
**STUDIES ON MEDICINE, EXPERTISE AND CONTROVERSY
(SMEC)**

**OPTIMISING HEALTH IN EUROPE THROUGH EVIDENCE-BASED AND
PERSONALIZED MEDICAL PRACTICES:**

**THE USE OF EXPERTISE, STANDARDS AND TECHNOLOGIES IN
HEALTH PROMOTION AND PREVENTIVE MEDICINE**

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Dick Kasperowski, and Morten Sager.**



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Optimising Health in Europe

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Optimising Health in Europe through Evidence-Based and Personalized Medical Practices

Denna rapportserie omfattar bland annat kompendier, forskningsrapporter och avhandlingar från ämnet vetenskapsteori, vid Institutionen för filosofi, lingvistik och vetenskapsteori vid Göteborgs universitet (<http://www.flav.gu.se/>). Serien innehåller både förstudier, del- och slutrapporter (godkända avhandlingar etc).

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Table of Contents

| | |
|--|-----------|
| OPTIMISING HEALTH IN EUROPE THROUGH EVIDENCE-BASED AND PERSONALIZED MEDICAL PRACTICES | 10 |
| INTRODUCTION | 10 |
| EVIDENCE-BASED PRACTICES AND PERSONALIZED MEDICINE | 11 |
| KEY QUESTIONS TO BE CONSIDERED: EVIDENCE, TECHNOLOGY & ADHERENCE | 12 |
| PRELIMINARY REVIEW OF CONCEPTS, PROBLEMS AND SOME AREAS OF RESEARCH: EVIDENCE-BASED PRACTICES, EXPERTISE, TECHNOGOVERNANCE AND PATIENTS | 14 |
| INTRODUCTION | 14 |
| OBSTACLES AND ENABLING FACTORS AFFECTING ADHERENCE | 14 |
| EVIDENCE-BASED MEDICAL DECISIONS AND DIFFERENT TYPES OF EXPERTISE | 17 |
| THE QUESTION OF HOW EVIDENCE IS SHAPED AS “EVIDENCE” | 19 |
| PERSONALISATION OF MEDICAL INTERVENTION, SELF-CARE, AND TECHNOLOGICAL MEDIATION | 22 |
| TECHNOGOVERNANCE – ONTOLOGIES AND EPISTEMOLOGIES | 25 |
| TRUST AND AUTHORITY – THE EXAMPLE OF SCIENCE ADVISORY BODIES PRODUCING “SERVICEABLE TRUTH” | 28 |
| CHANGING GOALS AND RECONFIGURATIONS OF PATIENT ORGANISATIONS | 31 |
| CONCLUDING REMARKS: POSSIBLE RE-CONCEPTUALIZATION? | 34 |
| THE ROAD AHEAD: PREPARING FOR A WORKSHOP IN APRIL 2012..... | 36 |
| INTRODUCTION | 36 |
| REFERENCES | 38 |
| APPENDIX I. SOME EU PROJECTS CONTAINING STUDIES OF MEDICINE, EXPERTISE AND CONTROVERSY | 46 |
| APPENDIX II. SOME INFORMATION ON THE SMEC GROUP..... | 48 |

OPTIMISING HEALTH IN EUROPE THROUGH EVIDENCE-BASED AND PERSONALIZED MEDICAL PRACTICES: THE USE OF EXPERTISE, STANDARDS AND TECHNOLOGIES IN HEALTH PROMOTION AND PREVENTIVE MEDICINE

INTRODUCTION

This is the working title of a workshop planned to take place in April 2012 as a step towards developing a grant proposal to meet the criteria of an appropriate EU framework call in the area of health policy and governance. The core idea is an interest in the use of expertise, standards and technologies on the one hand and on the other hand variations in adherence of patients to prescribed treatment - typically across a number of different lifestyle-related diseases or ailments, in comparison between a number of European countries.

The focus would, more specifically, be on two aspects: evidence-basing of relevant treatments and patient adherence to expert recommendations for preventive purposes in the cases of the disease categories selected.

At this point the selection of disease categories to focus on in the workshop and the grant proposal is *left open*; the following are only named as examples: irritable bowel syndrome (IBS), hypertension and cardiovascular diseases, high cholesterol, overweight/obesity, Type 2 diabetes and certain infectious diseases. This is in view of the urgent call to action issued by the WHO Regional Office for Europe in its Summary Report 2005 on European Health which identifies the high risks to health, related to tobacco and alcohol consumption, high blood pressure and cholesterol, overweight, low fruit and vegetable intake, and physical inactivity. The report urges that these health risks need to be dealt with in order to help prevent ischaemic heart disease, unipolar depressive disorders, cerebrovascular disease, alcohol-use disorders, chronic pulmonary disease, lung cancer and road traffic injury. The summary has a special focus on children's health, because health in childhood determines health throughout life and into the next generation (WHO 2005).

The present initiative comes from a group of scholars at the University of Gothenburg who have over the years done research that falls within the realm of science and technology studies (STS). Coming out of an amalgam of studies of scientific controversies, the role of expertise, critical studies of public understanding of science, scientific citizenship and governance issues, and earlier work in the field of science policy studies, several members of the group have now come to focus

particularly on Studies of Medicine, Expertise and Controversies (SMEC). For more information about the group, see Appendix II and <http://www.flov.gu.se/english/research/>.

EVIDENCE-BASED PRACTICES AND PERSONALIZED MEDICINE

In recent years, the term evidence-based medicine has been a catchword for profound changes in medical research and the provision of health care across the Western world. At the core of this concept, which was introduced in Canada in the early 1990s, is the idea that clinical decisions should be based on the most reliable knowledge available about the effects of medical interventions. Initiatives taken not only in the health care sector, but in a number of other areas as well, are frequently justified by reference to this idea. Methods and tools established under the banner of evidence-based medicine, such as randomised clinical trials, systematic reviews, and practice guidelines, have been introduced in social work, education, psychotherapy, and criminal justice. Applying these tools, however, in health care systems and elsewhere, has proved far more complicated than initially anticipated by proponents of evidence-based practice. The so-called evidence movement is homogeneous enough to be studied as a movement, but in order to move beyond the simple polemics of many current debates, careful empirical studies are needed.

Another trend is a turn from patient-centred to person-centred medicine, reflected for example in the recent coordinated global effort at a major conference in Geneva in May 2008 and its follow-ups in a second and a third Geneva Conference on Person Centred Medicine the same month in 2009 and 2010. A fourth international Geneva Conference is in the offing for May 2011. It involves broad ranging participation of physicians, researchers, representatives of patient organizations, social workers and other practitioners, and is expected to further consolidate efforts, develop research agendas and clinical capacity building in the same spirit (Mezzich 2011).

It is useful to think about the processes behind these movements of evidence-basing practices and person-centred medicine in terms of co-production of science/medicine and social order. For instance, there are several developments, both in society and in medicine, in relation to the trend of personalized medicine. There is a rapidly growing market of new and emerging diagnostic instruments with origins in pharmacogenetics, the science that seeks to determine how peoples' genetic make-up affects their response to medicines and offers the potential to develop a new generation of medicines tailored to individual needs. The idea is also that in the future, genomically based diagnostic tests can deliver reliable and rapid diagnostic data to healthcare professionals (Royal Society 2005). Even if pharmacogenetics, as yet, has very little impact on clinical practice, visions of rapid

advances in both the science and the underpinning genetic technologies are now strongly influencing research programmes, not least in Europe where the EU's Directorate General for Science and Innovation is a major actor in promoting S&T for relevant genomics, proteomics and other "-omics" developments.¹

In addition to the combined pressures of market forces and new technologies, actors such as patient organisations, health workers in caring institutions, as well as health administrators who want to reduce costs at the Point of Care (PoC) in the clinics are of course also important drivers in these developments (Martin et al. 2006; Paci and Ibarreta 2009).

