healthgov matters

Science in Society

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4.1 Final publishable summary report

Executive Summary

The HealthGovMatters project was a three-year (2009-2012) collaborative research project, which was co-funded by the European Commission as part of the Seventh Framework Programme, Science in Society' initiative. It was undertaken by a consortium of four institutions – Zeppelin University in Germany, the Interdisciplinary Centre for Comparative Research in the Social Sciences and the ICCR Foundation in Austria, and Goldsmiths' College in the United Kingdom. Over the course of three years, the researchers used rich social science and ethnographic methods, including textual analysis, interviews, and participant observation to explore the ways in which patients, family members, health professionals and researchers engage with the development, implementation and governance of predictive, diagnostic and therapeutic technologies and related medical knowledge.

Overview

Overall, the HealthGovMatters project explored patients' and professionals' formal and informal involvement in governing the production and mediation of health and medical knowledge. Our interest was in exploring interactions amongst constellations of actors (patients, care-givers, health professionals, citizens, patient and professional organisations) who become involved in mediating and articulating definitions and lived meanings of health, illness and disease in the context of encounters with new health technologies and medical knowledge. As a result of our initial fieldwork, we came to focus on four conditions – epilepsy, migraine and autism in the UK and Austria and mitochondrial disease in Germany. All conditions are neurological, with a significant amount of research being conducted at the interface of neurology and genetics. Both epilepsy and mitochondrial disease have been characterised by interviewees as an "invisible disability", while at the same time scientific research (via genome sequencing and imaging technologies) strives to render aspects of the conditions more "visible". With regard to technologies, we focused on new imaging (predictive and diagnostic) technologies, such as forms of genetic testing, magnetic resonance imaging and EEG, computer implants, such as the vagus nerve stimulator, and new pharmaceuticals/devices, which are being developed and implemented in the fields of genetics and neurology - two key sites in which new technologies enabled by the synergism of developments in such core fields as nanotechnology, biotechnology, information technology and cognitive sciences are being integrated. Often referred to as "converging technologies", their integration in the area of medicine is viewed as holding the potential to

vastly improve ICT capacity for medical data management and information generation and to provide the foundation for the translation of research knowledge into clinical trials and clinical practice. In the light of new developments, we were asking: How do patients and professionals at the experiential and institutional levels represent new diagnostic, predictive or therapeutic possibilities and make decisions regarding their development and use? Who produces representations of these technologies and related conditions and how and where do such representations circulate?

Attention to Gender and Generation

In both fieldwork and analysis, specific attention was paid to the visibility of women and men and adults and children within representations of emerging and converging technologies. We were interested in how individual gendered subjectivities, and roles in relation to decision-making on behalf of others, may influence involvement in patient organisations, professional organisations, and governance initiatives. Additionally, while much attention has been placed on decision-making and experiences of adults, less visible, perhaps, are the emerging cases of clinical trials and diagnostic or predictive testing situations in which children are the subjects. The analysis of the interview material and the narratives reveal gender specific aspects with regard to participation in governing measures, the perceptions of a condition and experiences with related diagnostic and therapeutic technologies. However, numerous other variables, such as education, cultural background, class, linguistic capacities and generation are also extremely important. In our discussion, we focus on gender and generation as they were two dimensions that we initially sought to explore. Our project was strongly ethnographic, heavily focusing on the narratives of experience. Gender seemed to make a difference with regard to processes of achieving diagnoses, the lived experience of a condition in relation to its gendered status, and reproductive decision-making in the face of emerging knowledge. Gender, was however, not uniformly associated with leadership of self-help/patient organizations, and differed as an axis of difference in the three countries and in relation to the specific conditions in focus. In the body of the report, we will highlight some of the ways in which gender and generation became apparent through the stories of individuals we interviewed.

Comparative Approaches in EU Research

In undertaking the HealthGovMatters project, we emphasized a “constantly comparative” approach, whereby comparative analyses were carried out throughout the project along the lines of condition, gender, generation, political context, language, implementation of governance frameworks, legislation, etc. in dialogue amongst the researchers. Outlined in our proposal and description of work as a methodological approach, this meant that what we explicitly proposed to do contrasted with the approach taken in many European projects, where the comparison is made using the country level as the dominant unit of comparison. In

the design and implementation of HealthGovMatters, we instead worked collaboratively to help elicit finer points of comparison at a much more local level. This then helped us in our analytical discussions to understand some of the ease and barriers to participation outside of a regional or national system. Thus, as planned, the outcome of WP1 includes a synthesis report that compares and contrasts the various forms of organizations that are becoming involved in the governance and production of medical knowledge and medical technologies, highlighting differences in structural forms in the UK, Germany and Austria. WP2 took a much more solid ethnographic approach and its outcomes are represented in the form of three mini-ethnographies. The analysis within these is informed by collaboration amongst the researchers. The differences and similarities that were noted throughout the fieldwork pushed the research in each country in new directions. Most notably, the interesting details were with regard to the diagnostic experiences and development of technologies in relation to the condition's visibility and 'disabling' effects. Furthermore, the commonality and rarity of the conditions, or their perceptions thereof, also impacted on the level of research funding and interest in them. As knowledge within the fields of health and science and health and science governance becomes increasingly mobile – along with scientists and patients – it will be extremely important to develop approaches to European research that can attend to such mobility. Such research will contribute to the European knowledge sphere by exploring practices of harmonization but also contestation outside of set frameworks of analysis based on geo-political boundaries.

Integrated Research – Research Subjects, Researchers and Knowledge Production

The HealthGovMatters project undertook a multi-sited methodological approach, following the work of George Marcus and Sarah Franklin. This meant that the research was conducted at various sites of knowledge production and governance, with the researchers following 'leads' and 'threads' of ideas and issues as raised by the research participants. This especially informed WP3, as participants directed the researchers to various events that were taking place. Importantly, as researchers we also introduced a variety of public representations to the participants, given that our research took us beyond local sites. We developed a specific work package to facilitate exchanges with interested parties and the so-called 'general public' at key intervals in the project. Using art and representations as the common thread, events were designed which both presented initial findings from the project and acted as a space for discussion about the issues that were being raised. The report on these events provides details of the interactions that ensued. Following the events, reflection and analysis informed some of the directions in which the research went next. For example, in Germany, the lack of participation at an open film and subsequent dialogue with a parent of a child affected by mitochondrial disease, led the research to a focus on the invisibility of mitochondrial disease and also the politics of attempting bilingual events. A subsequent event was organized which specifically addressed parents of children with neuromuscular

conditions. Organized much more as a conversation around the initial findings, this event led to a productive understanding of the links and disconnections between health and social services in Germany and the decision-making processes regarding enrolling children in new therapeutic or diagnostic studies. The responses here were used to fine-tune questions being asked in subsequent narrative interviews. Numerous presentations made to patient organizations often validated the representations of findings thus far. Questions that were posed were often integrated into the next phase of the research. Very often leaders of the patient organization made suggestions as to which events would be interesting to attend and extended invitations to those that they were organizing. The events held in the UK and Austria both had very good turn outs. The event in Austria provided input into both the focus of WP2 and WP3 in relation to epilepsy, offering many ideas about the contemporary frameworks of neuroimaging and notions of neurodiversity. In the UK, the event sparked discussions that were then integrated into the analysis of the data for WP3, specifically about the stigma that individuals with particular diseases face, and the role of self-representation as a means of self-advocacy and knowledge production.

Our findings highlight the complexities surrounding the role of contemporary 'patient organizations' in Europe and the influence of state-mandated involvement of patient representatives in health and science governance, the social and medical meanings of emerging technologies of diagnostic precision, and the multiplicity of representations of medical technologies, health conditions, and related social and ethical issues in the public sphere. With regard to the potential policy implications of our findings, we draw out key points for consideration in instigating and supporting multi-stakeholder dialogue that could promote an engaged participatory governance framework. One of the severe setbacks for smaller and/or newer patient groups, patient organizations that hold alternative or counter-normative perspectives on the etiology or management of a condition, and groups comprising members with various health concerns, is the lack of sustained resources, financial and health related, to participate in national and European networks, committees and policy development processes.

Summary description of project context and objectives

The HealthGovMatters project was a three-year (2009-2012) collaborative research project, which was co-funded by the European Commission as part of the Seventh Framework Programme, Science in Society' initiative. It was undertaken by a consortium of four institutions – Zeppelin University in Germany, the Interdisciplinary Centre for Research in the Social Sciences and the ICCR Foundation in Austria, and Goldsmiths' College in the United Kingdom. Over the course of three years, the researchers used rich social science and ethnographic methods, including textual analysis, interviews, and participant observation to explore the ways in which patients, family members, health professionals and researchers engage with the development, implementation and governance of predictive, diagnostic and therapeutic technologies and related medical knowledge.

Overall, the HealthGovMatters project explored patients' and professionals' formal and informal involvement in governing the production and mediation of health and medical knowledge. Our interest was in exploring interactions amongst constellations of actors (patients, care-givers, health professionals, citizens, patient and professional organisations) who become involved in mediating and articulating definitions and lived meanings of health, illness and disease in the context of encounters with new health technologies and medical knowledge. As a result of our initial fieldwork, we came to focus on four conditions – epilepsy, migraine and autism in the UK and Austria and mitochondrial disease in Germany. Epilepsy, migraine and autism are considered to be 'relatively' common disorders in terms of population distribution, whereas mitochondrial disease is classified as rare. All conditions are neurological, with a significant amount of research being conducted at the interface of neurology and genetics. Both epilepsy and mitochondrial disease have been characterised by interviewees as an "invisible disability", while at the same time scientific research (via genome sequencing and imaging technologies) strives to render aspects of the conditions more "visible". With regard to technologies, we focused on new imaging (predictive and diagnostic) technologies, such as forms of genetic testing, magnetic resonance imaging and EEG, computer implants, such as the vagus nerve stimulator, and new pharmaceuticals/devices, which are being developed and implemented in the fields of genetics and neurology - two key sites in which new technologies enabled by the synergism of developments in such core fields as nanotechnology, biotechnology, information technology and cognitive sciences are being integrated. Often referred to as "converging technologies", their integration in the area of medicine is viewed as holding the potential to vastly improve ICT capacity for medical data management and information generation and to provide the foundation for the translation of research knowledge into clinical trials and clinical practice. In the light of new developments, we were asking: How do patients and

professionals at the experiential and institutional levels represent new diagnostic, predictive or therapeutic possibilities and make decisions regarding their development and use? Who is producing representations of these technologies and conditions and how and where do such representations circulate?

The main overall objectives of the project were:

1. To examine the involvement of patient and professional organisations in the governance of health and medical knowledge production.
2. To explore patients' and professionals' experiences of obtaining information about and assessing the credibility of new technologies (including potential risks, benefits and expectations) and deciding whether or not to participate in new therapeutic experiments or the use of diagnostic and predictive technologies; and
3. To analyse emerging representations, communication and dialogue initiatives put forward and/ or undertaken by health and political institutions, civil society organisations, Artists, museum curators and journalists with respect to the implementation and governance of 'converging technologies' in medicine.

The HealthGovMatters project was organised into seven different work packages with specific objectives designed to feed into the aim of meeting the three main objectives. There were: 3 core research work packages (1-3); 2 'events/involvement' work packages (4-5); a dedicated analysis, synthesis and dissemination work package (6); and a project management work package (7). Each of these work packages commenced at staggered dates during the first reporting period. Each work package comprised particular activities (tasks), such as updating literature reviews, developing interview guidelines, conducting fieldwork, data analysis and the completion of a main report. The specific objectives of the individual work packages were as follows:

- WP1: To establish the role of lay, patient and health professional organisations in lobbying, with respect to the mobilization of resources, but also, as importantly, symbolic representation and publicity.

  WP2: To examine the experiences of patients and professionals with new "imaging" (predictive-diagnostic) technologies, computer implants, and new pharmaceuticals/devices. The objectives were to identify forms of and barriers to informal and formal practices of governing novel health and medical knowledge within health care encounters.
- WP3: To map and analyse the public representations and communication initiatives regarding the governance of converging technologies in medicine.

- WP4: To facilitate the exchange of experiences and networking amongst people engaged in health research and policy/governance studies or advocacy regarding converging technologies or emerging technologies identified as comprising elements of convergence.
- WP5: To encourage and facilitate conversations about medical technologies governance amongst people who may not be directly involved in decision-making regarding their implementation or use in specific contexts.
- WP6: To facilitate extensive integrated analysis and promote the on-going and timely dissemination of research findings and practice and policy recommendations.

As a starting point for our research, we distinguished between professional and patient organisations. Professional organisations were defined to include medical associations and associations bringing together representatives of the medical professions and/or the pharmaceutical industry working directly or indirectly with research labs, centres and organisations in the field. Patient organisations were defined as including organisations that were established to represent patient interests, including self-help groups.

