

# Genome-Based Health Literacy: A New Challenge for Public Health Genomics

E.V. Syurina<sup>a</sup> I. Brankovic<sup>a</sup> N. Probst-Hensch<sup>b,c</sup> A. Brand<sup>a</sup>

<sup>a</sup>Institute for Public Health Genomics (IPHG), School for Public Health and Primary Care (CAPHRI), Maastricht University, Maastricht, The Netherlands; <sup>b</sup>University of Basel and <sup>c</sup>Unit of Chronic Disease Epidemiology, Swiss Tropical and Public Health Institute, Basel, Switzerland

## Key Words

Public health genomics · Genome-based knowledge and technologies · Systems biology · Health information · Health literacy · Health policy making · Knowledge translation

## Abstract

So far health literacy has not been sufficiently discussed in the context of public health genomics. Primarily, not genomic but rather genome-based health information needs to be addressed taking into account genome-environment interactions and integrating all health determinants including genomics into a systemic and holistic approach. Translating findings from epigenomics and systems biomedicine will help to understand that individual biological pathways or networks are permanently interacting with environmental networks such as social networks. Thus, in the end also health literacy will become personalized. Genome-based health literacy is challenged by the question of which information is relevant for the individual, for what purpose, and at what time during the lifespan. Public health tools and expertise already in place can and should be used to tackle these huge challenges.

Copyright © 2011 S. Karger AG, Basel

## Introduction

Lately health care systems are facing considerable changes due to rapid advances in different branches of basic sciences including genomics, especially epigenomics, and systems biology. It is obvious that public health genomics (PHG) needs to translate these advances in a responsible and effective way into public health as the new understanding of the causation and pathways of diseases enables health care systems to modify their prevention strategies [1]. We are now moving from the era of genetic testing and genetic screening of primarily Mendelian disorders towards a more holistic and integrative approach that considers genome-environment interactions as well as a multitude of gene variants and their association with diseases formerly thought to be very different and unconnected.

These innovations will affect not only medical services but also public health as a whole. Genome-based information and related technologies will provide a possibility to identify individuals or subgroups at risk of developing health problems at a very early stage. Thus, the prevention and treatment strategies used in the current public health systems will be challenged and need to be communicated in a proper and timely manner not only

## KARGER

Fax +41 61 306 12 34  
E-Mail [karger@karger.ch](mailto:karger@karger.ch)  
[www.karger.com](http://www.karger.com)

© 2011 S. Karger AG, Basel  
1662–4246/11/0145–0201\$38.00/0

Accessible online at:  
[www.karger.com/phg](http://www.karger.com/phg)

Elena Syurina  
Institute for Public Health Genomics (IPHG), School CAPHRI  
Faculty of Health, Medicine and Life Sciences, Maastricht University  
Universiteitssingel 5, NL–6229 ES Maastricht (The Netherlands)  
E-Mail [e.syurina@maastrichtuniversity.nl](mailto:e.syurina@maastrichtuniversity.nl)

to health professionals but also to the general public, health policy makers, and other stakeholders involved in the various tasks of public health.

Health literacy is a relatively new but increasingly important task of public health around the world. The main value of the field is in its multidisciplinary. Uniting health and medical professionals with educational specialists creates the possibility to communicate health information to the general public by accessing, understanding, appraising, and applying all forms of information for sound health decision making. This article aims to describe the possible implications genome-based health information might have for the different stakeholders' health literacy. Already now genetic counseling, which is traditionally used in the setting of clinical genetics, aims to increase genetic health literacy not only in affected persons and families but also in the general public, and it is considered to be important as an educational strategy as well as a way to provide support and reduce psychological distress [2–6]. Although some aspects and experience are highly valuable, genetic counseling as such is too narrow to be used in the context of public health and PHG. Thus, in this article, special attention will be paid to the changing role of the patient/customer/individual.

We will start by defining health literacy and in particular genome-based health literacy. Then, the relation between public health systems and the place of health literacy within public health will be discussed using the approach of the public health wheel. Afterwards, we will identify important stakeholders for PHG. Furthermore, we will focus on the peculiarities of genome-based health literacy and the representatives of the general public as the major stakeholders as well as their changing status in public health policy and practice. Finally, conclusions will be drawn and the direction of future research will be mapped.

### **From Health Literacy to Genome-Based Health Literacy**

Health literacy is the ability to understand health information and to use that information to make good decisions about one's health and medical care. Genetic literacy has been defined as 'sufficient knowledge and appreciation of genomics principles to allow informed decision making for personal well-being and effective participation in social decisions on genetic issues' [7, 8]. This definition is similar to others proposed in the literature [9].

