation and Embryology Authority (2013) [*Mitochondria replacement consultation: advice to Government*](#).

Parker M (2012) *Ethical problems and genetics practice* (Cambridge: Cambridge University Press).

The President's Council on Bioethics (2002) [*Human cloning and human dignity: an ethical inquiry*](#).

UNESCO (2003) *Report of the IBC on preimplantation genetic diagnosis and germline intervention* (Paris: UNESCO).

World Health Organization (2002) *Genomics and world health: report of the Advisory Committee on Health Research* (Geneva: World Health Organization).

Global health inequalities

Overview

Global health inequality refers to the disparity in health outcomes and access to healthcare amongst the world's populations. Common measures of health inequality include life expectancy, maternal and infant mortality, morbidity rates and self-reported quality of life. Health inequalities, whether at a local, national or international level are largely man-made and reversible. Research shows a strong correlation between level of economic development and positive health outcome. Therefore, a general inequality exists between the health outcomes of lesser and greater economically developed countries (LEDCs and GEDCs, respectively).

Ethical issues

The case for reducing global health inequality is supported by a number of ethical principles including those of equitable distribution of resources and collective justice; healthcare as a human right; human flourishing; and the no harm principle. The ethical issues to do with global health inequalities include: determining whether health equality should be measured in terms of access or in terms of outcomes; clarifying when such inequalities become unfair or unjust; determining how far GEDCs have a responsibility to address them and establishing what interventions are necessary and permissible for each (state or non-state) actor. Benefits must be provided with a view to long-term sustainability, in a way which is culturally sensitive and non-paternalistic. Since such help incurs opportunity costs, potential benefits and risks of a given intervention must be weighed. However, decisions must be mindful of the tension between considerations of utility and of the inherent dignity and human rights of the affected individuals. It remains an open question how useful (if at all) the concept of solidarity is in explaining our obligations to reduce global health inequalities.

Policy implications

Improving health outcomes in deprived areas raises important policy challenges, particularly to do with determining the roles in such an effort for the various global organisations, governments, NGOs, corporations (esp. multinationals) and individuals involved. Coordination between these different groups is necessary if remedial work is to be effective. There is a danger that major philanthropic organisations and NGOs may, though good-intentioned, skew research and international development priorities in ways that are counterproductive. Furthermore, large-scale interventions by non-local entities can have unforeseen effects on the cultural and economic well-being of a region.

Effective policy must tackle underlying structural inequalities and the underlying social causes of poor health outcomes if long term gains are to be made. This may include changes in both the built and natural environments, as well as economic, cultural and social changes. Policy will balance legislative and non-legislative approaches, incentives and punitive measures. In certain respects the health model in LEDCs may be more efficient than its counterparts in GEDCs. The distribution of aid is therefore a reciprocal arrangement, involving benefits to GEDCs as well (e.g. experience for medical staff, opportunities to test new methods, learn about novel contexts, gain local knowledge etc.). Policymakers face the challenge of devising mechanisms which allow these benefits to be used effectively.

Recent literature

International Federation of Red Cross and Red Crescent Societies (2011) *Eliminating health inequities: every woman and every child counts* (Geneva: International Federation of Red Cross and Red Crescent Societies).

Marmot M, Allen J, Bell R and Goldblatt P (2012) Building of the global movement for health equity: from Santiago to Rio and beyond *Lancet* **379(9811)**: 181-8.

Royal Society (2012) [People and the planet](#) (London: Royal Society).

Ruger JP (2006) Ethics and governance of global health inequalities *Journal of Epidemiology and Community Health* **60**: 998-1002.

University College London (2012) [UCL Institute of Health Equity](#).

World Health Organization (2008) [Health equity through action on the social determinants of health](#) (Geneva: World Health Organization).

Health tourism in the UK

Overview

'Health tourism' is an umbrella term which encompasses a number of different practices. Popular use of this phrase in the media refers to individuals who are not usually resident in, or citizens of, the UK who seek to access NHS services. Thus the term 'health tourists' may be used to cover those who travel to the UK for the sole purpose of seeking medical treatment or care on the NHS, as well as those such as asylum seekers, migrants without leave to remain, and temporary visitors, who may also have cause to use the NHS. Thus the debates surrounding 'health tourism' are closely related to debates around access to public services by those who are not permanently resident in the UK, and around the extent to which the state has a duty to provide for individuals who are not citizens of the UK or the EU. The term may also be used in a much wider sense, as a synonym for (planned) international 'medical tourism' or 'medical travel': these wider issues are covered in a separate entry on medical travel.