The project addressed the plurality of governance of medical knowledge, by which we mean the different forms of knowledge production, reproduction and use within the spectrum of, on the one hand, face-to-face relationships and communication between patients and medical staff (e.g. doctors and nursing staff) and, on the other hand, the explicit interventions of patient and professional organisations through lectures, information material and position papers on new medical knowledge and the application of new technologies.

The HealthGovMatters researchers followed a multi-sited approach to ethnographic research (Marcus 1995; Franklin 1995), which supports the continuous development of the research project in conversation with the analysis of emerging data. We also engaged in what is referred to as ´constant comparative` analysis. Thus, while the fact that we conducted the research in three different countries presents one obvious unit of comparison – the country unit can be seen as a proxy for different health care management and social insurance systems, as well as different modes of funding and research oversight — it is one axis of comparison among many others. We were also extremely interested in exploring the commonalities and differences between the experiences of people of different genders and ages, but also knowledge about and perspectives on technologies or therapies related to prediction, diagnosis and on-going care.

Overall, we conducted over 142 semi-structured and/or in-depth narrative interviews and carried out participant observation in labs, patient organization meetings, scientific steering

committee meetings, informal gatherings of scientists, clinicians and patients, video EEG monitoring units, rehabilitation trade fairs, conferences, theatre pieces, performance projects and awareness-raising events. In the following pages, we will highlight some of the work that we undertook in the three core research streams and our findings.

Description of the main S&T results/foregrounds

The research for the HealthGovMatters project was organized in three core streams. As described above, as a starting point for our research, we distinguished between professional and patient organisations. Professional organisations were defined to include medical associations and associations bringing together representatives of the medical professions and/or the pharmaceutical industry working directly or indirectly with research labs, centres and organisations in the field. Patient organisations were defined as including organisations that were established to represent patient interests, including self-help groups. Over the course of our research, the terminology of patient organization or professional organization proved to be in many ways problematic, especially given the professionalization of patient organisations over the past couple of decades. On the other hand, this language was also useful in terms of thinking through and addressing the transformations to the goals of an organisation and their primary purposes. The visibility of those organisations naming themselves as 'patient organisations' is also important to note in relation to formal processes for identifying suitable 'patient representatives' for inclusion in decision-making processes at various levels and with regard to patient recruitment campaigns by pharmaceutical or medical device industry representatives.

In the following pages, the main findings from the three core research streams of the project are described, followed by a discussion of the policy implications emerging from the findings as a whole.

Stream 1: Patient and Professional Organisations

This stream of research focused on the involvement of lay, patient and professional organisations in discussions concerning the governance and implementation of medical technologies and the production, mediation and circulation of medical knowledge. We were attempting to explore questions such as: How do various organisations produce and mediate knowledge about a condition, as well as about new technologies and research or therapy directions. Which organizations are part of contemporary health and science governance? The design of this first research stream was intended to provide input into the further

development of our research project and, especially, to establishing contacts and identifying the areas of research that would become the focus of further intensive work. Over the course of the initial months of research, specific speciality areas with regard to clinical care and research and specific conditions were identified by the three research groups. In the UK and Austria, the research came to focus on epilepsy, migraine and autism, which are considered to be common neurological conditions, the genetic basis to which is varied and contested. In Germany, the research came to focus on mitochondrial diseases, a set of rare neuromuscular diseases, which are understood to primarily relate to underlying genetic differences. There are considerable discussions about ´co-morbidity` amongst epilepsy, migraine and autism and all three are understood to be possible symptomatic manifestations of mitochondrial disease. The research that we undertook thus allowed for comparison with respect to the associations that are made between epilepsy, migraine, autism and mitochondrial disease and the distinctions that were maintained in terms of the organisations associated with these conditions, people's experiential narratives and knowledge, and the ways in which the conditions and related medical technologies are represented (or not).

One of the key outcomes of our research was the formation of an understanding of the degree of complexity surrounding the notions of 'patient organizations' and 'professional organizations' with which we had started our project. In many ways, we had begun the project by using terminology that is common within European health and science policy and reflects the growing discourse on the inclusion of 'patient organizations' within stakeholder circles. Our ethnographic approach enabled us to be aware of and to pursue 'on the ground' means by which organizations are constituted, dissolve, professionalized, co-opted and so forth. Our initial language was challenged by new modes and structures of health and science governance that are emerging and by the existence of organisations ranging from informal ´support groups` to powerful national and international networks of representation as well as service provision.

We found that the initial categories of patient and professional organisations need to be reframed in the context of a general shift toward professionalisation and an increase in the knowledge base of these organisations. What we found were compositions of organizations that would more greatly favour the concept of a continuum and reflect notions of hybridity (lay/expert, patient/professional, etc.) First, the overlap of both categories is linked to the historical development of patient involvement and organisations. Small self-help groups became larger, created networks and resulted in the establishment of professional organisations. In this sense, former patient organisations changed gradually in terms of internal organisation and external communication, most notably with regard to

participation in decision-making processes and research directions. The characterisation of a particular organisation as professional undermines the historical roots of bottom-up processes in the field of patient involvement. Secondly, the notion of self-presentation and perception changed and changes. Patient organisations present themselves as ´professional` and express their will to be addressed on a similar level to the organisations that are already recognised as professional organisations. This shift correlates with the fact that the objective of these organisations includes the dissemination and provision of knowledge that is viewed as valid knowledge. Patient organisations tend to establish scientific advisory committees that strengthen their credibility as a ´professional patient organisation`. Thirdly, the increased involvement of patient organisations in decision-making processes and a focus on the representation of patients' interests in the political sphere justifies the notion of hybrid organisations. Important to this is that these organisations view themselves as patient organisations that ´professionally` represent patients within the health care system. The professional character here relates to the emphasis on being an actor and stakeholder who needs to be considered in the policy-making process.

These tendencies support the concept of a continuum that builds the framework for all sorts of patient involvement in the health system and the governance of medical knowledge. What was interesting as we came to these conclusions through comparative analysis amongst our three sites were the questions that were raised about the potential involvement of new self-help groups, informal networks of patients, clinicians or researchers, or individual patients themselves in discussions and debates about health care, medical research and science. In the face of overwhelming practices of professionalization, and with professional conduct in many ways becoming the base requirement for inclusion as a patient representative on various committees, what role does the non-networked, non-informed, non-expert lay individual have in health and science governance?

Stream 2: Patients' and Professionals' Individual and Familial Experiences

The focus of this stream of our research was on the individual narratives of patients, their families and health professionals. We set out to explore the experiences of people who are encountering medical technologies and/or being asked to participate in medical research, and who are making various decisions in direct relationship to their own care, their practice as a professional (mostly as clinicians or researchers, or often clinician-researchers), or their role as someone directly involved (e.g. as a parent, child, or friend) in the care of someone else. Given the complexities of distinctions between patient and professional organizations

described above, it is not surprising that the concept of 'patient' is also complex. We would suggest that the term "patient" in this project can be better understood in terms of one who is affected by a condition (in potentially multiple ways), one who encounters a technology/therapy, or one who moves in and out of what might be conceptualised as "patienthood". Retaining the term 'patient' in our writing and presentations (at the same time as pointing to the diversity of its meaning) in many ways reflects the ways in which individuals we met were mobilizing and lobbying for resources in line with their identities as 'patients' – people who require access to appropriate health services and who are invested in medical research and the development of new diagnostic and therapeutic technologies.

Our research led us to look closely at the use of well-established and emerging, technologies through the narratives of affected individuals, clinicians and researchers, raising questions about the definitiveness of a diagnosis, the social implications of being diagnosed and/or undiagnosed, and the use of diagnostic technologies and predictive technologies, related to the implementation of potential interventions (resective surgery, the implantation of a heart pace-maker, consideration of deep brain stimulation, etc.). We also looked at the implications of so-called "mundane" technologies or "non-technological technologies" (diet, nutritional supplements, sport, regulated activities), which may be part of daily routines of self-care. Some guiding questions for the research included: How might technologies shape understandings of the conditions we were studying, as well as people's sense of identity? How much authority is given to medical technologies and by whom? Do patients, family members, clinicians and researchers invest authority differently in particular types of technologies? How do medical, but also internet and communication, technologies influence relationships between sufferers and clinicians and researchers, and also between specialists of different disciplines or health care domains?

The details of the approaches and findings of the research undertaken are discussed in detail in each chapter of our main report. Here, we offer brief abstracts of the content to provide a sense of the work undertaken. In the work based on research in **Austria, Alice Vadrot** reports on the results of an ethnographic study that she conducted at an Epilepsy Monitoring Unit in Vienna. Her contribution aims to show how medical science and converging technologies are produced and applied in the field of epilepsy, and how they impact clinical realities and understandings of the condition. In a description of her contribution, Vadrot writes: "Neuroscience is increasingly dealing with the question of 'what happens when brain function goes wrong", instead of asking 'how does the brain work'. In this respect, patients with neurological diseases are increasingly seen as important and valuable sources of information ranging from genetic research to radiology and information and communication technologies (ICT). This shift, together with other general

developments in healthcare has implications for clinical realities as well as for the production of medical knowledge and the understanding of neurological diseases and mental-health. Together with the increased privatization and commercialization of healthcare and research this leads to a new identity of the patient as the amalgam of a client and a data-store."

Further, Vadrot focuses on the social constructions of epilepsy and the impact of new technologies on the identities of patients, doctors and scientists. She describes the production of knowledge at the crossroad of diagnosis and therapy and discusses the impact of new technological developments. One important result of her study is the observation that an increase in new technologies is often seen to be fundamental for overcoming the subjectivity of medical doctors in diagnosis and treatment. Vadrot concludes that the impact of converging technologies on clinical realities underlies a certain paradox writing: "On the one hand, new technologies especially at the crossroad of biotechnology, ICT, and biomedical engineering lead to an expulsion of the medical doctor as diagnostician. On the other hand […], this leads to a faster availability of a larger amount of data resulting in an acceleration of clinic realities and excessive demands on the side of medical doctors, who in turn need to interpret the data and to deduce individual therapeutic measures. Potentially this leads to more differentiated diagnoses, but, in fact, the convergence of technologies tends to have an impact on the self-identify of medical doctors who feel increasingly dependent on technicians and laboratory staff to help them in the interpretation of data, insofar as individual training programmes were not followed."

In the **UK, Julie Hartley** conducted a focused set of narrative interviews with patients and researchers around the governance of medical knowledge of autism, epilepsy and migraine – three common neurological conditions. As Hartley states: "These conditions represent some of the most cutting-edge research, though despite this, very little is understood about these conditions". Her contribution examines patients' narratives of their experiences of their conditions as well as the decision to undertake treatments in the face of uncertainty and lack of medical clarity of the exact nature of the condition. Hartley's chapter draws out the uncertainty of knowledge of the conditions and traces patients' rationales for deciding which treatments to pursue. Do they take their doctor's advice? Or do they take the advice of fellow sufferers? In this way, Hartley examines how and to whom people bestow authoritative knowledge about their condition. Further, she looks at the conditions in a comparative perspective to consider what role the presence of medically approved diagnostic and treatment technologies plays in people's decisions to take their diagnosis and treatment into their own hands.

In **Germany, Jacquelyne Luce** conducted narrative interviews with individuals who have

been diagnosed with mitochondrial disease and affected family members and conducted extensive participant-observation at patient organization meetings, weekends for families affected by neuromuscular illnesses, scientific symposiums, and clinical care workshops. Her focus is on the emergence of the 'mito patient' in parallel with the recent funding of rare disease research networks and the implementation of advanced diagnostic technologies, primarily in the research – but not yet clinical – contexts. Her contribution to the report explores the diagnostic pathway narratives of four individuals and examines the social meanings of achieving a diagnosis of mitochondrial disease. Narratives about living in an "undiagnosed" state for significant periods of time, very often followed by the achievement of a fairly 'imprecise' diagnosis, appeared strongly in the interviews. The chapter then interweaves such diagnostic stories into a discussion of some of the very specific technologies that 'mito patients' are encountering in Germany, primarily through their participation in research projects. In this chapter, too, emphasis is placed on concepts of self-understanding and relationships to health providers, researchers and technologies. Within this case study, however, the existence of the 'mito patient' as an identity is extremely new, with the first 'public gatherings' taking place in 2006. There is currently no form of medical treatment that is available for mitochondrial disease and there are very few clinical trials that are already taking place. Thus, the work of the patient organizations and individual patients tends to be quite focused on basic information dissemination, supporting the development of medical research, and learning about the experiences of others who are affected. As a core group of people who have participated in these foundational stages of patient knowledge production in Germany begins to develop, it will be important to explore the ways in which ideas about what constitutes a 'mito patient', the potential further or unintended implications of whole genome sequencing or cardiac MRI, and what research should be prioritized, are articulated and given room to be articulated.

