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The Power of Prediction: How Personal Genomics became a Policy Challenge¹

Dieser Beitrag geht der Frage nach, wie Internet-Genomtests in vielen Ländern Europas und Nordamerikas zu Politikproblemen werden konnten, obwohl ihre Bedeutung – gemessen an der Zahl der Personen, die weltweit einen solchen Test gemacht haben – sehr gering ist. Es wird argumentiert, dass interpretative Zugänge es uns erlauben, die tieferen Herausforderungen zu sehen, welche Internet-Genomtests für die grundsätzlichen Organisationskategorien medizinischer Systeme darstellen. So symbolisieren Internet-Genomtests etwa die teilweise Umkehrung der Rangordnung zwischen denen, die in der medizinischen Domäne traditionell als „ExpertInnen“ gesehen werden und jenen, denen bisher hauptsächlich die Rolle der „Laien“ zukam; und die Verwischung der Trennlinie zwischen dem, was wir unter medizinischer und nicht-medizinischer Information verstehen. Letztendlich zeigt die Anwendung eines interpretativen Ansatzes, der sich darauf konzentriert, wie AkteurInnen Konzepte, Klassifikationen und Kategorien verwenden und herausfordern, dass die Kontroverse über Internet-Genomtests in enger Verbindung zu der Frage steht, wer dazu ermächtigt sein soll, autoritative Voraussagen über das Leben anderer zu treffen. Dies stellt eine der Kernaussagen über die Verteilung von Macht im sozialen Raum dar. Es ist diese Neuverteilung der Macht, die einen Politikwandel in diesem Feld als notwendig erscheinen lässt.

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personal genomics (PG), interpretive policy analysis, genetic testing, clinical medicine*

1. Personal genomics: A new regulatory ‘challenge’ (to what?)

In autumn 2007, two enterprises started offering an online service which would soon become a concern of health authorities and policy makers: The company *23andMe* – named after the number of chromosome pairs in the human genome – in Mountainview in California, and the Icelandic company *deCODE Genetics*, started offering individual genetic risk calculations over the Internet for fees starting at a few hundred Dollars. Virtually everyone with a credit card and Internet access could order a so-called ‘spit kit’ – comprising of a plastic funnel, a container, and a few barcode stickers – online, fill it with their saliva, and post it to the company. The company would isolate DNA from the saliva, analyse it, and send an e-mail a few weeks later notifying the client that their ‘personal genome profile’ was available to be viewed online. Customers could then access their password-protected account and look at individual genetic predispositions to various diseases, traits, carrier status, and drug responses. A few weeks after *23andMe* and *deCODE Genetics* (featuring their genome testing service *deCODEme*) opened their business to online customers, *Navigenics* (Foster city, CA) started offering a similar service; and in 2009, San

Diego-based *Pathway Genomics* became the fourth Personal Genomics (PG) company to offer SNP²-based genome-wide risk predictions to consumers online. With the exception of *Navigenics*, which has restricted the scope of their tests to important health conditions from the beginning, all PG companies offer 'personalised' risk calculations for a wide range of phenotypes and traits (e.g. diabetes, alcohol flush syndrome, eye colour), as well as results of SNP-based analysis of carrier status and drug response.

While the prestigious academic journal *Science* almost instantly hailed research in human genetic variation as 'the breakthrough of the year' (Kaiser 2007), other commentators were less enthusiastic. The *New England Journal of Medicine* warned doctors that they might soon be confronted with growing numbers of genotyped patients demanding services and information that the former have not been trained to deliver (Hunter et al. 2008; see also Broom 2005; Forkner-Dunn 2003), and clinicians as well as scientists criticised the allegedly questionable scientific basis of the disease-risk information conveyed to customers of PG tests (Janssens et al. 2008): Some of the scientific studies upon which PG companies based their risk calculations had very small sample sizes, and had not been reproduced; they were seen as not robust enough to be used for medical diagnosis purposes. Others criticised the allegedly low clinical utility of the test results: some of the genetic loci analysed by PG companies account for as little as 0.2 per cent of all clinical symptoms of a particular phenotype; others have no established correlation with clinical symptoms at all (for these and similar concerns see Hogarth et al. 2008; Khoury et al. 2009; Foster et al. 2009; Platt 2009). Most of all, however, clinicians and ethicists were worried about the risks that these tests supposedly posed to test-takers: They could be needlessly worried, or groundlessly relieved of health worries (Hunter et al. 2008).