Ethical issues

Non discriminatory universal access to healthcare, free at point of need is one of the founding principles of the NHS. Whether this principle should be applied to non-British and non-EU citizens is the source of some debate. On the one hand, temporary visitors and illegal migrants do not contribute through the taxpayer system towards public services - they are therefore obliged to pay for any non-emergency treatment they require (unless they come from countries with reciprocal healthcare agreements with the UK). In the current economic climate, with pressure on the DH to make 'efficiency savings' of around £20 billion, financial pressures on the NHS are becoming increasingly acute, and there are concerns that the use of NHS resources to care for those who are not normally resident in the UK could have a significant adverse impact on those who are.

On the other hand, it has been argued that the cost generated by temporary or illegal migrants accessing NHS services is a very small fraction of the total NHS budget. Having a healthcare system that is universally accessible is arguably an ethical obligation of a state; people should not be discriminated against based on their country of origin. From a rights based perspective, individuals should have a right to access healthcare whether or not they are able to afford it. Furthermore, it may be much more cost effective to invest in preventative medicine, including that provided by primary care services: restricting access to primary care may simply increase the burden on other parts of the health service through emergency and long term admissions for chronic and unmanaged health problems. Restricting access to healthcare also puts clinicians in a difficult ethical position, by requiring them to make judgments about their patients' personal circumstances despite their primary professional duty of care towards each individual patient.

Policy implications

In July 2013 the coalition government launched a consultation on migrant access to healthcare services. It recommended changes so that non EEA temporary migrant workers would have to contribute a flat levy towards the cost of their care if they did not have private health insurance. Illegal migrants and non EEA patients would be charged for accessing primary as well as secondary care services. It is likely that these, or similar policies will be adopted in the UK, after the government signalled its intention to do so in the Queen's speech. However the plans remain controversial, particularly those that will require GP practices to record the immigration status of prospective patients. The proposed reforms have been criticised by the chair of the RCGP, and the BMA has indicated it will oppose the guidelines.

Recent literature

Hanefeld J, Lunt N, and Smith R (2013) Health tourism and the NHS: facts of fiction *The Lancet* **382(9890)**: e2.

Department of Health (2013) [Sustaining services, ensuring fairness: a consultation on migrant access and their financial contribution to NHS provision in England](#).

The Guardian (3 July 2013) [Health tourism: how much does it cost the NHS?](#).

Innovative therapies

Overview

An innovative therapy (IT) is a newly introduced or modified therapy with unproven effects. The Helsinki declaration allows for unproven interventions to be used in circumstances where proven interventions do not exist or have been ineffective, so long as the unproven intervention offers hope of saving life, re-establishing health or alleviating suffering. Like research, IT is experimental in nature, but its goal and context are such that it is exempted from direct answerability to research ethics boards. ITs range from procedures entirely without precedent (e.g. use of a novel untested drug) to variations from standard therapies (e.g. modifying dosage or combining treatments), to using conventional treatments in novel contexts.

Ethical issues

Ethical issues to do with IT include: balancing the potential benefits and harms to the patient, to third parties and to society; respecting patient autonomy; ensuring that consent is free and informed; ensuring that the research potential of the treatment doesn't undermine the doctor-patient relationship; and determining the boundaries of the doctor's rights and responsibilities in the use of IT. Research into unproven interventions raises questions about the equitable distribution of resources, both in terms of the opportunity costs associated with the development of IT and in terms of ensuring fair opportunities for access to its benefits. There are also issues surrounding the provision of IT by institutions surrounding if or when it is appropriate to integrate services that are experimental. Withholding potential 'rescue' therapies that may improve prognosis or QOL on the basis that they are experimental is contentious.

Doctors who view their patients as potential recipients for unproven treatments must ensure that this does not interfere with their primary concern for the patient's welfare. Patients (and their families) may feel 'objectified' if doctors view their condition as a subject for research (and potentially, for professional development via publication). Other patients may view the ability to participate in experimental therapies in a positive light; they may feel as though they are contributing to scientific advancement that will help future generations of patients. Controversial treatments (e.g. gene therapies or treatments using embryonic or foetal cells) have independent ethical implications; as do treatments for individuals who do not have capacity to consent such as children or incapacitous adults.

Policy significance

IT raise a number of issues for effective policymaking. The ability to give informed consent 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 can incline both patients and doctors to overlook or downplay risks inherent in a procedure. For this reason, some degree of independent review of the use of IT may be preferable. On the other hand, because such therapies are aimed at helping particular individuals, medical intuition as well as familiarity with the patient's history may be necessary to determine the appropriateness of a given unproven treatment. For this reason, research ethics boards may be inappropriately placed to evaluate requests for IT. The challenge for policymakers is to regulate the use of IT on global or national levels, while maintaining sufficient flexibility to allow for variations in individual circumstances. Professional consensus and judicial review may play some role in this system. Policy should consider the safety, effectiveness, efficiency, accessibility and quality of a given IT.

Recent literature

Chan TE (2013) Legal and regulatory responses to innovative treatment *Medical Law Review* **21(1)**: 92-130.