One of the HealthGovMatters main foci in this stream came to be the ways in which specific conditions are talked about and how they emerge as 'something real', distinct from other conditions. We also looked at the ways in which scientific, medical and lay understandings of the conditions have changed over time. The technologies that were most prevalent in our fieldwork were those related to achieving or refining a diagnosis. It was especially interesting to note how undergoing a diagnostic assessment was a process that might occur multiple times during an individual's lived experiences of a condition. Sometimes this was because a new 'treatment' possibility had emerged and one needed to be assessed as to whether one would be a good candidate to receive it. Other times, new technological possibilities had been developed and research participants were required to develop fine-tuned differentiated diagnostic parameters.

The notion of “visibility” also appeared strongly in people’s stories about their experiences with the conditions. Epilepsy, for example, is visible to others, yet many sufferers of epilepsy have never seen themselves in an epileptic state. Mitochondrial disease, in many forms, is considered to be very invisible to others and is for a very long time often rendered invisible to (and by) the affected person who might change their daily routines and ‘explain away’ their symptoms. It is thus extremely interesting that visualization and imaging technologies are of such importance to the diagnosis of both conditions. Technologies such as magnetic resonance imaging and video EEG monitoring, as well as next generation sequencing and genetic testing, which make the condition and bodily structures and substances “scientifically” visible, are integral to contemporary discussions about the development of improved diagnostic precision (and processes of making a condition real) and the implementation of medical interventions on the basis of being able to visualize and thus ‘predict’ clinical outcomes.

Stream 3: Public Forums of Information Exchange, Communication & Dissemination

In this stream of our work, we explored public representations of and communication initiatives about specific conditions, the broader fields of neurological and genetic knowledge, and converging technologies in medicine that occurred between September 2009 and December 2011. We paid attention to the work of health and political institutions; civil society organisations; artists (visual art, film, dance, theatre, etc.); exhibit curators (science museums, memorial museums, art exhibits, etc.); and journalists (mainstream, as well as alternative). We aimed to develop a better understanding of the diversity of ways in which health and medical knowledge is presented (the landscape of representations), and the manners with which complexity, especially in the face of increasing technological convergence, is translated in visual, audio and textual form to non-scientific audiences. Furthermore, we sought to understand who exactly is involved not only in the consumption, but also the production of representations destined for ‘the public’, who may be conceptualized as the ‘general public’ but in many ways are already distinct publics with particular investments in acquiring new knowledge in a particular field. Importantly, we sought to explore and understand the ‘behind the scenes’ processes and the multiple and intersecting factors that shaped the end form of such public representations and communication initiatives.

We found that self-representation and participatory art was used as a means to breakdown and challenge dominant medical and scientific discourses of expertise. Artistic

representations also reframed normative representations of disability, ‘patient’ status, and scientific and medical authority. It was possible for artistic representations of specific conditions to challenge dominant, often stigmatised, social and scientific representations. Art acted as a mode of dissemination that reached a wide audience and, at the same time, transformed the content of medicine and science. In some examples, there seemed to be a reduction of complex knowledge and messages in their dissemination to the lay public and it will be important to further investigate the consequences of this. While there may not be a straightforward relationship between art and science, art and artistic representations bring out the human and subjective realities of living one’s life in a constant relationship to (and in some cases dependence on) science.

In our assessment of trends in the print media and film, television and radio we found that discussions about both conditions and technologies are very tightly governed with regard to how and in what forms they emerge. We concluded that a general shift toward bio-medicalization and scientization has taken place, which is reflected in an increase in technical terms and a rather thin framework for discourses on neurological conditions. Another indicator is the observation that failures of technology are rarely mentioned, while failures of people to manage their conditions appear much more frequently. Representations of technologies in this sector are most often either abstracted from the reality of human interaction with them or are presented as being life changing.

In scientific seminars and meetings, as well as public talks which involved medical specialists, there was often a sense that the doctor’s role was to educate a public which was hungry for ‘real’ and objective information about the condition in question and the body. What we found interesting in many cases were the moments of dialogue and interaction that opened up between doctors or researchers and patients or caregivers during such seminars, symposia and public talks. These were often moments of disruption, which could easily go unnoticed, when the certainty of science, the claim to particular forms of credibility, and the subject positions of experts were open for negotiation.

The Internet, and especially YouTube, is a site where people have more freedom to self-produce and disseminate alternate perspectives regarding their condition. Not only is the Internet seen as providing a more egalitarian site in which information can be disseminated, it provides flexibility of content, coupled with the ability to disseminate information faster and to respond more quickly to emerging trends, thus circumventing the barriers in place within the mainstream media. Representations are also able to transgress geographical borders, facilitating access to Internet broadcasted media, virtual museums, and live-streamed or archived seminars and symposia by individuals who may be less able or unable to travel,

who may live in jurisdictions where such events are rare, or who may simply prefer to engage with the issues from home. The empowering dimension of the Internet, and especially You Tube, in the context of this research stream contrasted strongly with the sceptical assessment of its benefit and articulation of the possible harm it does that we more often encountered in our interactions with representatives of organizations and institutions.

The authority to represent and communicate health and medical knowledge has long been invested in 'professionals' like journalists, physicians, etc., where emphasis has been placed on so-called objectivity. Acts of self-representation and critical artistic forms of communication have the potential to shift this privilege, offering new ways of looking at a condition or a technology. Based on the work we have done, it seems that the activities which facilitated the greatest degree of reflection and/or critique were project based – often with time-limited funding from a government program or industry – or were self-funded (and by donation) and self-produced representations. In research centres and clinics, patients and their needs have been mobilized as the main justification and rationale for the advancement of certain technologies. In this sense, although technologies such as vagus nerve stimulation have been developed for certain conditions, these conditions are side-lined and/or are quite rigidly policed in public representations and debates regarding the usefulness and impact of the technologies. It is most often through the work of patients and family members, as well as patient organisations that the social implications of technologies in interaction with conditions are brought back into focus.

Axes of Difference: Gender and Generation

As increasing attempts are made to understand the relationship between science and society, and especially, the participation of citizens in the production and governance of medical knowledge and medical technologies, the differentiated experiences of people according to diverse life situations is important to pay attention to. In the design of this project, gender and generation were recognized as important axes of difference to be considered in the development of new health and medical technologies and the study of their use. Research has illustrated the ways in which technological developments in medicine have impacted differently on the bodies of women and men, shaping their experiences with technological innovation. For example, Margaret Lock and Patricia Kaufert in their edited volume *Pragmatic Women and Body Politics* offer key examples of the ways in which women have mediated knowledge generated by emerging technologies, locating new information within the contexts of their everyday life experiences. Marc Berg and Anne Marie Mol provide another set of case studies in their volume *Differences in Medicine*, illustrating the manners in which technologies (and not just their use) are shaped by histories, cultural contexts and lived experiences. Linda

Layne, Rayna Rapp, and Mette Nordahl Svendsen provide examples of the ways in which people engage in making sense of the medical information of others and the emergence of new collectivities and conceptions of relatedness on the basis of medical diagnoses. Women and men may engage with health care systems differently and often also, perhaps, in relation to their trans- and intergenerational roles of caring for others (as parents, sons, partners, daughters, friends).

In both fieldwork and analysis specific attention was paid to the visibility of women and men and adults and children within representations of emerging and converging technologies. We were interested in how individual gendered subjectivities and roles in relation to decision-making on behalf of others may influence involvement in patient organisations, professional organisations, and governance initiatives. Additionally, while much attention has been placed on decision-making and experiences of adults, less visible, perhaps, are the emerging cases of clinical trials and diagnostic or predictive testing situations in which children are the subjects. How might children's involvement with medical research and technologies be influenced by familial health and medical knowledge, and the introduction of new genetic testing and screening practices? Attention to differential involvements with technologies is crucial to a nuanced understanding of their use and implementation within a spectrum of health technology governance practices.

Methodology

Gender (and also sex)[1] and generation were taken into account throughout the HealthGovMatters project in key ways:

Choice of conditions: The conditions on which we focused are represented in medical and popular discourse and public spaces in gendered ways. Migraine is often conceived of as a "female" condition. Autism and epilepsy are often related and underpinned with male narratives and often male characteristics with both conditions being represented as being at the interface between genius and mad. In the media, they are often described as controllable brain diseases associated with the concept of "neurological diversity". This is not the case for migraine that is simply reduced to the dimensions of pain and life style. Mitochondrial disease, unknown as it might be, carries an image that is gendered woman due to the association with

[1] While the concepts of gender and sex are extremely complex, and very often used interchangeably or with a rigid distinction drawn –i.e. gender being the culturally-specific expression of biological sex – our account recognizes both as culturally produced. However, due to the manner in which the two were conflated in interviewees narratives and are conflated within much public discourse, we reserve a theoretical analysis of the distinction between the two for another paper. Herein, thus, we use the terminology used by those participating in our research.

mitochondrial DNA and maternal inheritance patterns. In many ways, women's bodies and life practices are at the forefront of much cutting-edge, publicly visible research due to efforts being made with regard to chromosome transfer techniques and prenatal testing. However, women and men, girls and boys can be affected and this may be due to mutations in the mitochondrial or nuclear DNA. Each of the conditions is part of contemporary debates about the genetic basis of disease and the politics of genetic knowledge. As well, there are somewhat broad distinctions with regard to patient support work that is undertaken by parents of affected children and affected adults themselves.

Involvement with Interviewees: Attention was paid to the gender of interviewees and ways in which gender may appear as important within their narrative. The gender of the interviewee was noted with regard to professional and patient organization heads that were interviewed. However, this was particularly relevant in the second stream of our research (work package 2) which focused on individual (patients and professionals) and familial narratives about encounters with medical technologies and knowledge production. The processes of identifying interviewees differed in each country, related to the specific methodological approach employed as well as, it turned out, the size of the field pertaining to our research. In Austria, for example, the researchers strove to achieve a gender balance with regard to interviewees when selecting heads of patient organizations, professionals and medical doctors to interview. With regard to professionals and medical doctors, this was difficult to achieve, but represents an interesting finding on its own. Most heads of self-help-groups and bottom-up initiatives are female. In contrast, most medical doctors and heads of organizations and associations in Austria who specialize in the fields of neurology relevant to the project are male. In the UK, potential interviewees were invited by notices posted and distributed through patient organizations and thus the interviewees were self-selected. In Germany, potential interviewees were met via patient organizations, patient information days and scientific conferences. Overall, there was somewhat of a 'gender balance' with regard to the individuals who were present, but somewhat of a gender difference with regard to the labour that was performed. A number of the early formal interviews with professionals were equally distributed amongst women and men, but the initial patient interviews were predominantly with men. It was thus a more concerted effort to ensure that interviews with women took place.

We paid attention to both gender and generation with regard to the three streams of our research, which are also levels of experience in the development of medical technologies in the diagnosis and treatment of neurological conditions. *Firstly*, the institutional and organizational level of participation and involvement, *secondly*, the individual level of experience, and, *thirdly* the discursive level, referring to the appearance of gender as category in the representation of neurological conditions and the respective health and medical

technologies. In the following pages, we will explore the ways in which gender was a meaningful category in relation to our research, using examples from our fieldwork-based research and referring to individual narratives and epistemologies, as the social scientific and ethnographic approach of the HealthGovMatters project suggests.

Findings

It is important to note that throughout the project we were interested in the governance of medical knowledge production and medical technologies. Firstly, we explored the ways in which patient and professional organizations implemented formal governance measures and participated in informal practices of governing the circulation of medical knowledge. Secondly, we examined the narratives of professionals, patients and family members with regard to medical knowledge about the condition in focus and their encounters with medical technologies involved in the production of this knowledge. Thirdly, we addressed the processes of producing contemporary public representations of both medical technologies and the conditions in focus in our research.

Gender

Gender is one of many axes shaping the ways in which converging technologies and medical research are governed and represented in the diagnosis and treatment of neurological conditions at different levels. The analysis of the interview material and the narratives reveal gender specific aspects with regard to participation in governing measures, the perceptions of a condition and experiences with related diagnostic and therapeutic technologies. However, numerous other variables, such as education, cultural background, class, linguistic capacities and generation are also extremely important. In our discussion, we focus on gender and generation as they were two dimensions that we initially sought to explore. Our project was strongly ethnographic, heavily focusing on the narratives of experience. The ways in which people experience and engage in these processes of governing both medical knowledge and medical technologies is individual, difficult to objectify and best assessed by pointing to subjective narratives and epistemologies. In the following pages, we will highlight some of the ways in which gender and generation became apparent through the stories of individuals we interviewed.

Austria

With regard to personal involvement and participation in both medical research and governing initiatives, such as in the form of self-help-groups and patient organizations, in Austria there

were no gender specificities found regarding the willingness to engage in medical studies. Both, male and female interviewees look at the involvement in such studies equally: some were in favour, some were against the involvement. Gender does not seem to make a difference in this respect. What matters is rather related to the different diseases and the severity of the condition: people with epilepsy or migraine who are suffering a lot and are desperate to receive an appropriate diagnosis and treatment show high willingness to participate in any study that could help to "control" the pain or the seizures.

