The Personal is Political: Ethics and Personalized Medicine

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ABSTRACT. It is argued that the ethical questions and challenges raised by the project of personalizing medicine are not sufficiently addressed without considering the possible effects thereof on our system of healthcare. I argue that the framing of ethical issues in light of the main principles of bioethics, such as autonomy, welfare and even justice, tends to be too narrow and the larger social implications thus tend to be neglected. Among the possible unintended consequences of the project to increase personal responsibility for health is a reduced emphasis on it's social determinants, for which we are jointly responsible. This presents important challenges for bioethics, and calls in turn for closer attention to be paid to biopolitics and the social context of bioethical discourse. The conclusion is that the benefits or damage that might result from personalizing medicine will depend no less upon political and policy decisions than on pharmacogenomic developments.

KEYWORDS. Autonomy, fairness, framing, personalized medicine, solidarity, welfare

I. INTRODUCTION

The main position of the present contribution is that the ethical discussion of personalized medicine must be located in a social and political context. I consider how some of the ethical questions raised by the project of personalizing medicine can be dealt with in light of the main principles of bioethics and ask whether the framing of the issues from this perspective might be too narrow. I argue that the moral issues must not be restricted to an evaluation of risk for individuals and emphasize the need to explore the broader social implications of the project. It

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is of major importance that we determine whether and to what extent personalized medicine will affect our systems of healthcare and whether it might undermine its solidaristic basis. The project of personalized medicine is often related to an increased emphasis on individual responsibility for health while neglecting social conditions that belong to the political domain and are vital for health. Bioethicists must, therefore, be on guard not to take part in prematurely legitimating controversial innovations by neglecting the bigger picture. Bioethics must consider the promotion of the democratic legitimacy of collective decisions about biomedical research and healthcare policy to be among its primary tasks, because it affects the kind of society that we are shaping.

The article is divided into four sections. In the first section (II), I briefly discuss the idea of personalized medicine as an example of a 'promissory science'. In the second section (III), I show what issues are brought into focus if the project of personalizing medicine is evaluated in light of the bioethical principles of autonomy and welfare. In the third section (IV), I discuss personalized medicine from the viewpoint of fairness and solidarity, and in the fourth section (V) I consider the main challenges involved if bioethics is to account seriously for the social implications of personalized medicine.

II. Personalized Medicine: A Promissory Science

Although much of my discussion is directed to pharmacogenetics as a study of the impact of genetic variation on the response to medications, it is not limited to that. The term personalized medicine refers to the project to 'tailor make' drugs and to translate genetic knowledge into more targeted therapeutic and preventive strategies for genetically defined groups and individuals based on predictions of genetic susceptibility to diseases. This project also implies adjusting health services to this goal by introducing genetic tests and genetic advice. Concomitant with these developments

are efforts to facilitate more choice for individual patients and to provide conditions for them to take a more informed responsibility for their own health.

As Hedgecoe has cogently pointed out, genetic variation is evidently not analysed at the individual level, so the term 'personalized' is misleading: "If we consider the parallel concept of 'tailor-made medicine', then what is being proposed is more a case of buying a small, medium or large T-shirt from the Gap than being fitted for a Savile Row suit" (2004, 5). However, the same author argues convincingly that the wording chosen is no coincidence. Personalized medicine is a positive term that is part of the expectation building of a 'promissory science': "a discipline that exists more in the speculations and promises of its supporters than in terms of scientific results and marketable products" (Hedgecoe 2004, 17).

The term also builds the expectation that medicine will become more personal in the sense that it will become more sensitive to each and every individual. And it is certainly possible that genetic information can help us to choose more targeted and beneficial treatment in particular cases. It can be argued, however, that it is inherent to good medical practice that it takes individuals seriously into account by listening carefully to patients and giving sufficient weight to what they have to say rather than adopting an objectivising attitude towards them (Katz 1984). Seeing patients primarily in terms of their genetic traits will not be conducive to personal medicine in the sense of opening up to them and respecting their subjectivity.