What had happened there? Four small companies had attracted a few thousand customers in total³ who had submitted their DNA for testing and learned whether or not their eyes were likely to be blue, whether they were likely to respond well to certain drugs, and whether they had a slightly increased lifetime risk of suffering from cardiovascular diseases. Despite the – at that time early in 2008 – very small number of people who had used PG testing, only a few months after these online services were set up, health authorities stepped in: During spring and summer 2008, the Department of Health of the state of New York and the California Department of Public Health sent letters to *23andMe* and *Navigenics* and a number of other companies warning them of continuing to offer their services over the internet without a genetic testing licence. Companies insisted that their legislation and regulation for clinical genetic testing should not apply to them, as their services did not intend to give medical information, but that they merely sought to educate and entertain their customers.⁴ At the same time, however, these companies also made sure that they complied with relevant legal provisions – which meant that licensed physicians had to 'order' (in practice, sign off, without ever having met with the test-taking person; see also Dvoskin/Kaufman 2011) the PG test, and DNA analysis had to be carried out in especially accredited laboratories. Although the conflict with the California Department of Public Health came to a preliminary halt in autumn 2008, in the US – where most of the PG companies currently operating are located (see Dvoskin/Kaufman 2011) –, conflicts with regulators have continued. Because of interventions by, most recently, the US Food and Drug Administration (FDA; see Vorhaus 2011), some companies started to sell their tests also or exclusively via licensed physicians (for more details see Lahnstein/Prainsack 2011; Dvoskin/Kaufman 2011). Also in Europe, where PG testing is far less well known than in the US, discussions among policy makers about how to address the challenges supposedly posed by PG have started in several countries. Austrian policy makers – led by the Department of Health –, for example, were in the process of

reassessing their legislation at the time of writing this article; the National Bioethics Commission at the Federal Chancellery in Vienna also issued a Recommendation on Genetic and Genome-Wide Testing on the Internet, highlighting risks that such tests may pose to test-takers (Austrian Bioethics Commission 2010). In Germany, the Genetic Diagnosis Law (*Gendiagnostikgesetz* 2009) was enacted in 2010, after almost eight years of controversy. Like its Austrian predecessor, the Genetechnology Act (*Gentechnikgesetz* 1994), the German Genetic Diagnosis Law contains the so-called physician proviso (*Arztvorbehalt*): The physician proviso stipulates that genetic tests must be prescribed by a physician, be performed by an appropriately qualified physician, and that test results must also be obtained through a physician. Thus, in Austria and Germany, direct-to-consumer (DTC) genetic and genomic testing is effectively outlawed; although because of the limitation of the remit of the law to genetic testing services offered from Austrian or German territory, the law is not applicable to current PG tests, which are all operated by companies residing in other countries. The UK employs a different approach than Austria and Germany in the sense that the policy debate here does not focus on how to limit access to PG testing, but on how to adopt it into the public health care system in a way that minimises risks to test-takers, and maximises benefits. For example, a report published by the House of Lords Science and Technology Committee in 2009 (House of Lords Science and Technology Committee 2009) focuses primarily on the translation of genomic research results into clinical practice, discussing possible obstacles and social inequalities in accessing such possible and future applications. Overall, the tone of the report is promissory and positive, although it also highlights ethical and social challenges pertaining to PG testing (see Lahnstein/Prainsack 2011).

In sum, although national approaches and policy discourses on PG vary, what most European and North American countries – in addition to some, mostly English speaking, countries in the rest of the world – have in common is that PG is seen as a challenge to the delivery of genetic testing as we know it. This is the policy ‘challenge’ that it represents.

2. Accounting for the need for policy change

If we hold that the policy challenge posed by PG consists of unsettling the delivery of genetic testing as we know it, then this opens up the question of how this has happened, and what particular form this challenge takes. We will first – and very briefly – discuss the insights that can be obtained with the help of a Foundationalist approach of looking at the difference in how genetic testing is carried out in traditional clinical genetic testing on the one hand, and PG testing on the other. In this view, the ethical challenges – and thus the ‘risks’ to test-takers that need to be addressed by adequate policy responses – are seen as emerging from the novel ways in which genetic testing is carried out within the realm of PG. We will then carry out our own analysis, employing an interpretive approach which focuses on the meaning of actions and institutions (Wagenaar 2011; Bevir/Rhodes 2004). We will conclude, in the final section of this paper, that the employment of an interpretive approach enables us to see that the power over prediction – more precisely, who is allowed to make predictions on behalf of others – is one of the core stakes in the policy controversies over PG. It is the hegemonic (clinical) discourse on how genetic testing should be delivered, who should be the producers and who the recipients of knowledge, which suggests specific policy solutions; in this case, the suggested policy solution in all places where this discourse is prevalent, is to limit or control access to PG tests to ‘protect’ potential or actual test-takers.