When it comes to the participation and involvement of male and female patients in self-help groups, patients' organizations and professional organizations dealing with neurological conditions one finds significant gender differences.. The contact persons listed in the index of registered self-help groups in Austria published every year are mostly women. The registered groups for epilepsy, migraine and autism as to the dates of 2013 feature even only female contact persons.[2] We interviewed approximately 80% of the registered groups and identified even some non-registered groups for epilepsy, migraine and autism in Austria in 2011 and only 2 out of 12 interviewees were male.

Hence, gender determines the forms of involvement as the following example shows: The network of official self-help-groups for migraine in Austria is composed of four regional groups. Three of these are led by women, one by a man. He reports that the group meetings that take place once a month are attended by 70 persons, of which 65 are female. However, at least half of these do not have migraine themselves, but came for their husbands who "have no time to come to the meeting":

In most cases, and this is what we found out, men send their wives to the events and these then say "actually, I don`t have headache, but my husband, but this is a big step forward.[3]

From the interviewees perspective this has two reasons. On the one hand the female participants want to better understand the condition of their husband and get information on how to help him; on the other hand often men with migraine avoid both to join self-help groups and to openly declare that they suffer under migraine.[4] Relatives and friends of patients with

[2] http://www.wig.or.at/fileadmin/user_upload/DOWNLOAD/Download-Bereich/SHG-Verzeichnis_2013_web.pdf

[3] Meistens, und da sind wir drauf gekommen, schicken die Männer die Frauen zu den Veranstaltungen und die sagen dann "eigentlich habe ich eh nicht Kopfweh, aber mein Mann". Aber das ist schon ein großer Schritt.

[4] *‚Also bei einer Veranstaltung von Migräne werden sie haben, von 70 Leuten, 65 Frauen. Und so viele können sie gar nicht haben, die Migräne. Und manche sagen es und manche sagen "ich komme, weil mein Mann keine Zeit hat" und das sind die üblichen Ausreden, aber im Grunde genommen erkundigen sie sich, was auch überhaupt nicht schlecht ist. Weil damit haben sie schon einmal den Weg, dass sie sich damit beschäftigen und das ist ganz wichtig und sagen auch die Ärzte, die uns unterstützen.'*

migraine, however, are suffering under this situation and wish to share their experiences with others.

Of course, there are conventional reasons for the female dominance in participation and involvement in patients' organizations and self-help groups: the cultural reproduction of the traditional role of women as pillar of non-remunerated work in the health care sector. However, when it comes to the constitution of more professionalized patients' organizations the participation of women and men is rather balanced and the knowledge dissemination to the groups is male dominated: most experts invited to join group meetings are male.

This shows clearly the gender gap in the modes of participation and involvement in the governance structure of the regulation of emerging and converging health and medical technologies; women's involvement is more visible in bottom-up initiatives and at the community level and male involvement is rare because of the stigmatization of the specific neurological conditions for migraine and epilepsy. At the professional level where the involvement is independent from the individual experience with the condition male involvement is more likely.

With respect to personal experience with and perception of emerging technologies, their application and potential impact gender issues are relevant as well: It starts from the different roles of the care-givers: nurses are mostly female and most medical doctors and researchers in leading positions are male. However, there are exceptions: For instance, the epilepsy monitoring unit at the pediatric university hospital (*Universitätsklinik für Kinder- und Jugendheilkunde, Pädiatrisches Epilepsiezentrum Wien*) is led by a female doctor and most of the staff are female doctors as well.

This, of course, impacts on the quite intimate relationship between patients and doctors. A good example is the following statement of a female migraine patient:

"*When a medical doctor is not against us [self-help-group], then this is a good beginning. We found medical doctors that became good partners. With my medical doctor it was at the beginning also different. I am sure that at the beginning he did not take me serious especially because I am a woman. You know, women are all hysteric and we know this, and this is a problem."*

She points out that it is very difficult to find a doctor with whom it is possible to establish a trustful relationship. The reasons is the lack of understanding and empathy of most male

doctors regarding the special conditions of women. Other female interviewees hold that regarding their pains they are not taken as seriously as men suffering from the same pain.
Some interviewees mention that only recently research has discovered gender specific conditions and hence gender specific treatment and medication. According to this view, not only the treatment of women and men tends to be gender blind, but the understanding and recognition of pains varies according to the gender of the "sufferer".

"*If my husband would have had such pain at that time, he would have been brought directly to the hospital and although I had a broken catheter and serious problem with my heart.. But nobody realized this. Only, when they did they removed it. My husband once had a panic attack, and then the emergency was there immediately and reanimated him*."[5]

Moreover, she points out that it is not just a matter of understanding, but also a matter of feeling and developing empathy between genders:

"It is a discriminating question (from doctors to women): 'How do WE feel?'[6]… Man and Woman, come on, if men among themselves ask this question, it is ok, or if women ask themselves this question, then I would say it is ok as well. But if a man asks me this, I sink down. You just get this inner "hhhmmmm".[7]

The gender differences are not just experienced by women, but by male patients as well, *albeit* in a different way. When it comes to treatment of pain and neurological conditions in general, male patients complain about the social and cultural pressure to downplay the symptoms of specific neurological diseases like migraine. The stigmatization of migraine as female disease contributes to an even worse stigma of man with migraine:

"*You will hardly hear from a man 'I have migraine of headache'. He will be given the hairy eyeball by society, because this is something only women have and because this specific condition is often viewed as lame excuse for under-performing"*.

[5] Ja. wenn mein Mann damals die Beschwerden gehabt hätte, der wäre sofort ins Krankenhauseingeliefert worden. und dabei habe ich aber einen abgerissenen Katheter gehabt, dass das Herz gewandert ist 8 cm[...] #01:00:17-1# . Und da ist man nicht draufgekommen. Erst wie man das entfernt hat. Mein Mann hat einmal Angstzustände gehabt, da war die Rettung gleich da und hat ihn wiederbelebt.

[6] This is a specific Austrian tradition: Doctors (and lawyers) say often 'we' in a patronising way, meaning only the patient/client.

[7] Das ist unglaublich. "wie geht es uns?". Und überhaupt noch die Frage einer Frau gegenüber. Mann und Frau, also bitte, wenn sich Männer untereinander Fragen, ok, oder wenn wir uns Frauen, würde ich sagen ist es auch ok. Aber wenn mich ein Mann dieses frägt, dann sacke ich mal ab. Da kriegst du immer noch dieses Innere "Hhm" (Schnaubelt)

He points out that this is a problem for the family life: young children do not understand when their fathers are just lying in the bad having pain. But whilst there are education book for kids explaining why their mother have migraine (such as “one day without my mom”) there are no such books for man.[8]

UK

In the UK, within the research among people with epilepsy, a condition which manifests equally among men and women, it was found that there were fewer instances in which gender arose as a significant dimension of diagnosis and experience. Epilepsy was a condition in which the social aspects of the condition, rather than the medical aspects of the condition were impacted by gender. Gender had very little impact on patient’s access to treatments and treatment technologies. Migraine, on the other hand, which affects women much more often than men, emerged as a condition in which people expressed their experiences through gendered terms. For instance, people with migraine felt that their pain was not taken seriously. Women migraineurs were defensive about the intensity and severity of their condition. Some felt that not only did their doctors not take their pain seriously; they did not feel that their families accepted the seriousness of their pain either. For instance, one woman said:

‘It’s not taken seriously. Any other type of condition that left you incapacitated several times each week or each month would be considered significant, serious. But not migraine, because it’s just a headache isn’t it?’

Having their pain taken seriously was not just about getting recognition of the suffering, but rather, related to how doctors prescribed medication for their pain. One woman from a migraine self-help group noted that *‘the only doctors which have ever been sympathetic are the ones that have migraines. The other ones are like, ‘these are too expensive. We can’t give you these pills. Or telling you ‘you shouldn’t be taking this or you shouldn’t be taking that.’* Getting adequate treatment thus required these women to negotiate gendered ideas about the body and about pain.

Despite feeling that they were not taken seriously by medical doctors, it was important for migraineurs to receive an official diagnosis as this was the only route to effective treatment.

[8] Sie werden kaum von einem Mann hören "ich habe Kopfweh oder gar Migräne". Erstens einmal wird er in der Gesellschaft schlecht angeschaut, weil das haben doch nur Frauen, weil das ist ja diese besagt Krankheit. Wir erleben es immer mehr, dass dann welche kommen "ja mein Mann hat Migräne und der nimmt eh schon die Pulver und der macht das eh richtig, aber ich kann nicht umgehen damit und auch nicht die Kinder. Ich kann mich erinnern, als meine Kinder klein waren. Es war ausgemacht, am Sonntag fahren wir in den Zoo und in der Früh steht der Papa auf und sagt, er hat Migräne und für die Kinder eine Tragödie. Die verstehen das nicht mit 4, 5 Jahren, dass der Papa. Noch spezieller ist es wenn es die Mama ist. Der Papa kann sich niederlegen, aber ein Tag- und es gibt auch ein Buch, das wir ausgeben gratis- "Ein Tag ohne Mama".

The treatments, however, were not always as straightforward. During the same self-help meeting mentioned above, a room full of women told stories about how they felt like 'drug addicts' because they not only took many medications to alleviate their symptoms, but because they would 'fiddle' with the quantities and frequency at which they took their medications. For instance, one woman stated, *'I feel guilty about it sometimes and I worry if I am a junky. I read about it in the paper that people get addicted to prescription pain killers. But what can you do? You have to live.'* While they all stated that taking their medication into their own hands was a necessity, they also noted that doing so made them feel like they were doing something wrong. In these instances, gender emerged as a critical dynamic which these women had to work through in order to deal with the social experiences of being a woman with migraine.

Germany

In Germany, the focus on mitochondrial disease, which is understood to be progressive and degenerative, elicited a number of ways in which the gendering of work and responsibilities of caring influenced the gendered engagements with patient organization work, medical knowledge and medical technology governance, and experiences with diagnostic processes. Throughout the research, the rarity of mitochondrial disease, as well as its 'invisibility' in many situations seemed to impact on the gendered experiences of individuals living with it. The symptomatic expression of mitochondrial disease most often includes weakness. Within binary structures of gender, in which strength is gendered masculine, the progression of the condition is often experienced by men as compromising their masculinity and their gendered roles as partners, husbands and parents. In Germany, the diagnostic narratives of a number of men noted the point at which they were retired – i.e., they were told that they could no longer go to work – as a very difficult time in their lives. In a context in which men are expected to provide for their families, but also in which work men's outside of the home is highly valued, being unable to do so compromised their sense of self. For some men who were not retired, it was a significant step to take to realize that they would have to request the possibility to work flexible or reduced hours. Interestingly in the narratives of women who worked at the time that their condition began to present severe physical obstacles, the women themselves reconstructed their manner of working in order to integrate an increasing level of disability into their lives. For example, one woman spoke about her recognition of the difficulty that she was having climbing stairs and her subsequent recognition that she had started to no longer take on clients who she knew had stairs to their offices. Amongst the individuals with whom I worked most closely, the ways in which mitochondrial disease impacted on their ability to perform work duties was very often cited as a strong turning point with regard to their involvement in the patient organization. This in some ways also presents itself as a difficulty

for the sustainability of an organization, given the progressive nature of the condition and related disabilities.

One of the very interesting findings, which is to be explored in future research, relates to the circulation of medical knowledge and the differences in diagnostic experience of women and men. Mitochondrial disease in children is increasingly easier to diagnose due to the improvement of testing technologies and awareness about the possibility of the disease. In adults, however, it most often manifests as a weakness in the body. One woman described her initial experiences as being like having a dry flu that came fairly regularly, rendering her almost paralysed. One of the men described the ways in which he noted how difficult it was for him to ride his bike to school. Another man talked about increasing mobility difficulties. It was not until quite late in the analysis that I realized that although achieving an actual diagnosis was elusive for both women and men, that men were often first diagnosed with a generic neurological condition, whereas women received diagnoses of psychological disorders, often depression. While the sample size is very small, it will be necessary to explore whether this remains the case as moves are made to develop more accessible blood tests reliant on biomarkers, rather than the more expensive and invasive muscle biopsies that have been the 'gold standard' for so long.

The diagnosis of children was also related to the advocacy of parents. The story of one mother of a child diagnosed early in life is telling of the ways in which both age and gender/mother impacted on the interaction with medical professionals and medical knowledge:

They kept telling me - I was young, I was 20 at the time - and they kept insisting he was fine and I had to relax and, you know, mom's having a nervous breakdown or something. He had started walking quite early and then started falling a lot. They did admit him for just over a week, but then sent him home saying it was just a post-viral reaction and that he would be back to himself in three months' time.

