Science, Technology and Society in Europe

volta 06

April 2014

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Editorial

Privacy is dead

If the cost of sports cars had fallen at the same rate as genome sequencing, we could all be driving around in Ferraris that cost 40 cents, reported a scientist from Stanford Medical School recently. But in the rush for the 1,000-dollar (or euro) genome, are we forgetting the many other costs and concerns that come with 'more data for less money'? Is technology moving faster than our ability to make sense of it?

Using genome based information and technologies for the benefit of public health is dependent on vast biobanks of data. And those data need to be linkable. From what we know already, it will not be our DNA or genes alone that will determine aspects of our health; we need to incorporate factors related to our environment and lifestyles. We need big data.

The privacy (or not) of those data is the focus of this issue's Special Report. How, when, and with whom, should genomic data be shared? Once whole genome information is included, it is generally believed that medical data cannot be effectively anonymised. Privacy is dead. Yet the use of biobanks and the genetic links they could reveal (even if so far, they have proved elusive) is the structure behind the future public health vision of predictive, preventative and personalised healthcare.

The chaos surrounding the UK Government's attempt to roll out the care.data project linking local doctor and hospital records (against a vigorous 'opt-out' campaign) shows just what happens when policy makers underestimate the need for public engagement. As the PACTIA Future Panel on public health genomics noted: "The extent to which genomics data are collected, stored, shared, and for what purposes, is first of all a political and societal issue and should not be regulated via individual consent alone."

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Volta - Volume 2014 – no 6

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Printing
Industrias Gráficas Galileo, S.A. (Catalonia)

Website
http://volta.pacitaproject.eu/

Legal deposit
B-40368-2011

Volta was made possible by

Volta is an initiative of fifteen technology assessment organisations that work together in the European Pacita project - a four-year EU financed project aimed at increasing the capacity and enhancing the institutional foundation for knowledge-based policy-making on issues involving science, technology and innovation.
www.pacitaproject.eu

Danish Board of Technology Foundation (Denmark); Karlsruhe Institute of Technology (Germany); The Rathenau Institute (Netherlands); Norwegian Board of Technology (Norway); The Institute of Technology Assessment (Austria); Applied Research and Communications Fund (Bulgaria); Institute of Technology of Biology and Chemistry (Portugal); Institute Society and Technology (Flanders, Belgium); Catalan Foundation for Research and Innovation (Catalonia, Spain); Swiss Centre for Technology Assessment (Switzerland); Knowledge Economy Forum (Lithuania); Technology Centre ASCR (Czech Republic); University of Liège, SPIRAL Research Centre (Wallonia, Belgium); University College Cork (Ireland); Hungarian Academy of Sciences (Hungary).

20 years at ITA

Public participation is a crucial source of knowledge according to Austria's technology assessment institute.

Text: Ann Maher

Photo: iStockphoto

Two decades of raising awareness

The ITA, Austria's only dedicated TA institution, celebrates its 20th anniversary in June with a kick-off event and conference at the Austrian Academy of Sciences exploring the connection between responsible research and TA. Two decades of research has seen the ITA's involvement in a wide range of projects dealing with the regulation of nanotechnologies, food safety, synthetic biology and recently co-hosting a large scale citizen's forum on surveillance technologies as part of the EU initiative SurPRISE. It is constantly strengthening its relationship to parliament and international TA networks such as EPTA and NTA. "Building a community is very important to us", stresses director Michael Nentwich. "Technology assessment is not something that is done just for a small group of experts. We want to offer up our research results to decision makers in a way that gives them more control over their respective fields, and we strongly believe that public participation is a crucial source of knowledge in this process. I am really looking forward to celebrate our 20th anniversary with so many colleagues who helped raise awareness for TA and bring it to a whole new level in Europe". Guest of honour is Professor Renate Mayntz, the German doyenne of sociology, who was recently given a lifetime achievement award by the German Sociological Association.

Luma.Launisch, winners of the city of Vienna's *Kreativ* award, will contribute an audio-visual installation and a visual symphony designed especially for the ITA.

The ITA – Celebrating 20 Years + NTA6-TA14, Vienna,2-4 June 2014
www.oeaw.ac.at/ita

Europe's only TA PhD programme

Enrolment open until June

The TA PhD programme at the Universidade Nova de Lisboa (Portugal) Faculty of Sciences and Technology (FCT-UNL) is the only one of its kind in Europe. It is structured in collaboration with the Karlsruhe Institute of Technology with support from universities in Frankfurt, Duisburg-Essen, Liège, Sofia, Vilnius, and other experts from TA institutes (mostly from the PACITA network). The PhD programme develops studies and knowledge in emergent knowledge fields including e-mobility, brain-computer interfaces, health TA, nanotechnology, energy storage, cloud computing, and railway and road transport. The duration of the programme is typically 4 years. Most students are actively involved in the national TA network, and take part in several PACITA activities (e.g. practitioner workshops, summer schools, TA conferences). Students from other countries such as Brazil, Austria, Turkey, Bulgaria and Lithuania have also taken part. The courses are in Portuguese and English. The enrolment period for the 2014 winter semester (starting in September) is open until the end of June.

Coming up

Building bridges in Cophenhagen
'Science building bridges' is the theme of EuroScience Open Forum 2014 (ESOF2014) in June when Copenhagen will welcome 2,300 visitors from 40 countries including superstars from the world of science. The exhibition, conference, ambitious Science in the City outreach festival, and the special area for students – ESOF Academy – make it a truly cross-cutting and multidisciplinery event.

www.esof2014.org

Euroscience Open Forum (ESOF) 2014, Copenhagen, Denmark, 21-26 June 2014

Science and wonder
The 2014 World Science Festival comes to Amsterdam in SeptemberIn partnership with the city of Amsterdam and other prestigious local partner organizations. WSF presents compelling educational and entertaining science events that capture the excitement and wonder of science, as well as the great potential that science offers for addressing the critical issues facing our communities today.

www.worldsciencefestival.com

World Science Festival Amsterdam Amsterdam, Netherlands, 6-7 September 2014

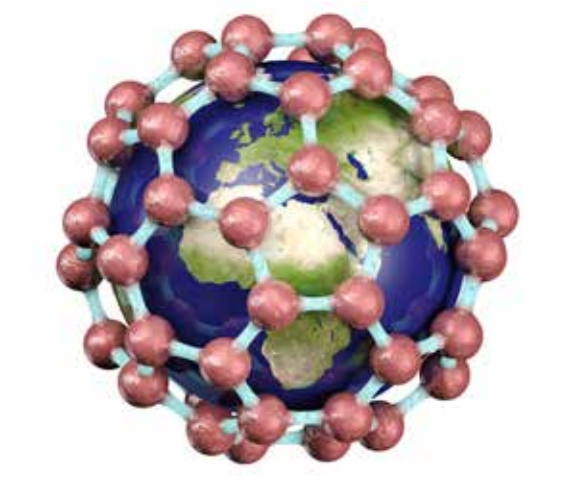
Better Technologies with no Regrets?
The Society for the Study of Nanoscience and Emerging Technologies (S.NET) holds its sixth annual meeting at the Karlsruhe Institute of Technology in Germany in September. It will address nanoscale science and engineering, biotechnology, synthetic biology, neurotechnologies, cognitive science and geo-engineering from responsible research to governance and politics.

www.itas.kit.edu/snet2014

S.NET 6th Annual Meeting Karlsruhe Institute of Technology, Karlsruhe, Germany, September 21-24, 2014

Megatrend with funding gap

Nanotechnology is a megatrend which will match or surpass the digital revolution's effect of science on the economy. But there are funding gaps. That's the view of participants in a strategic forum held by the US Government Accountability Office (GAO).