An interesting example of scientific promise associated with personalizing medicine can be found in a company profile produced by the Icelandic genetics research company deCODE Genetics, Inc. from 2003. It is stated as a major aim to "develop accurate tests that can predict individual responsiveness to virtually any drug of interest. deCODE is applying its unrivalled discovery capabilities to bring to market new drugs, DNA-based diagnostic products and pharmacogenomic tests. The company believes that such tests will play a crucial role in delivering personalized medicine

– contributing to the development of more effective means of diagnosing and treating disease by matching each patient with the most suitable drug" (Hakonarson, Gulcher and Stefansson 2003, 1). Later in the same document it is stated that the "new genetics promises to transform the practice of medicine by enabling physicians to assess the risks of disease, permit early detection of disease, determine likely responses to medication, choose the best courses of therapy and have at their disposal new therapies that target the disease process itself" (7).

The terminology of personalized medicine plays a major role in framing the discussion of genetics, raising hopes and motivating support for funding research in the field. Thus interpretations of the topic are based upon presuppositions that affect the way it is presented in the media. From this perspective, personalized medicine lends itself well to a critical social analysis of ideological discourse and the perception of scientific promises. My concern here, however, is about the ethics and moral analysis of the task of personalizing medicine. How well equipped is bioethics to deal with a 'promissory science' of this kind?

III. Bioethics: Patient Welfare and Autonomy

The main role of bioethics can be likened to the building of fences that are intended to prevent the fast moving vehicle of science from driving off the 'road of progress' and hurting people. According to this metaphor, the main objective of bioethics is to make sure that important human interests are not violated. These interests can be seen as the *raison d'être* of the main principles of bioethics: an interest in welfare (to provide benefit and prevent harm), an interest in self-determination (to protect the conditions for agency), and an interest in fair co-existence (to secure justice or fairness and solidarity). Bioethical evaluation of emerging technologies certainly must take these interests into account. This does not mean, however, that bioethical analysis is limited to these principles.

Recent developments in bioethics (as evidenced, for example, by the projects of the Nuffield Council on Bioethics on emerging technologies and solidarity[1]) show increasing concern for the social and political context of emerging technologies and these developments will be crucial in evaluating the implications of the project of personalizing medicine.

Before turning to issues of fairness and solidarity, which I take to be most important in this context, I will briefly discuss possible effects on people's welfare and autonomy. One major aim of personalizing medicine is to increase safety by reducing adverse drug reactions (ADRs) and to distinguish between those who will benefit from a medicine and who will not. Obviously, this in itself is a most sensible objective: "It is hoped that this will help target the prescribing of medicine more appropriately in ways that are sensitive to the genetic variations between people " (Smart, Martin and Parker 2004, 323). This squares well with the aim of reducing the risk of harm, which is at the heart of the classical Hippocratic *non nocere* principle of medical ethics. This can primarily be seen negatively in the form of advice not to take certain drugs, but it can also bring about more targeted benefits from prescribed medicine. Besides, there is an expected financial benefit from safer prescription of drugs. It would seem, therefore, that from the perspective of the interest in human welfare, there is an unquestionable benefit to be expected from the project of personalizing medicine.

Nevertheless, there are at least three reasons to be concerned about the unintended side-effects or sacrifice costs associated with this project. The first has to do with the possibility of so called 'orphan populations' being created because "the pharmaceutical industry may not have the financial incentives to invest in designing products for small markets, effectively meaning that individuals with very rare disorders lack treatment options" (Smart, Martin and Parker 2004, 327). This could clearly have harmful consequences for the said individuals, but since it is a general problem related to rare diseases it raises no particular questions in this context. This issue relates even more to concerns of justice than welfare and I will return to it briefly below.