In three months, the child wasn't back to himself and she had a follow-up appointment with the neurologist, who still insisted that it was a response to a virus. This interviewee states:

I told her point-blank that something was wrong. So she agreed to do an MRI and some blood work. She said [...], I can't remember exactly how she put it, but she basically told me that she doesn't see parents that say, something is wrong with their kid. She says most parents will come in and go: Is something wrong? Or, what's wrong? She said, when someone comes in and says, something is wrong, she... pays

attention. She still didn't think anything was wrong. She thought he was just taking a bit longer to recover, but they did the blood work and the MRI and it all came back very suggestive of mitochondrial disease. He had his biopsy a few months later and, it was exactly one year [...] from when he got sick that we got the diagnosis. And it was, I mean, he was as clear-cut as they get apparently. His blood work was exactly like they'd expected, the MRI was "bang-on" and the biopsy was very, very clear.

Here competing ideas about the gender of the carer in relation to her knowledge about her son's health are illustrated. First, she is the over-concerned non-knowledgeable and young mother. Then, she is the authority on her son's potential state of ill health. This young mother became one of the founding members of a new patient organization dedicated to sharing knowledge and building patient-professional relationships.

In the next section, we will address the ways in which generation – as an uncommon axis of difference to pay attention to – was relevant for our interviewees and their engagement in the health and scientific fields.

Generation

Generation has two key connotations in our research. First, we were interested in incorporating an historical perspective into our research in order to understand the experiences of patients and professionals with the governance of medical knowledge and technologies over time. Individuals who are active in research and who are leaders of patient organizations have often accrued experiences that can be linked to different paradigmatic understandings of conditions. While many are having experiences with technologies in use now, their narratives may articulate their perspectives of new technologies in relation to what was in use before. This then offers an understanding not only of novelty, but also of how incremental changes are perceived and whether these warrant special attention. Secondly, generation has to do with age, familial relationships and parenting. Given that there is increasingly a wish to include children in research and for technologies to be developed in child-specific ways, we wanted to pay attention to the stories that people might tell about their own diagnoses or experiences in relation to their children, the ways in which their children encountered and/or participated in medical knowledge production, and what role parenting and reproductive decision-making might play within these fields. In the following pages, we will highlight some of our findings.

Austria

With respect to generation our research in Austria was limited due to legal and ethical regulations. For conducting interviews with patients under 18 years in clinics a special

permission by the responsible ethical commission is required.
Prof. Dr. Martha Feucht, Head of department of the paediatric hospital for epilepsy in Vienna and responsible for the diagnosis and treatment of babies and young patients suffering from epileptic seizures has supported the request to get the permission to conduct an ethnographic study at the epilepsy Monitoring Unit of the paediatric hospital from the ethical commission of the General Hospital (AKH) in Vienna.
However, the ethical committee failed to issue the permission, hence we had to undertake our research through the non-participant observation at the second neurological department of the Rosenhuegel. But even there we did not get the permission to interview patients under 18 years. This in turn put a serious obstacle for looking at the impact of generational issues. The Austrian case study had to limit itself to gather indirect information collected from interviews with self-help groups and professional organizations. Interviews included information gathering from groups led by parents of children with autism or epilepsy. Furthermore, narratives of younger patients (20-35) and older patients (36 and 60) allowed for insights into some differences in the individual experiences and the representation of the neurological conditions.

With respect to generation, one finds two relevant issues:

Firstly, there seems to be a genetic dimension in the appearance of specific neurological diseases and, furthermore, these seem to appear at different stages of the life of those who suffer under the conditions. Hence the increasing importance of family research for better understanding the genetic causes of neurological conditions and the age specific appearance of certain neurological conditions. Whilst epilepsy and more specifically autism are classified as neurological conditions appearing in infancy, Alzheimer and Parkinson are conceived as conditions appearing rather in the older age.

According to a specialist in neuro-genetics doctors often identify the same gene-mutation in the DNA of family members of which some suffer from certain neurological, or - psychiatric and psychological conditions. However, this does not hold for all family members in the same way: some family members are not hit by the specific diseases (Professional D). A routine question during the the anamneses is whether there are cases of depression, or suicide in the family history (Professional E). “Families” are often conceived as valuable sources for the investigation of the brain and of genetic causes of neurological and psychiatric conditions. As a researcher points out: “You just need families and the blood, ‘the gold’, as we call it.” (Professional D, male 40). For the success of medical research the examination of whole families is required and as important as the technology. As for the latter, it depends from the

willingness of the hospitals' financial administration to invest in the newest equipment.[9]

Secondly, and against this background, some adult patients feel guilty when the condition appear in their children as they feel that they have caused the condition of their child. For instance, a male patient suffering from epilepsy got his first child that apparently is healthy. However, the second child is suffering from epilepsy since birth, for which he feels deeply responsible. He did refuse genetic testing and his wife accuses him often for this negligence. Even though the child has received immediate treatment she did not develop "normal" and according to the experts will be affected by cognitive impairments as his brain, hit by daily seizures, is retarded. (Patient, male, 34, C).

In this respect it should be noted that, according to a specialist, 20 to 40 years ago seizures were not and often could not be, treated immediately and accurately. This led to a high amount of mentally disabled persons. Today these could be treated easily, firstly because of better diagnosis and secondly because of new medication, medical devices and brain surgery. However, there are still a lot of cases were parents refuse to bring their child into the clinic as they don't want to realize that their child needs medical treatment. It is a question of shame and of guilt that costs a lot of time and challenges an early intervention.

The same is true for autism, where, according to the specialist the situation is even worse, This is due to the fact that autism in children is sometimes difficult to diagnose and family specific*:*

'With autism it is even worse. There are little therapeutic possibilities, well, you cannot cure it at all. When they are young you don`t notice and often one parent is also autistic, to a lesser degree, but enough to disturb and challenge communication between infant and parent […]. It is disastrous. There are certain development phases of the brain, where you can intervene, not only with medication, but with behavioural therapy and in such cases time is not beside the point. If someone reaches the age of 10 and the parents come and say 'we came to a decision, do something', I can only reply that a lot [of treatments] will not work anymore. We could save a lot of medication, which you primarily need to assuage the symptoms,

[9] *'What has changed for our understanding is that before, due to limited technological options, we always looked at individual variants that we had assumed to be related to a certain condition. Now I can conduct a systematic analysis without any previous knowledge. It's important for the findings, since it is possible to discover the genetic cause of a condition within a few weeks, where previously we would have needed years. And it is a fact that as soon as a technology becomes available, there is a real boost, not only in our establishment, but all over the world, these technologies are applied to all families and patients. Then you can – within a few years and sometimes within a few months – answer a lot of questions concerning the cause, the genetic cause of a condition and this through genome-sequencing. In a few days only, you can do a sequencing of some areas and one can say whether this or that gene is responsible. Actually it's not as you may think, because other factors also do play an important role. But these questions could simply not be answered until these technologies had been developed.' (Professional D).*

especially antidepressants. At our ward we often receive 16 or 17 year old patients experiencing manic depressive phases or psychotic episodes, that then really need medical treatment, because they are in the end weird and dangerous. I know some of them loafing in the country setting fire to barns and such things. And then, the families have no control anymore. With 19 he leaves home or he starts beating his mother. Often aggression is directed towards those persons that are close to them, but those get older and cannot defend themselves anymore. The proportions are inversed'. (Professional E)

This description reveals the scope of the problem in families where one or more family members suffer from one or more neurological condition that appear in childhood and were not treated appropriately and timely. This leads to the analysis of the social dimension in relation to the medical conditions, both the relationship between the individuals and the relation to the society. The interactions of the patient are often characterized by aggression and exclusion. The intra-familiar relations within families get often out of control. The analysis of this social and cultural dimension characterised by health related stigmata is dealt with in WP3. These stigmata are also part of the narratives and epistemologies as will be shown in the next section.

Another important aspect of generation dimension is the perception of and the experience with the condition itself: Stigmatisation plays often a role in the patient's age cohort. This is particularly true in the case of epilepsy, where the acceptance of the condition by patients and their relatives varies among the interviewees according to their age group: Young patients are normally supported by their relatives and state that they hardly ever experience social forms of exclusion, whilst older patients struggle much more with the impact of epilepsy on their overall lives. This can be shown by the case of a 50 year old patient. At the age of 14 she experienced her first seizure. When she was young people often thought of her to be 'crazy' or 'mad'. Furthermore, seizures were often interpreted as her being an 'alcoholic' or 'drug-addicted'. Compared to the reaction she experienced in her youth this has changed as '*today epilepsy is perceived differently; today you can talk about it*' (Patient H, female, 50). She relates the fact that epilepsy is not any more 'under a taboo' to the improvements in neuroscience and the potential of imaging technologies, genetics and neuro-engineering in managing and controlling the brain.

Hence, in the narratives and epistemologies of older patients, developments in neuroscience, genetics and imaging technologies have contributed to the decrease of stigmatisation: younger patients often outlined that they are suffering from a neurological condition, from something affecting their brain. Older patients rather focus on the symptoms and do not *per*

se identify the brain as being the “place” where epilepsy comes from.

Patients who were experiencing epilepsy in their youth and who are now in their 50ies or 60ies did often not receive an appropriate treatment and where thus much affected by their condition: at the time of occurrence the condition could not be controlled easily and especially when it occurred in infancy this led to severe cognitive impairments. For example, a patient argues that the diagnostic procedure even has worsened her condition: when she was 14 years old the now 50 year old patient was diagnosed with epilepsy. At that time she was diagnosed by a bone marrow examination and was narcotized for this purpose. In her narrative the bone marrow examination ‘made her being epileptic’, but this procedure was not precise enough to find the causes of her seizures. The changes in diagnostic procedures, e.g. EEGs and MRT helped to diagnose her condition, which in turn enhanced her understanding of the condition. However, the diagnosis did not lead to successful treatment, not even the implantation of the vagus-nerve-stimulator, to which she agreed after several modifications in her drug therapy: she still is not seizure free and expects from the VEM to finally get ‘better’ diagnosis and treatment (Patient H, female, 50)..

UK

Generation emerged as an important theme among interviews with migraineurs, especially regarding the way they came to learn about their condition. Migraine is believed to have a strong genetic component. Due to this, one of the first places people would have encountered migraine was within the home. Both men and women with migraine were able not only to identify/diagnose their symptoms by observing the experiences of people within their family, but they also learned skills as to how to manage their condition and techniques to treat it. More often than not, people told stories of how they watched their mother, or grandmother suffer with migraine attacks, and when they themselves started experiencing symptoms, they were able to identify what was happening. In cases where the migraineurs developed symptoms during childhood, it was with the help of their parents that they came to identify their symptoms as indicative of migraine. But while medical doctors were not as crucial in terms of diagnosing the condition as it was the earlier example, they were pivotal in terms of children’s access to treatments.

The impact of generation was also powerfully felt in relation to the understanding of the causes and treatment of autism. One mother expressed her fear that she might have caused her son’s autism because of something she did while pregnant. While another mother, who had two sons with autism, thought her sons’ autism might have something to do with the fact that she and her husband were first cousins. In contrast to epilepsy, parents of children with autism bore a fear that they were somehow responsibility for their child’s condition. Related to

this is the lack of a biomedical cause and hence ‘cure’ for autism. Parents of children with autism sometimes went to extreme lengths to find a biomedical treatment. The mother of two autistic sons who was mentioned above, sought out medically untested and unfounded treatments for autism such as chelation and vitamin B12 injections.

Generation emerged among epilepsy sufferers in unexpected ways. In interviews with patients with epilepsy who were 75 years and older, one could note a difference, not only in the terminology used to describe epilepsy but also in the stigma associated with the condition. In one example a woman, who was 79 at the time of the interview, noted that her mother attempted to ‘cure’ her of her epilepsy by taking her to a faith healer. This woman was in her late teens when she had her first epileptic episode, and as she was still living at home at the time, her mother came to be in charge of her medical care. When she was first taken to the medical doctor, she said that her mother, in a desperate attempt to mediate the shame of an epilepsy diagnosis, controlled her interaction with the doctor and with the public. This was an experience which made her feel like nothing more than ‘a pillow’ - an inanimate object which people could move about and use as they wanted. While this woman’s experiences are certainly not indicative of every older person’s experience of epilepsy, it does reflect the impact of generation on the experience of epilepsy.

In the previous example, and throughout the research in the UK, gender and generation were themes which were entangled, and interwoven into the everyday experiences of these conditions as well as the encounters with medical professionals and medical treatments and technologies. Autism has a strong generational component in the sense that it was most often a parent who made decisions for a child and decided if and how they should become involved in diagnostic and treatment decisions. Migraine, as noted above, has a strong gender and generational aspect which placed migraineurs in very interesting and unique positions *vis-à-vis*, doctors and medical authority.