A holisitic vision is needed for US nano manufacturing according to the US Government Accountability Office (GAO)

GAO report on nanomanufacturing

What are future nanotech developments? How big will they be? Are the US R&D investments in nanomanufacturing sufficient? What effect will nanotechnology have on the environment, our health and safety? Those were the questions nano experts addressed in a strategic forum held by the US Government Accountability Office (GAO). The report, *Nanomanufacturing: Emergence and Implications for U.S. Competitiveness, the Environment and Human Health*, is the result.

More intense competition

Members of the forum anticipate further scientific breakthroughs that will fuel new engineering developments and more intense international competition. Although limited data on international investments made comparisons difficult, participants see the US as likely to lead in nanotechnology research and development (R&D). Challenges to US competitiveness in nanomanufacturing include inadequate US participation and leadership in international standard setting; the lack of a national vision for a US nanomanufacturing capability; and the actions of competitor nations. According to a participant, some 'were playing by new rules'. There are funding or investment gaps in the United States which could hamper innovators' attempts to transition nanotechnology from R&D to full-scale manufacturing.

The Valley of Death and the Missing Middle

The significant development costs for nanotechnology projects has led to funding scenarios which participants described as the 'valley of death' and the 'missing middle': the research and funding gap that can occur after the initial development of in a new technology and its subsequent development; or the lack of funding related to maturing manufacturing innovation. "High costs can act as an effective barrier to entry for small and medium-sized companies that have innovations in technology but lack the resources needed to carry their innovations all the way to commercialization and full-scale production."

A participant suggests that this is not the case in China, Russia and the European Union. "Government investments in establishing technology platforms, technology transfer, and commercialization are higher in other countries than in the United States."

The Forum suggests three approaches to address these challenges: strengthen US innovation by updating current innovation-related policies and programs; promote US innovation in manufacturing in public-private partnerships; and design a strategy for attaining a holistic vision for U.S. nanomanufacturing. Significant research is needed to understand the risks associated with nanomaterials and multiple participants advocated a collaborative effort, in which nanotechnology stakeholders develop standards for measurement and nomenclature, to help assess and address environmental health and safety (EHS) risks.

Read More?

Nanomanufacturing Emergence and Implications for U.S. Competitiveness, the Environment, and Human Health. Highlights of a forum Convened by the Comptroller General of the United States GAO-14-181SP Jan 2014.

www.gao.gov/products/GAO-14-181SP.

About the GAO

The U.S. Government Accountability Office (GAO) is an independent, nonpartisan agency that works for Congress. Often called the 'congressional watchdog,' GAO investigates how the federal government spends taxpayer dollars. The head of GAO, the Comptroller General of the United States, is appointed to a 15-year term by the President from a slate of candidates Congress proposes.

06

Sharing DNA in a big data world

Private health?

Text:
Pascal Messer

Photos courtesy of the Portuguese Parliament

The success of Public Health Genomics - using genome-based information and technologies for the benefit of public health - is dependent on access to vast biobanks of data. But how, when and with whom should our DNA and medical data be shared? How can we protect patients' genomic data without stifling research?

'With the current speed of genomic advances…everybody, be it on a personal level, or at a European decision making level, needs to start forming an opinion on it.'

Last year, Yaniv Erlich, a 34-year-old ex-security specialist turned computational biologist, rocked the genomics world by showing that it is possible to discover the identities of anonymous people who participate in genetic research studies. He did so by cross-referencing their genetic data with surnames found on the internet.

Earlier studies, such as by Nils Homer in 2008, had already shown that people listed in anonymous genetic databases could be unmasked by matching their data to a sample of their DNA. All that was needed was some DNA obtained from a discarded paper coffee cup, and open source Genome Wide Association Studies (GWAS) datasets to associate particular individuals with specific diseases.

But Erlich, named 'The Genome Hacker' by science magazine Nature showed something else: that it is possible to identify people by linking their genetic data to freely available information. All it took was an internet connection and a smart piece of software - an algorithm called lobSTR,

Lisbon, 18 January 2014: The PACITA policy hearing on Public Health Genomics in the Portugese parliament brought together politicians, experts en TA practioners.

designed by undergrad student Gymrek - to expose vulnerabilities in databases that hold sensitive information on thousands of people around the world.

Privacy is dead

'In the genomics era, privacy is dead'. This phrase was heard several times at the PACITA Policy Hearing on Public Health Genomics that took place in January in Lisbon. It did not raise many eyebrows, though. The hearing, which aimed to address pressing political issues related to genomic technologies, brought together an eclectic gathering of international geneticists, technology assessment practitioners, public health experts, parliamentarians, jurists, patient representatives and policymakers. The PACITA ambitions were high: it wanted to bring stakeholders and politicians together to set a policy agenda for the 'responsible introduction of Public Health Genomics'.

Perhaps there was simply too much to discuss, that day in Lisbon, and too many aspects of public health genomics to deal with. When politicians were asked at the end of the day, what they would take home as a pressing political issue, a member of the European Parliament said: "With the runaway costs of spending on public health, and genomics being a possible tool for that, it is an interesting topic. But when I get home, nobody is going to care about what I learned today, because they are only interested in day-to-day politics." Another one answered: "Well, I guess I've got more questions now than I had before I came. I had a naïve hope that the experts would tell me what to do. I have got a kind of picture of where we're going, but no clue of how we will get there."

Compelling reasons

There are many compelling reasons for politicians to meet with geneticists and other stakeholders, though. In less than a decade, whole genome sequencing (WGS) has moved from a revolutionary moon-landing-style science project to a worldwide seedbed of entrepreneurial activity. The price of DNA sequencing technologies is dropping so rapidly that experts believe our children will have their full genomes read as part of their medical record, and as part of a completely new model of personalised public healthcare. But alongside the anticipated public health benefits, come lots

The ultimate identifier

Human DNA sequence is often called the 'ultimate identifier'. Our DNA is unique (except for identical twins). It can be used to predict a variety of medical conditions and traits. Think: hair, skin and eye colour, facial features, height, and, allegedly, even smoking habits. Recent studies suggest that our genes steer our voting and economic behaviour, and our ability to stick to our spouses in marriage.

of ethical and legal issues. How, when and with whom should we share our DNA and medical data? Policymakers and researchers will need to tread very carefully in crafting policies that protect patients' genome data without stifling research.

DNA and privacy

The privacy and confidentiality concerns about whole genome data go a lot further than a simple decision about whether to have your genome sequenced for private medical reasons, and if so, whether these data should become part of your medical record. Sequencing a whole genome is still primarily done for research purposes, as scientists piece together which genetic mutations play a role in diseases. This often happens in large-scale (cohort) studies, some of them open source, which compare the DNA of two large groups of individuals, one healthy control group and one case group affected by a disease. Whole genome research involves the collection and storage of a biological sample, the sequencing of the genome, data analysis, and, more and more frequently, the release and exchange of these data in scientific databases to facilitate research. But these processes are complicated by a number of other issues: the quantity of genetic information that is made available to commercial parties and public private partnerships, the commercialization of research results, the combination of genetic data and electronic health files, out of date consent procedures, data anonymisation capabilities and many other privacy concerns.