A Foundationalist approach: PG represents a policy challenge because it changes the way in which genetic testing is done

Foundationalism is ‘an epistemological doctrine’ (Bevir/Rhodes 2010, 42) holding that some beliefs are justifiable on the basis of other beliefs which are known to be true or justified. In other words, it is the idea that the world can be known on the basis of a ‘foundational’ truth. We can look at PG through a Foundationalist lens if we hold that some institutions – namely accredited clinical institutions, and medical professionals – are entrusted with diagnosing problems and determining prognoses in the field of health, and that their prerogative to do so serves a good purpose, namely to protect those in need of medical care from quackery. If we look at PG from this perspective, then we see that it deviates from the way in which genetic testing should be delivered in four main ways (see also Prainsack 2011): First, instead of looking at the absence or presence of a particular genetic mutation, it creates a large dataset which can be reanalysed when new research findings (suggesting a new correlation between a genetic marker and a phenotype) become available. Second, in contrast to classical medical genetic testing, which regularly takes place in a clinical context, PG does not always involve medical professionals, and even where it involves them, it typically does not do so in prominent places (e.g. test-results are disclosed to test-takers directly on the Internet, not via her or his physician). Third, as colleagues and I have argued elsewhere, the data provided by PG companies typically conveys medically relevant and non-medically relevant information at the same time (Prainsack et al. 2008). Fourth, PG focuses on complex diseases and traits, which are caused by the interplay of various genetic and non-genetic factors. Many of these factors are yet unknown or unexplored. Thus, the predictive value of the genetic markers tested by PG companies is typically very small.

This Foundationalist line of argument has given rise to the current alarmist public and policy debates focusing on the supposed ‘risks’ that PG poses to test-takers. Because PG is so fundamentally different from genetic testing as we know it, so it is feared, test-takers will submit themselves to PG testing with false expectations; they are likely to misunderstand the results; and they will suffer negative consequences, such as raised anxiety levels or the groundless relief of health fears, as a result of taking the test (Howard/Borry 2008; Feero et al. 2008; Hunter et al. 2008; Kraft/Hunter 2009; Caulfield 2009). Whenever actual or potential test-takers claim their right to direct access to their genome data – either practically, by taking a DTC test, or programmatically, by saying that clinicians should no longer be automatic gate keepers of such information –, then this can be seen, according to this Foundationalist perspective, as a reason for concern for the ‘safety’ of the people who buy into the rhetoric of greedy companies and are not fully aware of the ways in which DTC genetic and genomic testing could be dangerous for them. In sum, within this approach, the emerging policy problems are seen as a property of the change in organisational and institutional structures. We also sense that they stem from a change in power structures, although other than saying that those who were previously in charge – such as clinicians who function as gate keepers to genetic testing in clinical contexts – are being disempowered, such an approach does not offer a good analytical lens to analyse how power relations change. Thus, on the basis of such a Foundationalist view, the policy challenges – and thus, in turn, policy change – emerge out of a dissonance between (largely implicit) notions of ‘how things should be done’ on the one hand, and radically new ways of how things *are* being done on the other. While this is a helpful insight to be obtained on the basis of such a Foundationalist analysis, it is an interpretive approach that helps us to start to explicate these hegemonic ideas about how things should be done.

Taking an interpretive approach: PG represents a policy challenge because it challenges hegemonic ideas about who should be allowed to make predictions on behalf of others

Reactions from within clinical and bioethical communities to the emergence of online PG testing were discussed in the introductory section to this paper. They articulate concerns on the side of the traditional gate keepers to genetic testing services about risks that PG tests allegedly pose to test-takers. If we take a look at the voices of potential and actual test takers, the story we hear is a very different one.

This section is based on the analysis of texts and documents including PG service websites, news items, online discussion groups, consumer and genomics science blogs⁵ as well as on an analysis of the representation of PG companies in the scholarly literature and in conference presentations on PG from November 2007 to May 2011, and on communication with members of user groups of PG companies between July 2009 to December 2009 (see also Prainsack 2011). An interpretive approach will be employed, which – in Wagenaar’s (2011) typology – belongs to the tradition of the exploration of discursive meaning. Wagenaar differentiates between three different yet, in interpretive practice, partly overlapping types of meaning: The first type, hermeneutic meaning, signifies the ‘underlying meaning’ of an individual’s actions in a context of collectively shared practices and narratives. Researchers working in this tradition – which Wagenaar (2011, 41) calls the ‘default setting in interpretive analysis’ – focus on the self-understandings of the actors to ‘discover’ the meaning of their practices, with the relation between subjective and inter- and extra-subjective meaning(s) often being left unconceptualised and underexplored. The second type of meaning, discursive meaning, differs from the first in that it goes beyond the meaning-making practices and points of reference situated within the domain of the individual. As Wagenaar (2011, 51) puts it, ‘[i]f ‘self-understanding relies on background knowledge and if that background knowledge is available to individuals but not fully articulable, it means that it must be something over and beyond individual subjectivity’. Discursive meaning is anti-Foundationalist in that it assumes there to be no common or ultimate foundation for our knowledge of the world (Wagenaar 2011). The third type of meaning, dialogical meaning, is different from the other two in that it treats meaning as something in whose making the ‘observer’ – that is, the researcher her- or himself – is always also involved. This is not the same as saying that all meaning is subjective, in the sense that it is arbitrary; instead, this dialogical stance conceptually accommodates the complexity of interactions between a multitude of (human as well as non-human) actors in the world, from which meaning emerges, and from which the interpreter can never entirely extract her- or himself. The approach employed in this section of the paper fits most closely Wagenaar’s description of discursive meaning because it looks at how the actors in the controversy over PG understand certain terms, developments, and events – in other words, at some elements of their meaning making practices; however it also takes into account larger shared and/or institutionally enacted understandings that are outside of the domain of singular individuals and actors. Although our approach here fully embraces the understanding that the interpreter of meaning always also partakes in the making of meaning – i.e. the central stance in the domain of dialogical meaning –, it did not entail most of the methodical elements that a rigorous study on dialogical meaning would require. These would have been the interpreter’s interaction with actors *in the field*, to trace their practices and trajectories of meaning-making in their fields, which in our case would have spanned over different continents.

