Moving Beyond Our Mutual Ignorance. Or, How would Engaging the Public Benefit the Personalized Medicine Community?

Pascale Lehoux*

Department of Health Administration, University of Montreal, and Institute of Public Health Research of the University of Montreal (IRSPUM), Montreal, QC, Canada

Keywords: Medical innovation, personalized medicine, public involvement, public understanding of science, values.

1. EXPERTISE AND IGNORANCE: CONTESTED AND FLUID BOUNDARIES

In my different roles as an academic active in the field of health innovations, services and policy research, I have been invited half a dozen times to share ideas about personalized medicine. Most of the time I was not very receptive and have declined because I felt the topic did not fall within the scope of my expertise. But when the Editor in Chief of this Journal invited me to write an Editorial, I could not provide the same answer. He carefully specified why it is timely to reexamine, from the social scientific perspective my colleagues and I had articulated in a recent paper on public engagement [1], the “public knowledge deficit thesis” that seems to prevail within the personalized medicine community. As a result, my resistance vanished as my own ignorance was reframed as secondary.

As I will seek to clarify below, the dynamics and outcomes of this rather simple exchange between two individuals are not, after all, surprising. By inviting the personalized medicine scientific community to reflect on dichotomies that tend to be taken for granted such as ignorance/knowledge, acceptance/resistance, values/science and individual/social, I will argue that this simple exchange offers a few lessons to be learned. And if something like “ha, not other social scientist using jargon and referring to abstract concepts” just sprung to your mind, I invite you to continue reading (overcoming perhaps your own resistance).

The context in which personalized medicine is emerging is unique, but not so much from a scientific standpoint. It is the particular convergence of economic, political and social issues, which characterizes today’s health care world that renders the current development of personalized medicine different from most of its scientific predecessors. Scientists working in this area should, I believe, acknowledge the extent to which this broader context will be decisive of the future. In this context, the most important question to be tackled is, what value does personalized medicine bring to health care? And here I am not referring to its value in terms of costs and benefits, but in terms of its capacity to substantially improve the provision of health care as well as the lives of all members of society.

2. HOW DO WE KNOW WHETHER PERSONALIZED MEDICINE BRINGS VALUE TO HEALTH CARE?

While Ptolemy stresses that research “thus far produced relatively few indicators worthy of clinical integration”, he nevertheless observes that despite “this reality, researchers are not likely to temper their pursuit of biomarkers in the near future, as to many the potential rewards of such efforts far outweigh the potential risk of failure” [2]. This may be true when one considers only the scientific dynamics at play, but less so when one also ponders the context in which scientific practices are actually unfolding. They do so in an open and complex social and political environment, called by sociologists of science “Mode 2” [3], wherein the context of application, e.g., the milieu likely to adopt, transform and apply scientific findings and its stakeholders play a pivotal role. Within such a web of relationships, scientists are asked to demonstrate convincingly how their science will solve problems, lead to viable commercial activities and produce outcomes for which they can be made accountable to the public.

It thus appears understandable that the proponents of personalized medicine have sought to rally large segments of society, including public and private investors, entrepreneurs, physicians and the media, to its cause, even though at this stage in its evolution very little is known about how, in practice, its discoveries will be implemented in health care systems and generate health gains. Indeed, as noted by Khoury et al. [4], no more than 3% of the published genomics research has focused on the development of evidence-based guidelines or health services and systems research for genomics applications and their real-life health outcomes. As a result, even though personalized medicine has penetrated to the collective public mind, it also generates confusion since its four “Ps” (predictive, preventive, personalized, participatory) represent very different things to each of the stakeholders involved. For instance, prediction is too strong a word for several of the biomarkers that have been identi-
fied. And when surgical removal of healthy body parts is the only way to prevent the putative onset of a disease, one’s enthusiasm necessarily lessens. While personalized medicine diagnostics might potentially serve well in other application contexts, the attendant uncertainties that belong simultaneously to the social and techno-scientific domains are not always clearly articulated.

This may explain why critical observers of personalized medicine have emphasized the need to demonstrate how this science may benefit society. For instance, Ozdemir and colleagues suggest that the emerging new subfields of personalized medicine - nutriproteomics and proteogenomics - should muster efforts and seek to develop applications with “added societal value” [5]. Arguing in favor of economic analyses that adopt a societal perspective, Husereau stresses that the deployment of pharmacogenomic tests should be appraised within the context of “sustainable health system approaches” [6].

Despite such pleas made on behalf of society, one key actor who is easily left aside is the public. And this may be explained by the presumption that the science itself needs to be established on more solid grounds before its potential applications can be more fully disclosed to the public. For instance, Ptolemy recommends the use of strict definitions and the development of robust biomarker validation policies before engaging into deployment at the clinical level [2]. Although such a careful staging of the scientific steps that need to be accomplished may seem warranted from the basic scientists’ perspective, one problem is that any potential application relies on a social vision, e.g., a scenario of implementation that requires its own plausibility check. Importantly, within the Mode 2 of scientific practice explained above, this has to happen preferably in the early stage of development and outside of the laboratory, in the public sphere [7]. And this is where things get complicated since most scientists are reluctant to engage into public discussions, seeing ignorance of the broader society as an insurmountable obstacle [8].