'Care.data needs to work: in medicine, data saves lives'

Monetarisation of medical data

The day after the PACITA hearing in Lisbon, some of the urgent political issues surrounding Public Health Genomics – and it's dependence on big data – hit the headlines, as British newspaper The Guardian reported on the potential commercial availability of medical records in the new care.data service proposed by the National Health Service (NHS England). The scheme aims to 'join up' doctors' and hospital medical records of millions of citizens in order to improve medical services. To help diagnose drug side effects, for example, and evaluate the performance of hospital surgical units and procedures, by tracking their impact on patients. The newly established data services provider, the Health and Social Care Information Service (HSCIS) will have the legal right to extract data from GP Practices – a process that was meant to begin this month (see below). The extracted information is anonymised to some extent - stripped of the patient's name - but the records do contain (parts of) a person's NHS number, date of birth, postcode, ethnicity and gender. The care.data plan is part of a huge governmental investment scheme that aims to boost the British life sciences industry. Collecting, storing, and analysing 'national healthcare, public health and social care data, including personal data', should make the UK, the 'leader in the race for better tests, better drugs and above all, more personalised care to save lives', as Jeremy Hunt, UK Secretary of State for Health stated.

What's gone wrong with care.data?

Widespread unease expressed by both the medical profession and patient groups have led to the roll out of the scheme being put on hold for six months. Care.data has run into a volley of privacy accusations. Would police and government bodies have the right to access people's medical data? Even when medical data has been anonymised, how easy is it piece together evidence to identify an individual and thereby discover information about them from their health record? It doesn't help that the NHS has form in the sloppy care of medical records. Right wing newspaper *The Daily Mail*, reported that in 2012, the NHS 'lost track of 1.8 million confidential patient records in a single year'. 'Sensitive' paper records have been dumped in public bins and landfill sites. Computers containing medical records were found for sale on ebay, the newspaper reported. The opt-out procedure, rather than an opt-in scheme did not pass muster either. Patients who want to opt out of care.data need to arrange it with their GP. And it is not clear what data will be blocked. According to some experts, it is inevitable that the medical data of all Britons – whether with consent or not - will be sucked into the database. What seems universally agreed is that patient awareness – of the benefits as well as privacy implications – is at very low levels. Organisations such as the British Medical Association have therefore welcomed the delay. 'Care.data is in chaos', wrote Ben Goldacre in *The Guardian* in Feburary. "HSCIC needs to regain trust, by releasing all documentation on all past releases, urgently. Care.data needs to work: in medicine, data saves lives."

DNA and medical records

Selling sensitive medical data of citizens is one thing that would need careful democratic deliberation. But when DNA is to become part of electronic health records - as envisioned by Personal Health Genomics enthusiasts - many believe that public awareness and political scrutiny becomes even more important. In the UK, according to British NGO Genewatch, it is indeed the ultimate aim of the British Government to have the genomes of all 60 million Britons sequenced and attached to their electronic health records. In July 2013, the Department of Health announced the launch of Genomics England and the start of the 100k Genomes Project. Over the next five years, the personal DNA of up to 100,000 NHS patients will be sequenced. A spokesperson for this project said: "This unrivalled knowledge will help doctors' understanding, leading to better and earlier diagnosis and personalised care. Based on expert scientific advice, we will start by tackling cancer, rare diseases and infectious diseases." UK prime minister David

Cameron stated: "It is crucial that we continue to push the boundaries and this new plan will mean we are the first country in the world to use DNA codes in the mainstream of the health service. By unlocking the power of DNA data, the NHS will lead the global race for better tests, better drugs and above all better care."

For researchers, the linking of genomic data to data from medical health records is crucial. To fully understand what triggers disease or not, DNA has to be linked to other factors, such as health data and lifestyle and social and environmental factors. To figure out what exactly causes lung cancer, one would not only study genes and smoking habits but also demographics: postal codes, to see if air pollution plays a part in developing disease.

'The development of biobank infrastructure and the use of this as a basis for personalised medicine has become a central strategic goal in the fields of European biotechnology, genomics and international politics'

The collection of bio specimens, like samples of urine, blood, tissue, cells, DNA, RNA, and protein and other data, for research purposes is nothing new. It has a long history in educational and medical systems, remaining largely uncontroversial, hidden away in the seclusion of pathology institutes. But with recent genomics advances, big data claims and booms in IT technology, the potential of opening up existing collections of bio specimen in biobanks, or starting new collections, has become a feverish pursuit. All around the globe, governments and companies are rushing into ambitious projects to find out how genome technology can best be used in a medical context. Huge data sets, with the DNA of hundreds of thousands of people, are needed to uncover genetic links (that have so far proved elusive), but that are needed to address the promise of personal medicine. As a report by the European Commission states: "The development of biobank infrastructure and the use of this as a basis for personalised medicine has become a central strategic goal in the fields of European biotechnology, genomics and international politics."

World leaders

According to the European Commission, EU member states already are 'world leaders in the development of biobanking infrastructure to support research, making huge investments each year to support such initiatives'. To give some examples: over the past few years, the UK Biobank has recruited 500,000 people aged between 40-69 years to provide blood, urine and saliva samples for future analysis. They provided detailed information about themselves and agreed to have their health followed for a long time. The Faroe Islands, an autonomous country within the Kingdom of Denmark, is offering genomic sequencing to all of the citizens of this archipelago, to understand the particular genetic diseases prevalent in this isolated population.

The same is happening elsewhere. In November 2011, the Beijing Genomics Institute launched the Million Human Genomes Project, to decode the genomes of over 1 million people for projects based in China and abroad. In the US, the US Department of Veterans Affairs (VA) has been collecting the medical records and blood samples of a million U.S. veterans since 2012. Dr. Joel Kupersmith, the VA's chief research and development officer told US newspaper *The Baltimore Sun* that researchers: "have long seen the potential at the VA because the system has 8 million enrollees of various ages and ethnicities

Personalised medicine?

DNA is the basis of all life on earth, including human life. The methodologies for reading the DNA sequence - to unravel the code of life - are currently undergoing revolutions in both speed and cost. The first complete sequence of the human genome, completed in 2003, took more than a decade to complete, at a price of roughly 3 billion euros. These days, it takes roughly 2-4 weeks to read the full DNA of a human at a cost of 2,000-5,000 euros. Within the next five years, it is expected to take just one day, for less than 500 euros. According to genomics believers, the two major consequences will be: that medicine will become genome-based, personalised: products, tests and supplements tailor made to our unique building plan.

The second consequence will be an increase in 'predictive' diagnosis: our DNA could be used to reveal the strong and weak points of our body, our talents and any hidden risks including genetic diseases. Although we are still in the early days of understanding the genetic code, progress is being made regarding disease-associated DNA variants. Genome-based research is already enabling medical researchers to develop more effective diagnostic tools, to better understand the health needs of people based on their individual genetic make-ups, and to design new treatments for disease. Most new drugs based on genome-based research are estimated to be at least 10 to 15 years away. It is very difficult to predict how much of our lives will by driven by our DNA in the end. From what we know now, both disease and health stem from a combination of our DNA, our environment and our lifestyle.

with most every kind of age, health, and service-related disorder. All have an electronic medical record stretching up to 15 years."

