Chapter 4
Inventing Traditions, Raising Expectations. Recent Debates on "Personalized Medicine"

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Abstract Since the late 1990s, the term "Personalized Medicine" has been coined to enable collaborations between different stakeholders in and outside research units. As a concept, it constitutes an imaginary framework of expectations and claims for a better, patient-centered and efficient health care system. Rather than deciding whether such trends represent "hype" or "hope", scholars from the social studies of technology and science emphasize that the expectations revolving around new technology are not only accessory parts of scientific inventions or innovation networks. Instead, they regard them essential in shaping these technologies. The aim of the following chapters 4 and 5 is twofold: (4) analyzing the semantic and socio-cultural contexts in which new technologies could come into being or be implemented on a larger scale (5) analyzing the continuing significance of epistemological key categories (e.g. the focus on the biological individuality) in the field of medical research and practice, and their influence on past visions of medical future.

Chapter 4 analyzes writings about "Personalized Medicine" addressed to a scientific and a popular public. They represent different promoting strategies while sharing normative assumptions that are rarely articulated: "Personalized Medicine" is made to appear to be part and parcel of a venerable tradition of past medical advances, an "invented tradition" that seems to herald a brighter and more democratic future for (Western) societies. Debates about the implications of new trends need to render the normativity of such claims explicit to allow for more informed judgments, rational critique and a more careful choice of research priorities.

Keywords Personalized Medicine · Sociology of expectation · Medical history · Epistemology · Popularization

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4.1 Introduction

On April 16th 1999, two science journalists of the "Wall Street Journal" proclaimed a 'new era' of medicine, "the era of Personalized Medicine". Robert Langreth and Michael Waldholz described the formation of a huge single nucleotide polymorphism (SNP) consortium comprising of ten major drug companies, the Wellcome Trust and five academic research centers that aimed to draw up a comprehensive SNP map of the human genome. Surprisingly enough, only a few months later, a medical journal, "The Oncologist", republished the article in identical terms (Langreth and Waldholz 1999).

Langreth and Waldholz in the "Wall Street Journal" and "The Oncologist" were not the first to use the phrase "personalized medicine" in the way we understand it today. Two years before, in 1997, Andrew Marshall had already coined the term in an article entitled "Laying the foundations of personalized medicines", albeit in a more modest terminology and significantly writing of "medicines" in the plural (Marshall 1997a, also quoted by Tutton 2012, p. 1721). Instead of postulating an homogenous entity of "Personalized Medicine" (PM) as a nascent technology in itself and therefore using the singular, Marshall took into account the underlying idea of the new advances of genomic research, that is drafting new or more efficient therapies for patients (in the plural). In his following article on "Getting the right drug into the right person" Marshall abandoned the notion of PM replacing it entirely by "pharmacogenomics" (Marshall 1997b). He foregrounded a research field whose origins date back to the late 1950s, rather than making the case for a vague entity that invoked scenarios of how medical research and practice might develop in the future. Though no less enthusiastic about the advances in genomic-based and information technologies than the two science journalists, Marshall's idea of personalized medicines could more be seen as sequentially emerging in a continuing process evolving from an already well-known research field of pharmacogenetics, and -genomics. Whereas Langreth and Waldholz's report revolved around an economically and scientifically powerful and future-oriented merging research field.

By reporting on developments within drug and biotech companies, the two science journalists contributed to a rhetorical framing of what became known as "Personalized Medicine" (in the singular). Since then PM has become a powerful language through which significant change in medical practice has been imagined and in which the interests of various actors in politics, economics, science and patient organization seem to converge.

How did we get from the plural "personalized medicines" or "individualized therapies" (at which physicians of past times had taken great pains in both their daily practice as well as in their research efforts of finding new and better diagnostic and therapeutic measures) to "Personalized Medicine" in the singular, a powerful vision as a single set of concepts, practices and technologies, capable of bringing together actors from various fields, professions and disciplines? Many observers wonder whether the "Personalized Medicine" approach marks a beginning of a