Germany

Reproductive decision-making and parenting appeared as strong narratives within the interviews in Germany. Very often, amongst the individuals interviewed, reproductive decisions impacted on the family members rather than on the affected individuals themselves who were often already parents. While there is a significant amount of work done on prenatal testing, mitochondrial disease amongst those interviewed complicated the normative narrative of generational genetics which is more prevalent in the public view. An adult is tested for a genetic mutation prior to conceiving a child or the fetus is tested prior to being born. One of the families interviewed highlighted the intergenerational context of mitochondrial disease. In

this case, a woman with a five year old boy gave birth to a girl who was diagnosed with mitochondrial disease in the first few days of life. The mother tells of her worries at hearing that this was a genetic disease and what this new knowledge means for the young son at home.

In her early forties, the mother began to present symptoms of mitochondrial disease, suffering a stroke-like episode. It was her son, then 15, who attempted to explain to the emergency room doctors what was going on:

And who did the teaching when I had my stroke? What were you doing when…There were physicians standing around me and who was teaching them about the disease? It was you and you were 15. 15 years old and he's drawing pictures like the doctor did for him - on sheets in the Emergency Room - telling them, as I lost my ability to speak, about the disease.

In this case, neither the generational nor the gendered norms of caring are not upheld. The children in this case, who have the lived experiences and medical knowledge about mitochondrial disease, become the care-givers and advocates for their mother who is now a patient. Additionally, through a high school project, the son laid the foundations for a new patient support organization that aimed to provide support for families and, especially, mothers who were both affected by mito and were caring for children sufferers of mitochondrial disease.

Most of the interviewees were extremely clear that their participation in research would not result in a 'cure' within their lifetime. Their primary concern, across the board, was to contribute to research that might result in different diagnostic pathways for future generations. For many, the not knowing and the inability to name their difference and validate their disabilities or differences were extremely painful. If contributing their knowledge of the progression of the condition or their blood might help to make the diagnostic process smoother, their support is to be counted upon. There was only one woman who tied the question of biobanking back to reproductive decision making and the complications of genetic testing for future generations. This will be an area to follow up on as Germany implements preimplantation genetic testing for serious cases.

Relation to other relevant EU-funded projects- EPOKS and MEDUSE

HEALTHGOVMATTERS has a unique approach in that it explicitly proposes for its main part a different unit of observation than many other European projects. Most European projects use as unit of comparison the national level. Design and implementation of

HEALTHGOVMATTERS instead suggests finer points of comparison at the micro-level. This allows for a deeper analytical understanding of facilitators and barriers to the participation of patients, patients organizations and professional organizations likewise.

However, where appropriate we took other EU-funded projects into account by comparing activities at the national levels. This is particularly true for the report on '*Patient and Professional Organization Involvement in Governing Converging Technologies in Medicine*' (WP1). This report contains as a synthesis a comparison of the various forms of organizations involved in the governance and production of medical knowledge and medical technologies and highlights differences in the structures in the UK, Germany and Austria. With respect to this chapter of the HEALTHGOVMATTERS project one finds common interests with the EU-funded project EPOKS-*European Patient Organizations in Knowledge Society.*

During the lifespan of the project there was a constant information flow between the two projects; at the final conference of HEALTHGOVMATTERS in September 2010 researchers of both projects (and of some other projects) met in Brussels to present results and to discuss issues that were in common, but looking at differences of the research perspectives, objectives and aims as well.

Both the HEALTHGOVMATTERS and the EPOKS projects aimed at analyzing the forms and conditions for patients' involvement, but with different foci and methodologies. The entry point of the HEALTHGOVMATTERS project was the focus on technological development and converging technologies assuming that patients' organizations, individual experiences and public representations of these technologies are central to the understanding of various aspects in the development of health and medical knowledge.

The HEALTHGOVMATTERS analysis has put emphasis on only those neurological conditions that are difficult to diagnose and to treat and that as such pose a specific challenge for the development of new health and medical technologies, the representation of the conditions, and its communication. EPOKS has done, by contrast, a comparative analysis of case studies focusing on organizations: Rare and/or orphan diseases organizations, Childbirth organizations and coalitions and Alzheimer's disease organizations, ADHD organizations. The underlying logic for selecting the organization was based on the recommendation of the MEDUSE project differentiating between organizations according to "*the proximity of patient/user/civil society organizations and movements to biomedical knowledge and practices […] and the stability of the web of expertise and issues.*"[10]

[10] http://www.csi.ensmp.fr/WebCSI/EPOKSWebSite/index.php?page=project_choice_of_conditions

HEALTHGOVMATTERS starts from another understanding of how to assess and how to analyse patients' involvement in the fields of health and medical research. HEALTHGOVMATTERS has looked at the forms of patients' involvement on three different levels,

- the level of patients' and professional organisations,
- the level of patients' and professionals' experiences, and
- the level of public representation based on an ethnographic and qualitative approach.

By contrast, the EPOKS project aimed at a comparative analysis of "*the conditions of production and diffusion of lay knowledge, and at its statute [and] the role played by the European coalitions of patient and user organizations in the design of new modes of knowledge and know-how governance, allowing them to promote their involvement in the fields of medical and health research*".[11]

However, the results of the EPOKS project have been relevant WP 1 of the HEALTHGOVMATTERS project. This is particularly true for the analysis of the involvement of lay people, patients' organisations and professional organisations in discussions concerning the governance and implementation of new imaging technologies (predictive and diagnostic), computer implants and new pharmaceuticals and devices. EPOKS was dealing the "*different forms of action inspired by various sorts of activism (that) may co-exist and be articulated in multiple ways*". HEALTHGOVMATTERS was focusing on the ways in which various organisations lobby for or against the development of new technologies and research or therapy directions and came to the conclusion that a differentiated analysis of these ways is necessary as there are different types, forms and objectives of patient organisations and professional organisations. More specifically our results suggest that "*the initial categories of patient and professional organisations need to be reframed in the context of a general shift toward professionalisation and an increase in the knowledge base of these organisations. In this respect, of patient and professional organisations need to be reframed in the context of a general shift toward professionalisation and an increase in the knowledge base of these organisations. In this respect, the initial categories need to be rejected in favor of the concept*

[11] More specifically the objectives of the EPOKS project were

- *Characterizating patient, user, and civil society organizations' modes of involvement in the production of knowledge and expertise*
- *Making a Cross-national comparison between patient, user, and civil society organizations' modes of involvement in the production of knowledge*
- *Mapping and analysing the network of expertise and issues to which patient, user, and civil society organizations participate*
- *Describing the dynamics of the "Europeanization" of lay organizations, and its effects on the governance of knowledge and the place of knowledge in the governance of health and medicine*

of a continuum and against the background of hybridization."[12]

One important finding that HEALTHGOVMATTERS shares with EPOKS is the interest of patients' organizations in new scientific findings and research initiatives, their important function as diffuser of new knowledge and their active involvement in stimulating the debate on new technologies. The degree to which the different groups take varies significantly, especially in those areas where medical treatment is still contested, such as is the case of autism where behavioural therapy is important. Still, in this area one can identify a tendency towards a broad acceptance of new technologies, even though most of these, at least in the field of neurology, are still in the testing stage.

This is particularly true in the field of neurological conditions where stigmata remain to be an additional burden to sufferers and their families. The scientific and objectified representation of a condition and the reference to new developments of health and medical technologies provides an important source for communicating and "accepting" the conditions. We refer to this important finding as "*scientization*" which is visible in public representation of neurological conditions and the epistemologies and narratives of individual and family experiences. This is called in the EPOKS project "*evidence-based activism*".

EPOKS identifies three criteria of "evidence-based activism":

- patients' organizations contribute to the shaping of an expertise,
- social scientists play a crucial role as they engage in a reflexive collaboration with stakeholders and patients' organizations and thus contribute to their formalization, and
- "*evidence based activism amounts to collective investigation, including all concerned*

[12] "The empirical results show three major tendencies within the framework of patient/professional organisations First, the overlap of both categories is linked to the historical development of patient involvement and organisations. Small self-help groups became larger, created networks and resulted in the establishment of professional organisations. In this sense, former patient organisations changed gradually in terms of internal organisation and external communication, most notably with regard to participation in decision making processes. In this respect, the characterisation of an organisation as professional undermines the historical roots of bottom-up processes in the field of patient involvement. Secondly, the notion of self-presentation and perception changed and changes. Patient organisations present themselves as ´professional` and express their will to be addressed on a similar level to the organisations that are already recognised as professional organisations. This shift correlates with the fact that the objective of these organisations includes the dissemination and provision of knowledge that is viewed as valid knowledge. In this sense, patient organisations tend to establish scientific advisory committees that strengthen their credibility as a ´professional patient organisation`. Thirdly, the increased involvement of patient organisations in decision making processes and a focus on the representation of patients' interests in the political sphere justifies the notion of hybrid organisations. Important to this is that these organisations view themselves as patient organisations that ´professionally` represent patients within the health care system. The professional character here relates to the emphasis on being an actor and stakeholder who needs to be considered in the policy- making process." (Deliverable 1.1. of the HealthGovMatters project, page 65)

groups in the exploration of diseases and their consequences."[13]

From the perspective of the HEALTHGOVMATTERS project it is important to note that the political culture, the institutional and legal frameworks as well as the type of the conditions as such impact on the way in which patients' and professional organizations impact on knowledge production, public awareness and the representation of the conditions. Our comparison of patients' and professional organizations in the UK, Germany and Austria reveals strong differences, inasmuch as the comparison across conditions may impact on the way *in which* they engage and *how* they engage themselves in the debates. This is why, in its analysis of the way in which lay peoples' knowledge diffuses, HEALTHGOVMATTERS has decided to go beyond the organizational level and to take a closer look at both the micro-level of knowledge production in the clinic and the individual epistemologies, narratives and experiences of patients and their families as well as the public representations of new health and medical technologies and the conditions.

Both approaches have their merit and reveal important entry points for future research.

Conclusion

The HGM research considered the ways in which gender and generation were encountered by patients, especially in regard to their experiences of getting a diagnosis as well as their lived experience of their condition. While both gender and generation were important considerations throughout, the ways and extents to which these elements were encountered differed greatly according to the conditions. Across all conditions there was a significant amount of stigma attached to bodily and cognitive differences. One of the strong outcomes was the identification of the relationship between stigma, disability, knowledge and technology. A finding in the research in Austria noted that the notion of stigma is in a lot of cases gendered, though not always explicitly. Whilst in the perception of suffering patients, migraine continues to be framed as a female condition resulting out of "hysteria" or "the over-sensitivity" of the female sex,[14] epilepsy is sometimes, and especially due to its relation to the notion of "genius", conceived as a male condition, especially by male patients. Existing data from the WHO neither proves nor disapproves this, even though there is some data on the

[13] Akrich Madeleine, Rabeharisoa Vololona, 2011. EPOKS Project: Investigating patients' organizations and users' groups involvement in knowledge-related activities across condition-areas and national contexts. The INNOVIA Foundation Newsletter, 14: p. 6.

[14] Patient Migraine K: Etwas Lästiges. Eine lästige Frauenkrankheit. Man bringt das ja gerne mit Frauen in Verbindung - Kopfschmerzen mit Frauen und Migräne mit Frauen. Ja. Es ist einfach nur lästig.Ich glaube, dass man das auch in der Gesellschaft manchmal das den Anschein macht als wäre es nur eine Ausrede. Diese Floskel wird auch einfach sehr häufig verwendet: "Ich kann heute nicht, ich habe Kopfschmerzen." Was dahinter steht ... man kann es ja auch nicht nachvollziehen oder man kann es ja auch nicht beweisen. Man sieht es dann schon manchmal an den Augen oder irgendwie so, aber beweisen kann man es nicht. Vor allem, wenn es vom MRT her oder so keine Beweise gibt, dann spüre ich es nur selber und ...

different ways in which conditions embody themselves in the female or male individual. It was found that the individual experiences of the technologies themselves and the expectations directed towards their application is not gender specific, but rather determined by the education of the individual “story teller” and the disposition to gathering information on the condition. In this regard, emerging health and medical technologies in the field of neurological conditions are gender-independent and viewed as potentially contributing to the abolishment of stigma by objectifying the condition and revealing its material causes. One could ask though what the gendered relationship and access to knowledge is. Thus, while there may not be a difference concerning the perspective that new technologies will alleviate stigma of conditions according to gender, the access to these diagnostic technologies may in and of itself be gendered due to the historical and contemporary perceptions of the symptoms that are manifest. It is a cyclical ordeal. The notion of stigma can also be seen in the narratives of German interviewees who very often felt stigmatized not by the diagnosis of mitochondrial disease, but rather by the absence of any diagnosis in the face of progressing bodily manifestations of disorder and difference. For men, disabilities are often a challenge to normative notions of masculinity. For women, disabilities interfere with normative perspectives on women as the care-givers in the family. Stigma for a number of interviewees was reduced once they could name their condition – even if with a name that does not have a concrete reference point in the public sphere. The emphasis on genetics and genetic research or integrated uses of diagnostic technologies is rendering the intergenerational dimensions of these conditions prominent and will be deserving of further and future research.

