

The Ethics of Personalized Medicine: A Philosopher's Perspective

Ruth Chadwick |

Personalized Medicine. 2014;11(1):5-6.



It is a standard joke that when philosophers are asked to give a perspective on a topic, they first of all ask what it means and make no further progress. When it comes to personalized medicine, however, the question of meaning is very important insofar as our understanding of what is involved informs our understanding of the ethical issues.^[1] This is critical, especially as the way issues are presented affects the expectations of patients. 'Personalization' suggests association with an individualist paradigm in ethics, although it may emerge that what is envisaged is more accurately described, at least in some cases, as stratification of the patient population into, for example, good or poor responders to a particular drug. Alternatively, patients may be divided into groups according to their disease type as more is learned about, for example, cancer subtypes. The prospects of increasing use of whole-genome sequencing (WGS), however, may make personalization a reality in a stronger sense.

The central idea of pharmacogenomics, that information about the variation in genetic make-up between individuals is relevant to prescription of drugs, introduced a specific sense to the concept of 'personalization' in which personalization became associated with a person's genomic information. The ethical argument supporting this was the need to reduce the incidence of mortality and morbidity resulting from adverse drug responses. Personalized prescribing for a patient could be genetically informed, not only in relation to the choice of drug, but also in regards to dosage, thus minimizing the potential harm of inappropriate prescribing for a particular patient. Patients could be subdivided into those who could, and those who could not, tolerate a specific substance.

With the advent of WGS, the possibility of 'tailoring' medical advice and treatment to the individual throughout a lifetime becomes, at least, an in-principle possibility, although the term 'tailoring' was used by the UK Department of Health in 2003, before WGS was on the horizon.^[2] The use of the tailoring metaphor gives a much stronger sense to personalization: all the multiple variations between individuals could be taken into account. In the clothing industry, there is a distinction between clothes tailored for the individual and those ready to wear for the mass market, and it might be tempting to think that this mirrors the distinction between personalized and blockbuster approaches to pharmaceuticals. However, within tailored clothing there is also a distinction between 'bespoke' and 'made to measure'. Whereas 'bespoke' clothes are created without the use of a pre-existing pattern, 'made to measure' alters a standard-sized pattern to fit the customer. The move from genetic testing to WGS arguably suggests a move from 'made to measure' to 'bespoke'. There is a caveat here, however, and that is that the word 'bespoke' comes from 'bespeak', which suggests that the individual is in control of the process. This may be where the analogy between personalized medicine and tailoring breaks down.

It is important not to overlook the fact that, although the ethical argument for personalized medicine was initially made to prevent adverse drug reactions (deeming it uncontroversial from that point of view), once a richer version of tailoring appears, attention also increasingly turns to benefits and to issues of equity in access.^[3] The questions then are not only 'how can we prevent harm to this person?', but 'how can we maximise the benefit?' and 'how can we achieve justice in distribution?' For example, suppose information emerges that, in relation to the prescription of a very expensive drug for cancer, some people may achieve a life extension of only a couple of weeks, while others may benefit with 2 years extra life.^[4] It is not clear what criteria would be appropriate in such a situation. From one point of view, it might be argued that despite the variation in benefit, each person is entitled to receive the drug. From another, it might be argued that prescribing should be performed in order to maximize benefit.

There are also issues of international distribution to consider. Daar and Singer's classic piece on pharmacogenomics and genetic ancestry argued eloquently against a situation in which the benefits of personalized medicine not only reinforced an individualistic 'boutique-style' model of healthcare, but also operated to the disadvantage of less

developed countries.^[5] They argued a case for the possible benefits of 'drug resuscitation' in relation to products that had been taken off the market in the west, but which could also be beneficial in settings where the population had relevantly different genetic factors.^[5]

Issues of equity impact strongly on public perceptions. When a new technology is introduced, there are always questions, not only relating to whether there are any new ethical issues, but also whether there are any public perception issues that might be challenging. This might be the case, for example, where personalization or stratification coincides with other ways of dividing up the population that might, historically, coincide with discrimination, such as racial or ethnic categories.

Some of the worries about personalized medicine arise in connection with its implementation. The rise of companies offering direct-to-consumer tests, for example, has led to criticisms over how the results might be interpreted, conveyed and misused. There are also concerns about what tests are offered, and the time at which tests may be offered. While it may be considered acceptable for an autonomous adult to decide to undertake genetic testing, there are different considerations relating to WGS at birth or even prenatally, for the purposes of personalized predictive medicine.^[6] There is a view that prenatal genetic testing will become the standard of care.^[7] However, over the past 15 years or so, the argument for a right not to know genetic information about oneself has been advanced, on the grounds that such knowledge may change one's whole perception of one's future life for the worse.^[8] If widespread sequencing becomes the norm, to remain in ignorance may cease to be an option, and yet we should not necessarily think that knowledge here brings greater autonomy. The person 'bespeaking' the test is not identical with the one tested. There are also issues about the extent to which a genetic counseling model can be transferred to the new possibilities, or whether a consumer model is more appropriate.

For those who do want genetic testing and are prepared to pay for it, the price is falling, which may alleviate some of the concerns about access, but there are nevertheless concerns about control of the resulting data.

The promise of personalized medicine offers real exciting possibilities, and the language of personalization is becoming more than a rhetorical device: implementation is more complicated, partly because of the complexity of the mass of information emerging and partly because of concerns about implementation.

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Financial & competing interests disclosure

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No writing assistance was utilized in the production of this manuscript.

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