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WHAT'S IN A NAME: CONCEPTIONS OF PERSONALIZED MEDICINE AND THEIR ETHICAL IMPLICATIONS



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Sommaire



- 1 – Introduction
- 2 - Why is it important to elucidate different meanings of 'personalized'?
- 3 - Senses of personalization
- 4 - Combination of different senses?
- 5 - Conclusion

Medicine is said to be moving rapidly down the road towards personalization, but it is not entirely clear how we are to understand this term, or its implications for ethics. In understanding the concept of personalized medicine there are multiple possible interpretations of 'personalization' at stake. These may in turn presuppose different concepts of 'person', with resulting variations in the ethical implications.

Key-words: personalization, person, genomics, ethics, pharmacogenetics, stratification

1 – Introduction

Medicine is said to be moving further and further down the road towards personalization, but it is not entirely clear how we are to understand this term, or how it should be regarded from a bioethical point of view. In understanding the concept of personalized medicine there are multiple possible interpretations of 'personalization' at stake. This is important because the terms used to describe the type of medical interventions on offer may seem to promise much, and they have consequences for the expectations of patients, clients and society (see, e.g., Hedgecoe 2004; Tutton 2014; Wöhlke et al. 2015). It should of course be noted that while there have been and continue to be attempts to provide definitions of personalized medicine, there have also been moves to go beyond the term 'personalized' to use others such as 'precision' medicine. 'Stratification' is also a term that is frequently used with, at first sight, very different implications both for user perspectives and for ethics. This paper aims first to explain why the choice of term is itself an ethical issue, and then to provide a typology of senses currently in use and their bioethical implications. In doing this I aim to distinguish and explore ten different possibilities for understanding the term 'personalized medicine'. I do not claim that this is an exhaustive account: there may be others. The investigation of different senses will inevitably also uncover presuppositions about how 'persons' are being conceptualized in the health care context, and these presuppositions influence how health care encounters are framed from an ethical point of view (Prainsack 2014).

2 – Why is it important to elucidate different meanings of 'personalized'?

There are at least three reasons why investigation of the term

'personalized' is important. These include: the generation of expectations; implications for professional ethics; and implications for public health, including responsibility for health.

2.1 Expectations

The first reason, already alluded to above, concerns the expectations of patients, clients and society in the event of a new model of medicine being promised or forthcoming (Tutton 2014). It is true that, under a system that did *not* label itself as personalized, patients may well, even so, have expected that their doctor and other health professionals would act in the best interests of them *as individual patients*, whether their actual experience proved in fact to be good or bad. What must have been a familiar experience for many patients, however, and perhaps still is, was to be advised by a doctor to try a certain prescribed regime, and if it did not work, to return in two or three weeks to try something else – the 'trial and error' approach to medicine.

What were not highly publicized, until relatively recently, were the reasons for and drawbacks of this trial and error approach. While it was known that any given treatment would only work on a proportion of patients, and in fact could be positively harmful to some, there was no advantage in broadcasting widely the statistics of drug-induced mortality and morbidity. This is not to suggest that patients were not made aware of possible side effects, but the overall success rates of this model of medicine were not widely publicly discussed, although issues surrounding specific therapeutic agents (e.g. thalidomide) may have been. But when pharmacogenetics became a realistic option, there were indeed good reasons to publicise these statistics, in order to garner support for the use of genetically informed prescribing as a new way of offering medical treatment. It takes time, however, for these arguments to become widely recognised and accepted.

So what effect *does* it have on expectations to describe the new era of medicine as 'personalized'? There is some em-

irical evidence to suggest that the term ‘personalized’ still suggests to patients that their interests are somehow being taken care of in a ‘personal’ way (see, e.g., Heusser 2015) – this may be because they think they are being treated with the respect due to an autonomous person’s wishes, or because they believe themselves to be treated as more than ‘just another case’. Peter Heusser tackles the issue of the differing understandings of patients and clinicians in arguing for the integration of ‘personalized’ and ‘person-centred’ medicine (Heusser 2015), the latter corresponding to a sense of personalization discussed below.

2.2 Professional ethics

The second reason for examining the concept of ‘personalization’ in detail is that different conceptions have different ethical implications, not only for professionals and clients but for the relationship between the two, e.g., in the counselling encounter, and for data handlers and controllers. There are questions about the extent to which traditional ethical precepts can continue to apply in the context of personalization – for example, the ethos of non-directiveness in counselling. The very depiction of the counselling relationship in terms of who has what expertise, may need rethinking. The traditional picture of a counsellor being an expert in genetic risk information which has to be imparted to a client – who may themselves have expertise of a different kind (relating for example to detailed family history knowledge, experience of their condition, and values) – may not stand up in the face of a deluge of data emerging in the genomic or post-genomic era. The mass of data in this new context may require a different kind of specialism in the interpretation of data, with associated shifts in the locus of expertise.