Let us start with taking a look at the voices of potential test-takers in the very early days of the history of online PG testing. Early in 2008 – a few months after the first PG companies had just started operating –, the Internet site *Tech Crunch*⁶ opened a competition for a free *23andMe* spit kit; the person with the best explanation for why she or he ‘needed’ a PG test would win. The entries reflected hopes and expectations of potential early-adopters of PG at a very early stage in the process. The extent to which the entries conveyed a sense of individual responsibility for health, as well as curiosity about people’s genetic ancestry, was striking. Most contenders articulated what social scientists have termed an increasing individualisation of the responsibility for health (e.g. Rose 1999; 2008). The following words of a contender articulate the stance of a responsible, proactive, and ‘preventive’ subject very clearly: ‘I’m curious to see what recessive genotypic traits and/or disorders that I’m pre-disposed to, so that I can take precautions to avoid expressing them.’

Some ‘Anglo-Foucauldians’, as Bevir and Rhodes (2010, 49–50) call a group of British scholars who employ a Foucault-inspired approach of dispersed power, drew our attention to the Janus-faced character of liberal freedom: In advanced liberal democracies, so Nikolas Rose (1996) famously argued, it is typically no longer primarily a centralised governmental authority which seeks to ‘improve’ people by introducing compulsory education, or sterilising the morally and mentally ‘abnormal’. Today, individuals are increasingly being called upon – and calling upon themselves – to ‘enhance’ themselves by eating the right diet, going to the fitness club, and preventing disease and illness in other ways (see also Rose 2008). All of these life-style decisions are choices that most of us make freely and voluntarily. At the same time, however, by taking such voluntary choices according to internalised or even explicit standards of what a ‘rational’ and ‘responsible’ decision is, we proliferate hegemonic values which we have limited influence to participate in shaping. To shape what is seen as socially and economically ‘responsible’ and ‘rational’ decision-making is typically beyond the scope of action of individual actors. Instead, what counts as ‘good conduct’ is often determined by value choices of political and economic authorities. We govern ourselves by establishing truths about ourselves and by creating our lives in accordance with them (Rose 1996; Prainsack 2006). This trend is reflected also in institutional change in healthcare: The introduction of competition and corporate management styles in the public sector across North America and Europe both represents and exacerbates a shift from solidarity-based to actuarial reasoning in the distribution of duties and responsibilities, where those who are thought to incur more costs for ‘the system’ are increasingly held responsible.

This process of individualisation of responsibility for health is dissonant with a situation where genetic testing is delivered in a way that renders the recipient largely passive; where there is a clear separation between the roles of knowledge producers (the medical laboratory), knowledge communicators (physicians and genetic counsellors), and knowledge recipients (patients). This traditional distribution of roles and tasks between those who hold and apply knowledge on the one hand, and those on whom this knowledge is applied, underpins the very concept of the clinic. Here, the need for policy change emerges out of a misfit between the traditional distribution of roles in clinical genetic testing on the one hand, and the much more active role assumed by PG test-takers on the other. In the practical context of PG, it is impossible to clearly separate between the producers, communicators, and recipients of knowledge (see Lahnstein/Prainsack 2011), within the clinic and beyond.