Generally, it may be intimated that the different actors involved have different perspectives, with pharmaceutical companies accenting potential market gains, health administrators favouring speed and efficiency in diagnostic routines, and patients together with health workers in the field emphasizing validation and safety of treatments. In other words, there *may* exist essential tensions between those actors who perhaps first and foremost emphasize economic worth and technological efficacy and actors who put a premium on the caring perspective and see personalised medicine more in terms of enabling social relations in the interface between health workers and physicians. Analysis of interactions between value hierarchies at institutional and personal levels is therefore relevant in any inquiry that seeks to understand the role of new technologies as mediators between patients and those who diagnose and treat them or monitor their treatment (for a discussion of different value categories or "worth", see Thévenot 2009 and Zuiderent-Jerak 2007, 2009). This also extends to the role of health workers when it comes to issues of compliance or adherence to guidelines that ought to regulate patients' self-diagnostic capacity in the use of off-the-shelf diagnostic instruments that are on the market.

KEY QUESTIONS TO BE CONSIDERED: EVIDENCE, TECHNOLOGY & ADHERENCE

Of central interest preparing for the coming workshop in 2012, are the following questions:

¹ See the EC workshop in Brussels 12-13 May 2011 on European Perspectives on Personalized Medicine: http://ec.europa.eu/research/health/events-06_en.html, also EC workshop on Biomarkers for Patient Stratification 10-11 June 2010, http://ec.europa.eu/research/health/pdf/biomarkers-for-patient-stratification_en.pdf, and the earlier one on "-omics" in Personalised Medicine 29-30 May 2010, http://ec.europa.eu/research/health/pdf/summary-report-omics-for-personalised-medicine-workshop_en.pdf.

- (1) What is the state of the discourse on evidence-based health care and medical practices in a given country related to health promotion and preventive medicine; and secondly, what is it in respect of the selected disease categories? To what extent do policy makers, health officials, clinicians and other relevant experts subscribe to basing decisions about preferred therapies or medical interventions in such fields on existing evidence of best practices? How are such standards conceived and construed? What degree of consensus exists around this approach, or alternatively what controversies can be discerned; in other words, is the evidence and relevant expertise contested and if so in what respect(s)? Entrenchments, i.e. degrees and forms of embodiment in decision-making tools, quality registries etc., must also be considered.

- (2) What levels of adherence with expert recommendations are found in relevant target populations? Is adherence/compliance differently understood in different countries? And for any one country, are there major variations regarding patients' compliance, and if so what factors (e.g. cultural, tradition-related, socio-political, educational, gender and class-related, etc.) are typically identified as obstacles or barriers to such adherence? Secondly, what sorts of factors are contrariwise counted as facilitating? What kinds of measures are typically seen as desirable in the attempt of overcoming such obstacles or barriers in order to reach higher levels of patient adherence? How, if at all, are technologies used to reach adherence with expert recommendations in different countries in relation to specific health problems?

These two foregoing sets of questions and exploration of the links between them (cf. Helgesson 2004, cited below) can serve as a point of departure in cross-country comparative studies to probe similarities and differences regarding the policy of evidence basing of preferred practices, and likewise for the issue of patient adherence. How many patient categories should be focused, and which ones should be selected for suitable comparison of evidence-basing as a policy tool and concomitant approaches to adherence/compliance, is for the moment left as an open question to be addressed more precisely in the workshop as is what criteria should be used to select disease categories in order to get a meaningfully significant variation across therapy areas.

PRELIMINARY REVIEW OF CONCEPTS, PROBLEMS AND SOME AREAS OF RESEARCH: EVIDENCE-BASED PRACTICES, EXPERTISE, TECHNOGOVERNANCE AND PATIENTS

INTRODUCTION

Evidence and the roles of patients are continuously negotiated, shifted and reconfigured. A number of discourses and disciplines have conceptualized these complex relationships. Sociologists, psychologists, theorists of science, organisation scholars and others have attended to the varying relationships between knowledge production, transfer and contexts. Below, these discourses are briefly introduced as matters of compliance, evidence, self-care, technical interfaces, trust & authority, and the various roles assumed by patient organizations. The aim of this preliminary review is to map key concepts, problems and areas of research. How to draw on these in order to constructively re-conceptualize the issues of evidence and patients is a matter for discussions and research. For our part we conclude the review by suggesting a focus on the movements, mass media and the resulting mutualities of medical knowledge and want to introduce the threefold concepts of *travelling* expertise, *affordance* of expertise and *governance* of expertise.

OBSTACLES AND ENABLING FACTORS AFFECTING ADHERENCE

In recent years there has been a shift in the use of language from “compliance” to “adherence”. “Adherence” is the concept nowadays used in the research literature while compliance, sometimes interpreted as engendering a more paternalistic view (you should do as you are told) may be more prevalent in the clinical setting. It may be of interest to determine if this linguistic shift is relevant in non-Anglophone countries, and, moreover, if so, to what extent the distinction is/has carried through to the domain of clinical practice. It should be added that a possible lack of patient adherence is not the only dimension that warrants attention. Studies in Sweden, for example, indicate that the behaviour of physicians also varies considerably when it comes to complying with guidelines and recommendations laid down by national regulatory authorities (Bragesjö and Hallberg, forthcoming). One particular study distinguishes between “steerable” (*styrbara*) and “unsteerable” (*ostyrbara*) physicians (Lagrelius 2006).

The categories of “patients” and their behaviour in relation to health care interventions as well as attempts to improve these interactions are under continuous renegotiations in numerous fields. Researchers have focused on models

of adherence, personalized care, norms and social structures, health belief models, telemedicine and the configuration of health care systems.

In social medicine there are various theories to explain non-adherence. A distinction is made between intentional and non-intentional non-adherence. Theories originating in behavioural psychology tend to focus on the individual. For example reactance theory proposes that patients react to perceived threats to their autonomy or individual freedom. In a medical context patients' perceptions of threats to their freedom or control may therefore induce non-adherence. Social cognitive theory in research on health behaviour and health education focuses on peoples' potential to alter and construct environments to desired purposes they devise for themselves and emphasizes "reciprocal determinism" between the individual and his/her environment (Magnusson 2010).

The concept "empowerment" used in the vocabulary of the expert-patient encounters has been with us since the early 1990s (Rodwell 1996). Methodologically this may be linked to narrative interviews informed by hermeneutic theories of interpretation in tandem with quantitative surveys of risk groups (Edwall 2011). Political sociologist Stuart Blume (see below) maintains that the existence of an effective therapy is not enough; narrative approaches are invaluable for understanding context and influencing the social settings in which medical decisions are made, supporting the development of potential and abilities, and an action orientation in complex social processes and a broad political engagement. To underpin his position he refers to sociologist Zygmunt Bauman's definition of empowerment as a real (not just token) ability to make choices and act effectively on the choices made; which in turn requires the capacity to influence the range of available choices and the social settings in which choices are made (Blume 2010b:3; Bauman 2008).

The trend to person-centred medicine marks recognition of, among other factors, "contemporary developments in clinical medicine and public health challenging an overemphasis on specific organs and disease and seeking to place the whole person at the centre of medicine" (Mezzich et al. 2011:330). Person-centredness in this respect expressly accents personhood as an intrinsic quality rather than as an additional commodity.

A question that arises is how this tallies with the impact of genomic risk assessment and the implications of a personalized genomic approach to medicine - - is there an inherent tension here between two different approaches to personalized medicine, on the one hand that engendered in sophisticated pharmacogenetic and other biotechnologically based possibilities of tailoring medical therapies to personal characteristics and needs, and on the other hand an approach that strongly accents the role and worth of the person in medicine in a more qualitative sense? Or do

both approaches in equal measure recognize “the cruciality of a sense of identity, empathy and engagement for optimal clinical care and the value and impact of life experiences for the development in each individual of personalized medicine and health” (ibid.:331)? In other words does “empowerment” mean one and the same thing in the two cases? Also, given the dream of faster and more appropriate means of treatment afforded by advances in pharmacogenetics and new diagnostic methods, what are the expectations and values typically associated with or projected into this powerful technoscientific imaginary? (Hedgecoe 2004, 2006; Hedgecoe and Martin 2003). And who, ultimately, establishes “the conventions that underlie practices, which define the criteria that turn tools and novel entities into operational components of clinical settings? (Bourret 2005:41).