3. ABANDONING THE DEFICIT MODEL OF PUBLIC UNDERSTANDING OF SCIENCE

The example I gave in my introduction should help us reconsider the “public knowledge deficit” thesis that posits the putative ignorance of the public as an obstacle. For the exchange between the Editor in Chief and myself to take place, both of us had to acknowledge our respective ignorance, including that acquired through disciplinary expertise and blind spots. But both of us were also aware that the other one possessed knowledge. The Editor in Chief made the effort to seek and ponder the ideas I had articulated for the sake of my own scientific community. By accepting to write this Editorial, I had to do likewise. Hence, acknowledging each other’s ignorance and knowledge pave the way to a mutual learning process.

This is in a nutshell what the paper in question says [1]. It argues in favor of public involvement in health innovation policymaking, stressing that the asymmetry of knowledge between experts and non-experts should not be seen as an obstacle, but rather as an occasion to foster deliberative learning processes between participants. The paper also clarifies how normative assumptions (e.g., values and preferences) and knowledge are co-constitutive of each other, a phenomenon that applies to all members of society, be they experts or non-experts. In other words, the “knowledge” and the “knower” (and her/his values and preferences) are inseparable. Henceforth, “what researchers and policymakers might wish to know from publics is how their reasoning is anchored in normative assumptions (what makes a given innovation desirable?) and knowledge regarding the plausibility of their effects (are they likely to be realised?)” [1].

Exploring these two interrelated questions with members of the public would enable personalized medicine experts to debate explicitly the scientific and social visions underlying the scenarios according to which specific applications could be developed and implemented.

According to Boenink, for example, if biomarkers become part of the definitions used for specific diseases, they will transform how physicians and patients will have to deal with new kinds of knowledge and new kinds of uncertainty [9]. For instance, whereas until recently a general practitioner would have sent a patient “away with the reassurance that nothing was wrong”, sharing a positive result within the personalized medicine paradigm would mean leaving a patient with the disease [9]. Furthermore, the cascade screening model according to which the relatives of a person affected by a disorder are also considered “at risk” implies that physicians are no longer dealing with an individual patient, but with a broader and more complex social entity: the family and its understanding of what kinship entails [10]. In such clinical encounters, probabilistic knowledge does neither truly empower the clinician nor the patient(s). Predictive diagnostic testing does in fact alter one’s understanding of the ontology and timeframe of a disease [9]; “being at risk” is not the same thing as “being ill” and testing for future health states shifts one’s attention away from the present, firmly bringing the future(s) to the present.

When the public will understand that what is meant by personalized medicine is not what common understanding of that word usually entails, e.g., care that is tailored to one’s individual needs and particular health condition, thanks to a humane and effective health care provider, significant moral tensions will need to be clarified. At this moment, the media - which remain the most frequent if not the sole channel of communication between scientists and the public - portray as their culture dictates “personal stories” that reinforce an incomplete understanding of what personalized medicine entails. For instance, the full implications of the subgroup stratification principle that underlies most research in pharmacogenomics are rarely addressed. What will be offered to patients belonging to the subgroups of those likely not to benefit from a drug and those likely to experience adverse effects? Because the media can only draw a fragmented and largely uncritical picture of personalized medicine, I believe that scientists themselves should consider and learn to engage into productive debates with the public.

4. BRINGING THE “PERSONS” OF PERSONALIZED MEDICINE TO THE FORE

The goal should not be, however, to study, let alone foster, so-called public “acceptance” of personalized medicine.
Health innovation trajectories are typified by multiple possible future(s), including over- or under-use, tinkering and reinvention. Words such as acceptance should be banished from scientists’ discourse and the health innovation lexicon because like the plea for “intercultural tolerance” it implicitly carries in its very expression its opposite; to tolerate (or accept) signifies that something is somewhat irritating, questionable, strange or unwelcome. It also structures, a priori, the relationship between those who express the word and those to whom it is told; one knows what the other should accept.

A more productive way to engage members of the public is to be interested genuinely in listening to what they know and value, and to ensure that their involvement will be organized so as to make their participation meaningful and impactful [11]. From the local hosting of a Scientific Café (www.cafescientifique.org), which enables sharing in an informal setting ideas between experts and non-experts to the organization of a “citizens’ jury”, which may involve up to four days of hearings, a roster of expert “witnesses” testimo- monies and gradual consensus building, public involvement may take many forms and pursue very different objectives (i.e., consultation, priority setting, deliberation, generation and/or validation of sociotechnical scenarios, decision-making). The literature on public involvement is in fact steadily growing and offers a number of concrete examples of how to organize and manage various types of public involvement strategies [12]. These strategies are likely to be applicable to the field of personalized medicine and stimulating collaboration between social scientists and basic scientists could take place around their adaptation and implementation. Among other things, there is a need to better understand what specific outcomes may be reasonably expected from different types of strategy and how members of the public appraise their respective strengths and weaknesses.