According to the Institute of Medicine, health literacy has the following components: oral literacy (listening and speaking skills), print literacy (reading and writing skills), and numeracy (basic quantitative skills), in addition to cultural and conceptual knowledge [10].

In Europe the public health consortium of the European Health Literacy Project defines 4 dimensions of health literacy: (1) accessing, (2) understanding, (3) appraising, and (4) applying information in all forms to make health decisions in everyday life throughout the life span [11]. These 4 dimensions demonstrate that health literacy is not 'one uniform approach' but rather has different specific aspects which can be systematically tackled at different levels within public health.

### **Public Health as the Context for Health Literacy**

As described above, health literacy is a vitally important component of every public health system. However, nowadays the main target of health literacy is the general public. Shortly after empirical studies showed that when consumers are meaningfully engaged in the process of making decisions about their own medical care the health outcomes measurably improve [12–14], the new trend picked up in public health. Previously health care providers believed that it was their responsibility to make decisions about their patients' health for their benefit as they were the ones possessing the knowledge about it [15]. Currently more and more attention is being paid to educating the lay people on how to make meaningful choices about their health.

It is important to note that educating the general public is only 1 of the 10 tasks of public health. The whole variety of public health tasks is best described and widely used through the public health wheel, which is based on the findings of the report 'The Future of Public Health' prepared by the Institute of Medicine in 1988 [16]. In this report the 3 core functions of public health were defined: assessment, policy development, and assurance. Later these 3 areas were specified into the so-called '10 essential public health tasks' [17].

Looking at the public health wheel, it is quite obvious that health literacy is not 'just' education. It can be seen as 1 of the ongoing key tasks of public health covering several of the 10 essential public health tasks of the wheel including informing, educating, and empowering people.

As a consequence, also health literacy regarding genome-based innovations covers a wide range of topics: genome-based health literacy includes knowing not only

about the benefits, risks, and limitations of traditional genetic screening and testing but also about the implications of genome-based health information as a whole. This implies knowledge about the terminology and technologies of modern genomics and the social and psychological implications of modern genomics for the individual using this information as well as for family members. Thus, following the public health wheel, a variety of genome-based health literacy actions can be taken:

(1) Inform, educate and empower: This task can include the education of the general public regarding genome-based health interventions through campaigns or mass media, in-class education of the different groups, public lectures for the representatives of the public, and personalized advice.

(2) Mobilize community partnerships: Here the health literacy of both the public and the representatives of the authorities on the local or regional level is important in order to reinforce cooperation.

(3) Develop policies: At this stage attention should be paid to the health literacy of the relevant public policy officials involved in PHG in order to narrow the gap between the dynamics of basic science and the policy making. It can also include bringing the public together with representatives of other stakeholders for a consultation process.

(4) Link to/provide care: Not only people not directly connected with medical care and health care need to be capable of using genome-based health information. The health literacy of health professionals from all levels of the health care system is of crucial importance for the translational process. For example, the knowledge of general practitioners and nurses about genomic advances and their added value for health interventions is still very limited. However, for the effective introduction of genome-based knowledge and technologies, health literacy should start from the very basic level of health care provision.

### **Genome-Based Health Literacy: Some Challenges Are Quite Unique**

As genomic research is now also focusing on multifactorial diseases, new issues in communicating with patients and the general public about genetic contributions to disease have arisen. Genomics is no longer a medical specialty dealing with rare diseases affecting a small percentage of the population; it is also increasingly of relevance to most if not all people and medical specialties

[18]. In order to exploit the full medical and health potential of genomics, it is essential to identify the level, gap, and needs of the genome-based health literacy of various stakeholders ranging from health professionals (i.e. doctors, nurses, and dieticians) to politicians, media experts, and the population in general. Failure to achieve adequate genome-based health literacy will not only limit the translation of genomic achievements to a health benefit, but it may also eventually even lead to misuse of genetics and genomics [19].

Target populations including health professionals need to understand the risks and benefits of genome-based health information and related technologies. Some of the challenges in promoting genomic literacy will parallel those previously experienced in the more general health literacy arena. We know that more than one third of US adults have limited health literacy, and only about 12% have the levels of health literacy skills needed to understand much of today's health information [10]. People with limited health literacy generally have low levels of health knowledge, underuse preventive health services, and self-report poorer health. We can therefore expect that a large percentage of the population will face substantial difficulties and barriers in understanding and using genomic information [19]. A number of challenges deserve special consideration in the context of genomic and respectively genome-based health literacy.