Reluctant donors

A big problem with biobanking, though, is that in Europe, hardly anybody knows about it. A 2010 Euro barometer survey on life sciences and biotechnology, conducted in 32 European countries, showed that more than two thirds of all Europeans said they have never heard of biobanks. When there were told, many European citizens appeared to be reluctant to become donors or participants in cohort studies. According to the survey, concerns about privacy and confidentiality are the first things that spring to mind. Although many people these days seem willing to post their intimate information on social networks, medical data are still considered as being highly sensitive. Sharing medical information, illnesses and ailments, is tightly connected to the doctor-patient relationship, and the fundamental right of medical confidentiality. People also fear that the long term storage of their data could be turned against them, through the violation of their privacy rights or through discrimination by insurers or employers.

Consent

One of the most controversial aspects of biobanking is the current use of 'broad consent', for those enrolling in a biobank rather than seeking 'informed consent' from participants. For practical reasons, according to the EU Commission, 'broad consent is now the norm for biobank recruitment'. Participants are asked to consent once to the broad use of their samples and data, rather than to specific, new or future research projects. This is not simply because researchers are reluctant to add extra barriers to their work and would prefer to spend time on their research rather than wrestle with added layers of bureaucracy. Sometimes asking for renewed consent has no benefit for patients; sometimes it is simply impossible. This is a problem for studies that use archived samples, for example. These samples were often collected using a consent process (if a consent process was used at all) that did not anticipate the potential identifiability of genomic data. But the use of broad consent for biobanking creates tensions because "data may be shared with large numbers of researchers, including commercial companies, both nationally and internationally, for purposes which may be unclear when the data sets are collected." according to the PACITA Expert report. A recent international study involving European wide focus groups was very clear on consent. Despite the perceived (research) need for broad consent, a large majority of Europeans (67%) would choose narrow consent and only 24% broad consent. As the authors observed: "It was a minority of people who thought it appropriate not to be asked for permission to have their details and samples entered in a biobank."

'China has by far the biggest genomics industry worldwide, and we exchange lots of data with the Chinese, but do you think they care much for privacy or human rights?'

Lacking rules

Research and biobanking communities have a long tradition in successfully guarding privacy and medical confidentiality and are scrambling to maintain this within a big data environment. They are setting up research ethics boards and data access committees, reviewing and publishing codes of conduct and governance mechanisms, and developing encryption and key management systems to restrict data access. But at present, genome researchers simply have no model to follow for protecting the privacy of genetic donors. As one geneticist quietly joked at the PACITA hearing: "China has by far the biggest genomics industry worldwide, and we exchange lots of data with the Chinese, but do you think they care much for privacy or human rights?"

The problem is that there is no clarity on consent procedures, and no consistent and coherent rules in the areas of privacy, data protection, the use of human tissue in research, and the exchange of these data across national borders. There are big differences between the implementation and enforcement of legal provisions, even among the EU countries that have signed the Data Protection Directive. Data protection rules are currently being revised by the new Data Protection Regulation, which is expected later this summer. However, biobank managers have *en masse* expressed concern that too strict a regulatory framework for human biobanks within Europe will create uncertainty and inhibits the building of a biobank infrastructure.

Heightened tensions

The current regulatory vacuum leads to heightened tensions between the individuals' need for privacy and confidentiality, and the needs of researchers and biobankers for their pursuit of a societal benefit. Is asking for 'broad consent' in a genomic era ethically appropriate, and if it is, how should it be handled? Too strict a focus on privacy and confidentiality is likely to hamper research. Many researchers feel that because of privacy rules, a lot of what is learned from genetic studies is neither published nor shared, and is therefore lost. David Altshuler, deputy director of the Broad Institute of MIT and Harvard, recently said in Scientific

Maria De Belém Roseira (Portugal), Yvonne Gilli (Switzerland), Vittorio Prodi (Italy), Jens Henrik Thulesen Dahl (Denmark).

American: "There are literally millions of people who participate in medical research, and probably over a million people whose genomes have been characterized in some way or another, where the data is not freely available precisely because of privacy concerns."

Biobanks are often paid for with taxpayers money and strongly depend on public support – if only for donations of samples and data. As the EU Commission report notes how these are controversial undertakings: "Not all biobank projects are warmly reviewed by all groups in society." US President Obama's Bioethicist Commission reported in 2013: "Without public trust, people may not be as willing to allow scientists to study their genetic information." Securing acceptance and public trust, by creating awareness and transparency, and by finding solutions to balance a range of competing interests, is crucial to a successful translation of genome-based technology from research to the clinic. Weighing competing interests, setting boundaries, and finding a balance between protecting individuals' privacy and the greater good, is what politicians should do.

Awareness

The need for policy makers to address these public awareness issues more rigorously was emphasized at the PACITA hearing. Stressing the importance of informed citizens, awareness and education, Klaas Dolsma from the Dutch Erfocentrum, the national information centre on genomics and hereditary diseases, said: "With the current speed of genomic advances, it is for sure that at some time in our lives, each and every one of us will have to make decisions about genetic testing and hereditary disease. So everybody, be it on a personal level, or at a European decision making level, needs to start forming an opinion on it."

'There are probably over a million people whose genomes have been characterized in some way or another, where the data is not freely available precisely because of privacy concerns.'

Read more?

The Genome Hacker – Erika Check Hayden, Nature (2013)

Think tank on Identifiability of Biospecimens and -Omic Data, US Department of Health and Human Services (2012)

Biobanks for Europe - A Challenge for Governance, European Commission (2012)

Privacy and Progress in Whole Genome Sequencing, US Presidential Commission for the Study of Bioethical Issues (2012)

Whole Genome Sequencing: Innovation Dream or Privacy Nightmare? E. De Cristofaro (2012)

Data storage and DNA banking for biomedical research: informed consent, confidentiality, quality

issues, ownership, return of benefits. A professional perspective – B. Godard et al (2003)

Public Access to Genome-Wide Data: Five Views on Balancing Research with Privacy and Protection –P3G Consortium Church et al (2009)

Resolving Individuals Contributing Trace Amounts of DNA to Highly Complex Mixtures Using High-Density SNP Genotyping Microarrays, N. Holmer (2008)

PACITA - Expert Working Group Report, Expert Paper and a Policy Brief (2014)

PACITA Future Panel: Parliamentarians in Europe discuss genomics in public health care

Text: Dirk Stemerding and André Krom

An important future challenge facing healthcare systems in Europe is how to deal with data and technologies provided by advanced genetic research. DNA sequencing technologies are rapidly becoming cheaper and faster. Experts expect that this will ultimately give us the tools to understand individual genomes and to accurately predict their consequences, thus allowing for detailed risk profiling of individuals as the basis for targeted medical interventions. The promise is more effective health care practices that are more personalized, predictive, preventive, and consumer-driven.

However, experts also see a clear threat that premature technology and market driven applications of DNA sequencing will inundate physicians and patients with meaningless or uninterpretable data. There is a wide gap between our ability to generate 'more data for less money' and our ability to understand them or validate their clinical utility. Indeed, political intervention is needed to guarantee that the use of genomic technologies in public health services does not lead to detrimental consequences.

