



2nd Parliamentary TA Debate

Strengthening Technology Assessment for Policy-Making

7-8 April 2014, Lisbon, Portugal

Documentation on Technology Assessment and PACITA

Technology is one of the strongest forces of change in society today. As a consequence, the choices we make on the use and implementation of new technologies affect directly or indirectly the social, ethical, political and ecological dimensions of society.

During the last decades, Europe has seen the rise of Internet and mobile technologies, we have seen the birth of emerging technologies such as geoengineering, nano- and biotechnology. We see how society looks to new technologies when confronted by challenges such as terrorism, climate change, consumerism and aging populations.

The best technology policy rests on thorough understanding of how science, technology and society interact. As the pace of technological development increases, making informed decisions has never been more important. As the number of lobbyists and interest groups grow, policy-makers across Europe need unbiased and balanced advice on the technological challenges ahead.

The PACITA initiative is response to this challenge. Through documenting, training and debating technology assessment all over Europe, PACITA demonstrates how participation of citizens and knowledge-based policy-making may open for new possibilities, innovation and sustainability.

The PACITA partners

Danish Board of Technology (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)

Catalan Institution Foundation for Research Support (Catalonia, Spain)

Swiss Centre for Technology Assessment TA-SWISS (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).

The present document gives an overview of the PACITA project and the Technology Assessment approach. Goals and activities of the PACITA project are presented, as well as some of the results achieved so far. Full reports are available on the PACITA website: <http://www.pacitaproject.eu/>

About Technology Assessment

Technology Assessment (TA) is an analytic and democratic practice which aims at broadening the knowledge base of policy decisions by comprehensively analyzing the socio-economic preconditions as well as the possible social, economic and environmental impacts in the implementation of new technologies. It is thus engaged at the interface of science, society and policy making and particularly the national parliaments have been regarded the main addressee and client of TA. Since the parliament is seen as the main representation of the public in policy-making, it has to be transparent and inclusive of societal values in debates on new technologies and their impact on society.

TA methods and approaches

Technology Assessment uses an interdisciplinary approach in its analysis of the possible consequences of the use of particular technologies. A variety of quantitative and qualitative methods are used, such as brainstorming, literature research, document analysis, expert consultation, case studies, scenario development, and also participatory processes involving the public.

TA projects can have different perspectives, and thus delivering different type of advice for policy-makers:

- **Technology-induced** TA projects are concerned with the impact of a specific technology on society and the environment. Examples here include specific medical technologies or genetic engineering developments.
- In the **problem-induced** approach the main focus is on identifying the different possible solutions to an existing or future social problem related to technology developments. Examples here include TA studies into traffic, energy supply and use, or privacy.

Further reading

Decker, Michael & Ladikas, Miltos (Eds) (2004). *Bridges between science, society and policy*. Springer, Berlin.

Joss, Simon and Bellucci, Sergio (eds.) (2002), *Participatory technology assessment – European perspectives*. London: University of Westminster.

Vig, N.J. & Paschen H. (1999), *Parliaments and Technology. The Development of Technology Assessment in Europe*. New York: University Press.

“TA embraces the idea of a complex, comprehensive, open and transparent assessment of possible (positive as well as negative) effects of new technological developments in the light of a broad range of scientific branches and perspectives as well as a broad range of values and interests held by different groups in society. In doing so TA does not pretend to anticipate future developments and reduce uncertainties of decision making but to support society, politics and science in dealing with uncertainty in a pragmatic, rational and democratic manner.”

Hennen, L. & Ladikas, M. (2009). “Embedding society in European science and technology policy advice”, in: Ladikas, M. (ed.): *Embedding society in science and technology policy – European and Chinese perspectives*. European Commission, Brussels, 39 – 63.

PACITA aims and activities

The overall aim of PACITA is to increase capacity for parliamentary technology assessment (PTA) across Europe, enhance the institutional foundation for knowledge-based policy-making, build on the diversity of practices in PTA, and develop and test modes for cross- and paneuropean TA activities.