2.3 Public health and responsibility for health

The third reason for examining the meaning of personalization relates to the implications for *public health planning*, resource allocation in health care, and individual *responsibility* for health. Some interpretations of personalization appear to place more responsibility on the shoulders of the individual, at a time when there are already moves in different contexts to encourage or ‘nudge’ individuals to take measures to reduce alcohol, take more exercise, eat healthily, and so on. (Sunstein and Thaler 2008).

In sum, then, it is important to investigate different conceptions of personalization because they will inevitably have practical consequences for professionals, patients and clients, and the relationship between the two. There will also be implications for public health planning and resources, in light of opportunity costs of pursuing a certain model of health delivery. Michael Snyder has suggested that personalized medicine might not reduce health care spending overall, although this may depend on the context in question (Snyder 2016). With these points in mind I shall now proceed to the examination of different possible interpretations.

3 – Senses of personalization

3.1 Personalization = individualisation

First, to personalize medicine might be equivalent to treating

WHAT’S IN A NAME: CONCEPTIONS OF PERSONALIZED MEDICINE AND THEIR ETHICAL IMPLICATIONS

the patient as an individual: the application of medical judgment to the individual case, $n=1$. It might be objected that medicine has always been personalized in this sense; it is just that new tools have become and continue to become available. That being the case, it seems that this sense can scarcely denote something new in the modern era. Nevertheless, it might be thought that the application of professional judgment to the individual case could in principle be embracing of individual diversity. This depends, however, on the way the ‘individual case’ is conceptualized – whether, for example, it is conceived as a set of symptoms or as something richer.

The idea of the clinical trial involving N -of-1, however, which has been suggested as a consequence of individual variability, and which is also related to this sense of personalization, arguably *does* represent a significant shift in so far as it refers to a reconfiguration of the historic practice of conducting clinical trials (Schork 2015).

3.2 Personalization as person-centredness

The second sense in which medicine might be said to be personalized is in being ‘person-centred’ (Heusser 2015). To personalize medicine in this sense could be understood as *respecting* the patient as a person with their own ideals and goals. This sense presupposes that the patient, in the central case, is an autonomous adult with capacity to make decisions about their treatment: underlying this is the concept of a person as the subject of a life. (There are of course special issues concerning those with diminished or still developing capacity for autonomy). While this remains important, it is not the sense of personalization which is primarily commonly at stake in contemporary discussions of personalization in relation to emerging technologies, despite arguments for integration of different senses, a point to which we shall return.

3.3 Personalization as holism

It is important to note that the second sense of personalization above may or may not be combined with a holistic approach: the view that the patient should be regarded as a *whole* person. This may mean no more than that the individual should not just be identified with a set of symptoms, such as a broken leg or a case of tuberculosis. There is a perfectly ordinary way of speaking in which to personalize medicine *can* be understood in that way and it is possible that this may be envisaged by patients, their relatives and others on hearing the term ‘personalized medicine’.

While the relationship between holism and person-centredness is not clear, it is possible to practice ‘person-centred’ medicine, embracing the principle of respect for persons, while still viewing the ‘case’ in relation to one disease rather than in a holistic way. On the other hand, it might be argued that holism requires a broader concept of the person than the ‘subject of a life’ – for example, looking at the individual in context, in relation to others, rather than as an isolated individual.

Once again, however, this is hardly a new debate, so holism cannot be the, or *a*, sense that describes a developing and transformative model of medicine.

3.4 Personalization as enabling personal health self-monitoring

One development that is new and developing is the use of *wearable technology* to allow people to monitor their own health conditions. Devices such as Fitbits and the Apple watch are increasing in number and growing in sophistication in terms of the range of bodily functions they can monitor. Why might this be interpreted as the ‘personalization’ of medicine? Personalization in this sense is associated with an increase in personal *responsibility* for health, in some ways enabling the person to be more in control, not only in monitoring their own health status but also in taking steps (perhaps literally) to improve matters. In this category personalization is concerned not only with ameliorative medicine (although it may be used for existing patients) but also with prevention. We are going beyond the patient as person here to include the worried well (or not so worried), in the class of persons potentially affected by this development.