Of course it must be acknowledged at this point that the concept of the patient-turned-expert is by no means a result of PG, or even a novelty of the 21st century; scholars such as

Steven Epstein (1996), Sahra Gibbon, and Carlos Novas (Novas 2006; Gibbon/Novas 2007; see also Brown 2004) have traced the ways in which patients, or family members of patients, have become not only experts in the area of ‘their’ disease, but also important drivers of medical research, patent-owners, and policy makers, in the second half of the 20th century. There is indeed a dearth of literature deconstructing, challenging, or blurring the conceptual separation between ‘lay people’ and ‘experts’ in the medical field (for an overview, see Kerr et al. 2007; see also Turner 1995). Building on this important work, what I mean to highlight here is the very large scale at which this reversal of traditional hierarchies seems to be happening at present. While in the era of patient organisations, collectives of patients and their family members, and within that group, exceptional individuals have become important players in the domain of knowledge production and resource allocation within medicine and disease research, PG signifies a shift to an era where not only singular individuals or collective actors, but potentially *everyone* starts to challenge the gate-keeping positions and knowledge prerogatives of clinicians. You no longer need to be a patient or a family member with an exceptionally high level of motivation and determination to acquire detailed knowledge about diseases aetiology and treatment; all you need to do is spend time online and read the information provided on websites such as *SNPedia*, *PatientsLikeMe*, or blog entries of patients or scientists who make available all they know about a particular disease or case to anyone else who is interested (see, for example, Albanello 2011). Most people who have taken a PG test and read some of the educational material on the website of a company such as *23andMe*, *deCODEme*, *Pathway Genomics*, or a science wiki, and/or who consult other internet sources, are arguably better placed to interpret SNP-based genetic risk calculations based on their engagement with online resources on genetic factors influencing phenotypes than the average GP or family physician, who have typically not been trained for this particular task.

An exchange on a science weblog over who can legitimately claim authority to interpret SNP-based risk data is instructive in this context. The argument, which took place in autumn 2009, when online PG tests had been around for almost two years, was about whether SNP-based testing reveals any useful (and actionable) information on cancer risk for individuals.

*Physician*⁷: ‘I’m an excellent clinician and don’t need to defend myself to someone who obviously doesn’t know the clinical standards of care in cancer genetics.’

PG test user: ‘[G]enome SNPs [sans] may provide indications of possible disease risk. These possible risks are not validations and require (B) proper clinical tests to make firm medical conclusions. I firmly believe that there is a place for properly trained physicians within this scheme and that it is at point B. Not at point A. [...] Don’t bother me with the “I’m a doctor, so I know everything” stuff, it doesn’t work with me.’

Another PG user: ‘Just wait ‘til the computer vision algorithms out-perform the radiologists!!! (ducks)’

(Exchange on Genetic Future weblog, 9 September 2009)⁸

This brief exchange clearly illustrates a current challenge to the way that expertise has traditionally been distributed in the clinical realm. It is also telling that it takes place in an online forum, which is not built to accommodate such differences in professional power and status: Everybody with Internet access and the necessary language skills⁹ can make her- or himself heard, regardless of their professional training. Moreover, because of the increasing ease with which formerly

esoteric scientific knowledge is now publicly accessible on the Internet, scientists and clinicians can no longer claim exclusive access to much of the knowledge that their decision-making is based on. Against this backdrop, for many of those who are interested in taking a PG test, the obligatory involvement of physicians or other medical professionals in the PG testing process is nothing but a confidentiality risk. Many, if not most, doctors would be unable to help with the interpretation of the data, thus why should patients be *obliged* to share their results with them? In addition, ‘lay people’ – that is, in this context, those who are not trained medical professionals – have started to create their own tools and infrastructures to interpret genome-wide genetic risk data. The aforementioned open science site *SNPedia*, an interactive online encyclopedia for SNP-data, is only one example.¹⁰

Due to the ready availability of vast amounts of high-quality information on genome-wide genetic risk analysis to everybody with an active Internet connection, the crucial asset and decisive factor for whether or not somebody can become an expert is the availability of time, not professional training. Keeping track of new developments in a rapidly advancing field such as genomics requires resources and skills that one does not automatically acquire in medical school. In addition, flexible thinking and not having been trained to solve problems in a particular manner helps rather than hinders somebody’s capacity to become an ‘expert’ in interpreting genetic risk data. Such data can literally change in a day, depending on what new correlations between genetic loci and phenotypes have been found (Henderson 2009).