In order to achieve these aims, several activities are being conducted:

- **Documenting TA.** As a first step, a common knowledge on the state-of-the-art in Technology Assessment in Europe has been established and potential work modes for developing a cross-European praxis of TA have been explored. The work of the TA community has been made available through a TA portal (<http://technology-assessment.info>). A book summarizing the major findings of the project will be published at the end of the project (Spring 2015).
- **Training TA.** Two Summer Schools for scientists and other TA-interested persons are being organized within the PACITA initiative, as well as four practitioners meetings for TA project managers.
- **Dialogue on TA.** Debates have been organized in several country where PTA hasn't been established yet. Policy-makers have also been invited in two Parliamentary Debates on TA, and two European Conferences on TA are being held in order to have a broad dialogue on TA related issues and topics.
- **Doing TA with example projects.** The three main methodological clusters in PTA – expert based methods, stakeholder involvement, and citizen consultations – are being exemplified by cross-European projects. Each project is coordinated and synthesized at the European level, based on sub-activities at the national/regional levels. These projects cover key science and technology issues of the “Grand challenges for Europe” of the Lund Declaration, i.e. “Public Health Genomics”, “Ageing Society” and “Sustainable Consumption”.

All the results of PACITA and other activities related to knowledge-based policy-making are regularly presented in the VoITA magazine, the magazine of the PACITA initiative.

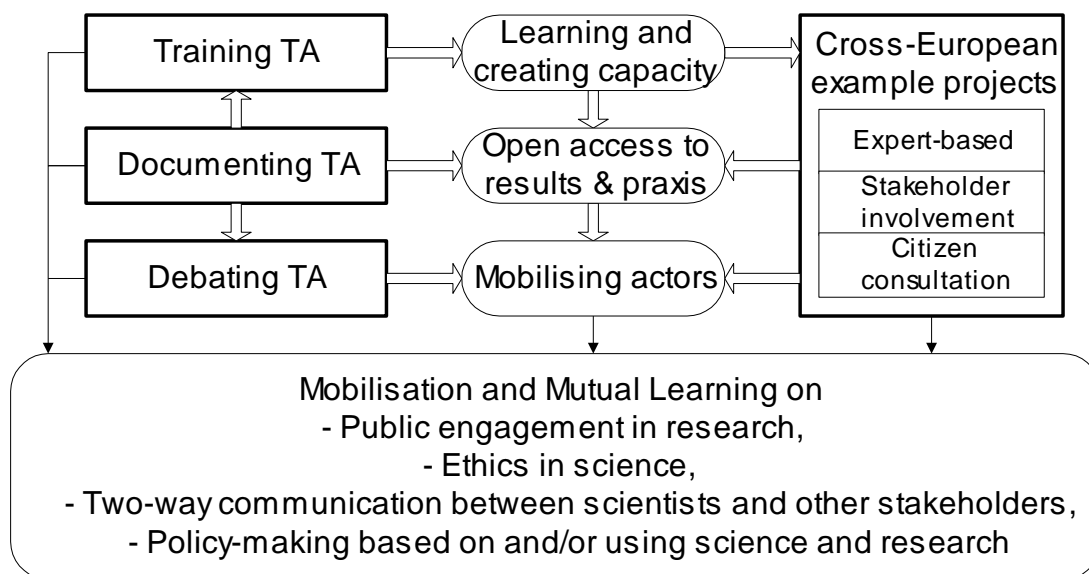


Figure 1 The PACITA project

PACITA Results – TA in Europe

Multiple faces of (parliamentary) technology assessment institutions

Policy brief PACITA WP 2.1: TA practices in Europe

When discussing the creation of a new or the future of an existing institution devoted to (parliamentary) technology assessment (PTA) policy makers are advised to look not only at its relationship with parliament, but also with government, science & technology, and society. Such an inclusive perspective is fruitful for both states with an interest in PTA, as well as for existing PTA organizations in need to respond to new political demands with regard to their advisory role.

The parliamentary technology assessment landscape is very rich and diverse. This has to do with the fact that PTA organizations are not only determined by their institutional relationship with parliament, but also by their relationships with other social spheres, in particular with governmental institutions, the science & technology communities, and society at large.

Accordingly PTA can be understood as an activity at the interplay between four spheres: parliament, government, science & technology, and society (see Figure). PTA may act as a knowledge mediator between these spheres. Actors from each of the above-mentioned spheres are potential clients of PTA. In particular, technology assessment (TA) that specifically aims at informing and contributing to opinion formation of members of parliament is called PTA. However, TA organizations establish and maintain multiple institutional relationships with and between those various social spheres.