"new era" (Langreth and Waldholz 1999; Jørgensen 2009), a "revolution in medicine" (Collins 2010a; Collins 2010b), a "paradigm shift" (Stock and Sydow 2013; Vanfleteren et al. 2014) or on the contrary if it is rather a "misnomer" and has always been within the scope of medical practice and research (see for the general discussion on "hype or hope" Dabrock et al. 2012; Pray 2008). Instead, this chapter takes a step back and views PM as a specific set of meanings, claims and visions in a broader social-cultural context. To consider PM as a social phenomenon is to take into account that proponents and opponents alike contribute to the shape of PM whether it will be implemented in future health care systems or not. This chapter also takes a step back concerning the specific "Greifswald Approach to Individualized Medicine" by considering PM as a broader movement uniting different biomedical initiatives, supported not only by big research consortia but also by other promoting and monitoring parties. Hence this chapter considers itself as a contribution to what has been called in literature the "Politics of Personalized Medicine" (Hedgecoe 2004) or "social practice of Personalized Medicine" (Brown et al. 2000; Tutton 2012). It is also for this reason that this chapter analyzes the term "Personalized Medicine" instead of "Individualized Medicine". This choice refers to the fact that it is the more common term in Anglo-American and in other European countries. Within the sample this study is based upon, scientists and popular authors mostly used the term "Personalized Medicine". Since the 1980s, oncologists often refer to "individualized therapies" (a fact that lies beyond the scope of this chapter). In contrast to the preceding chapter 2 that responds to the need for a clear definition of "Individualized Medicine," Part II focuses on the fluid and contradictory uses of the term "Personalized Medicine" in medical and popular literature, its function in different contexts and its normative claims.

How, then, can we most fruitfully approach PM in a perspective of social and historical studies of medicine? Certainly, PM does not emerge out of nothing and it is possible to write a history in a genealogical sense tracing back in time the technological, scientific or societal developments in the last decades leading to particular configurations and networks that enabled the emergence and the success of the claim to individualize medicine. PM as a set of visions and claims is deeply entrenched in a social and cultural context including researchers, drug companies, patient groups, consumer movements or political agendas. Furthermore, there is a narrower disciplinary history of pharmacogenetics or population genetics and other core research fields of PM. The interviews with clinical researchers conducted by the sociologist Adam Hedgecoe, whose book provides fruitful insights into the "Politics of Personalized Medicine", documents the hesitations and even resistance to these new technologies of genetic testing. Yet, this group often is excluded from the debate surrounding the future of PM (Hedgecoe 2004). The sociologist conducted the interviews between April 2001 and July 2003. At that time the rhetorical framing of PM had become very influential in medical and popular literature, by raising hopes and expectations of an economically more efficient, better and more individualized health care system.

At the same time, the marketing of consumer genomics companies has started to focus on the participatory aspects of PM as one of its main "promissory virtues"

(Juengst et al. 2012a). Social networks and patient or consumer groups fostered this idea of PM as a joint venture in which providers and consumers, as well as clinical researchers and patients could participate. Tracking one's own health information, making them public and sharing them with others in order to receive useful advice about one's behavior and have personal control over one's health, seem to attract more and more people. Meanwhile, there is an emerging advice literature concerning better health-related behavior available, empowering patients and consumers, particularly within the rhetorical framework of "Personalized Medicine" or personalized health care (Davies 2010; Goetz 2010; Collins 2010a). It seems as if there are diametrically opposed developments: wide-spread doubts in parts of the researchers' community directly involved with PM (Hedegecoe 2004) about the usefulness of some of these technologies declared as "Personalized Medicine" stand in contrast with multiple forms and co-operations in society as well as the agendas from drug companies and political parties.

As a social phenomenon in modern societies, PM is still largely unexplored. In this chapter it is not possible to address all the relevant aspects and multiple stakeholders in order to explore the complex dynamics that we could observe in the field of PM (for a more comprehensive approach see McGowan et al. 2014; Hedgecoe 2004). Instead, the sample on which the analysis draws consists on the one hand in the medical and popular literature that began to sprout up soon after the emergence of the rhetorical framing of "Personalized Medicine" (chap. 4). Commentaries and editorials at the beginning outweighed by far the number of papers presenting original works (Hedgecoe 2004). According to Hedgecoe, it is a particular kind of science writing that opens up a "discursive space within which to speculate about particular technologies and to create expectations about how pharmacogenetics may impact on healthcare provision and practice in the future" (Hedgecoe 2004, p. 18). Greg Myers makes a similar argument in his analysis of the role of review articles for the construction of knowledge (Myers 1990). On the other hand, chapter 5 emphasizes the particular role of the main pioneers in the young field of pharmacogenetics and –genomics throughout the twentieth century as well as around the turn of the millennium and the rhetorical invention of PM.