Step-by-step approach needed

These promises and concerns warrant a careful, step-by-step approach to the development and diffusion of genome-based information and technologies. The challenge for policy makers at the European and national level is what a step-by-step approach might involve in their own countries. As the Future Panel process made clear, we should not think of the future in terms of Public Health Genomics as a 'road map' taking us in one particular direction. We should rather carefully look at the variety of ways in which any single new development could affect the health care landscape in the future. Determining acceptable ways in which health care practices could be improved by genomic information and technologies thus requires political and societal debate.

One important issue is the increasing quantity of data travelling between research and patient care whereby data collected for medical purposes are shared for research purposes and statistical analysis. Most variation in our DNA has not yet been investigated and we cannot yet assign potential consequences to this variation for individual health and disease. In order to establish such relationships, it will be necessary to combine clinical and genomic data from large numbers of individuals and to collect these data in an extended network of 'biobanks '. This raises challenging questions about data security and privacy, as becomes clear from the Special Report in this VOLTA issue.

DNA sequencing technologies are also being introduced already in a clinical context, especially for diagnosis in children born with congenital disabilities and/or mental retardation, and for prenatal diagnosis of abnormalities observed during ultrasound. As available DNA-sequencing technologies are rapidly becoming cheaper and faster, it may become more and more routine to sequence genes or even whole genomes of individuals to screen them for particular medical conditions or health risks. Possibilities for whole-genome sequencing in widely established programs for reproductive and newborn screening are currently intensively debated by scientists and clinicians and may raise in the near future difficult questions of what and when to screen for.

Newborn screening

An important development raising debates about possibilities of genome-wide screening is the introduction of non-invasive prenatal testing (NIPT) as a replacement for established forms of prenatal screening for Down Syndrome. NIPT is based on the analysis of foetal DNA isolated from the maternal blood and can be used as a screening tool for Down Syndrome and other chromosomal abnormalities. However, as soon as NIPT becomes widely available in a setting of routinely offered prenatal screening, it may also create opportunities for the introduction of more genome-wide forms of screening. In this context, new questions will arise about what information to offer in the context of reproductive choice, questions that may become especially urgent as a result of commercial initiatives in offering NIPT.

Established programs for newborn screening (NBS) are another context in which genome-wide screening might be considered. NBS programs in Europe currently aim to identify 1 to 30 treatable conditions. Taking into account current developments in DNA sequencing, targeted genome-wide screening for a panel of well-chosen diseases could be envisaged based on the criteria used or suggested today to develop a screening program. If indeed a switch would be made to genome-wide screening in NBS programs, a more far-reaching possibility would be to keep the whole genome sequence of the newborn for future use. The sequence information could be stored in the clinical record to be available for analysis when dealing with specific individual health issues or risks later in life.

Obviously these new possibilities raise challenging questions, both about the scope of genome-wide screening options offered to individuals, and about the importance and meaning of informed consent as a fundamental patient right. How to avoid that genome-wide screening becomes an intractable burden to informed decision-making? And to what extent do parents have the right to make far-reaching decisions about full genome analysis for their children without knowing the possible benefits of such an analysis at the time taken?

Policymakers will increasingly have to face such questions in the near future. The aim of the PACITA Future Panel project has been to enable parliamentarians, policy makers, health care providers and other stakeholders to make informed and country-specific decisions about the introduction of genome-based information and technologies (GBIT) into a variety of health care settings. The project yielded suggestions for a step-by-step approach to the introduction of GBIT in health care on a European level. A challenge for national governments is now to determine what a step by step approach to the introduction of GBIT in health care will require in their country.

PACITA policy hearing experts & organizers: Iñaki Gutiérrez-Ibarluzea (Spain), Klaas Dolsma, André Krom and Dirk Stemerding (the Netherlands), Mara Almeida (Portugal).

Future Panel

In January 2014, a Future Panel of parliamentarians from Europe came together for a policy hearing in the Portuguese Parliament to discuss issues and options for the future of 'public health genomics'. The event in Lisbon concluded one of the three PACITA demonstration projects. The project was a collaborative experience involving partners from The Netherlands, Germany, Lithuania and Portugal.

At the start of the project in November 2012, parliamentarians from the Future Panel identified major policy questions relating to the future of public health genomics. These were the starting point for an expert consultation process resulting in four Expert Working Group Reports focusing on different themes. On the basis of these reports an Expert Paper was produced focusing on policy issues raised by developments in public health genomics. Finally, policy options for dealing with these issues have been described in an extended Policy Brief that served as an agenda for the Policy Hearing in Lisbon.

Read more

Find all the reports, interviews, presentations, photographs,
and the policy brief on Public Health Genomics on www.pacitaproject.eu

Grand Challenges

VolTA previews the proceedings of the conference on Grand Challenges, a new journal covering responsible innovation and a report from the Rathenau Instituut that shows how technology is getting right under our skins.

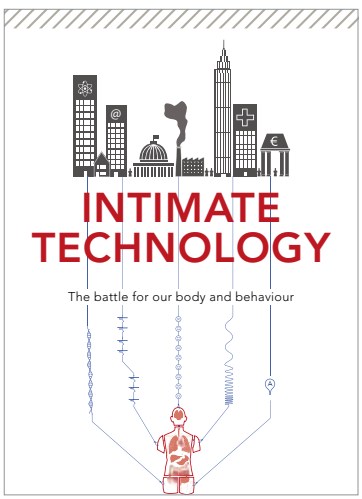
Text:
Tomas Mihalek,
Ann Maher

Proceedings from the PACITA 2013 Conference in Prague

Mankind has never before dealt with such an enormous quantity and intensity of life changing technologies. The European Technology Assessment Conference that took place in Prague in March 2013 shed a light on many of these grand challenges. In its 22 sessions, it became clear there should be a specific form of TA; one which is open to the general public. In the first keynote speech Wiebe Bijker spoke of how we must make TA about democracy: the state must return from its neoliberal retreat and become an advocate of democratic governance. Stefan Boeschen calls TA an important building block of the democratic culture. Rut Bízková mentioned smart infrastructure as a prerequisite for sustainable competitiveness. But symbols of trust and ethical values are essential for TA. The diversity of languages and lack of unified politics are just the most visible obstacles: cross-European TA must address tension that can arise between different national and regional structures. It's a need that is clearly manifested in all the contributions to these Proceedings, which will be available online in May 2014.
www.pacitaproject.eu

Journal of Responsible Innovation

The new Journal of Responsible Innovation (JRI) offers humanists, social scientists, policy analysts and legal scholars, and natural scientists and engineers an opportunity to articulate, strengthen, and critique the relations among approaches to responsible innovation, thus giving further shape to a newly emerging community of research and practice. These approaches include ethics, technology assessment, governance, sustainability, socio-technical integration, and others. JRI intends responsible innovation to be inclusive of such terms as responsible development and sustainable development, and the journal invites comparisons and contrasts among such concepts. JRI is open to alternative styles or genres of writing beyond the traditional research paper or report, including creative or narrative nonfiction, dialogue, and first-person accounts, provided that scholarly completeness and integrity are retained.
www.tandfonline.com/toc/tjri20/current#.UzBrYRbbrzI



Intimate technology

Smart phones, social media, cameras and biosensors mean more and more information about our bodies and behavior are becoming digitally available. Our lives are increasingly becoming intertwined with technology. But allowing technology into our private worlds collides with the most crucial issues of our humanity. It leads to a struggle for our intimacy. The Rathenau Instituut has called this the intimate-technological revolution. This report highlights how the application of human-like technology, such as digital coaches, realistic avatars and robots are blurring the boundaries between humans and technology even further. Important ethical questions touch on the basic rights and dignity of people, their right to privacy, physical and mental integrity, the right to live in a safe environment, the right to have private property, and freedom of thought and conscience. Governments and private companies want our data in order to create profiles and influence our behavior. Technologies with human features, such as digital coaches, realistic avatars and robots yield the ability to influence human behaviour. How can we avoid being manipulated? Which social tasks can we humanely delegate to machines, and which not? What autonomy do we wish to keep?