Eyadhy AA and Razack S (2008) The ethics of using innovative therapies in the care of children *Paediatrics and Child Health* **13(3)**: 181-4.

Stenck N (2007) *ORI Introduction to the responsible conduct of research* (Washington DC: Department of Health and Human Services).

World Medical Association (2001) [Declaration of Helsinki: ethical principles for medical research involving human subjects](#).

Sports medicine and ethics

Overview

This note identifies two issues. The first concerns the use of enhancements, and the second concerns the role of medical professionals in sports. Recent news has highlighted these issues, including reports such as that which 'outed' Lance Armstrong as a cheat who used drugs to enhance his performance, and reports of Harlequins RFC's fine of £200,000 when one of its physiotherapists provided a player with a fake blood capsule to bite so that he could be substituted for a more able kicker for his 'blood' injury. (It was later alleged that the team's doctor had cut the player's lip to hide the fact that fake blood had been used.) Such reports raise a number of ethical issues.

Ethical issues

The issue that perhaps receives most attention in the literature is enhancement. In sports medicine, athletes already take measures to improve performance: for example, swimmers remove body hair to reduce water resistance. If absolute restrictions on enhancement were endorsed, being hirsute would be a natural disadvantage for any professional swimmer. This raises a question as to where acceptable behaviour to enhance performance ends, and unacceptable modifications begin: is all enhancement in sport wrong? Or, should enhancement in sport be encouraged and celebrated (indeed legalised) for the good of sport, or indeed to level the playing field for those *without* natural advantages? An argument could be made that this is already the case in Paralympic sports, where technology is fêted for allowing disabled people to compete in events that might otherwise be impossible.

A further ethical issue is the role of medical professionals in sport. One of the basic tenets of medicine is "first, do no harm". This principle has, however, been undermined by reports of medical professionals acting in ways contrary to the spirit of the maxim. For example, the Harlequins case highlights the fact that medical professionals can be faced with a conflict of interest: their responsibility to care for sportspeople as patients, versus the pressure to support their employer to win. This raises a general question about the nature and purpose of medicine in sport, and it might be suggested that medicine in sport is very different to medicine in healthcare generally. For example, this type of medicine concerns itself primarily with the treatment of individuals who are healthy; and healthcare professionals are employed by clubs and agents rather than their patients, thus dividing their obligations.

Like "first, do no harm", the requirement to treat patients in their 'best interests' has evolved as a key principle of medical treatment. However, once physicians are employed by teams – themselves subject to sponsors' demands – questions about *whose* best interests they are acting in arise; doctors may be faced with a dilemma by acting in the best interests of the team (and employer) *or* the individual athlete. For example, treatments for short-term gain (e.g. applying local anaesthetics) may be preferred over treatment which will improve the athlete's long-term prospects (instructing an athlete to stop competing because of long-term injury risks). This raises the question of how 'harm' should be defined in sports medicine: is it physical, psychological, or is it financial (e.g. loss of income)? Additionally, maintaining the principle of informed consent – including discussing the risks and benefits of treatment, and alternatives – may prove impossible in the middle of sporting play, where the pressure to finish the game may outweigh the athlete's ability to carefully consider all relevant factors associated with proposed treatment.

The obligations of medical professionals also extend to confidentiality. For example, if they are aware of a condition in an athlete that might affect future performance, they may be faced with a dilemma as to whether to inform their employer, or allow the individual to play on. Further, this highlights the issue of patient autonomy in sport: in standard relationships between patients and medical professionals, there are usually just two parties involved; however, in sports, the relationship involves three parties – the sportsperson, the doctor, and the sportsperson's team/agent. This change in dynamics could lead to decisions being made by doctors/employers rather than patients.

Policy implications

Policy makers might consider the question of whether healthcare professionals who work for sports teams or agents should be employed by an umbrella organisation or foundation instead of being employed directly by teams. This might address concerns about safeguarding the basic standards of medicine, including informed consent and best interest standards. Consideration might also be given to whether drugs and innovative technologies that aim to improve performance should be endorsed, and indeed legalised by the relevant regulators and sporting bodies.

Recent literature

The Guardian (9 August 2004) [Faster, stronger, higher.](#)

Holm S and McNamee M (2009) Ethics in sports medicine *BMJ* **339**: b3898.

International Federation of Sports Medicine (2012) *Code of ethics* (Lausanne, Switzerland: International Federation of Sports Medicine).