A further question concerns the evidence-based movement and what it implies for person-centred medicine. A workshop can fruitfully explore some tensions between the evidence-based medicine movement and the movement for person-centred medicine, first of all on the conceptual level, secondly with regard to their significance and implications for clinical practices, and thirdly concerning policy options. EBM has considerable force today on the policy level, and evidence-basing of person-centredness obviously has hitherto insufficiently analysed implications for the levels both of policy-making and everyday practices in the care-giving clinic.

In order to improve practice along the guidelines provided by evidence studies, the latter still has to get slotted into a given situation. It does not become person-centred until one can find the “person/patient” in the evidence-based statistical surveys. Here again belief in technologies fosters the idea that treatment strategies can proceed quicker and easier if there is a suitable evidence-base. But since the technologies are, in turn, again dependent and founded on evidence-based knowledge the end result may well be that individuals still tend to get reconstructed in the idiom of the evidence paradigm. This question must also be born in mind in the sections below where we touch on the matter of how evidence gets constructed as “Evidence”, and respectively, personalisation of medical intervention.

Theories originating in sociology give primacy to norms embedded in social structures and will therefore point to the importance of developing cooperative social networks around the patient, for example in improving patient adherence in cardiac rehabilitation. Legislation against smoking in public places together with peer pressure appears to be an important factor in reducing smoking-related diseases. Health guidelines, standards and standardization are, however, in and of themselves insufficient and the idea of a “standard world” is not achievable, nor is it appealing if it implies a realization of Robert Musil’s world (Timmermans & Almeling 2009; Timmermans & Epstein 2010; Payne 2009).

Health belief models emphasize cognitive dimensions and capacity building in education and learning. Adherence models constructed to identify various behavioural factors and monitoring them are usefully complemented by norms and educational approaches. Self-management education for adults with welfare diseases has been subject to systematic review but much remains to be done in this respect (for Type 2 diabetes see for example Norris et al. 2002). Some recent developments in information and communication technologies (ICT) have influenced conceptions of ambulatory medicine and help reinforce a shift in focus from adherence to social self-regulation.

Some experts see technologies such as telemedicine as positively influencing incentive structures in patients' social environment and enhancing methods of (self-) monitoring. This view also finds support in STS (May et al. 2003). Pharmoeconomics is a further field where patient adherence is studied, providing knowledge for arguments to reduce the costs that non-adherence incurs both for the patient and his/her family etc. and for society.

One major barrier that health economics must take into account is access to the health system, which for a number of reasons is not necessarily equal for all potential users of health care and preventive medicine services. Here considerations of health insurance systems play in, as do demographic differences, or aspects of class, gender and cultural tradition. In some cases health reimbursement mechanisms may constitute a barrier for use of evidence-based models of care in as far as these are based on standardization; this creates a skew wherewith incentives for individualized care management or specialty consultation services that may be affiliated with collaborative care models are discouraged.

EVIDENCE-BASED MEDICAL DECISIONS AND DIFFERENT TYPES OF EXPERTISE

Shifting the focus to the evidence side of the equation the following two sections will introduce discussions of the relevance of evidence, different notions of expertise and competing definitions of evidence. Thus attending to issues of knowledge production and transfer will ultimately lead back to how persons/patients are configured. The emerging field of telemedicine will be a case in point.

Although advances have been made in health promotion to generate readily accessible systematic reviews of evidence on the effectiveness of interventions and programs, degrees of uptake of such knowledge in decision-making about health promotion interventions varies and is unclear. This is a problem addressed by political science and policy research. Two questions that stand out are:

1. Is the evidence that is available on the effectiveness of interventions actually relevant and useful to current policy and practice contexts?
2. What is the researcher's or reviewer's role in interpreting the available evidence and advocating action based on their interpretations? (Rychetnek & Wise 2004).

It has also been suggested that it may be more important how evidence is utilized than how it is defined. Based on the research and knowledge utilization literature, process models of evidence utilization provide a framework studying context-based evidence-based decision-making (Dobrov et al. 2004). Another dimension highlighted in the policy literature is the significance of management methods and the shift from public to private sector approaches, e.g., New Public Management (Vedung 2010). Here one finds arguments that hold the emphasis on competitiveness, the creation of quasi-markets in the health care sector and new audit cultures may have effects at a macro-level (Lane 2000) and in turn tend change processes at micro- and meso-levels of governance and systems for patient self-regulation (van Essen 2005 & 2009).

Systems for patient self-regulation also have a bearing on the epistemological issue of who may be considered to be an expert, who not, and why. In some of the literature on user participation in decision-making regarding science and technology (sometimes referred to as technoscience) the claim is sometimes made that laypersons are experts in their own right when the technoscientific imaginaries envisaged have a strong bearing on their life conditions. Therewith, it is held, the boundary between expert and lay knowledge changes. This view has also been underpinned by other arguments, for example based on the role of tacit knowledge. In recent years this same view, linked to a discourse on democratization of science and technology – within STS – has been challenged and countered by Harry Collins and Robert Evans at the School of Social Sciences at Cardiff University (Collins and Evans 2007; see also Collins 2007 & 2010).

They have introduced a threefold typology of different types of expertise. Apart from the formal propositional knowledge of the physicist or astronomer, for example, Collins identifies two other forms of expertise. The one is called “contributory expertise”, which is what a layperson can have if s/he is fully immersed in the specialist language of a specific research culture but not an actual practitioner in it (for example not a physicist in his or her own right). This is distinguished from what they call “interactional expertise”, referring to the case where the layperson is immersed in the specialist linguistic culture pertaining to the practical domain rather than the practice itself (Collins 2004). The typology has relevant implications for an analysis of the tension between evidence-based expertise advocated by specialists in the know and the personal knowledge of

patients who in their own way are also “in the know”. Further, the distinctions are important to keep in mind when dealing with the question of the role of patient organizations in contending with particular disease categories (see below).

Articulating evidence-based policy options and assessing their viability is also a problem area addressed by medical sociologists. In the field of public health and epidemiology with a bearing on the dual questions of evidence and adherence contextual contingencies relating to socio-economic status and migration are seen to be significant (Magnusson 2011).

Public health specialists when they strive to rise to the challenge of evidence-based practice tend to be frustrated by the experience that “most of the evidence is not very practice-based” (Green 2006:406). Some contemplate the possibility that systems thinking and modelling might offer an alternative by developing controlled trials with simulation as a source of evidence. The idea is that complex systemic indicator studies and modelling might be a way to take into account and make sense of a myriad of mediating and moderating variables that come into play when a proposed intervention has passed the efficacy test of clinical trials and is taken to scale from its controlled experimental setting to large communities or populations with an eye to disease control and prevention (ibid.:408).

THE QUESTION OF HOW EVIDENCE IS SHAPED AS “EVIDENCE”

The question of how evidence gets constructed as “Evidence” has preoccupied scholars in STS. A number of important distinctions have been introduced between information, data, scientific knowledge and different kinds of transdisciplinary expertise. Formalization and methodologies of standardization as central ingredients in the production of stable socially robust knowledge claims utilizable as a basis for decisions on disease preventive strategies and medical interventions is another dimension studied (Bohlin & Sager 2010).

The production of guidelines and procedures to steer clinical testing has likewise come under critical scrutiny. It is clear that a narrow concept of evidence is predicated on belief in the superiority of randomized clinical trials as a gold standard in knowledge bases for decision-making in health care and preventive medicine. This approach has been contrasted with broader concepts like “critical appraisal” that challenge the formalists’ tendency to monopolize the notion of “evidence”. Therewith the problem is linked to the one of reflexivity and a closer study of preferred epistemologies as well as the “politics of evidence” (Foss Hansen & Rieper 2010).

In the more critical reflexive perspective it is shown that internal stringency of randomized studies cannot be equated with external relevance of the evidential

weight when it comes to practice in real life cases of clinical treatment. Whereas “precision” and constructing evidential claims so that they by virtue of standardization may easily travel over distance (rubbing out individual case-specific particulars) tends to assure verifiability and hence enhances their credibility, this does not increase the relevance of recommended measures in the face of non-standard therapeutic situations (Helgesson 2010).