Policy Implications Emerging from the Research Findings

One of the objectives of the 2008 Science in Society work programme of the European Commission within which this project was funded was: '*to encourage greater public engagement and promote the participati*on of citizens and civil society organisations in research and science policy-making.' Our project approached this objective in a three-fold manner, attempting to understand the multiple forms that engagement and participation might take. We wanted to gain a sense of the formal and informal means by which people are involved in health and science governance. What forms does involvement take at the institutional and organizational level? What about those individuals who will be directly affected by medical research – and what is and is not funded? What perspectives do multiple stakeholders have on the development of new technologies or the integration of novel functionalities in established technologies? What are the discussions and representations of conditions and technologies that enter public space and how are these regulated?

At the end of our project, we held a one-day final conference at the European Parliament to present some of the findings discussed above and to introduce additional interventions by speakers who were representative of the different stakeholders involved in our research as well as representatives of related EU-funded projects. In what follows, we will briefly elaborate on some of the policy implications resulting from our findings.

Introduction: The implication of the governance concept

Our usage of the term 'governance' refers explicitly to processes of regulation, monitoring and decision-making that differ from those implemented top-down by governments. While thegovernance of health and science may still be quite strongly located within the domain ofpolicy-makers, there is increasing pressure to democratize science and the policy-making process. The concept of 'governance' implies a multi-stakeholder approach. It is based upon the assumption that all stakeholders must have and are able to take up their responsibilities. As we have explored in this project there are numerous barriers to doing so, faced especially by people affected by chronic, stigmatized and possibly isolating conditions. There is, however, also a strong movement toward action, the improvement of health and science literacy among non-scientist citizens, and formal inclusion of patients and patient representatives in governance initiatives by the state and regulatory institutions.

Unlike in traditional policy-oriented studies, the implications of the results of the HealthGovMatters study do not just address the political system, but all stakeholders involved. Hence, we elaborate on 'policy implications' rather than speaking about 'policy

recommendations'. There are, however, direct implications for policy-makers. Policy-makers hold particular responsibilities:

- Legislation: Setting an appropriate framework and being aware of social inequalities in the health sector
- Incentives-disincentives: Establishing suitable funding programmes to meet the challenges faced by individuals with chronic or rare diseases and currently under-funded conditions
- Persuasion: Establishing and supporting awareness-raising campaigns, helping to not only draw awareness to the need for health resources and medical research, but also to the need to de-stigmatize disabilities and fluctuating states of health

The responsibilities of other stakeholders are more diverse:

- Patients and relatives: Gaining an understanding of health, illness and disability and participating in self-care when possible. Taking part in discussions about what is necessary with regard to health care reform and science policy and offering expertise and challenges based on experience.
- Self-Help groups and professional organisations: Providing adequate support, participating on research committees, contributing to science and health policy discussions
- Doctors and health-care professionals: Professionalism and empathy. Interactions with other stakeholders.
- Research and Industries: Appropriate research and corporate social responsibility
  The Media: Knowledge-based reporting

Research and Technology: Private Research and Public Responsibility

The recent budgetary restrictions have had an impact on the governance of medical knowledge and have health implications. This finding is far from being trivial. Research in the medical field is becoming increasingly independent from industry. As medical research is costly, the industry stakeholders seem to concentrate on more widespread illnesses. This goes at the expense of chronic conditions and rare diseases, as public funding becomes more and more scarce. On the other hand, much of the research undertaken is focused on mere technology development. While we have noted that a high number of participants in this project placed significant value on the possibility

that future generations would receive quicker diagnoses and that there is an increasing degree of diagnostic precision, just as high a number expressed certainty that a 'curative therapy' is nowhere in sight. What often remains under-discussed is the lack of research – and funding for research – into therapeutic interventions, especially for conditions which do not affect a high proportion of the population.

We would suggest that this situation is exactly a case that calls for a multi-stakeholder approach and the efficient use of public money:

- Priority setting for public health policy must include all relevant stakeholders. Specific attention has to be given to research on chronic and rare diseases.
- There is room for improving the use of the knowledge of patient organisations, of self-help groups and of professional organisations. Their knowledge is based upon interactions with individual patients and their experiences with new technologies, as well as doctors and other medical staff.
- The funding of these organisations is insufficient and does not facilitate the full benefit of their knowledge and experience being taken into account. Many of the organizations are volunteer efforts, lacking sustainability, especially due to the health issues faced by leaders. Increasingly, the organizations have to turn to industry sponsorship, which might decrease their impartiality.

We would argue that research and technology development in the health sector need public support:

- There is a need for the efficient use of public money.
- Setting the framework for a dialogue between all stakeholders should be encouraged and the dialogue should influence research and research policy decisions.
- European health and research policies should encourage the exchange of best practice models and better coordination of national research programmes.
- Whilst ensuring data protection and privacy, data related to the safety of devices, as well as 'social risks' must become available EU-wide, to all stakeholders, in order to ensure the patients' well-being.

Awareness-raising: The Key to Success

The value of awareness-raising activities was highlighted by the various stakeholders who participated in this research. For patients, awareness-raising activities make a condition, and

very often experiences similar to their own, visible to the general public. In cases of rare conditions, they may also make a condition visible to an undiagnosed individual or may be the first opportunity an individual has to acquire more knowledge about their condition. For scientists and doctors, participation in awareness-raising campaigns has, in a number of contexts, become integrated into their professional practices. The shape that this participation may take is quite diverse. We interviewed clinicians who were extremely involved in medical associations with strong ties to the larger patient organizations in their field. We also interviewed scientists and doctors who became involved in public involvement projects, supporting citizen education about general health and science issues or specialized topics. Awareness-raising activities over the past few decades have also shifted the balance of authority over health and medical knowledge. This creates a platform, but also a need, for the development of new relationships and dialogues between patients, doctors and scientists about the diagnosis and management of conditions and, ultimately, the production of health and medical knowledge. Some of the key points that we have noted are:

Patients:

- There is uncertainty and ambiguity among patients.
- On the one hand, the expectations towards the new technologies are high; on the other hand, some patients feel like “guinea pigs”.
- The expectations of the therapeutically-induced impact on the improvement of individual health are often exaggerated.
- The traditional doctor-patient relationship is somehow fuzzy and the authority of doctors’ knowledge is questioned by many patients.

Doctors and healthcare professionals:

- There seems to be a gap between the younger and the older generation of doctors: For diagnostic purposes, the older generation of doctors are more sceptical towards the new technologies and rely on their experience; the younger generation is relying much more, and sometimes mostly, on these technologies.
- In a number of cases, the latter seem also to ignore the psychological aspects of the doctor-patient relationship: Their self-understanding is more a managerial one.
- A more balanced approach seems to be necessary.
- Awareness-raising is a challenge for all stakeholders involved
  Health authorities, in close collaboration with the stakeholders, have to play a role in awareness-raising.
- Patients with chronic or rare diseases are confronted with prejudices on the one hand, with a lack of understanding of their needs on the other hand.
-

Prejudices against chronic and rare diseases vary across cultures.

Training of doctors and healthcare professionals should increase patient-centred treatment.

- The understanding of the patients' needs increases the autonomy of the patients.

Research is needed to define target audiences and topics for the awareness raising campaigns.

The role of the Media and of the Arts: Increasing the public understanding by knowledge and emotions

Print and broadcast media reach a high number of the general population and, thus, have a significant role to play in the circulation of sound medical knowledge, but also in raising questions concerning this knowledge, the implementation of technologies, and the management and public perception of certain conditions. In many ways, the media are knowledge gate-keepers. The selection of the topics on which they report often depends on the personal assessment of each journalist, and very often their editorial offices, about what is currently considered to be topical or 'sexy'. We have made the following observations:

- There is room for lobbying on the side of the patient organisations, self-help groups and professional organisations for coverage of particular conditions. Institutions of journalism education could become targets of the lobbies as well.
- Public health authorities have their role to play as well. Advertising in the media and PR-campaigns of the public health authorities should be part of the awareness-raising campaigns as well. This is particularly important for rare and/or stigmatized conditions that are under-represented in media reporting.
- Exhibitions seem to have an under-estimated role in the diffusion of medical knowledge. The examples reported in the study show that, whilst mostly presenting artefacts, they have a wider audience than any other communication media and are able to increase understanding about the functioning of, for instance, the brain or the general nervous system.
- Art, and especially self-representations and participatory projects, seems to hold the possibility to challenge the authority of 'scientific' representations of conditions, address social and ethical issues related to emerging technologies or medical research and therapeutic interventions, and is often accessible to a broader audience due to transformations from one medium to another and the increasing use of the internet for dissemination purposes.

Potential Impact of Results

The HealthGovMatters project was fieldwork-intensive, employing rich multi-sited ethnographic methods. There are two sets of anticipated outcomes of the project. First, with respect to research in interrelated disciplinary and interdisciplinary fields such as medical sociology and anthropology, science studies, and science and health policy analysis, the findings from the project have resulted in:

1. The completion of much needed ethnographic research on experiences with converging technologies at the interface of medical research and biomedical practice;
2. The establishment of a set of key examples of emerging forms of representation and dissemination about the use of medical technologies in health research and care, as well as their relationship (or distance) from particular health conditions;
3. The implementation of an integrated approach to theoretical analysis and policy-relevant research pertaining to contemporary interfaces between clinical therapy and research practice and governance, which addresses the complexity of lived experience, differential policies and professional practice.

In a broader sense, the project findings contribute to understandings of the ways in which knowledge is produced, mediated, circulated, and contested and how activities that are both formal and informal are integral to how technologies are governed. The outcomes of the project are poised to contribute to a set of broader issues, including the development of a more nuanced understanding of the distinctions between patients and patient organisations as sources of knowledge and the recognition of visible, as well as unrecorded, acts of participation in governance activities. Attention must be paid to the potential differences, along with similarities, between questions asked at point-of-care and questions which may be articulated by individuals involved in health-related organisations. Our research also explored how individuals make sense of emerging technologies which involve the convergence of technologies, institutions, techniques, or even therapies that have been previously associated with another condition. We have identified information and policy needs in the areas of implementing medical and health technologies and the means by which experiential and embodied knowledge could potentially contribute to the perspectives of individuals and communities on what forms of governance are needed, what types of research should be supported, and what forms of novel experimentation are appropriate. Finally, as a result of our sustained engagement with representations, events, and communication initiatives, the outcomes of the project have the potential to contribute significantly to policy development in the areas of science communication, the identification of particular stakeholders for participation in dialogue, and the ways in which local activities might be embedded in broader European discussions.

Future Research Questions

A number of questions emerged over the course of this project, which are deserving of future research. Many of these were addressed in the presentation of the project's findings at a seminar held in the European Parliament in May 2012. Here we specify a few of them:

Sustainability of Patient Participation in Governance Frameworks: We have analysed the development and fluctuation of patient organizations (WP1) and the experiential narratives of individual patients, family members and professionals. The levels of participation differ significantly, are varied according to paid or volunteer status and in many cases the core work is carried out by a small number of people. For small organizations, limited funding and disabilities render their sustainable participation in political discussions at the national and international level infeasible. What are models of sustainability that could be implemented in order to include lay patient voices on a regular basis?

Efficiency and Effectiveness of Patient Organisations: In our study we discovered different *modus operandi* of NGOs in the field. There were differences both according to mission and activities of patient organisations and to national cultures. Which models are more likely to be successful and is transfer of models possible, even with some modifications according to cultural, social and political environments?

Transnationalization of research: Some of the narratives highlight the ways in which knowledge increasingly crosses boundaries. This was particularly evident in our analysis of patient organizations which are forming at a European level and/or are taking part in international actions. Future research should look explicitly at the internationalization of research and the mobility of patients and scientists in the production of knowledge and encounters with other healthcare systems. The patient mobility directive introduced during this project will provide a significant platform for such research.

Contemporary Issues Face the Past: In Germany especially in relation to mitochondrial disease research, the issues of assisted suicide and preimplantation genetic diagnoses highlighted key areas in which an intensive project might address contemporary legislative decisions and medical practices in the light of eugenics and racial hygiene politics.

Priority Setting: We focused on encounters with technologies and the production and governance of knowledge by various organizations. There is debate about which conditions are 'worthy' of significant funding for basic and clinical research. More extensive research should address the characteristics of funding distribution into conditions which are not life-threatening, but like migraine and epilepsy can be life altering.

From public representations to scientific research: In WP3 we specifically looked at the production of public representations. Much of this demonstrated the ways in which science is translated into publicly accessible forms, which foster debate, education, and awareness. A future project would be to look much more closely at the ways in which public representations and public ethics debates impact the progress of scientific research into treatment technologies.

Main Dissemination Activities

Citizen Studies Workshop Series

The Consortium organised a series of what we referred to as 'citizen studies' workshops over the course of the project. The workshops had a unified aim of facilitating public engagement with science and stimulating conversations around the governance of medical technologies amongst people who may not be directly involved in decision-making regarding their implementation or use in specific contexts. Additionally, this series of workshops was conceptualized as a means of experimenting with different possibilities for 1) moving on-going social science research into public space throughout the course of the project; and 2) incorporating the outcomes, feedback and questions posed during the events into the further research and analysis of the project.