The aim is twofold: (1) analyzing the semantic and socio-cultural contexts in which new technologies could come into being or be implemented on a larger scale (2) analyzing the continuing significance of epistemological key categories (e.g. the focus on the biological individuality) in the field of medical research and practice, and their influence on past visions of medical future.

Chapter 4 analyzes the rhetorical framing of PM today. Within the field of sociology a number of scholars have already adopted this approach by focusing on its different champions, critics and stakeholders (Hedgecoe and Martin 2003; Hedgecoe 2004; McGowan et al. 2014) as well as the role of the "promissory virtues" of PM (Juengst et al. 2012a). Based on the findings of these works the emphasis will be on the specific ways different proponents of PM have connected past, present and future. PM is first and foremost about the future. While much has been written about its promises and perils, we know little about the many medical and popular writers

who championed this new approach to medicine, invented traditions (Hobsbawm and Ranger 1992) and placed PM in a larger medical tradition.

Whereas chapter 4 considers how the past is constructed and used to explain and to legitimitate the emergence of the new field of PM, chapter 5 explores past visions of the future. It focuses on the past developments of some core fields of what would later be subsumed under the overall term of PM, especially the history of pharmacogenetics/-genomics. This chapter is not a history of the continuous discoveries and the trajectory of this scientific field. The emphasis will rather be on the self-conceptions of several spokespersons. For a better understanding on how a single set of visions, claims and meanings comes into being, it is of special interest to analyze when, how and why these actors considered themselves as part of PM or accordingly what have been alternative terms and prospects to it before the rise of "Personalized Medicine" as a powerful language.

4.2 Fashioning Continuities: Connecting Past, Present and Future

In the last two decades a growing number of studies in science and technology research provided new insights about the role of expectations, imaginings and visions in the emergence of new technologies (Van Lente 1993; Martin 1999; Brown et al. 2000). These expectations consist of both hopes and fears and not only describe a desirable or rejectable future, therefore being simply accessory, irrelevant parts in the emergence of new technologies. They are also part of the way this future is shaped because they actively contribute to the success or failure of nascent technologies. This new interest presumably accounts for a historical shift in the technology development itself. To the extent that in advanced industrial modernity, the intensity and pace of technology development has increased, research has become more strategic and has, thus, given rise to a rhetorical space for visions, imagining and promises (Borup et al. 2006, p. 268). Especially in the field of biomedicine, we have witnessed in the past decades several emergences of new technologies, their either failing or successful implementation into research strategies and clinical contexts accompanied by a powerful rhetoric of inexhaustible promises. Several of these biomedical research fields have been analyzed by scholars of the studies of science and technology, for instance xenotransplantation (Brown and Michael 2003), stem cell research (Martin et al. 2008), regenerative medicine (Wainwright et al. 2008), nanotechnolgy (Selin 2006) as well as pharmacogenetics (Hedgecoe and Martin 2003) to name only a few. PM is, though, a special case. As a rhetorical framing it is a reality what is more, unfolding an astonishing capacity of creating new coalitions, merges, institutional forms and funding sources. That is to say, there are materialities that begin to structure what PM is. But then again and in contrast to the new technological fields mentioned above, PM could hardly be (yet) understood as a new technology in itself. The use of the term is vague and fluid and its critics consider it even as a false and misleading labeling and a misnomer. The different