In addition to the ethical implications of increased responsibility for health and possible associated anxiety or even health narcissism, there are personal security issues associated with wearable technologies. The very fact of the use of these devices to collect data, without full awareness of those who use them, raises issues of personal privacy and security. Employees may be encouraged to wear these devices in exchange for health insurance benefits, or to monitor their activity for the benefit of employers (Rutkin 2014).

The concept of the person at stake here has to be one that is compatible with the idea of taking responsibility for one’s own health, which implies autonomous decision making, but could co-exist with greater or lesser degrees of individualism. Barbara Prainsack has drawn attention to the need to beware of assumptions about individual decision-making inherent in contemporary western thinking and has pointed towards the possibility of a more relational, solidaristic approach (Prainsack 2014). In a communitarian context, it may be important to take responsibility for one’s own health to avoid being a burden on the group. Indeed, the effect on others through passive smoking has formed a major part of the arguments that individuals should not smoke in shared environments.

3.5 Personalization as genetically informed prescribing

Turning from these debates it is fair to say, however, that contemporary discussion about personalized medicine began with a surge in interest in *pharmacogenetics*, especially following the completion of the Human Genome Project at the beginning of the twenty-first century. Pharmacogenetics is not itself a new idea: it has been around at least since the 1950s, but once again developing science and technology has facilitated considerable developments and moved it centre stage. The basic personalization idea here is that the prescribing of medicines should be in accordance with the person’s genetic makeup, and this can be relevant to both the choice of drug and the appropriate dosage (Alfirevic and Pirmohamed 2016).

What is striking here is the use of the term ‘personalization’ when what is significant about the person in this context is

WHAT’S IN A NAME: CONCEPTIONS OF PERSONALIZED MEDICINE AND THEIR ETHICAL IMPLICATIONS

identified with his or her genetic-make up rather than that they are autonomous individuals, or that they exist in a community in relation to others. On the contrary, what is of interest is the ways in which they vary, or are unique in respect to their DNA; within this context, what is important about persons is not what they have in common (e.g., a capacity for autonomy) but the ways in which they differ. Genetic variation, not phenotypic variation, counts under this interpretation as what is significant for the practice of personalized medicine. It might be argued, with good reason, that it is still a large step from this to saying that the ‘person’ him- or herself is *identified* with or reduced to their genetic make-up.

From an ethical point of view, it is interesting, as already noted above, that the emergence of interest in pharmacogenetics led to emphasis on the ways in which medicine does not work: the promise of the move towards pharmacogenetically informed prescribing is that it will facilitate a significant reduction in the incidence of iatrogenic morbidity and mortality (Alfirevic and Pirmohamed 2016).

On close inspection, however, pharmacogenetic information by itself allows only for a weak sense of personalization. A genetic test may allow for a patient to be categorised as a good or poor responder to a particular drug, a slow or a fast metaboliser. This is arguably better described as patient *stratification*, and in fact it is so called by some (Schleiden et al. 2015). And it might be asked what, in particular, is personalized about that? To that sense of personalization I shall now turn.

3.6 Personalization as stratification of the patient population

In *The Ethics of Personalized Medicine: Critical Perspectives* (2015) Sebastien Schleiden et al. describe the results of a systematic review as a result of which the definition they opt for is that “PM seeks to improve stratification and timing of health care by utilising biological information and biomarkers on the level of molecular disease pathways, genetics, proteomics as well as metabolomics” (Schleiden et al. 2015, p. 23). This is interesting in that they ultimately develop a definition that includes ‘stratification’ rather than ‘tailoring’, although they included the latter term in a preliminary definition. The authors argue that it would in fact be a mistake to give the impression that personalized medicine is about individuals rather than about categorising patients into groups: stratification is the more accurate — and, perhaps the more honest — term in relation to patient expectations. This is very important in the discussion of the ethics of personalization because if the term is misleading then there could be adverse consequences in terms of patient response.

Despite this rejection of the tailoring metaphor, it continues nevertheless to be very widely used, and it is to this that I shall now turn.

3.7 Personalization as tailoring treatment and advice to the person’s genome

The tailoring metaphor was used in the UK at least as early as 2003 in the Department of Health White Paper: *Our In-*

heritance Our Future. The then Secretary of State for Health, John Reid, wrote in the foreword that “[A]bove all, genetics holds out the promise of more personalized healthcare with prevention and treatment tailored according to a person’s individual genetic profile” (UK Department of Health 2003, p. 5). The importance of prevention is emphasized, suggesting that a patient and their GP will be “able to make more personalized decisions on lifestyle changes or drug therapy to reduce his likelihood of developing heart disease” (ibid. p 15).