Of course, any public involvement initiative should be conducted with a critical mind; it does not imply endorsing everything that is being shared. Like any scientific claim, an argument that is put forward within a public forum has to be openly criticized and put to test. Perhaps some scientists would be (happily) surprised by seeing how some members of the public are eager to engage into reasoned deliberation, seeking to make sense of, and contribute to the world in which they live.

In one public involvement experiment my colleagues and I observed, the participants took very seriously the task put forward to them: debating, from a citizen’s point of view, research and policy issues related to the organization of genetics services. It was crucial for them to make relevant contributions; rather than simply sharing a personal, spontaneous opinion, they wanted to articulate a well-thought-out citizen’s perspective. They also observed that experts were “citizens too” and, if they could separate themselves from their professional interests, they could speak as citizens as well [11].

Because setting aside one’s disciplinary or professional perspective remains however a difficult exercise and given the fact that experts are currently making several decisions on the public’s behalf, engaging non-experts into scientific issues should remain a priority. We recently observed that medical specialists’ appraisals of the value of controversial innovations were not only informed by scientific and clinical observations, but they were also shaped by a set of fragile, untested social assumptions (for instance, assuming that prenatal testing for Down syndrome would reduce costs to society). More precisely, medical specialists “defined social needs and preferences in ways they thought were appropriate given their patients’ expectations. As medical specialists are members of society just like everyone else, their social assumptions may be the same as those of many other people (including patients)” [13].

The problem is that medical specialists’ normative assumptions often remain undetected, while they enjoy a fairly unique position that determines which innovations is desirable or not and which will be used or not. While our study paid attention to values that may remain implicit, other studies found that experts may also argue in favor of the development of certain technologies on moral grounds [14]. Hence, given the context in which the development of personalized medicine is currently taking place, differentiating scientific claims from values while recognizing that both are shaping the scenarios by which some applications may become established is more than warranted.

CONCLUDING REMARKS

Reframing a putative lack of knowledge of the public as a mutual learning opportunity should help scientists reconsider not only their role as repositories of expertise, but perhaps more importantly as individuals who hold certain privileges and obligations toward the society they live in. One of these obligations is to acknowledge the extent to which one’s values and preferences frame one’s vision regarding the valuable outcomes of scientific discoveries. Doing so for the applications personalized medicine may generate should help improve the clarity of the social and techno-scientific choices awaiting to be made.

While the present editorial presented observations on scientific practices as viewed through a social scientific lens, this analysis would not be complete without asking why the public knowledge deficit thesis still prevails within several basic science communities, even though it has been contested and rejected for a long time within the social studies of science and technology community? [7] Considering the uniqueness of the economic, social and political context in which personalized medicine is emerging, perhaps the answer will come from the personalized medicine scientific community itself because it will be forced to reconsider how it can be made accountable not only to its private and public investors, but to the public as well. Today, innovations that are designed according to expert knowledge and values only while neglecting the knowledge and values of the broader society may never be considered desirable from a health care system perspective wherein the issues of sustainability and social health inequalities remain pivotal [15].

Although the evidence-based medicine movement tend to assume that it is possible to avoid engaging into complex, value-laden discussions by reverting to the principle of individual autonomy and of its accompanying informed consent
procedural logic, this approach “both simplifies and forecloses ethical debate” [9] because it simply disintegrates into a multitude of individual decisions the very possibility of engaging into a collective ethical reflection. Prenatal testing is a good example of how informed consent proves socially equivocal since such innovations are never used in a social vacuum; “technological imperatives” often go hand in hand with “social imperatives” that are left unquestioned [13]. While women who are offered breast cancer predictive testing may seem particularly receptive to such medical advances, this may be partly explained by the fact that they possess an intimate knowledge of the suffering other women in their family have gone through. The test, if negative, does not however alleviate the sense of guilt that often ensues and which contributes to the reshaping of the family relationships.

This last example illustrates the very social fabric that medical innovations are transforming and without which scientific discoveries cannot acquire any sort of value. Whereas social scientists have much to learn from the personalized medicine scientists whose 21st century practices go well beyond the classical laboratory space and unfold in novel configurations of research infrastructures, I believe that the personalized medicine scientific community could seek to learn more about society, social and political dynamics and the public understanding of science.

CONFLICT OF INTERESTS

None declared/applicable.

ACKNOWLEDGMENTS

The research the author conducts is funded by an operating grant from the Canadian Institutes of Health Research (CIHR; #MOP-89776). She holds a Canada Research Chair on Health Innovations (2010-2015). Her research group infrastructure is supported by the Fonds de la recherche en santé du Québec (FRSQ).

Although I take entire responsibility for the claims made in this editorial, I would like to thank Antoine Boivin, Geneviève Daudelin, Olivier Demers-Payette, Myriam Hivon and Vural Ozdemir for the very helpful and insightful comments they made on an earlier version of this paper. Two anonymous reviewers also provided helpful comments and suggestions.

REFERENCES