The second concern is personal and relates to the genetic testing that people will need to undergo in order to acquire information about their genetic susceptibility to ADRs. This has to do with the provision of information gained from testing, which should be limited to genetic disposition to the ADR in question and not convey more comprehensive information about susceptibility to diseases. However, this may not be a realistic option. The view that "pharmacogenetic testing will predict patients' responses to medicines, but that it will not provide any other significant disease-specific predictive information about the patient or family members" has been challenged (see Netzer and Biller-Andorno 2004). This is partly because patient stratification on the basis of genetic susceptibility to ADRs sometimes "corresponds to other clinically relevant differences, such as disease risk and prognosis" (Smart, Martin and Parker 2004, 232). This implies that it is difficult to distinguish clearly between ethical issues raised by disease testing and pharmacogenetic testing.

Moreover, as Lindpaintner has argued, if individual pharmacogenetic information is to serve its intended purpose of improving the patient's chances of successful treatment "it is essential that it is shared among at least a somewhat wider circle of participants in the healthcare process. For example, the prescription for a drug that is limited to a group of patients with a particular genotype will inevitably disclose the receiving patient's genotype to any one of a large number of individuals involved in the patient's care at the medical and administrative level" (2003, 151). This need not count as an argument against pharmacogenetic testing because, as Lindpaintner continues, patients could choose to "sacrifice the benefits of the indicated treatment for the sake of data confidentiality" (2003, 151).

Such considerations have induced the response that in the environment of genetic research "the ideal image of confidentiality" needs to be abandoned, and that this must be frankly acknowledged in discussions with patients and research participants (Lunshof, Chadwick and Church 2008, 2). The project of personal genomics and developments in both

medical informatics and bioinformatics require extensive data sharing and therefore "show that the guarantee of absolute privacy and confidentiality is not a promise that medical and scientific researchers can deliver any longer (Lunshof, Chadwick, Vorhaus and Church 2008, 406). These authors argue that the appropriate response to this is that "veracity should precede autonomy" (409).

Veracity is of crucial importance in research ethics as a major precondition both for non-deception in communication about the conduct of research and for transparency in the regulation of research practices. Moreover, veracity is also a precondition for autonomy and must precede it, since having the right information about research is a precondition for a voluntary decision to participate. The demand for veracity implies not only that people are made aware of the limitations of even the strictest standards of data protection, but also, and even more importantly, that they have trustworthy ways of knowing "how and to what end is it used?" (Lindpaintner 2003, 152). The importance of this demand has increased in the context of databases as resources for genetic research, which is often unforeseeable when data is first collected. Veracity is a precondition for a viable research opt-out preference and requires in fact continuous information about research developments making use of participants' data.

The bioethical principle of respect for autonomy aims to protect the interest in agency, or the capacity of a person to make decisions and act freely. The most obvious implication of the said principle in this context is that people should have a free choice whether to take a genetic test for ADRs or not. This relates to the right of people to know and not to know their genetic susceptibility to certain genetically determined or co-determined diseases. In this way, ethical considerations in light of the principles of welfare and autonomy are intertwined in the context in question, because persons cannot be protected from the risk of ADRs unless their genetic disposition to them is known.

As a rule, the right of individuals to take the risk by choosing not to know their genetic disposition should override the presumed benefits

they might gain from having that information. However, having the information might increase the rational autonomy of such individuals because their conditions for informed choice of treatment might be strengthened. The likelihood of this is reduced by the fact that the information disclosed by pharmacogenetic tests can often be hard to interpret and have limited application value (Haga and Burke 2008). Important translation research is being carried out to develop criteria for test introduction evidence-based guidelines for assessing the value of a genomic application for health practice. "Ideally, studies establishing the utility of an intervention should be conducted and evidence-based guidelines developed before a program is implemented (Khoury *et al.* 2007).

The discussion demonstrates the importance of keeping in mind that harm/benefit assessment must not be restricted to medical or physical harm, but needs also to be related to the handling of personal information. This could possibly be dealt with as a manageable risk by setting strict regulations about what information can legitimately be read from these tests and by trying to ensure that people are properly informed about the risk they are taking with regard to their privacy.