Demanding high levels of adherence, paradoxically, introduces a further complication when research results are translated to meet everyday clinical reality. A high level of adherence is important in clinical tests while at the same time in some areas low adherence prevails in clinical practice. Thus studies with high adherence (in clinical tests) imply lower external validity; however it is hardly reasonable to wish for lower adherence in the tests in order to render the studies more representative of clinical practice (Helgesson 2004).

The foregoing arguments may also be extended to the issues of adherence and individual self-regulation or expert (outside) monitoring (with advanced technical devices) of patients. The difference here is parallel to the one between an algorithmic or procedural model of expert evidencing and a socialization model that emphasizes contextual contingencies, learning and “intangibles” like social trust and tacit knowledge (Bohlin and Sager 2010: 221).

As just indicated, standardized patient models raise new problems when individuals fall outside the range of the norm, whereas discretionary decision-making based on the health practitioner’s accumulation of tacit knowledge perhaps may more readily deal with “deviance”. Critics of EBM react against a perceived tendency to favour one-fits-all types of intervention; in obstetrics, for example, it appears that in developing countries the influence of EBM and risk avoidance consciousness has led to a noticeable increase in elective caesarean births (Wendland 2007; cf. also Behague, D. et al. 2009).

An obviously important technological development that impacts patient-physician relationships more generally is the advent of the Internet and the consequent consumer access to health information. An indirectly related technological dimension appears in genetics and biotechnology that spur novel forms of personalized medicine, which in turn put new demands on detailed information flows between patients and their physicians for both diagnosis and treatment. This also ties in with the impact of genomics on the prescription drug market that gives the biotechnology sector a growing share of the pharmaceutical industry as a whole if one considers the largest 25 companies in the world in terms of sales of human prescription drugs and vaccines (Camacho 2009).

Relevant here is the work of Carl R. May (May et al. 2003), Professor of Healthcare Innovation at the University of South Hampton in the UK, who on the basis of constructivist analysis associated with STS has addressed problems of expert-patient interfaces and patient adherence in, for example, tele-medical systems. He asks if in new technologies may possibly afford a new way to bridge the gap between the heterogeneous life-world of the patient and the codified world of evidence-based medicine, bringing together qualitative discretionary knowledge and EBM-generated quantitative knowledge and clinical guidelines based on the latter to manage illness.

When embedded in a patient-centred preventive health care system telemedicine may be seen as a system that gives flexibility with patients' use or self-surveillance of prescribed health parameters. As a complement to traditional face-to-face encounters with physicians the methods may increase adherence to a prescribed medication regimen. There is a large market targeting lifestyle diseases; self-use toolkits are tailored to monitor vital indicators. Examples are asthma, Type 2 diabetes, hypertonia, obesity and secondary hyperlipidemia or hypercholesterolemia.

A recent evidence study in the USA reports on a search of five databases (PubMed, CINAHL, PsycINFO, EMBASE, and ProQuest) from 1995 to September 2009 to collect evidence on the impact of blood pressure (BP) telemonitoring on BP control and other outcomes in telemonitoring studies involving patients with hypertension as a primary diagnosis. Most studies looked at different measures of antihypertensive medication use. On the basis of fifteen articles that met the review criteria BP telemonitoring was found to reduce BP in all but two cases. Although some papers reviewed also included secondary outcomes such as healthcare utilization and cost evidence in those respects the outcome was less robust. Adherence with BP telemonitoring among patients was favourable, but physician adherence with examining BP information was not well documented or poor (AbuDagga et al. 2010).

May et al. (2006) refer to tele-medical activities as a new kind of clinical encounter in which non-human actors (technological aids) function as intermediaries in doctor-patient interactions, reducing hospital admissions. They note that "(M)uch of this field of practice is about shifting medicine and health care away from hospitals and back into the local community" (ibid.:1027). The shift brings into play new practices of governance, also called "technogovernance", in which "intermediaries are deployed to discipline and frame the individual subjectivities of both patient and doctor...and act to distribute accountabilities". Further, the epistemological authority of *both* the doctor's EBM-supported position and the patient's narratives that now include accounts of technologically generated self-knowledge, it is argued, are enhanced.

PERSONALISATION OF MEDICAL INTERVENTION, SELF-CARE, AND TECHNOLOGICAL MEDIATION

Telemedicine is of course not the only game in town. An overview of a whole range of self-management tools, a typology of differing device complexities and a discussion of four forces influencing the rapid development of a new market (clinical care, economics and politics, consumerism, and technological innovation) may be found in Barrett (2005). If technologies are considered as mediators between physicians and patients a further classification may distinguish information and communication technologies (ICT) from varieties of pharmaceutical, biotechnology and therapeutic medical devices. The devices may function as mediators between a person using them and the physician. With self-managing patients the role of the physicians then shifts from being a deliverer of medical care to that of a supervisor (Willems 2000).

It remains an open question however – and this is something our project would also investigate – if this development entails added democratization because patients experience a greater amount of individualization and person-centred care. Or, on the other hand, despite the patient's feeling that the encounter with the doctor is more democratic and participatory, may it be that the new methods actually represent a retrenchment of the evidence-paradigm in a new form? This is particularly pertinent to consider for areas where treatments also have clear population-related differences in mainstream practices.

Retrenchment might well be the case in as far as the new technology now shapes the patient's self-understanding in parametric terms based on categories inscribed in the virtual world supplied by the non-human actor. Jürgen Habermas in his younger days might have called it a further technification of the patient's life-world.

Discourse analysts of healthcare communications meanwhile point out how there is also a process in the other direction whereby medically literate patients develop their own expertise and now colonize the physician's world as they mingle professional with lay experiential talk (Candlin 2000). Physicians for their part take on hybridised modes of speaking, interpellating discourses of the patients' life-world in their discourses in the clinic; thus simple opposition between the patient's life-world and the doctor's medical world are seen to break down. The shift has also been described as one from a white-coat model to one of shared decision-making (Camacho et al. 2009).

Shared decision-making (SDM) involves negotiations. The notion of "negotiation", however, is rather general and has to be complemented with conceptual analysis in order to clarify and articulate various converging and competing values and ideals

of health care held by different actors or inscribed in existing institutional and technological arrangements. Sandman and Munthe provide a valuable point of departure in this regard; in their view SDM entails on a number of necessary conditions (Sandman and Munthe 2010:6):

1. At a minimum, both the physician and patient are involved in the treatment decision-making process.
2. Both physician and patient share information with each other.
3. Both the physician and the patient take steps to participate in the decision-making process by expressing treatment preferences.
4. A treatment decision is made and both physician and patient agree on the treatment to implement.

In their analysis of physician-patient interplay Sandman and Munthe distinguish several ideal-typical models of interaction ranging from traditional paternalism to new forms of patient choice, and they explore how aspects of these in different ways are incorporated in SDM. On this basis four alternative SDM models stand out. These are characterized by four different ways of obtaining a balance of the following values: *the patient's best interests, patient autonomy, effective decision for affording patient compliance or adherence, and a continued care relationship*. The four respective models are referred to as (i) Shared Rational Deliberative Patient Choice; (ii) Shared Rational Deliberative Paternalism; (iii) Shared Rational Deliberative Joint Decision; and (iv) Professionally Driven Best Interest Compromise. The authors discuss the dynamics of these models and then argue in favour of the fourth option as the most desirable one. (For a broader discussion of values relating to health care, see Zuiderent-Jerak 2007, 2009, Thévenot 2009, and also cf. Elzinga 2006.)

Paternalism refers to the traditional mode of decision-making where the professional makes the decision based on what she finds to be in the patient's best interest. Patient choice on the other hand refers to the situation where the patient makes the decision on the basis of information received from the professional, either without the latter's prompting, or with the professional helping the patient interpret her own preferences before she makes a decision in the situation at hand. The second of these two modes of patient choice is also called "interpretative patient choice"; here the professional makes the decision on the basis of the patient's preferences without letting the professional's own preferences influence the choice of treatment. The fourth possibility, finally, characterizes the situation where the professional and the patient arrive at a compromise in which the

professional's assessment of what is in the best interest of the patient carries more weight.

The point of the conceptual analysis and the resulting typology of SDM models is to provide an heuristic scheme for articulating values and choices and tracing the dynamics of differing trajectories that, in turn, also will depend on the relative degree of proactiveness of either partner as well as variations in institutional culture.