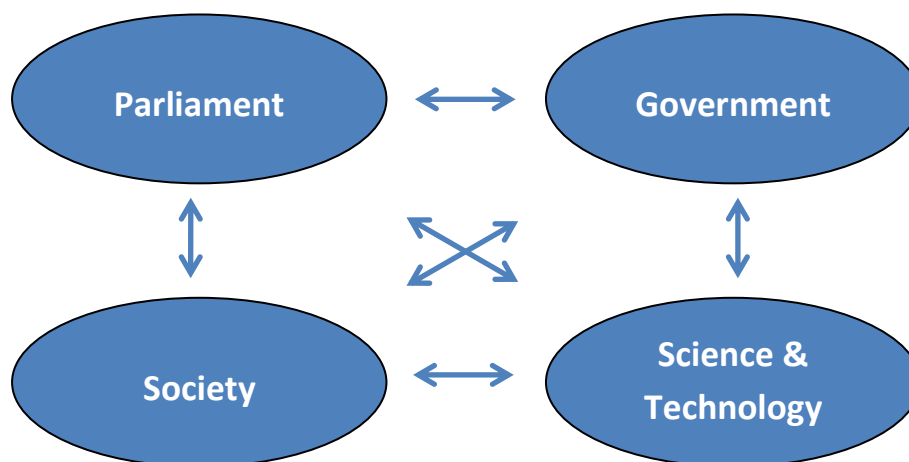


Figure 2 (Parliamentary) TA between parliament, science and technology, government, and society.

Currently five distinct interaction models for PTA are operational in Europe. Referring directly to the involvement of various social spheres in TA these models can be named:

- 1) *mainly parliamentary involvement* in TA (France, Finland, Greece, Italy),
- 2) *shared parliament-science involvement* in TA (Germany, UK, USA, EU, Catalonia),
- 3) *shared parliament-science-society involvement* in TA (Denmark),
- 4) *shared science-government involvement* in TA (Austria), and
- 5) *shared parliament-government-science-society involvement* in TA (Norway, Netherlands, Switzerland).

However, according to our model, besides these five interaction models empirically found in practice today, in principle many other ways of institutionalizing, organizing and performing PTA are conceivable.

Traditionally PTA was primarily understood as focusing on the institutional relationship between the TA organization and the parliament. The political debate about setting up such a type of relationship takes a long time; sometimes even more than a decade. From this perspective the institutional barrier to set up PTA is quite high. Understanding PTA organizations as hybrids, i.e. as relating to the other three spheres as well, provides a more fruitful way to look at the institutional challenges. This refers not only to existing PTA organizations, but also to organizations as well as countries and regions in Europe with an interest in becoming or setting up a (P)TA organization.

Background of the PACITA project's work package 2.1 "TA in Europe"

In work package 2.1 of the PACITA project various current practices of PTA in Europe were described and analysed. In particular Austria, Catalonia (Spain), Denmark, Flanders (Belgium), Germany, the Netherlands, Norway, and Switzerland were investigated. For each country or region, one TA project of the TA organisation was included as a case study, further illustrating the 'nuts and bolts' of daily practice. Overall, reporting was based on interviews, institutional archives, websites, earlier descriptions, and expert judgement. In the concluding chapter of the report, the comparative analysis was extended to organisations in Finland, France, Greece, the European Parliament, Italy, the United Kingdom, and the United States.

Lessons learnt

- Setting up institutional relationships between a TA organization and parliament is a long process and may take more than a decade.
- In thinking about setting up PTA the whole "possibility space" should be considered. This implies that the possible relationships between the PTA organization and each of the four social spheres have to be analyzed and carefully designed. Countries with an interest in setting up PTA do not have to choose among one of the existing, current models, but may find their own specific model that is particularly suited to their political and societal environment.
- The institutionalization of PTA organizations is a dynamic process. One may say that TA institutions that existed over a longer time period somehow drift in the "possibility space", that is institutional tasks of the existing TA institute may change over time. This implies that there are ample opportunities for existing PTA organizations to adapt to changing political demands.
- A step by step approach to setting up PTA is possible. A country may first set up a TA organization and later on gradually develop its PTA capacity. An organization eager to establish PTA in its country may start to build up stronger relationships with parliament and include parliamentary TA types of activities and thus gradually change into a PTA organization.

Further reading

Ganzevles, J. & R. van Est (eds.), 2012, *TA Practices in Europe*. Deliverable 2.2 of the PACITA (Parliaments and Civil Society in Technology Assessment) project, commissioned by the European Commission, September: PACITA Consortium, <http://www.pacitaproject.eu/wp-content/uploads/2013/01/TA-Practices-in-Europe-final.pdf>.

PACITA Results - A way forward for TA in Europe?