The tailoring metaphor is at first sight attractive and a neat way of illustrating the point. An analogy is made here between taking the precise measurements of a person in order to tailor clothes to their outer physical form, and finding the inner genetic key to their predispositions and risk factors, so that not only treatment but also lifestyle advice can be ‘tailored’ to their own particular genetic make-up, in all its rich variety. The presumption here, in order for the analogy to work, is that more than a single pharmacogenetic test is required – the whole genome will need to be sequenced.

As has been argued elsewhere (Chadwick 2014), however, the tailoring metaphor, despite its attractive accessibility, is deceptive. First, in tailoring itself there is a distinction between ‘made to measure’ and ‘bespoke’. “Whereas mass market shopping makes clothes to a universal pattern, made to measure adapts such a pattern to the measurements of an individual, and ‘bespoke’ tailoring proceeds according to the requirements of the individual person. It might appear that the move from blockbuster drugs (in the ‘trial and error’ approach) to genomically informed prescribing mirrors the distinction between mass market and made to measure, but it is more complicated than that” (ibid., p.6). In the word ‘bespoke’ there is a clue to something that is very significant. Bespoke tailoring requires one who ‘bespeaks’, i.e., an autonomous consumer. Transferring this to the medical context, the tailoring metaphor suggests the need for an autonomous patient/person to request the tests. In one possible vision of the future, however, individuals will be routinely sequenced in childhood or even at birth and their data stored throughout life (see Capps et al. 2013).

An objection from a completely different perspective was put forward in a classic article by Abdallah Daar and Peter A. Singer: such health care is a ‘boutique’ model, suitable only for resource rich countries with a very individualistic culture. Although they are not talking about tailoring here, or indeed whole genome sequencing, the use of the word ‘boutique’ implies a contrast between ‘designer’ and ‘high street’ clothing. They argued that the potential benefits of genetically informed medicine should, instead, be harnessed for deployment in resource poor environments (Daar and Singer 2005).

There are, then, different considerations at stake here. One is the presumption in the tailoring metaphor of the autonomous consumer: in Daar and Singer the emphasis is on the wealth (as in a resource-rich context) rather than the autonomy of the consumer. As far as the understanding of personalization is concerned, however, the main point is that the tailoring metaphor suggests a genome-wide interest in the person, rather than what might be a single genetic test in the context

WHAT’S IN A NAME: CONCEPTIONS OF PERSONALIZED MEDICINE AND THEIR ETHICAL IMPLICATIONS

of pharmacogenetics. Daar and Singer’s point can in principle apply to either in so far as it is a point about resources.

Ethical questions relating to tailoring include the implications for the health care professional-client relationship. The more that medicine delivers ‘precise’ results, it might be thought that there is less room for professional judgment – rather it may be envisaged that the right course of action would emerge from a correct reading of the data. There have been suggestions that what might be required is a specialist interpreter of data (Capps et al. 2014). Of course, it is possible to be precise and wrong: although the purpose of taking precise measurements is to get a perfect fit, a slight error in taking those precise measurements can result in an uncomfortably tight suit of clothes.

The newer term ‘precision medicine’, as in the Precision Medicine Initiative of the United States established under President Obama (White House 2016), becomes relevant here. While the introduction of the term ‘precision medicine’ avoids the focus on the person and the associated implication that medicine has not always been personalized (see sense 1 above) it might also be regarded as fitting very well the tailoring metaphor and the taking of exact measurements (see Juengst et al. 2016). In fact, precision medicine “is defined as the tailoring of clinical strategies based on genomic, genetic, behavioral and environment background of individual patients” (Wong and Deng 2015).

The definition of precision medicine here, however, includes taking into account factors over and above genetic and genomic information, and next in line for consideration is epigenetics.