Shared decision-making has several consequences. First it places a new burden on both patients/clients and professionals. Secondly in professional bodies one finds a shift in stance from the *compliance* metaphor to one of *concordance*, emphasizing a sharing of information, responsibility and agency, ideally on a basis of greater equality in patient-physician encounters. Thirdly, in these encounters discourse and meanings are co-constructed, while at the same time they allow for multiple interpretations (interpretative flexibility). An example given by Christopher Candlin is the term "viral load", a medical term originally referring to a human biological property having to do with the level of plasma viral RNA, or less technically, the amount of HIV in the blood of an infected patient. For the physician it may also be an indicator of treatment effectiveness (i.e., a second meaning), or an indicator of treatment compliance on the part of the patient (third meaning); for the patient it may at the same time be an indicator of personal wellness (fourth meaning – good if viral load is low, bad if viral load is high). Thus four different meanings of viral load may be in play in the patient-physician encounter, possibly giving rise to communicative and interpretative difficulties to be overcome to gain mutual understanding and situations of concordance.

The situation is even more complicated if one considers how the narratives alluded to here in turn interfoliate into discourses of health, two institutionalized ones and the third personal and subjective: (1) a discourse of health care with a language of treatment goals, treatment decisions, hypothesis and inference; (2) a discourse of health measurement with a language of biomedical, objective, measurable targets relating, for example, to a specific illness; and (3) a discourse of health experience with a language of subjective immeasurable person-bound qualities. The balance of institutionalized power in this equation suggests that even if healthcare professionals' communicative practices become more enlightened and sensitized to patient wellness, residuals of a paternalistic model of healthcare delivery will mostly continue to be reproduced.

There is a further complexity that must be taken into account. Candlin deals mostly with the relationship between physician and patient. However in modern hospital and health care one finds a situation – particularly when it concerns chronic diseases – that care is delivered by teams comprising a doctor, nurse, physical

therapist, psychologist, curator, etc. Consequently it is possible also to study the “multiple body” situation along the lines suggested by political scientist, philosopher of science and medical ethnographer, professor Annemarie Mol at the University of Amsterdam (Mol 2002, 2008 and Berg and Mol 1998). The interpretative flexibility of “measurements” becomes even larger than the four here discussed with reference to Candlin.

TECHNOGOVERNANCE – ONTOLOGIES AND EPISTEMOLOGIES

Interesting parallels of technogovernance manifested in practices of coaching and individual athletes’ self-surveillance and management of the body in several elite sports may also be worth exploring (markets, methods, motives and technified performance – cf. Kasperowski forthcoming). Coaching is a term that has become prevalent in many walks of life, from job-hunting to user participation in science and preventive health. Comparison of the concept’s usage in such diverse contexts as sports, clinical medicine and health care delivery may prove instructive (cf. also above the notion of the self-managing patient and the doctor as supervisor – Willems 2000). In elite sports there is also an issue of standards and norms, but in this case exceptional ability or deviation from the average is of prime importance while at the same time the ideal of equal opportunity also has to be factored in at an institutional level (Kasperowski 2009).

Another entry into the discussion of “technogovernance” in preventive health care touches ontological and epistemological questions. Here critical deconstruction of the very notion of the “new” is important in analyzing discourses on the benefits of telemedicine without getting captured by them. Distance and reflexivity is necessary when seeking to understand what professor of Anthropology of Science and Technology in the Department of Sociology at Lancaster University, Lucy Suchman, refers to as the moving interface between bio- and techno, bodies and machines in modern biomedicine. In a recent anthology edited by Ericka Johnson and Boel Berner (2010) she reflects on how medical practices are restaged and/or transformed in meetings between professionals, patients and their kin as bodily encounters that are crucially mediated and made sense of through machines (Suchman 2010).

So where does this leave us? Can it be said that “patienthood” conceived as a “construct” is differently understood in the policy context, and respectively by the patient, by next of kin and by the physician since it is shaped by both coaching and bio/techno boundary management? (Cf. also Landzelius 2006). The concept of “patienthood” like that of “scientific citizenship” also warrants a metatheoretical analysis in a reflexive theory of science tradition in STS (read *Wissenschaftsforschung*).

Strong economic and political forces, as well as new and emerging technologies are driving the current trend of Predictive, Preventive and Personalised Medicine (PPPM). Closely associated is a dream of using pharmacogenetically based knowledge in diagnostic devices to speed up patient throughput and tailor medical treatment to fit individual patient needs at the Point of Care (PoC), i.e., in the clinics. Speedy diagnoses and individualisation of medicines prescribed, furthermore, promise major cost reductions, an aspect welcomed by health administrators. Patient organisations on their side pin hopes on more effective treatments of diseases associated with specific genetic characteristics (biomarkers) as a road to more durable wellness as research, for example, is enabling the development of medicines which are effective in a relatively small proportion of patients. In other words a further driving force is an ideational one relating to pharmacogenetics (genomics, proteomics and other “-omics”) as a powerful technoscientific imaginary. With it perceptions of disease, ontologies and epistemologies are changing, and so probably – with considerable lag - will the underpinning structures of institutional arrangements and professions concerned with or directly involved in healthcare.

Molecular diagnostic technologies challenge a healthcare and financial system that has long depended on visible symptoms and gross clinical classification. As diseases are (re-)classified into distinct molecular subcategories there will be pressures to move away from the traditional pharmaceutical business economic models that focus on “one-size-fits all” drugs (Paci and Ibarreta 2009).

According to a BCC Market Research report published in the UK in July 2009 (BCC 2009 Press release) the global market for personalised medicine technology was projected to be 14.4 billion US dollars in 2009 and it was expected to more than double over a five year period to reach 29.2 billion US dollars in 2014.² It was noted that within this overall projection “pharmogogenomics is a major revenue generating market”, making up 4.1 billion dollars of the total personalised medicine market in 2009, and this segment will probably count for a market value of 9.5 billion US dollars in 2014. The next largest market segment is the “point-of-care market”, with 2.7 billion US dollars 2009 and expected to increase to 9.5 billion dollars by 2014. Other segments mentioned are: pharmaproteomics technologies, pharmacokinetics, pharmacogenetics, pharmacodynamics, stem cell therapy, metabolomics.

Point-of-care (PoC) medicine is a concept that has come into the literature to cover techniques for making the right *diagnosis* and start the right treatment immediately in first contact with the patient. Personalised medicine is the concept of *customising* an optimum treatment based upon detailed and specific genetic information about

² <http://www.bccresearch.com/report/personalized-medicine-phm044b.html>

the patient, and in order to tailor medication to the individual's needs. Both concepts and the practices they entail bring with them a variety of evidence-questions. These must be tackled successively as pharmacogenetic tests come on line to provide the key link to personalised medicine. Identifying patients most likely to respond to a particular drug is a process that requires (a) identifying, (b) developing and (c) validating "biomarkers", e.g. for diabetes, heart disease, cancer, etc. The technologies implied - for their development and marketing - also face several institutional "hurdles" before they are adopted into mainstream medicine: viz., regulation, reimbursement, physician education, as well as ethical, legal and societal concerns (Royal Society 2005; Martin et al. 2006; European Commission 2007).

Point of care (PoC) testing accounts for about 1/3 of the global in vitro diagnostics (IVD) market (BBC 2009). Rapid tests at the PoC by healthcare professionals or by patients in their own home are revolutionizing the diagnostics sector. Driven by the need for earlier, accurate diagnostic information to guide critical clinical decisions, technology advances including miniaturization are enhancing the role of diagnostic tests in healthcare systems. Products used in diabetes care make up the largest segment of the PoC market. Other important areas are urinary tract infections, tuberculosis, heart failure, early distant warning for stroke, bladder cancer tests.

Home use tests for HIV underline the need for quality control, insurance, and prevention of misuse of tests. Insurance companies are also making inroads into the personalised medicine market. Apart from safety and quality, another important requirement is that testing devices be user friendly. They must be convenient and simple to use, while also meeting the connectivity requirements of healthcare systems.