(1) The Internet has become a very important source of health-related information over the past decade, yet the USA study recently demonstrated that an Internet-based patient portal targeting adults with diabetes was less likely to adequately reach patients with limited health literacy [20]. The Internet is an essential source of genomic information and even guides decisions to undergo testing such as direct-to-consumer testing. A recent study demonstrated that healthy adults perceived evidence-based genomic information and communication approaches to be helpful for both decisions to test and decisions not to test. However, research is essential to ensure that these results are generalized to target groups that have lower literacy and are less Internet savvy [21]. It will be important to avoid the technical jargon with which genomics is heavily loaded.

(2) The promise that genomics holds for personalized disease prevention implies a shift from focusing on the treatment of specific diseases to focusing on the treatment of specific patients or even to focusing on preventing healthy individuals from becoming patients. The concept of numeracy will gain further relevance in ge-

nome-based health literacy, especially in the context of multifactorial diseases. Genome-wide association studies are identifying numerous gene variants linked to multifactorial diseases. The effects of single gene variants identified in large-scale genome-wide association studies are mostly very small. Accordingly, the clinical advantage of using these gene variants for personalized risk prediction is likely small, as was recently demonstrated for type 2 diabetes [22]. Nevertheless, accordant tests are offered directly to the consumer over the Internet (i.e. eg, 23andme, Navigenics, and DNA Direct). Many, but not all, persons undergoing direct-to-consumer testing will approach their doctors for support in the decision to undergo testing or in the interpretation of the test results. This raises important genomic literacy-related questions: Is the health literacy of health professionals adequate for guiding their patients in deciding to undergo testing and in making potential downstream medical decisions based on test results? Is the public capable of recognizing the limitations of the information generated by these tests? Will such test results motivate patients to adopt beneficial lifestyle changes even in the absence of their utility for risk prediction? Health numeracy is defined as ‘the degree to which individuals have the capacity to access, process, interpret, communicate, and act on the numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions’ [23]. A special challenge in health numeracy as it relates to genomics is that individual risk assignment may undergo changes over time as additional gene variants are being identified. This was shown for the progressive detection of novel type 2 diabetes genes in the Rotterdam Heart Study, where a subsample of the study population was switching back and forth between risk categories as result of the progressively increasing number of novel type 2 diabetes gene variants detected through GWAS meta-analyses [24]. Little is understood about how this uncertainty impacts information-seeking actions and changes in health-related behavior [25]. As was mentioned above, the increase in genome-based health information and related technologies is unprecedented and requires a unique level of lifelong learning, especially for health professionals. Genomics courses offered to health care professionals and the lay public require continuous updates. As it is difficult to foresee medical genomic practice in the years to come, a central aspect of promoting genomic literacy in today’s students is the motivation for pursuing lifelong learning [26].

(3) Genomic information affects an individual’s biological network [25]. The impact of a genetic test result on

family members in the context of direct-to-consumer testing and low penetrance is a novel issue in that context. Any physician should be able to recognize and interpret familial clustering of diseases such as specific cancers, kidney disease, or cardiovascular disorders in order to refer patients in need to genetic counseling or screening for disease. For example, 2 of the proposed objectives of Healthy People 2020 are (a) to increase the proportion of persons with newly diagnosed colorectal cancer who receive genetic testing to identify Lynch or other familial colorectal cancer syndromes and (b) to increase the proportion of women with a family history of breast or ovarian cancer who receive genetic counseling [27]. Over the past years, to promote the assessment of family history for health risk assessment and health promotion, several federal, state, and private organizations have partnered with the Office of the US Surgeon General to raise the awareness of both health providers and the general public. Internet-based family history tools are available to assess the individual familial risk for several diseases such as heart disease, diabetes, and certain types of cancer [28]. Genomic information can also have potential negative social implications (i.e. insurance coverage, employment status, and discrimination) and be linked to positive and negative psychological consequences of a result predictive of severe disease in the absence of symptoms. Both health professionals and the public need to be aware of these potential consequences.