The third concern about the unintended side-effects or sacrifice costs associated with the project of personalizing medicine has to do with the possible societal consequences thereof for the practice of healthcare. While creating a serious challenge for health policy, this is not strictly a manageable risk and any discussion of this concern will ultimately lead us into a territory that has been largely unexplored by mainstream bioethics. I will return to this point below.

IV. Fairness and Solidarity

Research in Scandinavia has shown that participants in genetic research find it most important that the results are used fairly and for the benefit

of science and society (Hoyer, Olofsson, Mjörndal and Lynöe 2004). This implies that people's decision to take part in research is dependent on how they see its usefulness. The discussion on respect for autonomy must not, therefore, be reduced to a mere consent to participate in particular research projects or individual testing. It needs to be placed in the context of the potential societal consequences of personalizing medicine for the practice of healthcare. It is important to acknowledge that the principle of autonomy protects the conditions of moral agency and these are related to the social institutions that provide primary goods for all citizens, without which they are unable to plan their lives.

These social aspects do not come fully into the picture in bioethical discourse until we discuss the principle of justice that protects our common interest in fair co-existence. In the mainstream bioethics discourse, this principle most often invites an evaluation of whether the benefits of a given treatment or research are distributed fairly and whether there is just access to such treatment. As regards the project of personalizing medicine, one issue of concern has been about the possibility of so-called 'orphan populations' being created as an indirect result of tailoring drug development to patient groups with suitable genotypes (Rothstein and Epps 2004; Nuffield Council on Bioethics 2003). According to Smart, Martin and Parker (2004), this could occur at the drug discovery stage, because it would be rational from the viewpoint of efficacy to focus on patients with either the most common genotypes or "genetic groups identified as 'good responders' (patient stratification)" (328). Orphan populations could also be created through efforts to improve the efficacy of drugs in the redesign of clinical trials with pharmacogenetic means, where 'good responders' would be favoured and 'non-responders' excluded.

This development implies that the expected benefits, i.e. more effective and targeted medication for certain patient groups, can have unintended undesirable consequences from a moral perspective. In order to ensure equity and justice, it is important to create incentives to develop new drugs for marginalized populations. Sensible suggestions have been

made to help policy makers in the difficult task of fairly allocating resources for the prevention, diagnosis and treatment of rare diseases (Pinxten, Denier, Cassiman and Dierickx 2011).

Without going into discussion on the actual prospects in this regard, I will simply invoke the widely accepted principle of justice, namely that the unequal distribution of social goods is justifiable only insofar as it benefits the worst-off (Rawls 1971). This principle can be used to evaluate any change of policy in the healthcare sector from the perspective of fairness. It squares well with the principle of solidarity, as concern for the shared social conditions of fair co-existence and joint responsibility for sustaining them.

Individual rights cannot be protected without defending and strengthening "the soil in which such rights take their roots, the form of life in which relationships of mutual recognition can flourish" (Reichlin 2011, 369). The principle of solidarity is of major importance in the discussion of health and genetics due to the emphasis laid upon the protection of weaker groups in society and commitment to the fair distribution of healthcare services (Houtepen and ter Meulen 2000).

This principle can be regarded as the backbone of many European systems of social healthcare, most notably the Nordic welfare systems (Árnason 2007). This is evident, for example, in many governmental reports, such as the Swedish: "Solidarity also means devoting special consideration to the needs of the weakest" (SOU 1995, 105). Solidarity is also a major issue in a Dutch report: "Risk solidarity is when the healthy pay for the ill and good risks pay for the bad risks. Income solidarity is when the financially able pay for the less wealthy" (Government Committee on Choices in Health Care in the Netherlands 1992). This implies, however, that the emphasis on efficacy be subsumed under the requirement of fairness, which demands strong political commitment to solidarity and resolute resistance to forces that seek to undermine it.