networks, coalitions, movements or stakeholders are equally varying from context to context in a more or less stable manner. In their insightful contribution on the "Rise of Membrane Technology: From Rhetorics to Social Reality" which provided the methodological and theoretical framework to a study of "Sociology of expectation", Harro van Lente and Arie Rip took another stance and analytical framework. The two sociologists analyzed the function of such an umbrella term within the nascent field of membrane technology and came to this conclusion: "Together with the introduction and establishment of the umbrella term, a *history* is created, the history of membrane technology, which in a sense creates the field henceforth to be covered by that term" (Van Lente and Rip 1998, p. 227). In this reading an umbrella term has the capacity to merge different histories into one. Analogically, by launching the admittedly appealing umbrella term of PM, one history is created. This essay analyzes the history, or more precisely, the construction of traditions of PM. The focus will be on the one hand on medical literature, especially editorials or commentaries keen to shed light on what we should understand by the rather cloudy and fuzzy term of PM (sect. 4.2.1). In order to take into account that PM is not only a new approach within scientific and research context, but moreover a joint venture between politics, science, economy and society, the focus will be on the other hand on the popular discourse that has developed over the last years (sect. 4.2.2). Indeed several recent books aim to explain the prospects and goals of PM to a wider public by emphasizing its participatory potential. Based upon this sample of writings, which addresses both academics and a wider public, the aim of the following section is to explore and to identify strategic issues in the promoting of PM.

4.2.1 Medical Writings: The Timeline of "Personalized Medicine"

In an introductory article to a special issue on the sociology of expectation Borup et al. point out that "expectation of technology is also seen to foster a kind of historical amnesia—hype is about the future and the new—rarely about the past—so the disjunctive aspects of technological change are often emphasized and continuities with the past are erased from promissory memory" (Borup et al. 2006, p. 290). Social Studies of Science and Technology have focused on how the future of new technologies is designed by promoting or opposing parties (Guice 1999). Rarely, the shaping of the past has been considered as constituting a strategic way to foster technologies even if they are oriented towards the future (Tutton 2012; Selin 2006). In regards to nanotechnology, Cynthia Selin has identified different "timescapes"—a term borrowed from Barbara Adam (Adam 1998)—in discourses of the future technology. By this, she means that "time is built into stories" (Selin 2006, p. 126) and distinguishes a more linear model of trajectories and path dependency, discontinuous and disruptive timescapes as well as timelines marked by immediacy and indetermination. Each of these timescapes corresponds to specific temporal codings and innovation strategies. The coordination and negotiation of

these different timescapes by different stakeholders, she argues, constitutes a great part in building up stable networks or contributes to their failings. Either way they are constitutive in the shaping of nascent technology.

Similarly, the promises revolving around PM could be analyzed within a framework of different timescapes. A first approach would be to look at specific historical narratives sketched out in medical writings. PM is actually neither defined as a clearly outlined research field (by comparison to pharmacogenetics or -genomics for example) nor could it be narrowed down to a simple technological, material invention (by comparison to SNP array analysis). Even if the highly performative sequencing technology prepared the grounds to develop its full potential, PM is primarily emerging at the crossroad of past developments of multiple methods, instruments and disciplines on the one hand and overlapping scientific, economic and political interests of different actors on the other hand. In this sense the corresponding historical narrative is a multiplicity of histories, all of which converge at one point in time and under specific circumstances giving rise to what is called PM, and which is accordingly the inevitable end point of a development. This linear vision of PM is clearly expressed by Charles Cantor, one of its fervent promoters in the early years. Having accounted for the genome-technological advances in the last 20 years, Cantor drew the following conclusion:

> Like it or not, we will soon have the ability to predict the variation in drug responsiveness of large numbers of individuals in large numbers of therapeutic settings. Once this ability is established and its usefulness is validated, it should become standard medical practice. The tools for gathering, analyzing, and explaining such data to physicians and patients will become mainstream and not rare curiosities. A dramatic change in the practice of medicine over what we know today is certain. Each patient will in practice have to be treated as the individual we already know he or she is (Cantor 1999, p. 288).

Instead of historical amnesia, I would like to argue that medical literature establishes a specific connection between past, present and future marked by the following features: a presumable culmination of logic and irreversibility (“like it or not”), the temporalities of an innovation life-cycle, which includes the prophecy of profound change (“we will see soon”) followed by large-scale standardization (“should become mainstream”), as well as the ability to finally and adequately respond to a long-lived knowledge drawing upon the individuality of each patient (“we already know”) and going along with strong normative claims (“each patient will have to be treated”).