(4) Especially in the PHG context, not only genomic information but also genome-based health information needs to be addressed when talking about health literacy. That means taking into account genome-environment interactions and integrating all health determinants including genomics into a holistic approach. The highly technology- and bioinformatics-driven dynamics of genomics as a ‘moving target’ from the Human Genome Project to the Personal Genome Project is currently challenging public health research, policy making, and practice in a fundamental way towards a systemic and holistic understanding of the etiology of diseases or health outcomes (‘systems thinking’). It is a new paradigm; primarily translating findings from epigenomics and systems biomedicine we start to understand that: (a) what we call common complex diseases might be a sum of ‘rare diseases’, (b) we move from diseases towards ‘diseasomes’ (disease nodes), (c) we move from risk factors to individual pathways or networks, and (d) we move from clinical utility to personal utility. Furthermore, genome-environment interactions change from day to day within an individual. That means that neither genomics nor the envi-

ronment is stable information. Biological pathways or networks are permanently interacting with environmental networks such as social networks. Thus, a comprehensive model of future health care taking into account integrative genomics alongside environmental, social, and lifestyle factors will become essential to realizing P4 Medicine as the future paradigm of health care systems being predictive, personalized, preemptive and participatory [29]. That implies that in the end also health literacy needs to become personalized.

### Stakeholders' Roles in the Health Literacy Process

In health care, there is a huge number of parties involved, and they all possess certain interests. These parties attempt to pursue their various (and sometimes conflicting) interests by exerting an influence on health policy. All of the involved sides are connected with each other, creating a complex grid of relations that cannot easily be broken down.

Providers comprise both the institutions and the health care professionals. Two main types of institutions can be distinguished, i.e. those that take care of patients (e.g. nursing homes and psychiatric institutions) and those that cure them (e.g. various types of hospitals). Seeking an overview of health care professionals gives an even more intricate picture – for instance, numerous specialties, having an individual practice, or working in health centers, being self-employed, employed, or self-employed/employed.

Health care insurers might have a for-profit or a not-for-profit character, or they might handle both categories of those receiving insurance. Their coverage can aim at covering the entire population, or it may target only a distinct portion of it.

Within what could be labeled as industry, we can distinguish pharmaceutical companies (those manufacturing medical appliances included). Their role as the managers of the health care process is ever expanding and thriving [30].

All stakeholders should be included in health literacy actions, not only patients. However, because the majority of attention in health literacy is paid to the patients' perspective, it is also necessary to focus on the changes needed in order to ensure the successful integration of genome-based information and technologies into the public health system and daily practice.

### Focusing on the User

As mentioned above, at the moment, the degree to which the public is involved in genome-based health policy development, at least in certain cases [15], does not seem to be ample and reflects insufficient utilization of the already instituted mechanisms. Thus, we would like to focus on the changing role of the stakeholder group which is now commonly labeled as 'patients'. It is important to note that defining the group as 'patients' is not objective because it excludes the representatives of the general public who are not currently ill. With the introduction of genome-based information and technologies into health care we can assume that the term 'users of health information' will become more widely used.

The general public representatives need to be provided with novel opportunities which would enable them to participate (pro)actively in their own care. This might be done by targeting behavioral changes and developing their self-management skills. It has been proven that those chronic disease programs that successively increase people's knowledge about their own disease and health are more effective [31]. Endeavors such as this require integrating numerous concepts of knowledge. One example is diabetes type 2, where a patient needs to comprehend and adopt different levels of knowledge and understanding of all disease-related aspects for a successful guidance towards lifestyle modification to take place [32]. Aside from being able to understand his or her inherited risk, the person needs to grasp the details of the environmental exposure. For instance, nutritional information, i.e. choice of the food group, portion sizes, content of nutrients, energy value, and rankings of these values among different foods, can be a very complex set of information to take in. The cognitive processing demands of the information related to diabetes education can be overwhelming; therefore, it requires the enhancement of competencies as well as self-sufficiency [32].

There are ongoing efforts to educate the public about genomics, which comes as no surprise given the tremendous potential that genomics brings. These efforts are mainly founded on the assumption that scientifically literate people tend to feel more positively about science and scientific progress [33]. This kind of relation, however, is not observed in all cases [34].

The concept of a 'consumer' entails a relationship that individuals have with their services. A consumer can act as a service user and in that sense can have a justifiable interest in provision from his or her personal aspect. There are different approaches when attempting to an-

swer the question of what kind of influence different stakeholders should exert. There should also be a balance between individual strivings and desires on one hand and what would be deemed beneficial for the entire community on the other [35].

Future consumers of health information will have increasingly more means to use this information according to their own preference and desired extent – health information is available beyond any past expectations. The speedy developments of new technologies (particularly information and communication technologies) aid in promoting self-care and healthy behaviors. This will inevitably lead to better-informed health decisions which can result in more suitable demands for health services. One of the major outcomes can be reductions in the overall costs of illness. The fact that almost any health question has an available answer nowadays brings another major implication into the spotlight. The ability of the Internet and related technologies to provide support to individuals in making informed decisions related to their health may inevitably drive us to the decentralization of knowledge [36]. Another question is whether the increasingly available body of knowledge would benefit everyone and equally; however, that is an entirely different and extensive issue.