Two things need to be discussed at this juncture. First, how the project of personalizing medicine may pose a threat to the norms of

fairness and solidarity that are constitutive of social systems of healthcare. Second, how the project of personalizing medicine may reinforce existing inequalities by serving populations in rich countries more than in poor countries. The former has to do with solidarity based on joint participation in a particular community, while the latter refers to a shared belonging to humanity. Since my concern in this paper is primarily about the former, I will be brief about the latter. There are mixed arguments about the possible impact of personalizing medicine on the populations of the poor countries of the world. On the one hand, it is argued that developments in this area will be restricted to rich countries and will thus increase the existing inequities between the rich and the poor (Smart, Martin and Parker 2004). From this perspective, it would make more sense to spend resources on improving basic healthcare for all than increasing healthcare options for the affluent. Others have argued that the possibility of 'drug resuscitation' will bring benefits to developing countries (Daar and Singer 2005). In any event, it seems that the project of personalizing medicine can either increase or decrease health inequalities both globally and within individual countries. Which way it goes will depend no less upon political and policy decisions than on pharmacogenomic developments.

Most European healthcare systems are based on solidarity, while the discourse on personalizing medicine encourages the mentality of facilitating individual responsibility for health. The concern that the project of personalizing medicine may pose a threat to the norms that are constitutive of social systems of healthcare may seem strange in light of the fact that people are not responsible for their genetic endowments. However, the argument is that the more information is available about genetic susceptibility to a disease will bring about a "shift from reactive disease-treatment oriented medicine towards the proactive approach of preventive medicine with an emphasis on personal responsibility for health" (Gefenas *et al.* 2011, 141). Rather than appealing to passive patients, it is claimed that we should address

people as active citizens who are empowered by increased health literacy and can better manage their own health (Brand and Brand 2011).

The lure of the appeal to individual responsibility for health is so strong because no sensible person is against increasing the awareness and health related literacy of both the public and professionals. No one seriously argues against more targeted preventive measures or the reduction of ADRs. The language of individual responsibility for health also motivates people as healthcare consumers who perceive themselves as empowered by the potentialities of personalized medicine. "Such a citizen is obliged to inform him or herself not only about current illness, but also about susceptibilities and predispositions" (Rose and Novas 2004, 441). However, undue individualization of responsibility for health is double-edged and even dangerous, and can in fact be self-defeating if it brings about a corresponding disregard for the social, environmental and political determinants of health (WHO 2008). If it involves directing intellectual and financial resources towards high-tech ways of resolving health problems at the expense of low-tech approaches towards societal determinants of health, which would have greater impact for the underprivileged, it would not only reinforce existing inequalities but outright increase them.

This statement appeals to the theory of justice, which emphasizes the status of the least advantaged in society who are most vulnerable to the social determinants of health. If increased emphasis on personalized medicine leads to a further neglect of the social circumstances that greatly affect people's health and life expectancy, then injustice will be increased: "These inequities in health, avoidable health inequalities, arise because of the circumstances in which people grow, live, work, and age, and the systems put in place to deal with illness. The conditions in which people live and die are, in turn, shaped by political, social, and economic forces" (WHO 2008). The project of personalizing medicine must not be thrust aside by such considerations, nor must it make us blind to grave injustices

and wrongs that are more urgent tasks for the improvement of health than tailored drugs for the affluent.

If a radically increased emphasis on genetic factors in healthcare services would bring about the neglect of many other influences on public health, it is likely to reduce the effectiveness of treatment, which is the main argument for the project of personalizing medicine in the first place. It is tempting to argue that a proper medical education about the possibilities and limits of genetics would work against such an overemphasis, but it may not be realistic. If genetic testing becomes a standard part of examining a patient and a normal precondition for prescribing drugs, there is reason to believe that the doctor-patient relationship will be altered and the gaze of the doctor will be directed more towards genetic factors than other factors relevant to the patient's condition.

Although this might in many cases be of benefit to individuals, the social benefits of such a practice would be increased if it could be combined with knowledge of behavioural and environmental risk factors in the formation and penetration of disease (Halliday *et al.* 2004, 895). If the focus is limited to genetic risk of disease, at the expense, for example, of improvement in people's working conditions, this 'transformation of the practice of medicine' could lead to a transfer of emphasis from social determinants of health – for which we are jointly responsible at the political level, to individual control of getting a disease. This is one of the main features of the geneticization of healthcare (Árnason and Hjörleifsson 2007).