Some studies predict a future where new technologies will replace the traditional physician's reliance on their senses – vision, hearing and touch. Molecular diagnostics requires genetic literacy, and the genetic approach helps enhance the doctor's "senses" while customising treatments and prevention strategies for individual patients (Pai 2009). Furthermore as diagnosing illness and monitoring a patient's condition gets increasingly automated and technologised, self-managed diagnostic devices place this part of the process in the hands of the patients themselves. Since the era of personalised medicine is touching millions of people it is expected this will also change disease perception and management.

Larry Hood, the inventor of the first automated DNA sequencing machine claims that "personalised medicine is too narrow a view of what is coming" (Singer 2010). The shift will be much broader, including a move from *reactive* medicine to *proactive* medicine. Medical practice of the future, he says, is characterized 4 "P"s:

Powerfully Predictive, Personalised and Preventive, with a focus on wellness and patient participation. Technologies identified as important in this context are:

- Digital technology to store and manage medical records with genetic information (this will also require suitable security systems to assure personal integrity)
- Nanotechnology to measure 2500 proteins from a singled drop of blood is up and coming (on hopes and risks attending *nanomedicine* see European Commission 2007).
- Technology to diagnose and analyse a single cell to immediately inform the physician about normal mechanisms and disease mechanisms in the body
- Computational tools

Even if these developments may not be fully in place until 2020-2025 (Royal Society 2005) they already promise to dilute the traditional health care role of physicians, in as far as nurse practitioners take over functions that used to be performed exclusively by physicians. Thus there will be a sociological shift of a role that used to be dominated by physicians and gave them some of their authority, over to another *profession* – a new class of para-professionals emerges that assume more and more responsibilities as the new and emerging medical technologies come on line. These para-professionals may be expected to rely on technology rather than years of education and experience to diagnose and treat patients. According to the Royal Society report it is clear that in addition all traditional categories of professionals (doctors, nurses, pharmacists) will need a much stronger training in the fundamentals of human genetics to offer and interpret key diagnostic tests. Traditional tacit knowledge and skills therefore will to some extent be replaced by new forms of tacit knowledge associated with genomic literacy and molecularly based disease classification systems.

TRUST AND AUTHORITY – THE EXAMPLE OF SCIENCE ADVISORY BODIES PRODUCING “SERVICEABLE TRUTH”

After exploring the materialities of evidence and the ramifications for the identities of doctors and patients the two final sections widen the discursive scope by bringing in institutional arrangements such as government bodies and patient organizations, which lead back to issues of expertise, evidence and the shifting roles of patients.

Professor in Health Care Governance Roland Bal at Erasmus University in Rotterdam together with colleagues also draw on STS concepts; they do so in a major

evaluation of the efficacy of new approaches to health care delivery in the Netherlands. In a first report they have pinpoint a gap between what they call “the view from nowhere” of evidence based medicine and “local contingencies” (Straating et al. 2008). Referring to contingency theory (Donaldson 2001) they argue that in the context of practice local specificity by and large defines which interventions lead to the best results in an organization (Straating et al. 2008:18). In their introduction to the report the team also cite the Netherlands Health Council (Gezondheidsraad), a scientific advisory body to the Dutch government. In an important advisory report 2000 that Council noted how “approaches within evidence-based medicine have for too long taken the route of ‘implementing’ evidence within healthcare practices, ignoring specific contexts in which both evidence is produced and the practices in which it has to be implemented” (ibid. 5).

The problems of science advice to policy-makers are the topic of a book by Wiebe Bijker, Roland Bal and Ruud Hendriks (2009); the book incorporates interesting findings and reflections in the authors’ close-up study of the inner workings of the “Gezondheidsraad”. The Council is similar to institutions that operate at arms-length from government in various countries. Characteristically it manages to balance meticulous attention to the state of the art scientific knowledge with sensitivity to the policy relevance of the advice delivered. The authors refer to this as the art of being able to produce “serviceable truth”. The Council’s authority rests on its independence from both government and various stakeholders that have particularistic interests in the issues upon which advice is solicited. Vital to the integrity of the process whereby the scientific advice goes from problem identification, striking a committee of experts, expert deliberations and on to the writing of a report for the Minister of Health is the maintenance of confidentiality and involving only recognized experts.

Stakeholders may provide information in various ways, including through hearings on the issue being investigated. They do not, however, enter the process as experts. This goes equally for representatives of industry and patient organizations, respectively, concerned in their different ways with the desirability and efficacy of new medical technologies. To ensure the integrity of the process of expert deliberations the hearings, moreover, are not public; they are held behind closed doors.

When a representative of a patient organization that possesses exceptionally relevant knowledge and can articulate it, that person can be allowed to become a member of the investigatory committee as an “expert”. A patient organization in such a case is by the committee as a whole held to meet the criterion of “maturity”. This status when ascribed a patient organization means that in the organization at hand there is an “absence of a claim culture, no nagging attitude, good insight in the

limitations of medicine, good insight in the relevance of the individual relation of a patient with his doctor, but also a firm sustained notion of the autonomous role that patients should have” (Bijker et al. 2009:87). The “expert” moreover is *à titre personnel*, that is, in her or his personal capacity since the special knowledge is seen as tied to the person. In Britain it is customary to find the same approach. This differs from the German and Swedish traditions where reliance on personal credentials is rare; it is more often the powerful backing of institutional support that decides. In the Swedish case the latter ties in with the oft-cited political culture of liberal corporativism (Elzinga 1982).

An ongoing study in Sweden traces how the country’s National Board of Health and Welfare (NBHW) met critics who pointed to a biological bias in its approach to Attention Deficit/Hyperactivity Disorder (ADHD) in the late 1990s. The ambition to standardize clinical neuropsychiatric practice via a state of the art review in this perspective was complicated by an intense public controversy and led to schisms and negotiations between the Agency’s medical and social service sections and eventually a compromise position in the final report which in turn reflected a partial move from governance through eminence towards governance through evidence. Important in this process was working behind closed doors to assemble evidence and arrive at consensus and rehearsing backstage (backstaging) before making information public. This strategy was at the same time an important ingredient in the Board’s effort to re-enhance its credibility and maintain epistemic and political authority (Hoshor forthcoming).

Sheila Jasanoff in a number of comparative studies of the implementation of “regulatory science” in different countries uses the term “civic epistemologies” to distinguish country-specific differences in science advisory processes and procedures. Bijker et al. draw upon Jasanoff’s work, and hence in their analysis of the Gezondheidsraad the “expert” is taken to be a “social kind who has to be accountable as well as knowledgeable” (ibid.:85, citing Jasanoff 2005: 267).

In clarifying the role of patient organizations and their representatives Bijker et al. also make use of Collins and Evans’ typology relating to different kinds of expertise, noting the fine line that separates interactional expertise from contributory expertise (see above). In other words the hearings referred to above is referred to as a mechanism for attributing “contributory expertise” to patients, whereas patients who only participate in the hearings (but are not “experts”) do so in their capacity as possessing “interactional expertise”, as well as the willingness to engage in interaction under the conditions laid down the expert body, the Gezondheidsraad.

Melissa Leach at Sussex University in her recent work has also explored the politics of science and knowledge in policy processes linked to health care; she and co-

workers address - among other - cultural and political dimensions of vaccine delivery (including aspects like social justice and the disadvantaged position of poor and marginalized people in society), medical research trials and the medical establishment's (in)ability to adequately deal with emerging infectious diseases (Dry & Leach 2010).

CHANGING GOALS AND RECONFIGURATIONS OF PATIENT ORGANISATIONS

Another important question regarding democracy in governance of health and preventive care has to do with the role of patient organizations. During the past couple of decades there has been a trend where these have become much more vocal, not least concerning biomedical research. Information and communication technologies (ICT) are an important dimension in this changing landscape. Whether or not these enhance new forms of democracy is an issue of contention along lines similar to opposing views regarding the question of "scientific citizenship" (Bertilsson & Elam 2003; on the agonistic mode see further Mouffe 1999 & 2000). Additionally, a distinction must be made between patient organizations and various kinds of patient driven supportive networks or lobby organization that serve as a resource for participants' individual self-management as mentioned above in connection with telemedical monitoring systems. These constitute new types of epistemic communities (Akrich 2010). For *life-style diseases* this is an important development. Patient organisations relating to diabetes and obesity, for example, appear to have more the character of supportive networks organizations than the kind of advocacy organisations that have grown up around HIV/AIDS or rare diseases.