Intimate Technology The Battle for our Body and Behaviour.

Rinie van Est, with the assistance of Virgil Rerimassie, Ira van Keulen & Gaston Dorren. Rathenau Instituut 2014.
www.rathenau.nl/en/publications/publication/intimate-technology-the-battle-for-our-body-and-behaviour.html

www.issues.org

Focus groups

Policy makers need to know what people think about certain topics and why. This important information can be revealed through open discussions in a focus group.

Text:
Marianne Barland
Photo:
Birgitte Heneide

Technology Assessment has a large toolbox of methods involving a range of different actors. The CIPAST-project (Citizen Participation in Science and Technology), which ended in 2008, described many of them, particularly those involving citizens. The focus group was one of the methods presented.

A focus group is a structured group interview, first used in the United States in the 1980s by sociologist Robert Merton. A group is composed of participants who have specific knowledge or experience of the topic at hand. This could be 'teenagers who use smart phones', or 'parents of children with asthma' or 'workers at a car factory'.

The scope of a focus group is limited and defined in advance by the researcher. They follow a semi-structured interview format, where the researcher asks prompting questions. However, it is important that the discussions are open, so that the participants can share their experiences and comment on each other's views. This is the strength of this method: the discussions and interaction between the participants produces more information than the participants would provide one by one. Another advantage of the focus group is that it allows the researcher to document the processes whereby group meanings are shaped, elaborated and applied, by letting the participants discuss and share with each other. As the participants are selected based on their own experiences, the focus group is an effective method for providing information on attitudes, values and societal norms – for example what teenagers think about privacy issues related to their own smart phone use.

Several institutions in the field of technology assessment have used focus groups in their projects. In 2010 the Norwegian Board of Technology (NBT)'s Patient 2.0 project was trying to ascertain what people with chronic illnesses thought about online health services. Recruitment for the group was done in cooperation with some of the largest patient organizations in Norway with a total of 21 patients participating.

"The focus groups provided important insights on what kind of services the patients needed, what they expected from the care services and their experiences with already implemented online solutions", according to NBT project manager Jon Fixdal. Drawing on their own experiences with the health care system, patients wanted the possibility to add information about their daily condition into their patient journal, so that it could be discussed with their doctor later. Another recommendation was to establish an online health portal, for finding quality assured health information.

'Teenagers who use smart phones' is a topic suitable for a focus group

Fixdal highlights another aspect of the focus groups – the fact that it is well suited for multi-method projects. In Patient 2.0, focus groups were held together with an expert group. Both methods proved valuable and the recommendations produced for the decision-makers were listened to. Getting expert opinions from research and industry, but also user experience from patients, was welcomed by parliamentarians.

Read More?

CIPAST – Citizen participation in science and technology
(www.cipast.org/cipast.php?section=10111)

Attila Havas on strategic thinking: The benefits of foresight

'Thinking 20-25 years ahead is almost beyond the imagination of decision-makers.'

Text:
Katalin Fodor

Photos courtesy of the Hungarian Academy of Sciences

"There are even stronger needs for strategic thinking in Central and Eastern European (CEE) countries than in the advanced ones, given their specific challenges", claims Attila Havas from the Hungarian Academy of Sciences. "In particular, their fundamental political and socio-economic transition processes, as well as major changes in their external environment. Yet, long-term thinking is discredited across the region for historical reasons. Although the CEE countries would clearly benefit from conducting foresight programmes, policy-makers do not rely on modern decision-preparatory tools to a sufficient extent."

Obstacles to foresight

There are various obstacles. "To start with a very simple one, in several countries the history of the current legal entity goes back just over twenty years. Therefore a foresight project with a time horizon of 20-25 years sounds shocking." Although CEE countries are faced with a compelling need for fundamental changes in their health care, education, and pension systems, among others, decision-makers tend to focus on fire-fighting rather than thinking about long-term issues in a participatory way.

'Because of the historical legacy, the mind set of people is not geared towards future-oriented thinking and consensual decision-making.'

In other words, short and long-term issues are competing for problem-solving intellectual resources, the attention of politicians and policy-makers who decide on the allocation of funds, and the attention of opinion-leaders who can set the agenda. These intellectual and financial resources are always limited, thus choices have to be made. A well-designed foresight process can help identify priorities, in terms of striking a balance between short- and long-term issues. It could also raise the profile of science, technology and innovation (STI) on the political agenda. CEE politicians tend to look at STI as a burden on the budget, and not as a source of solutions. When public expenditures need to be cut, the first victim would be the budget for STI, education and culture. Changing that attitude would be crucial.

Changing the historical mindset

In some European democracies, the role of government is shifting from being a central steering entity to that of a moderator of collective decision-making processes with the conviction that stakeholders need to be involved for government policies to be more effective. However, in CEE countries there seems to be distrust towards decentralised decision-making.

"It is probably due to the history we shared for centuries where consensus was not the main method of making decisions", suggests Havas. "CEE history is laden with severe conflicts, including wars and civil wars and empires occupied large parts of our region for long times. Simply because of this historical legacy, the mindset of people is not geared towards future-oriented thinking and consensual decision-making."

Foresight is always a learning process for those involved. It is not only the 'products' – i.e. the different documents, final reports, and policy recommendations – that are important but also the 'process' itself, namely disseminating a new, participatory, transparent, future-oriented decision-making culture; intensified networking, co-operation and institution-building activities. In other words, a foresight programme can contribute to the strengthening of the national system of innovation in two ways: through reports, recommendations as well as via facilitating the communication and co-operation among various professional communities.

The power of informal communication

CEE policy-makers should be inspired to rely more on modern decision preparatory tools and a mix of methods would be needed to foster understanding the relevance of these tools. Tailored workshops to stimulate interactive learning would be particularly effective (not the one-way, codified knowledge flow of traditional training seminars). Writing lengthy and elaborate reports will not be as successful as direct, face-to-face communication between policy-makers. Networking, personal communication, the transfer of tacit knowledge is crucial, even if it is not measured directly. "I think the close links among the members of the European foresight, TA, and evaluation community, along with the collegial atmosphere, is really a strength. I have only met colleagues who were ready to help, share their experience, and reflect critically as well."

Havas has recently been involved with the preparation of the smart specialisation strategies for 2014-2020. (Smart specialisation is a new policy concept designed to promote the efficient and effective use of the EU Structural Funds.) Foresight methodologies have not yet been used in Hungary to that end. "I can recall a few cases when foresight is used to prepare the new planning documents. One is Lithuania. They have just completed a national

Attila Havas is a Senior Research Fellow at the Institute of Economics, Centre for Regional and Economic Studies Hungarian Academy of Sciences, and regional editor of International Journal of Foresight and Innovation Policy. His academic interests are in evolutionary economics of innovation, systems of innovation, innovation policy, and technology foresight. In 1997-2001 he was Programme Director of TEP, the Hungarian Technology Foresight Programme, the first programme of its kind in Central and Eastern Europe.

foresight programme on their research and higher education system and are using the results to prepare the smart specialisation strategy for 2014-2020. Portugal is also planning a foresight-type programme to underpin their smart specialisation strategy."