Moreover, a pervasive implementation of genetic testing in healthcare is also likely to be expensive: "the introduction of pharmacogenetics will demand a sophisticated testing and information technology infrastructure" (Smart, Martin and Parker 2004, 334). Quality assurance is also needed, such as an independent body to assess clinical validity and utility of genetic testing and its relation to drug safety. To further complicate the matter: "Pharmacogenetic testing would likely not be feasible in many clinical settings if genetic counselling were routinely

recommended or required; uptake would likely be discouraged, costs increased, and an already limited workforce would be further strained. Yet some tests may generate complex risk information that would require detailed pre-test counselling to assure informed consent" (Haga and Burke 2008, 393). All of this works towards placing undue demands on the public system, which in turn might feed into arguments for increased commercialization of healthcare services and the introduction of private healthcare insurance based on risk calculation. Such a development would undermine the solidaristic system of healthcare, which implies that individuals are not only responsible for themselves but are also co-responsible for their fellow citizens, and especially for the underprivileged. As the recent report from the WHO convincingly demonstrates, a publically financed system of healthcare based on equity is a vital good for all citizens and developments that undermine it present dangers not only to health but threaten welfare, justice and autonomy as well (WHO 2008).

While this is clearly a fictional analysis of a possible course of events, such analyses can be valuable in order to foresee scenarios that we have good reasons to avoid and thus motivate responsible policy decisions. It has been argued that "medical innovation or a novel diagnostic or therapeutic strategy or tool will not be accepted by medical professionals and patients unless it is compatible with the existing societal framework of values and lay perceptions of the human body, health and disease". It is important to remember, however, as the authors immediately add, "that scientific developments also influence and alter existing values and perceptions" (Paul and Ross 2003, 138). The framework of values that are based upon the fundamental democratic requirement of the moral equality of all citizens and the corresponding solidarity, which implies sustaining the social fabric of universal recognition of anyone's needs and rights, has been hard won through a long historic process, but it can be quickly undermined if we are not devoted to the foundational principles. This relates once again to the role of ethics.

V. Challenges for Bioethics

Bioethics must be constantly on its guard not to become an 'innocent accomplice' in the introduction of a controversial new technology as that under discussion. The danger resides mainly in framing the ethical questions too narrowly to the neglect of the larger social implications. I will risk overgeneralizing by stating that bioethical analyses tend to focus on questions concerning a particular set of crucial issues relating to basic human interest, such as privacy and consent, risk of harm or discrimination. If there are good reasons to believe that these interests can be protected, a particular bioethical technology could legitimately be introduced. For example, the introduction of genetic testing could be discussed primarily in terms of the main principles of autonomy, non-maleficence, beneficence and justice, evaluating whether the practice would duly meet the requirements for the informed consent of patients undergoing the tests, whether the test would put the person at a considerable risk, e.g. relating to knowledge of non-treatable disease, whether privacy of information would be protected so that the patient would not be in danger of being discriminated against on the basis of his or her genetic susceptibility for certain diseases.

All of these are important questions that must be addressed. Answers to them do not, however, provide sufficient reasons for taking a moral stance on the issue. It is not enough to assess the harm-benefit ratio for individuals. Questions about the sacrifice costs for society also need to be raised and critically discussed. As I have tried to show in this article, questions concerning the effects of introducing pervasive genetic testing upon healthcare services and the practice of medicine must be taken into account as well. Without dealing with them, the ethical discourse will be ideological in the sense that it implicitly covers up important moral aspects of the effects of biotechnology while claiming to analyse its main ethical implications. Bioethics is then in danger of taking on a premature legitimating role by focusing too narrowly on particular ethical questions while ignoring others (Turner 2009).