Suppressing the extra chromosome in Down's syndrome

Overview

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. Trisomy on chromosome 21 causes the clinical features associated with Down's syndrome, including developmental delay, learning difficulties, and a characteristic physical appearance. Some individuals with Down's syndrome experience complications such as immune and endocrine system dysfunction, congenital heart defects and dementia, amongst others. However it is important to note that not all individuals experience these complications and that Down's syndrome exists on a spectrum of severity. Normally, an RNA gene called XIST¹ 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. It is thought that this research may potentially pave the way for chromosomal therapy of Down's syndrome in the future; while in the meantime inspiring related research. Preliminary research is being carried out on mice that aims to silence the Trisomy on chromosome 21, in mouse embryos. Whilst chromosome therapy for humans is not likely to be available for some time, there are a number of ethical and social issues that it raises that warrant analysis.

Ethical issues

One of the key ethical issues of silencing the extra copy of chromosome 21 is whether or not this is in fact desirable. With social and educational support individuals with Down's syndrome can lead meaningful and fulfilling lives. There are criticisms of the medical model of disability which focuses on curing or fixing disability and impairment; as opposed to a social model which aims to facilitate and support individuals in their day to day lives. Disability can also form part of an individual's identity and ideas about personhood. Issues concerning prenatal chromosome therapy include reducing genetic and social diversity, and making decisions on behalf of future persons whose wishes are unknown. Chromosomal therapies targeted at adults or children with Down's syndrome (for example to enhance cognitive function) thus have the potential to be problematic because of issues of capacity to consent, and whether or not such therapies would be in their broader best interests. In favour of chromosomal therapy are arguments that such treatments have the potential to improve the quality of life of individuals with Down's: from a rights based perspective, for example, it could be argued that if such treatments are available, people have a right to benefit from them. Parents in particular may feel that they have a duty to reduce 'genetic harm' to their offspring. This raises the question of what constitutes genetic harm; many children are born with genetic abnormalities and anomalies, or are subject to damage in utero. The question of degree and 'severity' of genetic damage is contested; some fear that prenatal genetic manipulation could be used to screen out undesirable traits for eugenic purposes. Some argue that this is already being done to a certain extent through terminations based on fetal anomaly screening programs. In the UK, 91% of women who receive an antenatal diagnosis of Down's terminate the pregnancy.² If made available, chromosomal therapy may further perpetuate the idea that a life with Down's syndrome is worth less than a 'normal' life; and could lead to increased stigma and discrimination towards those with the condition.

Policy implications

Chromosomal therapy is a very novel concept, still in the experimental stage and may not be available to patients for many years, if at all. Those involved in policy making would have to consider whether this therapy should be made available prenatally, or to individuals (or both) and the social and ethical ramifications of this. Genetic counselling and advice should be promoted and made available to all individuals involved in the therapy. National and International co-ordination and policy would need to be formulated to regulate such therapies and monitor their implementation and outcomes.

Recent literature

Jiang J, Jing Y, Cost G, et al. (2013) Translating dosage compensation to trisomy 21 *Nature* **500**: 296-300.

Malek J (2010) Deciding against disability: does the use of reproductive genetic technologies express disvalue for people with disabilities? *Journal of Medical Ethics* **36**: 217-21.

Reynolds TM (2003) Down's syndrome screening is unethical: views of today's research ethics committees *Journal of Clinical Pathology* **56(4)**: 268-70.

¹ 'XIST' : X-inactive specific transcript; which is an RNA gene on the X chromosome.

² Morris JK and Springett A (2013) [The national Down's syndrome cytogenetic register for England and Wales: 2011 annual report.](#)

Cross-cutting themes

Council might also like to consider the possibility of working on one of a number of broader cross-cutting bioethical themes. Suggestions put to Council include:

- **Justice.** A report on justice might use a 'case-study' approach, looking for example at distribution between rich and poor countries, or within the UK healthcare system; another approach might focus on intergenerational justice. Is justice best understood as a 'virtue'?
- **Autonomy:** could include changing models in decision-making such as more 'relational' approaches to autonomy
- What is meant by '**naturalness**'? (with a possible case study in GM insects and/or GM animals for food)
- What is meant by '**normalness**'? (potentially to be reviewed as part of the cosmetic procedures project; alternatively might include consideration of sex/gender and intersex individuals)
- **Dignity:** and how the term is understood in different settings or legal systems (potentially could include issue of existence in MCS)
- Further **neuroscience** studies: eg human identity, what is 'normal' behaviour, addiction, neuropsychology
- **Privacy**
- **Influences of different voices** in the bioethics policy area: for example how faith groups contribute to debates on bioethics

Topics to be developed for 2014 longlist

The following topics either emerged too late for consideration in the 2013 longlist, or emerged in discussion as potentially more appropriate (narrower/broader) approaches to topics that were removed from the list in their then form.

- Artificial gametes
- Food: ethical issues (looking at questions of 'artificial' vs 'natural' food, and at the exporting of western models of food)
- Sharing genetic information in primary care (not necessarily focussing specifically on confidential/circumstances in which information may be shared, but also about the practicalities of health professionals holding/storing information that cannot be shared until later)
- Social care robots
- Specific aspects of psychiatric ethics