Cross-European comparative analysis of barriers and opportunities for establishing Technology Assessment as a means of policy advice

Policy brief PACITA WP 4.1: Expanding the TA landscape

What are the barriers and opportunities of establishing Technology Assessment as a means of policy advice in countries which so far are lacking any (institutionalised) form of TA or do not have established TA at the governmental or parliamentary level? This was the guiding question of explorative studies on opportunity structures and barriers for introducing and establishing the concept of Technology Assessment in seven European countries carried out in the framework of the EU funded PACITA project (Parliaments and Civil Society in Technology Assessment). The countries explored are the Czech Republic, Bulgaria, Hungary, Ireland, Lithuania, Portugal, and Wallonia (Belgium). The exploration of opportunity structures was organised in a way that the exploration itself, at the same time, would initialise reflecting, networking, and possibly planning with regard to national TA infrastructures in the countries explored.

The socio-political context in the countries explored

The comparative discussion of the country studies clearly revealed that the situational context for establishing TA in the countries explored differ significantly from the historical situation in the 1970s and 1980s when most of the existing national (parliamentary) TA units in Europe were established. Whereas back in the 1970s and 1980s, S&T were subject to vivid public debates with relevant parts of the general public asking for being involved in decision making, public awareness of S&T policy-making issues is rather low in the countries explored. Other than in the 1970s and 1980s, there is also no expressed demand for unbiased scientific advice for policy making in the field of S&T policy related to problems to legitimise decisions taken in view of the vivid public discourse with often conflicting interests. Furthermore, the countries explored are busy with building up or strongly reforming existing R&D structures with an urgent need for keeping up with the pace of globalisation, whereas 30 years ago the establishment of TA took place in countries with strong R&D infrastructures forming the basis of quite well developed economies and public welfare. Thus, whereas questions of environmental and health risks and the socio-political steering of S&T dynamics in a socially sound way were in focus 30 years ago, today, it is very much about “economy first”, i.e. initialising S&T dynamics and innovation for economic development in a climate of global competition and financial crisis.

Background of the PACITA project's work package 4.1 “Expanding the TA Landscape”

In work package 4.1 the exploration of opportunity structures and barriers for introducing and establishing TA has been undertaken in seven countries (Czech Republic, Bulgaria, Hungary, Ireland, Lithuania, Portugal and Wallonia). This was successfully done by a set of interviews with relevant actors as well as by two workshops with policy makers, stakeholders, representatives of science, public administration, media, and civil society in each of the 7 countries. The findings with regard to existing R&D policy structures and to their workings, with regard to the national S&T system and to existing infrastructures for scientific policy advice as well as with regard to the level of public discourse on S&T were laid down in country studies. These can be found under http://www.pacitaproject.eu/wp-content/uploads/2014/02/4.3_Expanding-the-TA-landscape.pdf

Expectations and demands with regard to TA

Due to this situation TA as a concept is confronted with specific expectations and demands which have to be taken into account when searching for ways to install advisory TA structures:

- With regard to on-going often not well coordinated activities of governments to build up or restructure the R&D system, TA is often explicitly expected to contribute to strategic planning of the R&D landscape and to the evaluation of R&D capacities.
- Setting up innovation policies to improve competitiveness is the central R&D policy issue in the countries explored. TA could position itself, with respect to these activities, by providing support for identifying socially sound and robust country-specific innovation pathways (“constructive TA”) and to contribute to lower costs of trial and error learning.
- Democratic and transparent decision making structures are often not well developed. Part of this is a low profile of parliaments in S&T policy-making as well as a lack of communication among relevant actors. TA could find a role here as an independent and unbiased player to induce communication on “democratic” structures in S&T policy-making among relevant actors.
- “Involving the public” is seen as a challenge by many actors in the countries explored. Motives of democratising S&T policy-making, however, are often merged with “paternalistic” motives of “educating the public” (media, lay people). It has to be clarified to what extent TA’s mission of “stimulating public debate” can adopt that purpose (without becoming “persuasive”).
- A widespread awareness of problems such as in-transparent decision making, lack of trust in democratic structures, lack of competences of relevant actors, bounded rationalities of relevant actors, and lack of strategic long-term thinking often results in an explicit demand for “knowledge-based policy-making”. In this context the (not very well known) concept of TA is welcome as a means to underpin decisions with the best available knowledge in an unbiased manner. Specific ideas about how to institutionally build it into the existing system are, however, missing and it might well be that, in terms of institutional solutions, none of the models so far realised in Europe might be appropriate.

