

Health literacy and public health genomics

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Health Literacy and Public Health Genomics: Innovation Management by Citizens

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It is difficult to implement an innovation. Often innovations are neither desired nor welcomed at all. You interfere with a status quo everybody seems to be happy and at terms with. Also, of course, it depends on the position or expectations you have regarding the innovation. For example, there has been a strong and continuing resistance from the medical profession to accept a nonmedical public health intervention for the prevention of sudden infant death (SIDS): simply putting babies in a supine position and avoiding a prone position instead of performing ‘fancy’ blood tests or having a medical intervention. Such a resistance prolongs the diffusion of an idea and thus the timely implementation of an innovation. In the case of SIDS in several European countries this took even more than 2 decades [1].

Some approaches of the social sciences, on the other hand, still have reservations against innovations in the field of genomics per se, and persistently narrow genome-based health information down to genetic tests for dreadful monogenic diseases. The same arguments applied against the use of genome-based information are now, for instance, used in the discussion of nanotechnologies. But also professional bodies play an important role here: the idea that any genomic test – even for multifactorial diseases which are always based on genome-environment interactions – should be performed by a specialist in hu-

man genetics is more about keeping the shop closed than serving the public’s health.

However, things are beginning to change. The innovation of the internet has paved the way for the success of social networks in which citizens (including patients!) now have direct access to information and contact with people who share their problems and beliefs. In this editorial the expression ‘citizen’ is used in its meaning of the French ‘citoyen’, i.e. the politically mature and responsible citizen. This democratization of information poses a threat to many health professionals by challenging their expertise. The argument that there is a lot of ‘garbage’ on the internet is a valid one, but whose job is it to separate one bit of information from the other? In addition, what information is useful to the person at what time for what purpose?

If not the citizen herself or himself, who else can decide? Here health literacy (HL) comes in. The ability to access, understand, appraise, and apply health information – the four dimensions of HL [2] – will be a cornerstone for the citizen of the future.

The interest in HL is not only a ‘bottom-up’ movement empowering the citizen. Also governments would like to offer citizens more choices – even in healthcare. But how far can or should they go? That is one of the reasons why the European Commission has funded the development

of a HL survey to obtain an overview of the status quo of HL in Europe. Public health experts are often convinced that you should not even think of offering choices as citizens cannot judge regarding difficult things such as 'health and diseases'. However, real life is different. In most areas of life we make decisions under uncertainty: which pension plan or which life insurance shall we choose, which job shall we take, or even which partner shall we marry?

In the context of public health genomics this has serious implications. Dealing with a highly innovative and dynamic field of science that aims to prepare society for the future does not make the situation easier. It is quite obvious that all of the already mentioned hindering factors can be observed, but in addition what is new and even more challenging is the free direct access to genome-based information, respectively genetic tests, of the citizen and consumer. This puts the citizen, and no longer the researcher or the physician, in the driver's seat. Hence, any investment in HL will contribute to a responsible translation of genome-based health information and related technologies for the citizen. This implies that we should not regulate everything to protect the ignorant consumer [3]. We should rather concentrate on regulations related to health protection as in the area of toxi-

cogenomics. Finally, this would put limits to public health paternalism, too.

We would eventually move from the one-dimensional 'informed consent' via 'informed choice' to 'shared decision making' and then on to 'personal ('myself') decision making' as we have learned from the success story of the self-help movement. Citizens would create their own personal data warehouse of health information keeping it, for example, on a USB stick and will not just leave this issue to health professionals. As in the context of public health genomics the useful and personal health information will change over the whole life course, so will HL [4]. It will be a lifelong learning exercise, and it will change the citizens' role from being passive to active or from being a consumer to being a prosumer as well as a citizen.

Might there be harm? What about the issue of assuring not only the 'right to information' but also an obligation to be informed? Where are the boundaries? Maybe that is why the citizen will always demand and need some help from experts. However, this kind of support will be more in the form of assistance, leaving behind paternalistic decision making for the citizen. Let's make public health genomics a success story by accompanying it with HL measures!

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