3.8 Personalization as tailoring to the person’s genome, read in the context of the epigenome

The rapidly developing science of epigenetics and epigenomics has further complicated the picture of what is envisaged in personalized medicine. Epigenetics is concerned with factors ‘over and above’ the genome which affect gene expression, such as environmental factors, but also individual behaviour and lifestyle. One of the mechanisms by which this happens is methylation, whereby different sites on the genome come to have epigenetic markers attached to them, which can then, in turn, be transmitted to future generations (Chadwick and O’Connor 2013). While the fact that environment affects gene expression is not new, for a long time it was akin to heresy to suggest that epigenetic changes could be heritable, which is now clearly the case. There has been considerable interest in the ways in which behaviour during pregnancy can affect not only the fetus in question, but also future generations (Hessler 2013). This has given rise to concerns about burdens of responsibility for women, but there are issues for men also. A study in Denmark showed differences in epigenetic markers between sperm samples taken from lean and obese men (Barrès 2016). Further work is planned to investigate whether the preconception weight of fathers can affect embryos.

The ethical implications here are considerable. First, the science of epigenetics suggests that the concept of the person

has to extend beyond the genome: it has to be environmentally situated. The picture of the isolated autonomous individual taking decisions about his or her own body is too narrow to cope with epigenetics, in a situation where decisions about one's lifestyle and environment can affect future generations through the epigenetic mechanisms. These difficult questions about responsibility, for one's own health and that of the next and future generations, involve taking into account much more information than previously supposed. It would be a mistake, however, to think that epigenetics brings to the fore new questions of responsibility only for individual persons. Toxins in the environment have epigenetic effects, so there are issues of responsibility, regarding public health effects, for institutions and corporations as well. Epigenomics may in fact be empowering for individuals. Chiapperino and Testa suggest "different framings of epigenomic evidence and empowerment discourses... are in fact likely to have a fundamental bearing upon the roles and obligations of agents in the emerging vision of PM, including quite possibly on our *self-understanding* as citizens, patients and health-care consumers" (Chiapperino and Testa 2016, p. 216).

The main point to take from this section is that a tailoring that looks at the genome in isolation from epigenetic data is going to risk missing out significant relevant factors. If precision medicine leads to potential rethinking of the professional-client relationship (Juengst et al. 2016), however, the need to take environmental factors into account arguably requires even more thinking about the kind of expertise needed in order to offer accurate and helpful lifestyle and treatment advice.

3.9 Personalization as tailoring medicine in the light of multi-omic information

Beyond epigenomics, different kinds of 'omics' are themselves reproducing, however, so that we are now contemplating an era of multi-omics. The microbiome, for example, is increasingly of interest, as research turns to the health effects of the populations of bacteria that inhabit the human gut, along with a plethora of advice in health and lifestyle literature about prebiotics and probiotics. The definition of personalized medicine in the EU, used by the Horizon 2020 Advisory Group, has defined personalized medicine in the following way: "a medical model using characterization of individuals' phenotypes and genotypes (e.g. molecular profiling, medical imaging, lifestyle data) for tailoring the right therapeutic strategy for the right person and the right time, and/or to determine the predisposition to disease and/or to deliver timely and targeted prevention" (European Commission 2016).

Monitoring what is happening in all the different 'omics' in our bodies is going to require increasingly sophisticated wearable technology, which involves a link with the fourth sense of personalization listed above. Scientists such as Snyder have demonstrated ways in which taking these precision measurements on a daily basis can lead to openings for timely interventions and making significant changes to lifestyle with real time measurable results (Snyder 2016). For example, he discovered that if he stopped cycling for only a few days it provoked a spike in certain adverse measurements. For Snyder,

this information can be very beneficial for individuals, but he envisages that the data collected will have relevance to mental as well as to physical health, which may give rise to additional ethical concerns.

Consideration of this development, then, suggests that the future of personalization requires a combination of developing scientific research and wearable technology, with the attendant concerns mentioned earlier about the access to and use of the data.

3.10 Personalization as analysis of 'big data' about the person

The discussion of the coming together of multi-omics and wearable technology suggests that one possible interpretation of personalized medicine requires regarding the person as a site of 'big data'. Those aspects of, or indeed accounts of, personal identity (rather than the concept of person as such) which depend on the narrative of a person's life story, are very much downplayed in the context of increasing collection of micro-level data. Barbara Prainsack notes the broadening of the term 'personalisation' to include the analysis and interpretation of data at multiple stages "in an era when we, ourselves, are becoming data" (Prainsack 2015 p. 167).

Snyder's monograph does not give a precise definition of personalized medicine. He acknowledges, as others have, that the practice of medicine has always been personal, although his account of what that has traditionally meant is slightly different. He argues that doctors have always taken into account *extensive personal information* about a patient (Snyder 2016). What makes it different now, and what is leading to a new paradigm of healthcare, he argues, is the *amount* of 'big data' that is and will be available about an individual. As already indicated, data will be collected not only about genomic medicine but will increasingly draw upon other --omic information, along with environmental and lifestyle data, including nutrition and exercise. Snyder's characterization is interesting because it is a point about quantity rather than quality, but it might be argued that the sheer volume of data will in itself amount to a qualitative change.