Modes of “institutionalisation”

Depending on the country-specific situation, existing models of institutionalisation of TA are taken up by certain actors, such as: establishing a TA function at the parliament or building up TA capacities at scientific institutions (e.g. at the national academies of sciences) as a support for policy-making. The comparative analysis, however, has shown that the national initiatives taken in the countries explored imply new visions for the institutionalisation of Technology Assessment besides the (traditional, but still up-to-date) support of the parliament. As a further step to introduce the concept the “network model” of TA might be most appropriate. This model seems to be of use, especially in the exploration and starting phases of national TA initiatives when serving as a platform to share knowledge and to connect relevant actors. Its practicality, however, has yet to be proven. It will be a challenge for the TA community to react to this in a way that is supportive for policy-making in the respective countries but, at the same time, allows for keeping the conceptual core of TA as an unbiased and, as much as possible, as a comprehensive endeavour to reflect on the societal implications of new R&D developments.

Next steps?

As next steps to be taken in order to assure the results that have been achieved by the PACITA project – namely raising awareness on TA among relevant actors as well as instigating first joint reflections on how to adopt the concept in the national context it is suggested suggest:

- To further support on-going networking activities around the concept of TA by further raising awareness on the concept and by identifying possible “TA entrepreneurs” as well as by supporting reflections on the role of TA in national political settings through further input from existing TA institutions.
- To set up some kind of “prototype activities” like pilot TA-studies, policy briefings, participatory experiments, etc. which, at the same time, can function as a starting point for a collaboration between relevant actors and as mutual methodological learning processes as well as as a show case for the potential of balanced TA analysis.
- “Prototype activities”, furthermore, provide a very good basis for further cooperation with the international TA community. Joint work on TA-projects seems to be especially promising in this respect as it allows not only for the development of a shared problem orientation and an exchange and reflection on methodological approaches, but also for a cross-national analysis of specific questions in the fields of science and technology.
- A joint European TA network which would function as an umbrella for existing as well as for newly emerging national TA initiatives would form an important platform for future activities. Such a network could, on the one hand, stabilise emerging TA activities by providing an international framing for the national exploration processes. On the other hand, existing TA institutions would be challenged to react to new demands, new ideas, roles, and functions for TA, thus, providing for continuous development of the concept alongside of emerging new demands. A continuation of the processes that were initiated by the PACITA project thus seems to be promising for both, for existing as well as for newly emerging TA actors in Europe, but also beyond its borders.

Further reading

Hennen, Leo and Linda Nierling (eds). 2013. *Expanding the TA Landscape*, Deliverable 4.3 of the PACITA (Parliaments and Civil Society in Technology Assessment) project, commissioned by the European Commission: PACITA Consortium

(http://www.pacitaproject.eu/wp-content/uploads/2014/02/4.3_Expanding-the-TA-landscape.pdf)

PACITA Results – Genomics in Healthcare as a Societal and Political Challenge

Genomics in Healthcare: Clinical Utility, Not Technological Ability

Policy brief PACITA WP5: Future Panel on Public Health Genomics

As the cost of genome sequencing drops rapidly, the gap widens between our ability to generate data and their meaningful interpretation. How can innovation and research in genomics benefit public health? Given the many uncertainties in medical genomics research, clinical practice and governance, an incremental approach to the medical application of genome based information and technologies is to be recommended.

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. The expectation is that this will enable detailed risk profiling as the basis for targeted interventions, potentially improving health outcomes. It may lead to healthcare practices that are more personalized, predictive, preventive, and consumer-driven.

However, there is a clear threat that premature technology and market driven applications 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. Political intervention is needed to guarantee that the use of genomic technologies in public health services does not lead to detrimental consequences.

These concerns warrant a step-by-step approach to the development and diffusion of genome-based information and technologies (GBIT: see Box 1). The challenge for policy makers at the national and international level is what a step-by-step approach might involve in their own countries.

Currently we should not think of the future in terms of concepts like “Public Health Genomics” (PHG: see Box 1) defining a “road map” taking us in one particular direction. We should rather carefully look at the variety of ways in which any new development could affect the healthcare landscape in the future. Determining acceptable ways in which healthcare practices could be improved by GBIT requires political and societal debate. For instance, the extent to which genomics data is 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.

Focusing on the themes of *medical research, clinical practice and governance*, this policy brief highlights key developments and needs as expressed by experts from a broad range of relevant scientific branches, some of the main issues raised by these developments, and potential ingredients for an incremental approach.

Box 1: Definitions

Genome-based information and technologies (GBIT) is a term that addresses developments in genetics, genomics, functional genomics, systems biology and systems medicine, which aim to understand not only people with diseases, but also healthy individuals.

Public Health Genomics (PHG), as a new paradigm of practical genetics, aims to promote the introduction of GBIT into practice by a responsible and effective translation of genome-based knowledge and technologies for the benefit of population health.