But besides illustrating an increasingly difficult struggle over the power of understanding and interpreting medical data and their clinical utility, the aforementioned quote also illustrates something else: The shifting boundaries between what is seen as ‘medical’ and ‘non-medical’. Social scientists have been studying processes of medicalisation since the middle of the last century (Zola 1972; 1991; Conrad/Schneider 1992). As Conrad (2005) summarised, while early analysts of medicalisation – understood as a form of medical imperialism – had focused on psychiatry (e.g. Szasz 1970) and other instances of expanding medical authority, later scholarly work considered medicalisation as the result of more complex interactions between social, market, and other factors (e.g. Conrad/Leiter 2004). Adele Clarke and colleagues have introduced the concept of ‘biomedicalization’, emphasising that medicalisation is no longer driven by ‘the’ medical profession but it is effectuated by both human and non-human elements of what the authors call ‘the Biomedical TechnoService Complex, Inc’ (Clarke et al. 2003, 162; see also Clarke et al. 2010). This framework is particularly helpful in understanding the challenges that PG seems to pose to the very concepts underpinning clinical medicine. PG test results convey both medical and non-medical information, and some of the information conveyed is both medical and non-medical at the same time, such as risk profiles pertaining to alcohol flush syndrome, which was found to be linked to esophageal cancer (Brooks et al. 2009). Furthermore, only two of the four companies which currently offer PG testing DTC online maintain – at least programmatically – a clear ontological separation between what is supposedly medically relevant, and what is non-medically relevant: *Navigenics* claim that all their risk profiles pertain to ‘important medical conditions’, and *Pathway Genomics* include only traits and conditions which are commonly seen as health conditions in their ‘health test’ section (although they disclose genetic ancestry information in a separate category). The other two companies, *23andMe*, and *deCODEme*, disclose genetic risk information which is commonly seen as medical (such as cancers) and genetic risk information on phenotypes which are not commonly seen as medical (such as bitter taste perception) subsumed under the same category headline.

This reflects an increasing ontological ambiguity about the boundaries of ‘the medical’ in a larger societal context. This ambiguity manifests itself, for example, in ongoing debates about where treatment ends and enhancement starts (e.g. Gordijn/Chadwick 2008); about what is ‘natural’ vs. ‘non-natural’ (e.g. Newton 2007) in fields such as human reproduction, or about whether public health care systems should cover costs for certain elective surgeries. What does ‘medical’ mean after the ‘omics¹¹ turn’? In a context in which differences between individuals have become a paradigm guiding scientific inquiry, can we continue to link situations that merit medical attention with what medical professionals diagnose as deviations from the normal, physiological functioning of the human body? Or do we consider as ‘medical’ what merits or necessitates any form of *clinical* intervention? Does the attribute ‘medical’, when combined with information that claims or assumes predictive value, suddenly become actionable in our minds, that is, does it become something that people can legitimately *want* to know so that they can change health behaviours or undertake particular preventive measures (even if there are no known measures which could prevent or influence the expression of a certain phenotype, such as Huntington’s Disease)?

It remains to be explored systematically in empirical studies how PG test-takers understand test results, and what aspects of them they consider to be ‘medical’. Amy McGuire and colleagues (2009), who carried out a survey among 1,087 users of social networking sites on the internet, found that 34 per cent ‘consider[ed] information obtained from personal genome testing to be [a] diagnosis of [a] medical condition or disease’ (McGuire et al. 2009, 7), and 53 per cent of those who said they had already taken a PG test reported to have discussed results with their physician. The value of this finding is compromised by the fact that only five per cent of all survey participants stated that they had already taken a PG test (McGuire et al. 2009, 6), and that it was unclear whether these respondents classified PG test results as a ‘medical diagnosis’, or only some of them (see Bunnik et al. 2009; see also McGowan et al. 2010). In any event, however, the classification of ‘medical’ vs. ‘non-medical’ in the field of PG is not primarily determined or performed by medical experts, or by the pharmaceutical industry (Conrad/Leiter 2004). Instead, such classifications comprise of three main elements: First, the publication of research findings on the genetic bases of a disease, condition, or trait (here the classification work is done by the scientists carrying out the study); second, by the translation of this information into the graphics and texts at the website’s user interface by the PG company; and third, by the acceptance of such medical categories as ‘actionable’ (or not) by the test-taker. It will also be important to see what bottom-up classifications of phenotypes as ‘medical’ or ‘non-medical’ entail in terms of practical consequences for people’s life decisions, self-understandings, and strategies. What is most important in our context, however, is that the increasingly unstable boundary between medical and non-medical, and clinical and non-clinical, increases the amount of uncertainty associated with PG: Not only do we lack consensus on who should be allowed to interpret PG test-results (customers? Genetic counsellors? Specialist physicians? Or all of these groups?), but we are also faced with the situation that the ontologies and nomenclatures of PG do not fit the traditional ontologies and nomenclatures of clinical genetic testing. All this contributes to the perceived need for new regulatory instruments that do no longer rest on the classifications and labels of traditional clinical genetics.

3. A struggle over prediction: What we can we learn about PG employing an interpretive approach

However, not every instance of life where practices do no longer fit traditional labels amounts to a call for policy change. What is it about PG that has rendered it a ‘recognised’ policy issue in many countries, despite the small number of people who have engaged in it? The answer to this is twofold. First, as we have seen in this and the previous section, although representatives of PG companies continue to insist that their service is not meant for medical diagnosis and has in fact nothing to do with clinical genetic testing as we know it, by mobilising a rhetoric focused on health and medical susceptibility testing, PG has stepped on territory that traditionally ‘belongs’ to the clinic. Clinical services, in turn, are linked to public policy by the way in which they are financed and regulated.