About future recommendations for the region Attila Havas is very clear: There should always be a very strong national commitment. It is important to engage in international co-operation, but it is always crucial to have commitment from domestic stakeholders. "If at some point there was a pressure on the EU to conduct or fund TA activities in this or that country, I don't think that would be a good idea. Co-financing might be helpful, especially in terms of covering the costs of foreign experts, but there should always be a strong domestic commitment, in terms of the financial and human resources devoted to TA. Without that there is no hope that these tools might become part of the decision-making process in this region."

'A well-designed foresight process can help identify priorities, in terms of striking a balance between short- and long-term issues.'

Big Society

The EU's latest Framework Programme for research and innovation kicked off in 2014 with a new name and it's biggest ever budget. Over the next seven years, nearly 80 billion euros (plus further private investment) will be spent on collaborative projects across Europe.

Text:
Marianne Barland

Photo:
iStockphoto

'We need a new vision for European research and innovation in a dramatically changed economic environment.' *Máire Geoghegan-Quinn, Commissioner for Research, Innovation and Science.*

How can we overcome the challenges related to health and wellbeing posed by demographic changes all over Europe? How can we provide safe societies for citizens? Or food security, sustainable agriculture, smart transport, clean energy? These are just some of the societal challenges in Europe that Horizon2020 will be addressing in the coming years.

Since 1984, the European Union has organized its research and innovation efforts in Framework Programmes. It has sought cooperation between different types of actors and supported the entire process from basic science to innovation through to implementation in society. Lars Klüver, Director of the Danish Board of Technology Foundation, has been involved in EU-funded projects for many years and has seen this trend of involvement evolve: "The focus has slowly moved from new technology to finding solutions to societal challenges. This shift started with the Fifth Framework Programme, but has got real momentum in Horizon2020."

"Simultaneously we see increased interest for engaging different actors in the research. It started with small and medium sized enterprises and civil society organizations in the last Framework Programmes but in Horizon 2020 the involvement goes further," reports Klüver. "Several calls encourage the direct involvement of citizens, users and stakeholders. Seeing how societal challenges demand a broad knowledge base and support from citizens, this involvement seems only natural".

This is not unfamiliar territory for technology assessment professionals. Through three example projects - public health genomics, the future of ageing, and sustainable consumption - the PACITA project has started looking at the grand challenges of Europe and the example projects have shown the importance of involvement of different actors. With experts, stakeholders and citizens playing a role, technology assessment can be one way of dealing with these challenges. There are many possibilities for TA-projects to get funding through Horizon2020, believes Klüver, especially for those institutions that involve citizens and civil society in their work.

PACITA has a long-term goal of strengthening the basis for technology assessment (TA) in Europe, both on a structural and methodological basis. Klüver is convinced that the Commission sees the value in a project like PACITA, and recognizes that it takes time to implement this work into 'real life'. "We do hope there will be opportunities to continue this work in one form or another through Horizon2020. Looking at the intentions of Horizon 2020, one could say that a natural development would be to strengthen the field of technology assessment all over Europe. Technology Assessment has always strived to identify solutions and maneuvers that are robust for society – both technologically and politically."

Read More?

http://horizon2020projects.com
The latest information on projects and partners.

http://ec.europa.eu/programmes/horizon2020/
The European Commission's home page on the Framework with links to other Commission departments.

Real Humans

In the drama series Real Humans written by Lars Lundströ, humanoid robots are servants, workers, company for the lonely and even sex partners. His inspiration? “Technology has slowly taken over our lives, not only in the practical sense but also socially and emotionally”.

Text:
Katalin Fodor and
Pál Hegedûs

Photos:
Portrait: Jesper Brandt

Picture from the TV series: Johan Paulin

State of mind?
Right now, I'm working on several serial projects for television. We are still awaiting a decision for a third series of Real Humans.

Biggest success?
A series called *Tusenbröder* (Brothers in crime) was a huge success in Sweden, so was also a comedy series called *Pistvakt*. But the greatest international success has been *Real Humans*.

How did you get where you are?
I've had my share of luck, combined with hard work and stubbornness.

Failures?
Oh yes, some stuff will fly and some will not. That's the way it works. You have to be an explorer and in being that, you will always take a wrong path every now and then. You can learn a lot more from failures, to be honest. But with no successes you won’t keep that privilege to fail.

Dreams?
I seldom remember my nightly dreams. I can daydream uncontrolled sometimes about a relaxed life with no ties or worries on a tropical island far far away - just like the majority of people in the north of Europe. You know, it's my job to dream in a way, and I write them down for a living.

What will it take?
More hard work I'm afraid.

Biggest fear?
To be struck by a deadly disease or that something bad will happen to those I love and care about.

What inspires you?
Life and the human struggle.

Could you share your plans for the future?
Right now I don't know what's going to be my next project to be realised. I'm developing a few pieces and I'm also engaged in the development of other projects in Matador Film. Of course we are hoping for a third series of Real Humans.

What would you change?
Right now, nothing of the stuff that really matters.

See More?
The Swedish sci-fi drama series Äkta människor (Real Humans) premiered on 22 January 2012 on SVT1 and has been sold to around 50 countries around the world. It raises key ethical issues related to the encroachment of technology in society, according to Lundström: “How can we sustain humanity and tolerance despite these changes? What is a ‘human being’?” His favourite character is re-programmed (with a free will) hubot Mimi: “She is the main conflict-zone in the series, the bridge between humans and machines”.

www.svt.se/akta-manniskor/

Will we need geoengineering to save the world?

Despite numerous international climate conferences, agreements, protocols and treaties, we are not managing to reduce global carbon emissions or stall climate change. Is geoengineering the answer?

Text:
Jon Fixdal

Photos:
iStockphoto

Imagine looking up in the sky. There, many miles above your head, you see what looks like a gigantic mirror. It is actually an enormous solar shield launched to reflect sunlight and reduce the amount of solar energy heating the earth. It is part of a last ditch effort to save us from total environmental catastrophe. It is geoengineering.

Geoengineering is an umbrella term for large-scale interventions to counteract anthropogenic (human caused) climate change. These efforts can be divided into two broad categories: those aimed at carbon dioxide capture from the atmosphere and subsequent long term storage, and those aimed at counteracting the effects of global warming through solar radiation management (SRM).

The main difference between these two types is that the first aims to reduce the concentration of CO2 in the atmosphere, thus making it more likely that our emissions not will exceed 350 ppm (parts per million), often quoted as the 'target' ratio for carbon dioxide molecules in order to prevent significant climate change. Those aimed at limiting the amount of solar energy on the other hand, are aimed at reducing the direct heating of the globe. They do not address the problem of increased amounts of carbon gasses in the atmosphere.

Space reflectors are just one of a wide range of geoengineering proposals. For CO2 reduction, suggestions include **Ocean fertilization or nourishment**: sprinkling iron on oceans to stimulate

Will geo engineering pave the way for reducing CO_2 emissions?

the growth of certain types of plankton. These small organisms feed on CO_2 and live near the surface of water where there is sufficient light to support photosynthesis. **Afforestation on a very large scale**, would enable the removal of CO_2 until the trees were cut down or decomposed. **CO_2-capture from the air** would involve building huge processing towers that suck in air and using sodium hydroxide, remove the CO_2 as the air passes through the tower.