MEDICAL GENOMICS RESEARCH

Data sharing and privacy

Developments and needs

Emerging medical practices that are based on genetic information depend on increasing the quantity of data travelling between patient care and research. Large-scale biobanks in Europe are becoming part of this 'big data' environment. However, these biobanks are not currently interoperable. Moreover, protocols for data collection and legislation governing cross border data exchanges are not harmonized. Experts emphasize the need for further integration of these biological datasets with information on environmental variables, lifestyle and nutrition etc.

Issues

- There is a potential tension between collecting individual patient data in a care context (requiring confidentiality), and involving patients as 'donors' to a biobank (entailing large-scale data sharing).
- The extent to which data sharing in medical genomics will yield health benefits is a matter of debate.
- Legislation covering data exchange across national and regional borders is not in place.
- Medical data in biobanks cannot be effectively anonymized, especially once whole genome information is included.

Possible steps

- Closely monitor the public governance of genomics databases in biobanks.
- Pay attention to the specific rules which guide and guard clinical care and research as two different domains. Consider the need for harmonization of legislation governing these two domains.
- Support the development of an appropriate ethical and governance framework for data sharing across the EU and emerging players in e.g. China, India and Latin America.
- Consider special forms of data protection for genomic data as part of the current revision of the EU Data Protection Regulation.

Quality Assessment

Developments and needs

Reduced sequencing costs are expected to stimulate the analysis of healthy genomes as well as those of people with diseases. Some experts suggest that this will give us the tools for detailed risk profiling, so delivering improved health outcomes. However, these promises have so far not been fulfilled.

Issues

- Critically, there is a funding gap: research funding is available to develop genomic knowledge and technologies but not for the studies needed to establish clinical validity and utility.
- The marketing of direct-to-consumer tests is therefore generally seen as premature.
- Publically funded projects such as Eurogentest have developed standards for regulating genetic testing and quality assessment of genetic services, but these standards are voluntary.

Possible steps

- Invest in well-designed studies in populations that are representative of an intended healthcare application of genome-wide sequencing. Multiple smaller studies tailored to the intended applications may have more value than one analysis using data from a large generalized biobank.
- Consider the need for stricter regulation to protect the consumer, control societal healthcare costs and allow commercial DNA testing, all at the same time. The European Commission has recently published a new *draft* for a revised in vitro diagnostic medical device (IVD) which proposes a ban on DTC marketing of genetic tests without the involvement of genetic counsellors.
- Make participation in quality assessment schemes mandatory for genetic testing laboratories.

CLINICAL PRACTICE

What to screen for and when?

As DNA-sequencing technologies become cheaper and faster it may become routine to sequence genes, or even whole genomes of individuals (WGS), for both diagnostic and screening purposes. An improved understanding of the genetic basis for common, complex conditions including cancer, heart disease and diabetes, as well as advances in testing of genomic biomarkers, might increase the relevance of genetic services for the general population. Options for the introduction of WGS in practices of screening are currently discussed for newborn screening and for reproductive screening, including pre-implantation genetic screening, non-invasive prenatal testing (NIPT) and genetic carrier screening. However, these new possibilities raise important questions, both about the *scope* of whole genome screening options offered to individuals, and about the importance and meaning of *informed consent* as a fundamental patient right.

The scope of screening options

Issues

- Will genomic data ease the burden of informed decision-making or exacerbate it? Most likely it will be the latter, due to the potentially large amount of information produced.
- To what extents 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?

Possible steps

- Define a clear and guiding role for public health authorities in decision-making about the introduction of whole genome sequencing in programs of reproductive and new-born screening.
- Limit the range of screening options to a well-defined standard offer when introducing whole genome sequencing in carrier or prenatal screening. Broader tests might be available for parents only on an opt-in basis.
- When introducing genome-wide newborn screening, keep the data that are provided to parents limited to information that is actionable and of immediate clinical utility for the child.
- Preserve the right of a child to an 'open' future in defining the scope of genome-wide screening.

Informed consent

Issues

- Data sharing in biobanks poses challenges to informed consent, because data may be shared for purposes and by stakeholders that are unknown at the moment the data was collected.
- Generally, medical tests may reveal unsolicited findings. This issue is exacerbated in the context of whole genome sequencing. Finding acceptable and workable approaches to informed consent will become a major challenge in this context.
- There are notable shortcomings in the current level of genetic service provision in Europe and new challenges will arise for service provision in the context of emerging practices of genome-wide testing, especially with regard to procedures for informed consent.