Negative reactions to novel genomic technologies have not consistently been found to be inversely correlated with knowledge and understanding of genomics. People do not necessarily need to understand genomics to trust new technologies as long as they have trust in their health care providers or public health agencies [37]. However, if the understanding and complexity of genome-based health information is too limited or in fact wrong, this can impact on at least 3 aspects of health-related behavior. First, people may underuse genetic/genomic counseling when it is indicated. Second, people may not benefit from recent advances in genomics that reach practice in a justified manner (i.e. pharmacogenomic testing such as in the case of a specific cancer diagnosis). Third, subjects lacking an adequate understanding of genetic testing and its potential implications are a susceptible target for inappropriate genetic testing such as that offered directly to the consumer over the Internet in the absence of solid evidence about clinical utility [38]. Genome-based health literacy is also of relevance to policy setting [38]. Finally genome-based misconceptions can have problematic implications for how people stereotype and think about subgroups of the population [38].

Studies on the status of knowledge related to genes among nonexperts in the public in both the USA and var-

ious European countries have generally shown limited levels of genetic literacy [37–42]. Despite the fact that most people are familiar with terms related to genes and genomics and with the multifactorial nature of common diseases – either through biology courses in school or through media reports – the actual knowledge and understanding of the terms is often scientifically incorrect [18, 37]. Much research on the beliefs about the causes of diseases and the role of genomics has focused on contexts around specific diseases only [18].

Quantitative literacy, which is of special relevance to genetics and genomics, is generally lower than other aspects of health literacy. According to the 2003 National Assessment of Adult Literacy only 13% of US adults exhibited proficient levels in quantitative literacy. Twenty-two percent had below-basic quantitative literacy and a third had basic quantitative literacy skills according to the National Centre for Education Statistics, 2006. Populations of a lower social class or educational level had lower numeracy skills on average, as is true for health literacy in general. Little is known about numeracy as it relates specifically to genomics and, respectively, genome-based health information.

Platforms for educating the lay public in genomics, equivalent to those described above for health professionals, are still few in number and include those from the National Human Genome Research Institute [43] and the University of Utah [44]. Those are model programs to improve the genomic literacy of the lay public.

## Conclusions

Despite of the relative novelty of this area, health literacy is already an important and established area in public health. However, like the public health system, health literacy is changing in response to advances in basic sciences and changes in the society in general. Due to rapid and vast developments in genome-based knowledge in the last decades, genome-based health literacy's importance is gradually increasing. However, most of the attention is still being paid to genetic literacy of the Mendelian disorders rather than to genome-based health literacy linked to a multitude of gene variants and their interaction with the environment (common complex diseases).

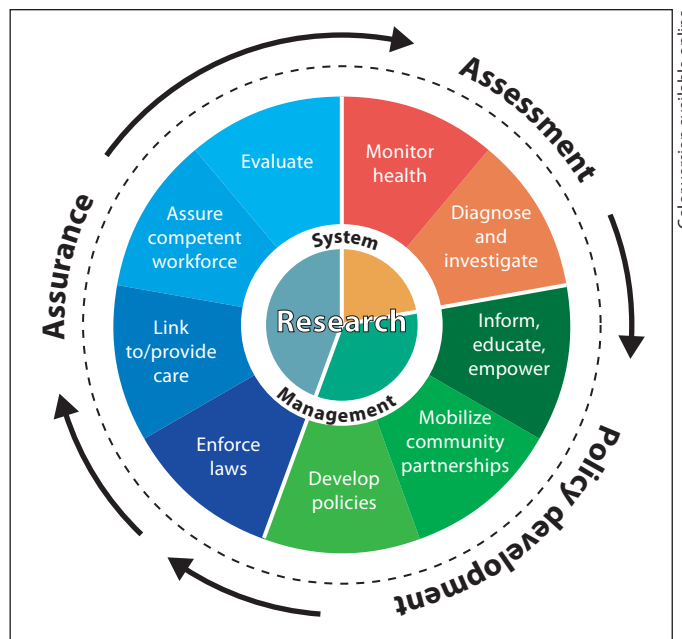
It was mentioned that the range of health literacy in general and genome-based health literacy in particular should not be limited to the provision of genome-based information and related technologies to the representatives of the general population. It should rather help to

narrow the information gap among all stakeholders in the public health system and be implemented in different tasks of the system (figure 1). Regarding the various stakeholders in public health, it is important to note that the group labeled as ‘patients’ no longer reflects the real situation as it presents all people or individuals as possible patients. Due to the stronger focus on empowering ‘patients’ and paying more attention to the process of health decision making, it would be more appropriate to call the stakeholder group ‘users of health information’.