This connection between past, present and future in a teleological perspective makes a strong argument for promoting PM as an unavoidable and irreversible development. This timeline becomes even more important when its beginning is situated in the early stages of medical history. Jain in his handbook on Personalized Medicine, even starts the account of the landmarks in the development of “Personalized Medicine” with primitive medicine 10,000 years ago, passing by nearly all medical discoveries and ending up with the “Personalized Medicine Act” of the later President Obama in 1996 and the “Genetic Information Nondiscrimination Act” in the USA in 1998 (Jain 2009, p. 4). In the construction of this impressing genealogy, PM is not a revolution, as Jain explicitly claims, but more than that: PM is deeply

rooted in the evolution of a medical thinking in its historical dimension and another step in the medical progress we have been witnessing in the last thousands of years. In contrast to the promotion strategies of other new technologies, it is noteworthy that the timeline of PM is generally marked by continuities and not by disruptions. The revolutionary rhetoric suggesting a sudden change ostensibly stands in sharp contrast to this continuous and slowly developing timeline. However, what counts as revolutionary or "dramatic change" prompted by PM, is exactly its capacity to be the solution to a centuries-old problem of medical history, or in other words to be at the core of medical history.

Besides this example of a comprehensive genealogy of PM, different spokespersons or pioneers are being granted of having introduced the concept of PM long before the term had been coined. Most frequently medical commentaries quote Hippocrates which is tantamount to invoking the mythical origins of medicine as a science. Hippocrates' statement "It is more important to know what sort of person has a disease than to know what sort of disease a person has" not only inscribes PM in an medical long-lasting, venerable tradition addressing each patient in his or her individuality. The reference also suggests that genomic-based instruments provide present medicine with powerful tools in order to implement into scientific practice what physicians in ancient times only were able to perform intuitively and arbitrarily. The same is true with the "father of modern medicine" William Osler: "If it were not for the great variability among individuals, medicine might as well be a science and not an art." Osler, known and admired for his clinical skills, embodies a perfect figurehead for the claim to bridge the gap between clinic and research or, in other words, art and science. Here again, the strength of this historical argumentation stems from the suggestion to consider PM as a systematic, scientific-based solution to a centuries-old problem of clinical practice (Kennedy 2007; Hamburg and Collins 2010; Horwitz et al. 2013). What was the art of medicine—the intuitive, therapeutic decision-making of physicians based on their clinical experience—has now become a science—a systematic, data-driven and more precise way of patient care. PM, as Allen Roses puts it, is about to reverse the logic of Osler's statement: "Sir William Osler, if he were alive today, would be re-considering his view of medicine as an art not a science" (Roses 2000, p. 857).

Not surprisingly the debate surrounding the promises of PM is shaped by these classical divides. As several scholars have convincingly shown, "science" and "art" are often invoked when new technologies are implemented into the clinic leading to a redistribution of power within the realm of medical practice (Schlich 2007; Gordon 1988). In an account about the historical dimensions to contemporary expectations of Personalized Medicine, Richard Tutton shows how different historical forms of medical "universalism and specificity" have marked Western medicine by opposing individualized efforts on the part of clinicians to the production of universal knowledge in research since the middle of the nineteenth century (Tutton 2012). It is questionable if this historical account does not simply relocate the ongoing debate into the past. Nonetheless, Tutton's brief historical overview reminds us that the tension between "universalism and specificity" was in medical history and is still a very active tension, giving rise to a contest of older systems and new forms

and innovative approaches to medicine. Against this historical backdrop, conjuring this classical divide between medicine as an art and medicine as a science leads us to a powerful strategy for promoting PM today. It is not the purpose of this chapter to answer the question whether this promise of PM is well-founded or not. For the purpose of this analysis, the emphasis should be rather on the recurring discursive pattern in these medical writings, stressing the convergence of art and science—a strategy that accompanies the professionalization of medicine since the nineteenth century (Bynum 1994). In this powerful but also contested line of argument, the promises of PM mean individualized care by means of scientific-based instruments: "Listening, evaluating, and responding to the patient to promote his or her interests is the foundation of clinical medicine. Using genetics to customize care, in whatever form that may take, could be a powerful tool to further refine the healing process" (Yurkiewicz 2010, p. 16).

What makes the strength in promoting PM as a promissory technology is at the same time its weakness. The criticism that PM is a misnomer and only refers to what physicians already do in their daily practice is following the same logic, but stresses the down sides of a complete scientization of medicine. In this reading, a scientific-based instrument could never replace the art of medicine, this means clinical experience and doctors knowing his or her patient best. Whether PM will fully realize its potentials in the future, as part of the transformation of the health care system, is still unclear. However what can be said is that the debate surrounding PM is following the opposition lines that were drawn during the transformation of medical practice and research since the nineteenth century.