Possible steps

- Examine what kind of counselling framework needs to be created for whole genome screening given the volume of data and the type of information generated.
- Distinguish different settings, such as research, clinical care and screening, in designing procedures for informed consent.
- Limit unsolicited findings by the use of filters that restrict the amount of data generated to particular clinical purposes.
- Establish clinical genetics as a profession in every country, stimulate collaboration between geneticists and other medical specialists, and integrate genetic services into primary care in order to secure a proper framework for informed consent.

GOVERNANCE

Developments and needs

A step-by-step approach framed by well-defined and informed policies is needed to deal with the manifold uncertainties surrounding GBIT in a responsible way. Evidence-based quality assessment is required and Health Technology Assessment is vital. This will enable healthcare policy makers, healthcare providers and other stakeholders to make informed and country specific decisions about the application of GBIT into a variety of healthcare settings.

Issues

- The introduction of genomic tests in (public) healthcare practices should not be based on their technological availability, but on an appropriate evaluation of their clinical utility. Without political intervention, GBIT could somehow find their way into the public health landscape with detrimental consequences.
- While genome sequencing may become increasingly accessible due to its decreasing price, it is doubtful whether this will lead to a decrease of the costs of screening. The costs of analyzing the large amounts of data generated, the cost of counselling, the cost of false positives and negatives (and their medical consequences), could largely outweigh decreasing sequencing costs.
- Health Technology Assessment is not spread all over Europe, and often it is not embedded in decision-making procedures concerning the provision of healthcare.

Possible steps

- Organize pilot experiments in different contexts and countries as support of a step-by-step approach to the introduction of GBIT in healthcare systems.
- Engage stakeholders, including patient advocacy and civil groups concerned with genome sequencing issues, in experimentation, assessment and decision-making.
- Use the best practice guidelines and legislation that is already available for genetic testing services to inform the development of HTA practices all over Europe.

The introduction of Genome-based information and technologies in healthcare requires a societal and political debate, both on the European and the national level.

What will a step-by-step approach to public health genomics in *your country* require?

Box 2: “The Future Panel on Public Health Genomics”

The Future Panel on Public Health Genomics is part of the PACITA project (*Parliaments and Civil Society in Technology Assessment*). The Future Panel consisted of parliamentarians from Europe who, at the start of the project, 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 with a focus 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 a Policy Hearing involving the Future Panel and a variety of experts (Lisbon, 18 January 2014).

For more information about the “Future Panel on Public Health Genomics”, see: www.pacitaproject.eu

PACITA Events – First Parliamentary Debate on Technology Assessment (Copenhagen, 18 June 2012)

Knowledge-based policy making

How to ensure a stream of high-quality knowledge in the political decision making processes on innovation? What is the role of «knowledge brokers», such as the technology assessment institutions? Is there a special need for knowledge in respect of policy making on science, technology and innovation? How is national policy making embedded in global issues? Policy makers from all over Europe discussed these questions in Copenhagen on 18th June 2012, in the premises of the Folketing (Danish Parliament). They shared their opinions, practices and prospects on knowledge based policy making through statements and during dialogue sessions.

Regarding the very complex nature of science and technology issues, facts have to be made understandable to policy makers, and risks and values pertaining to innovations have to be made transparent. Policy makers are expecting technology assessment to create transparency on the issues they are dealing with. For TA institutions and other TA-like bodies this implies their being independent of industry and science, as well as of politics. Policy-makers also stressed that some issues they are dealing with need rapid decisions and urged Technology Assessment to develop tools that can be implemented on short notice.

Knowledge-based policy making is increasingly challenged by the fact that science and technology are moving up to the global, or at least transnational level. This move towards the global level is challenging policy making in that parliaments have to deal with the global dimension of science and technology while having to decide on a national or regional constituency. And it challenges technology assessment in that it has to reflect on new forms of policy advice able to serve policy making on global and cross-border issues. But participants were convinced that Parliamentary Technology Assessment needs to have a global dimension. It should be in the essence of technology assessment to combine a global approach to science and technology with an in-depth consideration of the national context and issues at stake. For small countries where the institutionalization of technology assessment may encounter structural barriers due to the lack of expertise availability or financial resources, transnational collaboration may also offer a pragmatic solution for knowledge-based policy making.

Participants were challenged to think about the future of technology assessment: «what should be the mission and function of Parliamentary TA for the next 20 years?» they were asked. Participants pointed out

About the first Parliamentary Debate on TA

This event was part of the EU-funded PACITA initiative (Parliaments and Society in Technology Assessment). It has been jointly organized by the Danish Board of Technology (DBT) and the Swiss Centre for Technology Assessment (TA-SWISS). It was the first of two “Parliamentary Debates on TA”, which are expected to favour the dialogue between the Technology Assessment (TA) community and the policy sphere.