Advances in genome-based sciences also lead to some challenges. First and foremost, in order for the representatives of the lay public to be able to use genome-based information it is important on the one hand to avoid the intense use of technical jargon; on the other hand it is important to provide the opportunity to understand personalized information enabling informed health decisions. Lifelong learning of both health professionals from different levels and the general public has a crucial role since individual risk assessment may undergo changes as additional gene variants and their interaction with environmental factors are identified. Attention should also be paid to the influence personalized genome-based information can have on the individual’s biological network, especially the family.

To be able to overcome the difficulties described as well as the ones that can arise in the future, some priorities for future actions in health literacy should be identified. A recent workshop under the auspice of the US National Human Genome Research Institute identified public understanding and use of genomic information as a priority area in communication and behavioral and social science research [19]. In order to shape public genomic literacy we must understand questions such as ‘What is the best way to make the public understand the concept of pleiotropy?’, ‘How can the concept of gene-environment interactions best be explained to the public?’, or ‘How does genomic knowledge influence lifestyle and behavior?’. When developing genomic and, respectively, genome-based health literacy programs we must understand how individuals and societies develop a balanced consideration of genomic tests or the use of genome-based health information and which systems and tools work best for which message and target group or even person. Furthermore, evaluation of the impact of information made available through the Internet is of fundamental importance.

Efforts to improve genomic literacy should consider Roger’s knowledge framework [45]. It suggests that education and research on the genomic knowledge of the



**Fig. 1.** The public health wheel with the 10 essential public health tasks [16].

public should distinguish between (a) awareness knowledge (knowledge about the existence of an innovation), (b) how-to knowledge (knowledge about the proper use of the innovation), and (c) principles knowledge (understanding of the theoretical principles underlying the innovation). According to a recently conducted Dutch study assessing genomic knowledge, a minority of the general population was aware of the genetic risk factors of multifactorial diseases, whereas the overall how-to knowledge seemed relatively fair, and principles knowledge was generally poor. Misconceptions about genomics and its influence on disease development were observed [45]. Previous evidence suggests that adequate decision making can occur without proper principles knowledge. However, principles knowledge diminishes the risk of falsely using perceived knowledge of genetic risk factors in decision making. Not understanding the principles of genomics also has an impact on the principle of autonomy for decisions regarding medical interventions and genetic testing. Even though many people have a basic understanding of Mendelian inheritance, this knowledge is not sufficient to understand the genetic background of age-related disorders which are mostly the focus of media reports on genomics. Improvement in understanding the principles of the genomics of complex diseases is needed in both health professionals and the lay public.

Improving genomic literacy and making people understand the benefits and limitations of a genetic test may be more challenging in subjects with misconceptions than in subjects who know that they have no or limited understanding of genomics [37]. In light of studies in the USA and Europe that demonstrate that there is still a high level of misconception about genomics, it is essential to invest in genetic education at all levels. As mass media are the primary sources of genetic information for the lay public, but they seemingly also contribute to misconceptions about genomics, the primary education effort should probably be in the training of health care professionals that also still exhibit severe limitations in genetic knowledge. Educating health professionals will also be fundamental for the persuasion stage in the decisional process related to genetic testing. Furthermore, it is also important that health care professionals consider their clients' know-how and beliefs in the area of genomics. It has been suggested that individuals in older age groups, who may well be the subgroup with the greatest potential, benefit from advances in the genomics of complex age-related diseases, have lower levels of genetic knowledge, and may be more in need of additional and targeted genetic information from health professionals [46]. Prior knowledge and assumptions as well as the beliefs of the target learner in genetic literacy should be considered in all efforts to improve genetic literacy [37].

We still know little about how to measure genomic knowledge: what genomic knowledge is adequate for medical and social decision making in the lay public needs to be further determined [42, 47]. In the USA an instrument was developed to understand undergraduate students' genomic knowledge [8]. Different assessment tools are needed for different target populations of genomic literacy programs. There is some evidence from a study comparing genomic literacy in different gender and ethnic groups in the USA that, even though genomic literacy was comparable and generally poor in all groups, there were some culturally and socially relevant items that seemed to influence specific aspects of genomic knowledge. Genomic knowledge that is retained reflects own and social group interests [38]. Another determinant of genomic knowledge and understanding is the family history of genomic diseases [18]. In addition, research on the effects of mass media on the public's understanding of genomics contributes to the discussion, especially given the often overpromising reporting of new genomic findings and the unknown impact of this on knowledge and beliefs in the public.