The second part of the answer to the question where PG is seen as representing a policy challenge in many countries is less obvious. I argue that the question of who should be allowed to interpret PG data is so heavily discussed because it is a shorthand for a larger question: Who should be allowed to make predictions on behalf of others? In other words, who knows enough in the present to be able to say something about the future? As the aforementioned quote, which is representative for many discussions on PG among test-takers and other stake holders, shows, the question of who has access to the most relevant knowledge lies at the core of the controversy. In the field of PG, the notion of prediction rests on four elements:

- (1) the underlying assumption that crucial elements of our future health can be predicted if only we obtain enough information about the factors that condition them;
- (2) the willingness to receive, or to actively obtain, such information;
- (3) a ‘preventive mindset’ which is well attuned to embracing probabilities rather than certainties;
- (4) the conviction that although not all elements of our future health can be predicted (because some aspects result from the complex interaction of many genetic and non-genetic factors), obtaining as much information as possible about the predictable elements enables us to work towards preventing their occurrence.

The notion of predictability is therefore closely related to the notion of prevention (Hood 2009), which signifies a departure from medicine understood as *reactive* to problems. However, the notion of predictability goes beyond prevention in the sense that it allows for the co-existence of both probabilistic and non-probabilistic statements about the future in one category. The notion of predictability entails elements of virtually ‘certain’ events, such as that an individual who carries a particular ‘faulty’ genetic variant will be affected by Huntington’s Disease; that an embryo or fetus with trisomy of the 21st chromosome will develop into a child with Down’s syndrome; or that ultimately, we will all die. However, it goes beyond the mere ‘prediction’ of a certain event because its reference point is the life of a person and her or his predicted medical situation with all its diagnostic, therapeutic, social, financial, and economic aspects. In the case of a fetus with Down syndrome, for example, the notion of predictability as I understand it here conveys the medical/clinical information that the child will be affected by Down’s. At the same time, however, this prediction brings along a bundle of additional assumptions, expectations, and probabilities relating to the social, psychological, and financial scenarios that this entails. Thus, the notion of predictability always transcends the ‘purely’ medical realm. It operates by bringing together different knowledge and information bases such as clinical tests, media coverage, personal experiences, and, importantly, also modes of self-governance. People rely on all of these

sources and mechanisms when constructing their present conduct vis-à-vis a possible future. What we believe to know, and believe not to know, about the future often has tangible effects on decisions and practices of the present. What sounds like a truism is of decisive importance to understanding the functioning of PG. This is the case because people relate to knowing the future in very different ways.

Let me illustrate with an example what I mean by this last sentence, that people relate to knowing the future in very different ways. In the aftermath of the broadcast of the celebrated HBO TV series *The Wire*, featuring the lives of police investigators and criminals in Baltimore, journal *darkmatter* published a special issue on that series. In its editorial, Ash Sharma (2009) discusses the work of the sociological work of Venkatesh (2008), who let real-life criminals watch the TV show. Sharma quotes Orlando, one of the ‘real thugs’ involved in Venkatesh’s study, commenting on bloggers’ predictions of how the plot of the show would continue:

These people are crazy! [...] Bloggers, they think they can predict what’s happening in the ghetto. Rule number 1: there is no future. [...] The one thing I don’t like about this show is you never make plans when you’re hustling. Not for more than a few days, anyway. (cf. Sharma 2009)

What this quote illustrates is that images of the future, and therefore, strategies of relating to the future when creating the present, are intimately linked to social and economical factors, and to one’s place in society. As Orlando’s quote shows, predictability of the future is something that those outside of the law (and arguably also those living in existentially threatening circumstances) cannot afford. Predictability presupposes order, and it assumes manipulability of the elements which make up our lives. It is therefore unsurprising that the way PG companies portray themselves, and defend their strategies, is defined by an emphasis on the benefit of information, the right to know etc. It is fair to say that the rhetoric of PG bears witness to an obsession with knowing as much as possible about the present so that the future becomes as predictable as possible as well. This, in turn, renders those who engage with PG testing ‘in control’ in ways that challenge the claims to control of traditional professional experts. PG bears the promise – or the threat, depending on how we look at it – to say something about who is likely to be strong and productive, and who is likely to become weak and unproductive, in the future. So far, this task of diagnosis and prognosis were situated in the clinical realm, where professionally trained, licensed, and typically publicly accountable individuals made decisions on behalf of patients. The labels and categories that they used had been reviewed and approved and often also ‘tested’ by public bodies, and the financial consequences – both for the health care system, and for the affected person – were either known or at least knowable. In the field of PG, in contrast, ‘predictions’ about the future of people are made by a variety of actors outside of the realm of control by national authorities and professional organisations. In this sense, PG is an instance of ‘citizen science’ not primarily (but also: see Tung et al. 2011) in the way that scientific knowledge is produced, but also in the way in which it is applied and rendered useful.