As noted above, in medical writings PM seems to follow its own internal, historical logic, deeply rooted in medical thinking. This common historical narrative comes frequently along with evaluative conclusions. The moral imperative precisely consists in pushing forward the developments of PM in order to realize what in previous times physicians could only have done intuitively and had never fully achieved. From an ethical point of view, the legitimacy of such normative claims could surely be questioned. If the consideration of the patient's individuality should be without doubt a strong moral requirement and directive for physicians in their daily encounter with patients, it does not mean that this argument alone leads to a decision about the allocation of resources pouring into different research fields. Even if the likely benefit for one single patient or one single patient group is very high, in a broader ethical discussion one has to weigh the effect of different research strategies which are likely to lead to improvements of health. Besides ethical considerations the historical narrative in itself is flawed. Clinical practice and even more medical science was often centered on a better understanding of the pathological in terms of common, universal traits, although this was by no means an effort to deny one's individuality or neglect the range of variability in therapeutic response. Hence, it is a fallacy to assume that the best way for improving health care is uniquely based on the individual level and on research strategies finding out what makes us different rather than what we all have in common. The normative claims going along with historical argumentation, as implicit as they are, have to be made explicit and reconsidered in a broader ethical and historically informed discussion.

4.2.2 *Popular Writings: "Personalized Medicine" as Democratic Empowerment?*

Editorials and commentaries in medical journals articulate the visionary, but nonetheless past-oriented, character of PM. Despite its highly technological character, PM is regarded as deeply rooted in venerable medical traditions. In contrast to medical writings that commented on PM research projects and consortia, popular writings not only address a wider public, they also refer to another phenomenon that emerged at about the same time: social networks on internet platforms, as well as commercial genetic testing companies sprouted up since the beginning of the twenty-first century as a Personalized Medicine movement "from below" (Gollust et al. 2002; Prainsack 2005; Prainsack 2014; Paul et al. 2014). In the last couple of years several books have been published for a wider audience of readers with the aim to instruct how to join this movement (Collins 2010a; Topol 2012; Goetz 2010; Angrist 2010; Frank 2009). As fashionable as these writings may appear, this literary genre adds to the tradition of the nineteenth century advice literature on health related issues. Especially, the idea of prevention and the assumption of a predictable and manageable future led to new forms of activism and thus to a booming market of health related advice literature and other forms of health education initiatives (Lengwiler and Madarász 2010). Since the late nineteenth century, new preventive and predictive possibilities have been accompanied by an appeal to individuals to stay healthy for the sake of one's own well-being or for the sake of the community. The connection of the four "Ps"—personalized, preventive, predictive and participatory—is certainly not new. At least in Western societies, preventive measures have been and are still centered upon individual responsibility and activism. What is more remarkable is that today, ever more importance has been attached to the participatory aspects of the PM venture, even though it is not yet sure whether PM will fulfill the three other promises of "personalized", "preventive" and "predictive". On the contrary, one of the main messages of these books is that only by joining the movement, PM could realize its full potential. In this reading, the four "Ps" are conceptually not on the same level. Only an expanding public participation could guarantee that more and more information is gathered and stored on digital platforms from which personal information could be extracted. Participation is seen as a means and necessary condition to achieve "personalization", "prevention" and "prediction".

That is to say that these writings are not only an explanatory commentary on current research efforts, they are considerably broadening the scope of PM. Eric Topol, for example, describes how digital advancements in the "science of individuality" will create more knowledge about diseases or other medical problems of a patient. In this perspective, he suggests that "the need for activism" (Topol 2012, p. 218) of a patient in the digital revolution might even lead to a "democratization of medicine" (Topol 2012, p. 12). In this reading, the promise of PM concerns not only medical improvements but political issues on justice and fairness. Henceforth, PM is not simply and exclusively a scientific research program, but beyond a narrow

and hermetic circle of specialists, it is a joint venture in which every person could participate. These new forms and platforms are blurring the boundaries of people carrying out scientific research and those benefiting from it. While sharing its health information with others and gathering more and more data, the promise is to use this information sampling, and even biobanks, for potential research issues and to increase the awareness of individuals about their own health which could lead to better decisions on how to improve it. The production of knowledge and health-related behavior are no longer separate courses of actions but closely linked and coordinated by one platform.