This is sometimes expressed using the metaphor of upstream and downstream tasks of health policy. Responding to issues 'downstream' is like damage control, trying to save people from drowning who have already fallen into a river. Protecting the interests of individuals in medical contexts from harmful effects of an already accepted technology is of this nature. Responding to issues 'upstream' is like prevention, trying to prevent people from falling into the river in the first place. Placing the interests of citizens in a larger societal context of determinants of health and guarding against unintended detrimental consequences of technology for healthcare systems is of this kind. But it is not enough to build strong fences against the forces of accident, disease and damage to the social fabric. Returning to the image of the fast riding vehicle of science that I mentioned above, it shows the need for having a clear and critical sense of direction. Where are we heading on the road? Is it truly a road to progress?

These questions reach beyond the particular effects of new and emerging technologies and raise issues about what kind of healthcare system we want to have and what kind of society we envision. The direction in a democratic society has to be up to its citizens, but they can only assume such responsibility if they are well informed about the issues. This fact poses major challenges to shaping more democratic ways of policy formation that go beyond the strategic goal of finding efficient means of securing more public support without properly informed critical debate (Irwin 2001). A major task is to promote the democratic legitimacy of collective decisions about biomedical research and healthcare policy by searching for ways to enhance public accountability (Chambers 2003, 308).

It should be clear that the ethical questions related to the project of personalizing medicine cannot be properly discussed without placing the issues in a political context, because it insists that we think seriously about the kind of healthcare system we want and can defend with good moral reasons. This question cannot be answered without informed public

deliberation, which facilitates collective understanding about what will best serve our public interests (Gutmann and Thompson 1997). This means in effect that a bioethics that takes the social implications of personalizing medicine seriously cannot be clearly distinguished from democratic biopolitics. This requires that bioethical issues are not only monologically addressed by experts, but that ordinary citizens are engaged in public deliberation about the issues. However, if the bioethical discussion of personalized medicine is framed exclusively in terms of saving individuals from illnesses and protecting them from harm and risks, the fact that they are also reflective citizens who are capable of assuming a public standpoint in a dialogue about policy issues is ignored.

A common way that has been chosen to discuss such questions in deliberative exercises is important, but it is fraught with difficulties. Sociologists who have studied these experiments ask crucial questions: How can meaningful engagement of the public be facilitated? (Powell, Colin 2008). What sort of information is provided and how should it be presented to the public? How are issues to be framed for public debate (Felt, Fochler, Müller and Strassnig 2009)? How is public consultation to be institutionally located and are there ways to ensure that it will inform government policy? (Irwin 2001). In addition, new complications arise when the subject matter is a project of a promissory science that intends to revolutionalize healthcare as in the case of personalized medicine. Since we have no experience of these practices, members of the public are unusually dependent upon expert information. It is of crucial importance, therefore, that the expert input is not just from the scientific and bioethical point of view, but also from critical sociology, so that the secenarios are portrayed from a sufficiently broad perspective. The aim must be to provide citizens and policy makers with food for thought and imagination that enables them to think sensibly about the steps to take in the direction of translating genetic research into medicine and adapting the public healthcare system accordingly. They can reflect on questions that not only relate to medical advances, but also on the effects they may have

upon the solidaristic foundations of public healthcare. In a society that takes its democratic task seriously, there is no other option.

VI. Conclusion

The project of personalizing medicine has debatable implications both for individuals and society. The expected benefits for individuals and groups can also have unintended undesirable consequences, both on a national and on a global scale. Bioethical discussion about this issue must be on its guard not to take on a questionable legitimating role by focusing too narrowly on the effects of this new technology on individuals. Personalizing medicine could have major effects upon the practice of healthcare and the development of social medicine. It is a challenge for bioethics not only to place the discussion of personalizing medicine in a broad social context, but also to facilitate informed public deliberation about the implications of this new technology and how to regulate it – with all the challenges and complications it invites. The result will depend no less upon policy decisions than on scientific developments.[2]

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NOTES

1. www.nuffieldbioethics.org

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