To conclude, what is the ‘analytical surplus’ that the employment of an interpretive approach (in our case, in the form of the exploration of discursive meaning) provides over other approaches? As we have seen, on the basis of a ‘Foundationalist’ approach it could be concluded that PG has become a policy issue because of the difference in which genetic testing is delivered there, as opposed to how genetic testing has been – and should be – delivered traditionally. This insight points us in a very relevant direction; yet it leaves the underpinning classifications, labels,

and separation lines (e.g. what is ‘medical’ vs. non-medical, ‘clinical’ vs. non-clinical, and the distribution of tasks within these systems) untouched. Only when we look at the meanings (Wagenaar 2011) of these labels and how they are challenged in the discourses of actors, we understand that the policy challenge is one of either pushing the unruly practices back in the traditional categories (which requires restrictive legislation or regulation, e.g. prohibitions of DTC genomics such as in the recent German Genetic Diagnosis Law), or establishing new classifications. The process of establishing new classifications has already started; for example, proposals have been made to replace the de-facto distinction between medical genetic tests (which are to take place in the clinic) and non-medical DNA tests (such as tests looking into genetic ancestry, which have been available DTC for over a decade, without much concern by stakeholders) by a risk-assessment-based approach towards which genetic tests should require pre-market approval by health authorities and/or be ordered and interpreted by medical professionals (e.g. see McGuire et al. 2010).

In sum, employing an interpretive approach to answering the question of how PG has become a policy challenge enables us to discern the many ways in which the controversy over PG is one about the distribution of power: at its core, it concerns a struggle about who possesses relevant knowledge to be allowed to make authoritative predictions pertaining to the life of others, and thus contribute to the organisation of social and political space.

NOTES

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- 2 Single nucleotide polymorphisms (SNP) are variations in the DNA at the level of single bases (nucleotides: A, T, C, and G).
- 3 This is an estimate; companies have refused to disclose the number of their paying customers. In 2011, *23andMe* was reported to have the DNA from 75,000 people ‘and counting’ stored in their database (Timmerman 2011), although it is unclear how many of these individuals were paying customers (the company had given out free spit-kits at various society events and science fairs). In this context, the estimate of several thousands of paying customers within the first year of PG companies operating is probably relatively generous.
- 4 For example, Forbes (Langreth/Herper 2008) quoted *23andMe* spokesperson Paul Kranhold as saying: “*23andMe*’s services are not medical ... they are educational”. A New York official, who preferred to remain anonymous, replied to this that it “blows my mind that someone would be saying that looking at whether you are going to get multiple sclerosis is recreational” (quoted in Langreth/Herper 2008).
- 5 These documents were obtained by means of daily internet searches with the key words ‘personal genomics’, ‘GWAS’, ‘*23andMe*’, ‘deCODEme’, and ‘Navigenics’, from 30 October 2007 to September 2010 (via the Google Alerts tool: <http://www.google.com/alerts>).
- 6 In January 2008, readers of the TechCrunch weblog were encouraged to explain why they would like to undergo PG testing and promised that the person with the ‘best’ explanation would receive a free *23andMe* test kit (‘Just tell me in the comments why knowing your genetic background is important to you, and we’ll choose a winner’). See <http://www.techcrunch.com/2008/01/22/1000-free-23andme-kits-for-davos-attendees-plus-one-for-techcrunch-readers/> (accessed: 5 October 2009).
- 7 Real names were removed as they are not relevant for the argument presented here.
- 8 Some interjections of other posters were omitted due to limited space for the quote. The exchange in its full length can be found here: http://scienceblogs.com/geneticfuture/2009/09/new_york_times_adopts_medical.php (accessed 5 October 2009).
- 9 These requirements lead to a situation where Internet fora reflect their own inequalities and power differentials; yet these do not correspond with professional hierarchies in the clinic or elsewhere.

- 10 See <http://www.snpedia.com/index.php/SNPedia> (accessed 22 August 2011).
- 11 The term ‘omics’ applies to mapping (and partly also to analysing) characteristics such as the DNA sequence (genomics), gene expression data (transcriptomics), and the gene products (proteomics) of an organism or a tissue. Some researchers and scholars use the term omics more widely to include any instance of data-rich research where data are systematically mapped, mined, and analysed (they have coined terms such as metabolomics, interactomics, or even culturomics).

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