The authors of these writings range from renown health planners and scientists such as Francis S. Collins, the former director of the National Human Genome Research Institute and now director of the National Institute of Health, or Eric Topol, cardiologist and professor at the Scribbs Institute to science journalists, the Wired-Magazine editor Thomas Goetz or the Danish journalist and biologist Lone Frank. Accordingly, there are no clear-cut expert roles within these writings. Collins and Topol as researchers aim to share their expert knowledge with a wider public, whereas Goetz reports on his own experience with social networks or consumer testing. These different forms of PM, "top down" or "bottom up", are understood as partly cooperative, partly competitive. Especially doctors are accused of ignoring the revolution going on under their eyes. As Francis Collins puts it: "From reading this book, you almost certainly know more than your doctor about personalized medicine" (Collins 2010a, p. 277). Expert knowledge does not arise from professionals with a special training, but from participating in the revolution, and could easily bypass the doctor-patient-relationship. This transformation implies that market forces are structuring henceforth what generally is seen as constitutive for a trustful medical encounter. In contrast to past medical developments, PM in popular writings is propagated by genetic consumer companies such as "deCODEme", "23andMe" or "Navigenics". Most of the authors outline their interviews and meetings with the companies' CEOs and write about their experience in having their personal genomes decoded. Hereby, they give the impression that these companies and joint ventures are considered to be the relevant future stakeholders, or "research revolutionaries" as Lone Frank labels them. Eric Topol's text about the "Creative Destruction of Medicine" is the most outspoken in this category of books. The title obviously alludes to Joseph Schumpeter's thesis of innovation as a form of creative destruction (Schumpeter 1942) of outmoded structures. Accordingly, journalist Scott Gottlieb praised Topol's oeuvre in a book review of the Wall Street Journal as a "venture capitalists delight" (Gottlieb 2012).

According to most of the writers, destruction and creation concern firstly patient identities that are shifting from being the medical patient, who either suffers from a disease, carries it or is at risk of becoming ill, to the medical consumer who is defined by his or her personal data and acts accordingly. Start-up direct-to-consumer testing companies first circumvented the personal encounter between patients and doctors. Despite state regulations, for example in California, where genetic testing could formerly only be ordered by a physician, the genetic consumer industry established an internet ordering service and a massive lobbying effort to

have these regulations abolished. In the age of information technology, individual data sampling and transferring, it might not even be necessary to have eye-to-eye contact with an examining physician. Although many companies sell their products without a physician or a geneticist as intermediaries today, some of them have successfully applied for FDA approval and turned to a model, which includes a health care professional (Howard and Borry 2012). It remains to be seen in how far this modulates the current effects of direct-to-consumer marketing of genetic testing or if there is an economic pull for physicians to participate in and contribute to this market.

Secondly, as the title of Topol's book indicates, the status of medicine itself is changing. As seen in the precedent analysis on medical writing, the boundaries between medicine as an "art" and medicine as a "science" are voluntarily blurred by celebrating the triumph of PM as another step or even the last step to overcome this traditional distinction. In the case of the popular discourse on PM, this becomes even more important. The greater the emphasis on the collection of huge amounts of data and individual health (care) information, the more marginal the art of medical practice becomes (Tutton 2012). Even though doctors collect personal health information in diagnostic tests on the basis of which diagnosis they make, the vast amount of information seems to render medical practice as clinical experience obsolete. For this reason, the popular writings stress the participatory aspect presenting PM as a widespread digital movement (see also Juengst et al. 2012b). For example, after each chapter Collins gives a summary and recommendations under the topic "What can you do to join the personalized medicine revolution", often with links to websites where one could register, for example, to document the family's history of breast cancer (Collins 2010a). Wired-Magazine editor Thomas Goetz aims to provide the reader of his book "The Decision Tree" with a complete set of guidelines on how to "make better choices and take control of your health" in the context of PM developments (Goetz 2010).