Not only do we have to improve our idea of how to best measure genomic knowledge but, even more importantly, we need to improve the understanding of what relevant genomic knowledge that people need and use in a profitable manner for decision making is [42]. We also need to systematically investigate how genomic literacy translates into health behavior in different subgroups of the population identified by gender, age, ethnicity, culture, and family history of disease or even in different individuals in the end. Genomic information could motivate healthy individuals to undergo more regular screening for diseases, reduce risky behavior, and be more compliant in medical treatment or it could lead to the development of a fatalist perspective of being genetically doomed [19]. A body of literature reports on the change in screening behavior and other preventive actions as a result of genetic testing. Most of these studies focus on familial genetic conditions such as hereditary breast and colorectal cancer. Improvements in screening behavior after testing positive for inherited cancer syndromes have been reported [19]. While there is some evidence for improved preventive health behavior, these studies' findings do not necessarily translate to other ethnic groups and cultural contexts or to multifactorial disorders. Only very limited evidence is available for the latter. For example, in a small study of smokers, those who were confirmed by a genetic test to be severely AAT deficient were significantly more likely than both carriers and noncarriers to seek information on treatment, use pharmacotherapy for smoking cessation, and report greater reductions in their smoking. However, the group differences in smoking behavior disappeared within 3 months of abstinence [48]. According to a recent Cochrane review on the impact of genetic testing on behavioral changes, the limited evidence available does not point to a substantial benefit for now. None of the studies on behavioral change examined the modifying effect of health literacy or numeracy, and little is known about how to achieve sustainability in behavioral change.

Finally, so far health literacy has not been discussed in the context of PHG. The public health community will lose credibility if on the one hand public health promotes health literacy in a value-pluralistic and democratic society and enables and empowers individuals for decision-making, while on the other hand it does not keep up with the dynamics of genomics leading to a paradigm shift not only in public health but also in health literacy. Especially in the PHG context, not primarily genomic information but rather genome-based health information needs to be addressed and provided. That means taking into ac-



count genome-environment interactions and integrating all health determinants including genomics into a systemic and holistic approach. Translating findings from epigenomics and systems biomedicine will help to understand that individual biological pathways or networks are permanently interacting with environmental networks such as social networks. Thus, a future health care model taking into account integrative genomics alongside environmental, social, and lifestyle factors will become

essential [49] to realizing P4 Medicine as the future paradigm of health care systems being predictive, personalized, preemptive, and participatory. In the end also health literacy will become personalized. Genome-based health literacy would then be challenged by the question of which information is relevant for the individual, for what purpose, and at what time during the lifespan. It would be wise to use the public health tools and expertise already in place to tackle these huge challenges.