Solar radiation projects include **stratospheric aerosols**: dispersed into the stratosphere, these aerosols are designed to reflect sunlight and increase cloud condensation. **Sun reflectors in deserts** would involve large desert surfaces being covered with sun-reflecting sheets. The basic idea is the same as for space reflectors - to reflect sunlight and thereby slow down the heating of the globe.

'If geoengineering is to play a key role in the future, it needs to be scaled up raising numerous questions related to technological readiness, costs, safety and possible side effects.'

Ongoing afforestation can be considered as an example of existing geoengineering but is currently on a small scale. If geoengineering is to play a key role in the future, it needs to be scaled up raising numerous questions related to technological readiness, costs, safety and possible side effects.

Some geoengineering technologies are 'readier' than others. Injecting sulfur into the stratosphere will probably not be technologically difficult neither will afforestation. But building reflectors large enough to reflect significant amounts of solar energy presents an enormous technological challenge. Air capture with CO_2 removal? Will we be able to store the necessary amounts of CO_2?

Costs and side effects

The costs and financing of geoengineering projects will obviously be a major issue but also the side effects of intervention. For example, ocean fertilization could lead to nutrient depletion. As the plankton grow, they will not only eat the CO_2, as intended, but also other nutrients that other organisms eat. Another example of side effects is that spreading aerosols into the atmosphere is can reduce rainfall in the tropics. The particles that are meant to absorb heat from the sun may also absorb some of the heat energy that comes from the surface of the planet. This heat plays an important role in the production of tropical rainfall, with a danger of causing significant harm to some of the most important ecosystems of the globe. The key point is that geoengineering will come at significant cost, and side effects will be difficult – if not impossible – to predict.

We already know what needs to be done to mitigate climate change. Enormous, costly and high risk projects need not be part of the solution. On the other hand, you do not have to be a full-blown pessimist to believe that the need for large-scale geoengineering may arise. Despite numerous climate protocols, international climate agreements, climate conferences and climate treaties, global carbon emissions are not falling. We must believe (and hope) that any geoengineering activities will only be done on the basis of numerous and very extensive analyses. These should involve a very broad variety of institutions (research, civil society, TA-institutions etc.) and cover issues ranging from technological possibilities, possible consequences and economics, to risks, safety and ethics. It will most probably require broad international cooperation.

TA institutions could play a particularly important role in fostering public debate. Several TA intuitions are highly competent in designing and facilitating participatory processes that provide opportunities for affected citizens to have their say. Geoengineering raises profound questions about whether we should risk tampering with nature, which risks we are willing to take, and how the benefits should be weighed against possible negative consequences. These will essentially be normative questions of great importance to future life on earth. They should not be left to any single group in society, whether technologists, scientists, lawyers or policy makers. The choices should be based on broad societal debate in which ordinary citizens should be included.

Building reflectors large enough to reflect significant amounts of solar energy presents an enormous technological challenge.

Is Geoengineering a Case for TA?

Yes. With a mission of providing advice to policy makers on pressing policy issues, TA can foster critical reflection on which of these (if any) technologies should be developed and how the benefits should be weighed against possible side effects. And not least, TA can stimulate public debate as a means for the democratization about technological choices.

Several TA institutes have done studies on geoengineering:

In 2009, the **UK Parliamentary Office on Science and Technology (POST)** published Geo-Engineering Research, which summarized the arguments related to research funding. It suggested: “A relatively modest research programme, with a UK contribution of £10-20M could advance relevant knowledge significantly.” Climate engineering research programmes are currently ongoing at several universities in the UK.

The Rathenau Instituut is conducting research into various forms of climate engineering and in 2013 published a policy brief entitled Climate engineering: hype, hope or despair? One of their recommendations was to put Carbon Dioxide Removal technology on the agenda of the climate negotiations in 2015 in order to include regulations in the Climate Agreement.

The Office of Technology Assessment at the German Bundestag Büro für Technikfolgen-Abschätzung beim Deutschen Bundestag **(TAB)** is currently working on a comprehensive overview (2011-2014) of the current state of knowledge with regard to technological and natural scientific aspects of the different geoengineering concepts proposed and exploring the facets of these concepts in terms of (international) law, ethics, socio-economics and politics. “Science has only just started to deal with these and other questions so that there is still a considerable lack of knowledge.”

Read More?

Rathenau Instituut - www.rathenau.nl/en/themes/theme/project/geo-engineering.html

POST - www.parliament.uk/business/publications/research/ briefing-papers/POST-PN-327/geoengineering-research-march-2009

GAO (Government Accountability Office, USA) - www.gao.gov/products/GAO-11-71

Energy 2030
The policy of the future

Declaring the European Commission's 2030 framework for climate and energy policies 'short-sighted and unambitious', the European Parliament called for tougher energy targets and an amendment making the renewables target nationally binding. What do members of parliament think?

Text:
Katalin Fodor

Photo:
iStockphoto

We need three binding objectives

"If we want to reduce our energy imports we have to produce more in Europe. If we have a broad energy mix with greater energy efficiency, this is the best option to reduce greenhouse gas emissions, to encourage new technologies and innovation, create jobs, and change our economies into greener economies. This is why we need three binding objectives. The European Commission proposal is an acceptable work base but needs to be strengthened. It is disappointing that we cannot yet confirm the benefits of energy efficiency. Energy efficiency alone would enable us to reduce our energy bills, our dependence on countries producing oil and gas and our energy trade balance and to create thousands of jobs in Europe, not to mention improving our protection of our environment and our climate."

Anne Delvaux (Belgium) European People's Party, co-rapporteur for the environment committee
www.anne-delvaux.be

Targets still fall short

"Apart from the 40% greenhouse gas reduction goal, these targets still fall short of what is needed, if only to be credible to our global partners. I regret that the Commission didn't propose a binding target on energy efficiency. We believe the opposite: in the interest of our industry and our jobs, we must have a firm political commitment to emission reduction, renewables and energy efficiency."

Matthias Groote (Germany), Group of the Progressive Alliance of Socialists and Democrats, chairman of the environment committee
www.matthias-groote.de

Binding objectives are not flexible

"This result is not satisfactory. We are promising ourselves, Europeans and European industry, that this new climate policy would be realistic, flexible and cost- efficient[...]Binding objectives on renewables and energy efficiency is not a flexible arrangement. We know well that member states and individual sectors have different capacities. The European Commission hasn't understood the current impact and influence of the climate policy on the European economy. Increasing the binding target for energy from renewables to 27% does not take into account the electricity price impact of this policy. Raising the CO_2 reduction target to 40% is at best premature."

Konrad Szymaski (Poland), European Conservatives and Reformists group, co-rapporteur from the industry committee but withdrew his name from the report
www.konradszymanski.pl

Unrealistic

"These numbers are madness. How many times will they change by 2030? Our industry needs a stable and foreseeable framework to boost long-term investments. Instead, the parliament proposes unrealistic numbers! [...] We should have focused on one objective of reducing greenhouse gas emissions by 2030. Member states should have the necessary freedom and flexibility to decide their energy mix."

Françoise Grossetête, (France) European People's Party
www.francoise-grossetete.eu

Read More?

www.euractiv.com/energy

http://ec.europa.eu/energy

www.europarl.europa.eu/oeil