As in medical writings, this popular discourse about PM invokes invented traditions and nurtures expectations about a brighter future. In general, popular writings are less reluctant to postulate a turning point for the history of medicine and more broadly for mankind. So, for example, Collins refers to the historical dimension of the new scientific findings. We could live in an "astounding time of our history", he explains, and the historical impact would be so significant that everybody "will remember this" and the participants will tell their future grandchildren (Collins 2010a, p. 2). Therefore, "revolution" as a keyword is used at times in an inflationary manner. A fragmentary search in Kevin Davies "The $ 1,000 Genome: The Revolution in DNA Sequencing and the New Era of Personalized Medicine" indicates that there are more than 100 hits for the word in his text. For the Danish science journalist and biologist Lone Frank, the new research findings will answer the essential questions on one's future health "because a revolution is under way" (Frank 2011, p. 8). Regardless of that, Frank championed in 2009, in a precedent book how brain science also will change the world (Frank 2009).

What are the histories that are written in these books? Mostly the promise of progress refers to the eradication of diseases within a historically classical account

on the continuing medical progress witnessed in the last decades: "Medical science has made stupendous progress over the past 100 years" writes Goetz (Goetz 2010, p. xi). He compares the situation of today with the one 100 years ago in respect to diabetes, polio and smallpox. Once deadly and incurable, they are now regarded as harmless due to medical progress. The next step concerns the eradication of other common diseases such as cancer, diabetes or Alzheimer diseases. For another writer, medical progress is tantamount to technological advancements. Kevin Davies describes in his book "The $ 1,000 Genome" how technological developments, and therefore cheaper genome sequencing, will offer the breakthrough in personal and genetic medicine. "Will history repeat itself?", he asks, and he also alludes to the once deadly ages of polio and smallpox (Davies 2010, p. 266). Davies presents his readers the obviously widely shared opinion that a cheap genome might even "eradicate most kinds of genetic diseases". However he mentions that there are also geneticists who believe this prospect is too optimistic (Davies 2010, p. 266).

Francis Collins even compares the decoding of the genome sequence, and thus the possibilities of PM, to quasi-mythical events in American history: "We have been engaged in a historic adventure. Whether your metaphor is Neil Armstrong or Lewis and Clark, your metaphor is at risk of falling short", he cites his keynote speech at a Cold Spring Harbor Laboratory meeting (Collins 2010a, p. 2). Collins alludes here to the frontier-myth of American history, to astronaut Neil Armstrong, the first man on the moon, or to explorers like Meriwether Lewis and William Clark who discovered and mapped the American West at the beginning of the nineteenth century. What they have in common is that they were considered pioneers in the discovery of formerly unknown territory. They pushed the boundary further whether on land or in space thereby shaping the future of American society. According to Collins, the scope of PM, once it will have realized its full democratic and participatory potential, will be beneficial well beyond clinical issues or medical practice.

4.3 Conclusion

To summarize the first chapter of Part II on recent debates on PM it can be said that the expectations raised in writings addressing a medical and a broader public differ. They represent different strategies to promote PM, even if both types of writings share evaluative assumptions. The rhetoric of PM emerging since the late 1990s is not a neutral one, but goes along with far-reaching normative claims neatly linked to a historical argument. According to medical writers, PM is the logical culmination, deeply entrenched in past medical thinking, bridging formerly irreconcilable opposition lines between medicine as an "art" and medicine as a "science". In contrast to this presumably old tradition in medical thinking of which PM becomes a part, the popular discourse presents PM as a modern phenomenon, integral to advances in modern medicine and to a democratic project changing our societies. It is equally imbued with normative requirements presuming that the way to deepen the understanding of one's individuality and act in the purpose of bettering one's health is

by joining PM as a digital revolution. This synergy between commercial interests, normative claims and promises for individual and societal well-being makes this discourse a powerful means to promote PM. The historical narrative is here (information) technological and medical progress and accordingly the myth to push the (last) frontier further into unexplored territory. The appeal of this framing stems from the fact that scientific and technological progress is considered as being carried out by a joint venture societal movement, rather than in a more conventional form by a small, hermetically sealed community of researchers and funding parties.

PM certainly provides a powerful rhetorical framing and an astonishing integrative potential. Nevertheless, current medical research and practice would be well advised to pay careful attention not only to what is included but also what is excluded in current promoting strategies. In both medical and popular writings, the meaning of medicine as professional practice becomes blurry. Either "science" grows at the expense of "art" or the participatory power of PM overshadows or even eclipses the relationship between professional health care providers and their patients.

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