Each of the workshops had a unique and individual approach, which related to the work that had been completed by or was being focused upon at that point in the project and in the particular research context in which the workshop was held. The various workshops were held in Germany (July 19, 2010), Austria (May 25, 2011), and the United Kingdom (January 13, 2012). The three events focused on different issues related to the representation and governance of new predictive, diagnostic and treatment technologies. Nonetheless, there were overarching themes such as 'visibility', and the 'layering of representations' which, although not explicitly integrated in the conceptual approach for all three events, emerged more fully in the analysis of the collective outcome.

The workshop in Germany touched upon issues of visibility regarding mitochondrial disease and the numerous medical technologies which are part of the diagnostic and on-going care processes. The workshop brought out the paradoxical 'visibility' of medical technologies and disabilities by showing two short films. Both films focused on personal experiences of mitochondrial disease to show that the condition, while debilitating and life-limiting, does not always 'look' like a disability. This point is most vividly seen in the short video 'I'm Brianna Couture', where three young women play the part of Brianna in order to highlight the fact that a person with mitochondrial disease might be anyone around you because the condition does not debilitate a person all of the time. In addition to the often invisible physical manifestations of the condition, there is an added layer of invisibility in the sense that the condition is rare and little known rendering the achievement of a diagnosis difficult.

During the event in Austria, visibility emerged with regard to new technologies such as fMRI, which are said to be able to make thoughts and impulses visible on the machine before an individual is aware of them. In this sense, the new technologies allow researchers to 'see into

people's minds' and make the invisible visible. The usefulness of 'making the invisible visible' was called into question by workshop participants, as these technologies clearly seem to present a philosophical paradox regarding free will. However, the second speaker at the Austrian event highlighted the usefulness of the technologies for medical diagnoses. The pragmatic use of the technologies and the integration of these technologies into clinical day-to-day life with the aim of helping patients was the medical doctor's priority. One might ask, though, how practice might change if philosophical problems which arise from the use of new technologies (in this specialist's case it was PET) were to be integrated into the practice of everyday usage.

In the UK, the theme of visibility emerged in a very different way. Here, it emerged with regard to the ways in which epilepsy, a largely hidden condition, becomes visible within the public domain. The three speakers from the UK – a neuroscientist, an artist and a woman who has epilepsy and had made an epilepsy video – all have taken part in public representations of epilepsy in some way. What is interesting about these different representations is the way they are perceived and judged. While there were no definitive conclusions drawn regarding which type of representation was most publically acceptable, the observation can be made that medical representations of epilepsy dominate mainstream media and receive praise, while alternative, artistic representations only make their way to the public via non-traditional media outlets such as YouTube.

A summary report of the workshop series is available, providing detailed reflections not only on the content of the workshops, but also the methodological significance of integrating such a series into the context of an ethnographic research project.

International Workshop

The Consortium organized an international workshop, entitled The Role of Patient and Professional Organisations for EU Health Governance, which took place in Brussels, September 21-22, 2010. The objective of the workshop was to bring together representatives from patient and professional organizations, representatives of civil society organizations, as well as researchers working in the fields of medical sociology and anthropology to exchange views about how new knowledge and emerging technologies are impacting on medical research, clinical care and stakeholders' mobilization. Organized by the ICCR and hosted by the Austrian Mission in Brussels, the workshop featured presentations by 12 speakers from diverse organizations. The workshop provided a solid overview of emerging issues in the governance of health care and medical research, especially with respect to the role of patient organizations and their interaction with professional organizations and the medical establishment.

Patient organizations are growing in importance as intermediaries in the field of health care and medical research. They are repositories of patient experiential knowledge besides being important information resources for patients and their families. For professional organizations and the health care system they represent partners for diffusing information and for recruiting participants for clinical trials. The growing importance of patient organizations is among else evidenced by their inclusion in various committees, such as ethic committees, commissions mandated to elaborate clinical practice or clinical trial guidelines as well as discussion forums concerned with the authorization of new medicine. One possible concern raised about the growing significance of patient organizations as new partners in health care and medical research is that they run the risk of being appropriated into a specific system of stakes and interests, thus losing their assumed speaker role for patients.

The workshop also offered an intensive forum in which to exchange ideas about the role of the social sciences in dialogues about health governance, science-society interfaces, and knowledge production and circulation. Given the multi-disciplinary and interdisciplinary composition of participants, the workshop also offered possibilities to work at communicating across disciplinary borders and engaging in comparative conversations.

The workshop participants were part of organizations and both national, European and international projects. Thus, this workshop provided a sound opportunity to liaise with other ongoing work in the field, both with respect to academic/research work and advocacy work. The list of participants offers a sense of the diverse perspectives that were included:

Madeleine Akrich	Centre for the Sociology of Innovation, MINES ParisTech, France - EPOKS
Marina Bentivoglio	University of Verona, Italy
Rebecca Buckley	International Alliance of Patients' Organizations, UK
Lauren Ball	Rohde Public Policy, Belgium
Stuart Blume	University of Amsterdam, The Netherlands
Nadia Ceratto	EC, DG Research, Belgium
Benjamin Ewert	Justus Liebig University, Giessen, Germany
Loes Knappen	McGill University, Canada
Maria Lubs	Egmont Royal Institute for International Relations (RIIR), Belgium
Ilina Markova	European Generic Medicines Association, Belgium
Rod Mitchell	Bournemouth, UK
Nina Hallowell	Newcastle University, UK

Harald Kratochvila Coachtrain, Austria
Katrina Perehudoff Health Action International, The Netherlands
Vololona Rabeharisoa Centre for the Sociology of Innovation, MINES ParisTech, France - EPOKS
Silke Schicktanz University Medical Center, Goettingen, Germany
Peter Wehling University of Augsburg, Germany
Kim Wever Dutch Genetic Alliance, The Netherlands
Viviane Willis-Mazzichi EC, DG Research, Science in Society

Further interaction was developed with regard to work on patient organizations between Jacquelyne Luce and Silke Schicktanz (guest lecturer, invited conference participant). Furthermore, the workshop drew awareness about the project, with it coming to be mentioned in a recent article: Civil society organisations, social innovation and health research in Europe by Dace Beinare and Mark McCarthy and published in the European Journal of Public Health.

Final Conference

A final conference entitled “Health Governance Matters: How to Govern Medical Knowledge, Converging Technologies and Neurological Disorders” was held at the European Parliament on May 16. 2012. This event was organized at the invitation of MEP Angelika Werthmann, whose office also co-hosted the event. The conference was conceptualised to inform policy makers, representatives of patient organizations, scientists, and relevant stakeholders about the results of the HealthGovMatters project. One of the core aims was to shed light on a highly relevant issue, namely the production and governance of medical knowledge and related implications for science, policy, and health care, as well as patients and their families. The conference brought together members of the HealthGovMatters research consortium and clinical and patient representatives as speakers, creating a forum for dialogue across perspectives and invested interests in the production and governance of health and medical knowledge. The interaction with registered participants was very productive, especially given the possibilities for extending the analyses that project researchers made with regard to the particular conditions we focused on to other patient support groups and advocacy organizations with varied agendas and foci.

Other Presentations and Networking

The HealthGovMatters project was designed as a multi-sited, qualitative study, which emphasized a "constantly comparative" approach, whereby the "units" of comparison were not fixed. This enabled comparative analyses along the lines of condition, gender, generation, political and cultural contexts, language, styles of implementing governance frameworks, legislation, etc. Approaching the fieldwork with an ethnographic perspective, and thus allowing what was going on during the time of our research to shape both the research questions and foci, opened up numerous possibilities for nuanced and comparative discussions amongst ourselves and with the individuals who have participated in the research in various ways.

Members of the consortium were active in disseminating preliminary findings and participating in informal and formal exchanges about the project and the cross-thematic issues that it addresses. One of the key successes of the project involved the intensive networking with various patient and clinician groups that took place throughout the project and the presentations of the preliminary results of the research to various audiences within the context of the project's lifetime. This enabled the researchers to receive feedback on the findings while fieldwork was on-going and analysis was taking place.

The presentations of consortium members are listed below:

- May 2012. Jacquelyne Luce. Active Patients: Stories of Emerging Expertise. "Wissenschaft und Demokratie" Colloquium, Ethik und Geschichte der Medizin, University of Goettingen, Germany
- May 2012. Alice Vadrot. Health Identities, Scientization & the 'Normal' Brain. Presented at the Final Conference | Health Governance Matters: How to Govern Medical Knowledge, Converging Technologies and Neurological Disorders. European Parliament, Brussels
- May 2012. Ronald J. Pohoryles. Lessons Learned - How to Govern...? Presented at the Final Conference | Health Governance Matters: How to Govern Medical Knowledge, Converging Technologies and Neurological Disorders. European Parliament, Brussels
- May 2012. Jacquelyne Luce. Engaging Research, Engaged Patients: Relationships of Medical Knowledge Production and Governance. Presented at the Final Conference | Health Governance Matters: How to Govern Medical Knowledge, Converging Technologies and Neurological Disorders. European Parliament, Brussels
- April 2012. Alice Vadrot. Knowledge production, convergence and automation in the treatment of neurological diseases: an ethnographic study in an Epilepsy Monitoring

Unit in Vienna. The Mutual Challenges of the Neurosciences and Public Health, European Neuroscience and Society Network Final Conference, hosted by the Department of Social Science, Health and Medicine, King's College London, London, UK

- April 2012. Julie Hartley. Seizing Control. The Mutual Challenges of the Neurosciences and Public Health, European Neuroscience and Society Network Final Conference, hosted by the Department of Social Science, Health and Medicine, King's College London, London, UK
- November 2011. Jacquelyne Luce. My Biology: Mediating and Producing Knowledge about Rare Diseases. Cramer Seminar Series. Department of Biological Sciences, Dartmouth College, US.
- November 2011. Jacquelyne Luce. Lay Expertise, Trust and Coincidence: Intergenerational Experiences of Rare Diseases. American Anthropological Association Meetings, Montreal, Canada.
- September 2011. Jacquelyne Luce. Vorstellung eines EU-Forschungsprojekts: Erfahrungen mit Mitochondrialen Erkrankungen. Gemeinsame regionale Fachtage Nord-Ost für Patienten mit mitochondrialen Erkrankungen. Malchow, Deutschland.
- July 2011. Ronald Pohoryles and Alice Vadrot. Presentations of the project in Belfast (QRPM) and Paris (ALMA).
- June 2011. Jacquelyne Luce. Patients' and Families' Perspectives on Scientific Research and Clinical Care with Regard to Mitochondrial Disease. United Mitochondrial Disease Foundation Mitochondrial Medicine Conference, Chicago, U.S.
- June 2011. Jacquelyne Luce. "Battery Operated": The Work of Making Mitochondrial Disease Visible. Poster Presentation at the 2011 Berkshire Conference on the History of Women, Amherst, MA, US
- May 2011. Alice Vadrot. First Results of the HealthGovMatters Project. Presented at the workshop: Experten im Gehirn: Wie entscheiden neue Technologien über Krankheit und Gesundheit in der Neurologie? Vienna, Austria.
- February 2011. Jacquelyne Luce. Gesprächsrunde. Tag der Offenen Tür. Ernst-Barlach-Schule. Münich, Germany.
- January 2011. Jacquelyne Luce. Wissen aus dem Täglichen Leben: Rare Diseases, Disabilities and Activism. Zeppelin University Research Day, Friedrichshafen, Germany.

Publications

Main Research Reports

The main reports from each stream of our research will be made available for download from the HealthGovMatters website. These reports provide detailed accounts of the research specific to the conditions and technologies on which we focused. The voices of many affected individuals, representatives of patient organizations, self-help groups and medical societies, scientists, and doctors are to be found within these pages. Additionally, these reports include our analyses and reflections on numerous public representations and communication initiatives.

Brief Synthesis Summary Report

As part of our dissemination work package, we completed a brief synthesis of the research findings in accessible language to be disseminated to interviewees and made available on-line.

Other Publications

There are publications in progress that will become available in the coming years as the analyses presented in our project reports and presentations are transformed into scientific publications and patient/lay-oriented publications. The following are articles published in a widely read general health journal and a patient organization newsletter.

Vadrot, Alice (2012): Nur noch Datenmanager? Das österreichische Gesundheitswesen – ÖKZ 53 (5), www.schaffler-verlag.com

Luce, Jacquelyne (2011): The Patient University. The Innovia Foundation Newsletter, 15, http://innoviafoundation.org/wp-content/uploads/2011/10/NEWSLETTER-15.-pdf.pdf

Vadrot, Alice (2012): 'Rather a Manager and Networker than a Researcher': Converging Technologies in the Clinic, in: Innovation – The European Journal of Social Science Research, Vol. 26, Issue No. 3