In January 2011 the European Association for the Study of Obesity (EASO, estd. 1986) and European Obesity Day (EOD) forged a strategic partnership, launching the 'European Obesity Community' to combat soaring obesity rates across Europe. EASO prides itself as the cornerstone of European obesity science and innovation while EOD provides a high-visibility campaigning platform to engage patient and consumers, healthcare professionals and politicians.

Another example that gives an idea of what a network of this kind entails is the Irritable Bowel Syndrome (IBS) Self Help and Support Group (est. 1987). It is a patient advocate group in support of self-management for those who suffer from IBS, those who are looking for support from someone who has IBS, and medical professionals who want to learn more about IBS. Much of the involvement in this group involves members sharing their knowledge in the group's forums. In addition to forums, there is a website that provides electronic links, booklists, Apple iPhone, iPad, iPod Touch, Android and Blackberry device apps and media, research studies,

brochures, medical tests, diagnostic criteria, recommended diets and treatments for the disease.³

During the past twenty years increasing numbers of STS scholars have made studies of the influence of patient groups, disability organizations and related social movements on research. As explained by a pioneer in this development, sociologist Steven Epstein at Northwestern University in the USA, it reflects a movement in STS “beyond the lab”, new approaches to public understanding of science and a more recent so-called “policy turn”. Professor Epstein himself is especially known for two books that have had significant impact: *Impure Science: AIDS, Activism, and the Politics of Knowledge* (California, 1996), and *Inclusion: The Politics of Difference in Medical Research* (Chicago, 2007). Most recently, he is a co-editor of *Three Shots at Prevention: The HPV Vaccine and the Politics of Medicine’s Simple Solutions* (Johns Hopkins, 2010). His review article (Epstein 2000) gives a comprehensive overview of driving factors, conceptual frames and research agendas in what now is a vital field in STS (cf. Epstein 1995). His discussion of the lay-expert divide and the distinction between “lay expert” activists and “lay lay” activists has helped nuance different positions a shifting range from expert to activist where epistemic and political dimensions both collide and converge (Epstein 1996).

Stuart Blume, now Emeritus at the University of Amsterdam, has recently come with a major book on the subject in relation to cochlear implants and the culture of deafness (Blume 2010a). His current research focuses on the history and dynamics of the global vaccine system and, secondly, the development and uses of technologies for and by people with disabilities. In 2000 he established *the Innovia Foundation on Medicine Technology and Society* as a virtual research institute concerned with user perspectives on new health care technologies. Innovia’s rationale derives from the idea that research taking the lived experience of illness and disability as its starting point, suitably synthesised and made accessible, can be a valuable resource in the empowerment of people whose ill health or disability renders them vulnerable or disadvantaged. The Foundation produces a Newsletter. Regarding contextual problems of evidence and adherence mention must also be made of Blume’s work on the history and politics of vaccination (Blume & Geesink 2000; Blume & Rose 2004; Blume 2005).

As already noted, Blume emphasizes the importance of narratives to enhance authenticity in person-centred medicine and health care, a view apparently shared by the prime movers in the International Network for Person-Centred Medicine that is effecting a turn whereby the category “patient” is in part replaced by that of personhood.

³ Cf. further <http://www.patientsorganizations.org/>

At the Centre Sociologie de l'Innovation (CSI), L'École des Mines, Paris, several researchers have over the years produced novel studies on medicine and health. Three main objectives are covered within this broad theme: to analyze the role of patients' organizations in the structuring of spaces for expression and intervention (scientific, medical, political, economic, etc.), to study the emergence of new forms of knowledge production (and the participation of new collectives in this process, such as patients' organizations), and to understand the regulatory, ethical and political challenges in the field of health and medicine. Madeleine Akrich, Vololona Rabeharisoa, Michel Callon, Florence Paterson, Catherine Rémy and several other researchers are active in this area.

The role of patient organisations in the production and circulation of knowledge is of particular interest. Rabehaisoa has developed a useful typology of different models of patient organizations, ranging from the traditional lay groups who try to make their problems visible for scientists, to activist organizations that have a capacity to procure research and set agendas, and over to a newer model of reciprocal interplay between patient organization and researchers in the context of which new research projects are defined (e.g., Callon, M. and Rabehaisoa, V. 2008; Rabehaisoa, V undated – STAGE Project paper). Three models of patient self-help are identified as having developed over the course of more than fifty years to reshape the relations between experts and lay people.

The first is the traditional "mutual-help model" found in organizations like the Alcoholics Anonymous where the idea is mainly one of exchanging the experiences between individuals suffering from the same disease. This approach was challenged in the 1960s-1970s for being too much enclosed in themselves and refusing to articulate their problems in the public space. This paved the way for the second model, called the "advocacy model", entailing a struggle for public recognition. In the 1980s-1990s this led to a quest for empowerment as witnessed by the birth of numerous patient organizations demanding not only the right to information on activities concerning them, but also the right to intervene in these activities.

This led to the third model, referred to as the "self-description model". It is based on an identity claim: patients no longer accepted the idea of being defined in a negative way interrelating to experts and professionals. Here the disease is somehow an open entity and the patient organization has a collective identity that now refuses to accept the pre-eminence of experts and professionals when it comes to the definition and management of the disease. The circulation of "patient knowledge" becomes an important ingredient in objectifying disease-specific collective experiences. Today all three models coexist and interact. An important part of the SCI-group's work has been - on the basis of various case studies - to analyse and contrast the different forms of engagement of patient organisations

into research and the “configurations” involved in each of the three models – (1) auxiliary and lay-expert configurations (leaving research agendas to outside experts and commissioning research from these and helping to fund it); (2) emancipatory configuration (freeing patient organizations from specialists’ monopolies of disease definition and intervention); and (3) partnership configuration, involving mutual collaboration between patients and experts. The third approach represents a relatively more advanced form co-production of knowledge between lay people and “experts”. Each of the three configurations entails epistemological and political dimensions that are fruitfully contrasted.

CONCLUDING REMARKS: POSSIBLE RE-CONCEPTUALIZATION?

In order to see the central questions about evidence and patients anew, we suggest a special focus on the movements, practices and technologies of medical knowledge and the resulting emerging mutualities between actors. These aspects of medical knowledge can be analyzed in turn, and together, through three analytical lenses. First, medical knowledge exists as *expertise travelling* through health care systems, from medical companies, state authorities, expert bodies and patient organizations, to individual treatment decisions between doctors, clinical teams and patients. Second, various material cultures are utilized when expertise travels. It may be technological devices or genetic microarrays that are supposed to enhance the interaction between the health care system and patients, or it may be guidelines, protocols, algorithms or even organizational forms, such as formal or informal networks. Different *materialities afford* different relationships between actors in the health care systems, for example, patients are empowered or disempowered, or doctors’ autonomy is confirmed or constrained. Third, the travelling and affordance of expertise can be understood as various forms of governance; governance then as a composite of the materialities involved when knowledge is produced and set in motion through health care systems. Using this heuristic scheme, we believe, it may be both interesting and policy relevant to identify ideal typical patterns or configurations for purposes of comparative analysis across disease categories and governance approaches in different countries.

THE ROAD AHEAD: PREPARING FOR A WORKSHOP IN APRIL 2012

INTRODUCTION

With the foregoing position paper (written in April 2011) as a point of departure, the SMEC group will now start working along two lines of action.

Firstly, we will in contact with possible partners and workshop participants discuss and further develop the empirical and theoretical focus of the workshop. Can the suggested three-folded concepts of travelling expertise, affordance of expertise and governance of expertise serve as a common analytical framework? Which health-related problems and diseases are interesting and meaningful to study on a comparative European level? Comments are also invited on questions of methodology (“comparativeness”), political relevance and subject matter.