The first Parliamentary Debate on Technology Assessment was designed around three main topics:

- 1) When science and technology come into Parliament
- 2) Responding to global challenges: the role of technology assessment
- 3) Parliamentary TA: lessons learnt and future developments.

Each topic was introduced by a keynote speech and by policy-makers’ statements. Participants exchanged their opinions and personal experiences on the topics in discussion rounds, and then presented the highlights of their discussions to the plenum.

that Parliamentary Technology Assessment started from a technology-oriented perspective and evolved to integrate problem-oriented questions. This should continue in the future, because there is a growing need by policy makers to get advice on setting priorities and on research and innovation policies. Participants also suggested various missions for Parliamentary Technology Assessment in the future, which could add up to the traditional mission of assessing scientific and technological options. But whatever the mission will be, participants agreed that TA should, as in the past, contribute to the innovation and development of democracy, work in the interests of future generations and improve collaboration between science, parliament, government and society.

One of the aim of the PACITA initiative is to broaden the TA landscape across Europe, which implies to explore the paths to establish Parliamentary Technology Assessment in countries where it doesn't exist yet – or exists only in informal settings. Participants stressed that TA-like activities are often performed by existing institutions. But this is mostly done on an ad hoc basis. There is thus a need to institutionalize Parliamentary Technology Assessment in order to define its mission and approach, and to allocate resources. It was also suggested that the European Union should establish a law saying that national governments cannot propose a new law to their Parliaments without providing a kind of societal impact assessment.

The meeting offered many questions for the PTA community to think about ... and also for policy makers who are defining the mission and mandate of technology assessment in their country. The call for knowledge-based decision-making and technology assessment has been made clear, as the call for international engagement and collaboration.

Further reading

Full report: http://www.pacitaproject.eu/wp-content/uploads/2012/10/PACITA_4.2_1st-Debatre_report_def_print-version.pdf

Presentations of the keynote speakers and interviews with some participants: http://www.pacitaproject.eu/?page_id=1049 .

PACITA Events – First European Conference on Technology Assessment (Prague, March 13-15, 2013)

Technology Assessment and Policy Areas of Great Transitions

Technology assessment has experienced a renaissance during the last 5 years, mostly connected to the appearance of visible and widely accepted “grand challenges” of the modern societies, such as problems connected to climate change, pandemics, public health, security, etc. Globalization and the global financial crisis add challenges of new demands for competitiveness and innovation, and the increased speed of the technological development gives rise to a parallel need for proactive technology assessment and public/political clarification processes. This development has increased the focus on inclusive, proactive and forward-looking activities, such as technology assessment and foresight, including a strong emphasis of broad societal engagement in policy-making, which has been a trademark of participatory TA for more than 20 years. However, the professional discourse on TA has not followed troop, leaving an undesired gap in the mutual learning between practitioners and STS academia in Europe which needs to be counteracted. For this purpose two European TA conferences were and are being held.

The First European Conference on Technology Assessment (Prague, March 13-15, 2013) addressed examples of societal areas witnessing great transitions like healthcare and medicine, energy supply, climate change and mobility in addition to the use of computer technology in all areas of society.

The main subject areas covered included:

- The kinds of knowledge and dialogue needed for decision-making in societies in order to accomplish the great transitions
- The kinds of projects and programs, institutions, approaches and methods needed by technology assessment in these processes
- Novel methods, such as the use of various art forms, to reach different types of actors and target groups
- The special interests and needs of EU member states in the various areas of the European Union with respect to policy advice for the great transitions
- Results of projects on topics related to the great transitions, for example:
 - Healthcare in an ageing society (e.g. e-Health, robotics for home care, ambient assisted living)
 - Energy supply in the aftermath of the Fukushima disaster (e.g. renewables)
 - Mobility (e.g. urban transport, e-mobility, logistics)
 - Changes to societal relationships through ICT (social computing etc.)
- The use of project results in policy-making and other activities.

The conference was addressed to all groups of actors in science and policy studies: policy makers in legislation and administration, civil society organisations as well as academics and TA practitioners.

The second European Conference on Technology Assessment will take place in Berlin, from February 25th to 27th 2015. For more information, see: <http://berlinconference.pacitaproject.eu/>

Further reading

Book of abstracts: <http://www.pacitaproject.eu/wp-content/uploads/2013/03/Book-of-abstracts-Prague.pdf>