The collection, storage and use of personal data has widely been recognised to give rise to ethical concerns, with considerable attendant discussion of privacy. The era of big data leads to additional concerns about interpretation and access. The monitoring of mental health is a potential issue: Snyder mentions efforts currently under way to monitor online activities to identify early symptoms of mental illness and emotional disturbance (Snyder 2016). 'Personalized' medicine might offer alternative monitoring modes, which may be to the benefit of individuals concerned but may also have a stigmatizing effect.

In terms of the concept of the person at stake here, one possibility is that the person is to be understood in terms of information, and this view has indeed been put forward by Luciano Floridi (Floridi 2011). According to Floridi my data is not just 'mine' it is 'me', so talk about ownership of information in the context of debates about privacy misses the point. It has been argued by Freeman Dyson, however, that while

the essence of life is information, information is not synonymous with life. “To be alive, a system must not only hold information but process and use it” (Dyson 2016). Dyson further writes that in a human, information is to be found in two places, in our genes and in our brains. “The information in our genes is certainly digital, coded in the four-level alphabet of DNA. The information in our brains is still a great mystery” (Dyson, 2016).

Arguably there is a danger that the interpretation of the person as big data could mark a reversal to the picture of the patient as a set of symptoms, in a much more detailed form (a set of measurements, or data), rather than the ‘patient as person’ picture discussed above. If this is combined with a reduction in the scope for judgment in individual cases, ‘person-centredness’ in biomedical ethics may also be at risk.

A big data interpretation of personalization might require both whole genome and epigenome sequencing at birth plus ongoing monitoring with wearable technology, with associated challenges about data storage, control and access throughout life.

4 – Combination of different senses?

It is not the case that different senses of personalization are necessarily incompatible. Heusser, for one, has argued for integration of genomic personalization and person-centred care (Heusser 2015), but this arguably does not go far enough. It is surely possible, in principle, to bring together a multi-omic approach to the person while holding on to the idea of the person as autonomous chooser. It may be inappropriate to interpret the person as a collection of –omic information. Dyson distinguishes the information in our genes from that in our brains, suggesting that there is something to the person irreducible to –omic data. Of course, those who think that there is something over and above the brain, such as the soul, might not be satisfied with this approach. But we have to distinguish between those interpretations which really tell us what a person is and those which tell us something about what personalization means as a practical approach to health care, which could be compatible with different understandings of person.

Arguably the most important potential transformation is the importance, demonstrated by epigenetics, of regarding the person as *situated* in an environmental context. This requires going beyond even the relational account of the person, as to give thought to the interaction between the human body and its environment that affects biology itself. This may be regarded as not a new idea – after all, we do know that viruses leave traces in the bodies of those whom they infect. But, we are talking about traces that are heritable and this is an important step-change in thinking about the relationship between the human body and its environment.

WHAT’S IN A NAME: CONCEPTIONS OF PERSONALIZED MEDICINE AND THEIR ETHICAL IMPLICATIONS

5 – Conclusion

This discussion of personalization, both in interpretations and applications, constitutes a reminder of how important terminology is. The shift to the term ‘precision medicine’ perhaps marks an attempt to ditch some of the ‘baggage’ associated with the terms ‘personalization’ and ‘person’ (Juengst et al. 2016) and has also been argued to be relevant to global health (Lancet 2017). Even if we adopt the term ‘precision medicine’, however, ethical issues remain, such as ‘Who is deciding?’, ‘For whose benefit?’, ‘What are the (global) resource implications?’, ‘What are the implications of regarding the person as a collection of –omic data?’.

None of the senses of ‘personalization’ discussed provides a completely adequate picture and thus the term cannot be regarded as sufficiently descriptive to indicate what is involved in the purported new model of medicine. Whether the term ‘personalization’ endures or not, respect for persons certainly remains important. Genomics and other –omics information will provide increasingly actionable information, but accessing this information may also require greater and more intrusive monitoring and individual responsibility. The future of health care, if it is ‘personalized’, is personalized on multiple levels, requiring thought about the professional-patient/client interaction and about the extent to which the person’s interaction with the environment can be understood by the individual, carers, and health care planners. This is a considerable challenge which is not at first sight apparent in the superficial attractiveness of the concept of personalization.

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