Secondly, the SMEC-group will present a paper at the 4S Conference at Cleveland, Ohio, in November 2012. This will be in a session organized by Richard Tutton, Lancaster University, UK and Michelle McGowan, Case Western Reserve University, US. The session theme is “Personalizing Medicine: Futures, Past and Present” and the session abstract reads as follows:

In histories of medicine in the twentieth century there is little or no reference to personalized or individualized medicine. Yet, in the first decade of this century, these have become powerful and persuasive visions of how medicine should be practiced in the near future. The 2007 National Institutes of Health report on personalized medicine articulates a future in which healthcare professionals customize treatment to individuals based on information about their genotype, and work alongside increasingly scientifically literate patients who will actively shape their own treatment plans through generating personal data on their gene sequences, family histories, etc. The vision of personalized medicine therefore anticipates a potential reconfiguration of the sociotechnical relationships between healthcare organizations and patients who will utilize a range of health-related services. This vision of personalized medicine represents what Michel Callon calls the irrepressible movement in contemporary markets towards the singularization of goods and services. This session includes empirical, theoretical and historical studies on personalized medicine from Science and Technology Studies perspectives. Papers in the session address questions such as: How are doctors and researchers anticipating personalized medicine? What kind of "users" are imagined and enacted by these visions? What instruments, devices and services are patients utilizing in pursuit of personalized health and wellbeing? How are contemporary commitments to personalized medicine prefigured by previous debates within medicine?

The paper to be presented by the SMEC group within this session has the following abstract:

Between evidence, persons, and things: Travelling, affordance and governance of expertise in personalized medicine. A paper presented by the SMEC-group, represented by Aant Elzinga, Fredrik Bragesjö, Amelie Hoshor, Dick Kasperowski, and Morten Sager, Department of Philosophy, Linguistics and Theory of Science, University of Gothenburg, Sweden.

The paper delineates some recent work being developed on pertinent dimensions in a perceived gap between evidence-based medicine and personalized medicine. The approach is mainly conceptual. The approach is informed by investigations of ramifications of a recent movement from patient-based medicine to individualization and personalisation in the management of health care. In addition it takes account of the role of new and emerging technologies in efforts to bridge the cited gap with special reference to three dimensions of expertise: we refer to these as the travelling, governance and affordance of expertise. Expertise then is taken to include inscription of rules and procedures in monitoring devices. Questions asked are: what kinds of technologies typically come into play; what modes of governance are therewith enhanced or, respectively, marginalized; what repertoires of “objectivity” are preferred or shaped when expertise is transported and embedded in technologies? Closely related is the question of what types of authority that may be associated with these “epistemologies” ranging from the charismatic to the institutional and technological? Given our analytic tri-focal lens of travelling, affordance and governance of expertise, we expect to elucidate the ways in which evidence-based and personalized medicine interact and construct identities of patients, staff, and next of kin. The purpose of the paper is, first, to invite comments on the conceptual take and, second, to receive viewpoints on future directions of the research program.

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APPENDIX I

SOME EU PROJECTS CONTAINING STUDIES OF MEDICINE, EXPERTISE AND CONTROVERSY

The European Commission has funded both the thematic network (Identifying Trends in European Medical Space. Contribution of social and human sciences, FP5) and MEDUSE (Governance, health, and medicine Fp 6) aimed at setting up a dialogue between social scientists and non-academic actors directly concerned with three issues: the dynamics of patient organizations in the European area (see Akrich et al. 2008); the emergence of new technologies and responsibilities for health care at home across diverse European systems and cultures; and cross-national and European perspectives on health safety agencies (Akrich et al. 2010). A current project, EPOKS (European Patient Organizations in Knowledge Society), continues analysis of the contribution of patients' organizations to the production of knowledge and studies the governance of knowledge production through a comparative approach (in collaboration with research teams in several other European countries) focused on several health parameters.

The CSI is also pursuing investigations on collective mobilization in the field of medicine and health. These investigations are carried out since 2006 within the framework of the MAPO (Mapping and Analyzing Patient Organisation Movements on Rare Diseases) project. Emphasis on the dynamics of issue agendas and of cross-organizational coalitions, both at the national and European level. Controversy studies are a theme in which the CSI a team at participates in a collaborative network of international partners in the research project called MACSOPOL (Mapping Controversies on Science for Politics). It Visualizes debates on risk issues <http://mappingcontroversies.net/>, and is an initiative to exchange, strengthen, and synchronize the capacities to analyze controversies, emphasizing instruments of quantitative analysis, cartography and visual representation.

Under the auspices of the European Commission, its Directorate for Health, a number of workshops have been developing input for life science, medical and health science research on personalised medicine with a strong focus on pharmacogenomics. (Cf. See the EC workshop in Brussels 12-13 May 2011 on European Perspectives on Personalized Medicine⁴, also EC workshop on Biomarkers for Patient Stratification 10-11 June 2010⁵, and the earlier one on -"omics" in

⁴ See http://ec.europa.eu/research/health/events-06_en.html.

⁵ See http://ec.europa.eu/research/health/pdf/biomarkers-for-patient-stratification_en.pdf.

Personalised Medicine 29-30 May 2010⁶). Hopefully some of the research envisaged will continue studies in the social sciences and humanities relating to standardisation, expertise and controversy, including comparative studies of expertise and governance with an eye to addressing questions of evidence-based guidelines and concomitant issues of adherence.

⁶ See http://ec.europa.eu/research/health/pdf/summary-report-omics-for-personalised-medicine-workshop_en.pdf.

APPENDIX II

SOME INFORMATION ON THE SMEC GROUP

The present initiative comes from a small group of scholars at the University of Gothenburg who have over the years done research that falls within the realm of science and technology studies (STS). Coming out of an amalgam of studies of scientific controversies, the role of expertise, critical studies of public understanding of science, scientific citizenship and governance issues, and earlier work in the field of science policy studies, several members of the group have now come to focus particularly on studies of medicine, expertise and controversies. A considerable number of their publications relate to this latter area.

The Department in which we are housed also includes philosophy and linguistics, disciplines in which further scholars address – among other - questions of medical and bioethics, forensic science, health communication, language technology for communicative disability. Studies include analysis of discourses in health care and legal contexts, philosophy of health, medicine and quality of life. In addition there is analysis of MR images, philosophy of psychiatry, and the concepts of health, disease, happiness and quality of life applied in health care, policy and research.

The conceptual framework and methodologies that lie closest to hand in the work of the theory of science group in the present context may be characterized by the acronym SMEC (Studies of Medical knowledge, Expertise and Controversy). Broadly speaking this covers studies of the interaction of medical science, practice, policy and public understanding in areas of controversy involving claims to expertise.

Topics hitherto have included diagnostic categories (autism, ADHD, pain syndromes), standard-setting in science and policy, stem-cell science, and vaccination. The SMEC-group has also developed analytical tools for general science and technology studies. Several recent projects have involved external funding - from the Swedish Research Council (VR) and some sectorial research councils (e.g., the Swedish Council for Working Life and Social Research), as follows: The controversy on the linking of MMR-vaccination and autism (FAS, 2005-2007); Sexual abuse of children – a meta-study of acting parties, social consequences and the construction of problems (FAS, 2007-2008); Research and politics (VR, 2008-2010). Spinoffs have involved work in reports commissioned by public agencies. Within Gothenburg University collaboration exists with researchers in health science, pedagogy and sociology, nationally with STS-scholars at the universities of Linköping, Örebro and Uppsala, and outside Sweden with York University (UK).

Work done by the SMEC-group overlaps with earlier and current scholarship in Science Policy Studies (SPS): the governance of science and technology, the interplay between science and policy, and public understanding of science. Topics include financing and quality assessment of research, polar research, the regulation of internet, and the application of science in sport. Additional interests are mathematics education, and the global transfer of academic culture.

More information can be found at <http://www.flov.gu.se/english/research/>.

"Optimising Health in Europe through Evidence-based and Personalized Medical Practices" is the working title of a workshop planned to take place in April 2012 as a step towards developing a grant proposal to meet the criteria of an appropriate EU framework call in the area of health policy and governance. The core idea is an interest in the use of expertise, standards and technologies on the one hand and on the other hand variations in adherence of patients to prescribed treatment - typically across a number of different lifestyle-related diseases or ailments, in comparison between a number of European countries.

The focus would, more specifically, be on two aspects: evidence-basing of relevant treatments and patient adherence to expert recommendations for preventive purposes in the cases of the disease categories selected.