## References

- Brand A, Brand H, Schulte in den Baumen T: The impact of genetics and genomics on public health. *Eur J Hum Genet* 2007;16:5–13.
- Braithwaite D, et al: Psychological impact of genetic counseling for familial cancer: a systematic review and meta-analysis. *J Natl Cancer Inst* 2004;96:122–133.
- Evers-Kiebooms G, Vanden Berghe H: Impact of genetic counseling: a review of published follow-up studies. *Clin Genet* 1979;15:465–474.
- Veach P, et al: Client Perceptions of the impact of genetic counseling: an exploratory study. *J Genet Couns* 1999;8:191–216.
- Meiser B, Halliday JL: What is the impact of genetic counselling in women at increased risk of developing hereditary breast cancer? A meta-analytic review. *Soc Sci Med* 2002;54:1463–1470.
- Wang C, Gonzalez R, Merajver SD: Assessment of genetic testing and related counseling services: current research and future directions. *Soc Sci Med* 2004;58:1427–1442.
- MedlinePlus: Health literacy. 2010. <http://www.nlm.nih.gov/medlineplus/healthliteracy.html> (accessed November 27, 2010).
- Bowling A, et al: What do patients really want? Patients' preferences for treatment for angina. *Health Expect* 2008;11:137–47.
- McInerney JD, Education in a Genomic World. *J Med Philos* 2002;27:369–390.
- Nielsen-Bohlman L, Panzer AM, Kindig DA: Health Literacy: A Prescription to End Confusion. Washington, The National Academies Press, 2004.
- The European Health Literacy Survey (HLS-EU). 2009. <http://www.health-literacy.eu> (accessed November 5, 2010).
- Brody DS, et al: Patient perception of involvement in medical care: relationship to illness attitudes and outcomes. *J Gen Intern Med* 1989;4:506–511.
- Greenfield S, et al: Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. *J Gen Intern Med* 1988;3:448–457.
- Kaplan SH, Greenfield S, Ware JE: Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Med Care* 1989;27(suppl 3):S110–127.
- Hiller EH, Landenburger G, Natowicz MR: Public participation in medical policy-making and the status of consumer autonomy: the example of newborn-screening programs in the United States. *Am J Public Health* 1997;87:1280–1288.
- Institute of Medicine: The Future of Public Health. Washington, National Academy Press, 1988.
- Public Health in America. 2008. <http://www.health.gov/phfunctions/public.htm> (accessed November 5, 2010).
- Lea DH, et al: Communicating genetic and genomic information: health literacy and numeracy considerations. *Public Health Genomics* 2010, E-pub ahead of print.
- McBride CM, et al: Future health applications of genomics: priorities for communication, behavioral, and social sciences research. *Am J Prev Med* 2010;38:556–565.
- Sarkar U, et al: The literacy divide: health literacy and the use of an internet-based patient portal in an integrated health system—results from the diabetes study of northern California (DISTANCE). *J Health Commun* 2010;15(suppl 2):183–196.
- Kaphingst KA, et al: Consumers' use of web-based information and their decisions about multiplex genetic susceptibility testing. *J Med Internet Res* 2010;12:e41.
- Talmud PJ, et al: Utility of genetic and non-genetic risk factors in prediction of type 2 diabetes: Whitehall II prospective cohort study. *BMJ* 2010;340:b4838.
- Goldbeck L, Melches J: Quality of life in families of children with congenital heart disease. *Qual Life Res* 2005;14:1915–1924.
- Mihaescu R, et al: Evaluation of risk prediction updates from commercial genome-wide scans. *Genet Med* 2009;11:588–594.
- Johnson JD, et al: Genomics – the perfect information-seeking research problem. *J Health Commun* 2005;10:323–329.
- Guttmacher AE, Porteous ME, McInerney JD: Educating health-care professionals about genetics and genomics. *Nat Rev Genet* 2007;8:151–157.
- Amos CI, et al: Genome-wide association scan of tag SNPs identifies a susceptibility locus for lung cancer at 15q25.1. *Nat Genet* 2008;40:616–622.
- Khoury MJ, Feero WG, Valdez R: Family history and personal genomics as tools for improving health in an era of evidence-based medicine. *Am J Prev Med* 2010;39:184–188.
- Hood JR, Parker C, Atrash HK: Recommendations to improve preconception health and health care: strategies for implementation. *J Womens Health (Larchmt)* 2007;16:454–457.
- de Gooier W: Trends in EU Health Care Systems. New York, Springer, 2007.
- Herzlinger RE: Consumer-Driven Health Care: Implications for Providers, Payers and Policymakers. San Francisco, Jossey-Bass, 2004.
- Ershow AG: Environmental influences on development of type 2 diabetes and obesity: challenges in personalizing prevention and management. *J Diabetes Sci Technol* 2009;3:727–734.
- Zarcadoolas C, Pleasant A, Greer D: Advancing Health Literacy: a Framework for Understanding and Action. San Francisco, Jossey-Bass, 2006.
- Pardo R, Calvo F: Attitudes towards science among the European public: a methodological analysis. *Public Underst Sci* 2002;11:155–195.
- Callaghan G, Wistow G: Publics, patients, citizens, consumers? Power and decision making in primary health care. *Public Adm* 2006;84:583–601.
- Eng TR, et al: Access to health information and support: a public highway or a private road? *JAMA* 1998;280:1371–1375.
- Lanie AD, et al: Exploring the public understanding of basic genetic concepts. *J Genet Couns* 2004;13:305–320.

- 38 Christensen RK, et al: Value of fine-needle aspiration biopsy of salivary gland lesions. *Head Neck* 2010;32:104–108.
- 39 Human Genetics Commission: Public attitudes to human genetic information: people's panel quantitative study conducted for the Human Genetics Commission. 2001. <http://www.hgc.gov.uk/Client/document.asp?DocId=41&CategoryId=8> (accessed October 5, 2010).
- 40 Molster C, et al: Australian study on public knowledge of human genetics and health. *Public Health Genomics* 2009;12:84–91.
- 41 Etchegary H, et al: Attitude and knowledge about genetics and genetic testing. *Public Health Genomics* 2010;13:80–88.
- 42 Condit CM: Public understandings of genetics and health. *Clin Genet* 2010;77:1–9.
- 43 The National Human Genome Research Institute: Education. 2010 <http://www.genome.gov/Education/> (accessed October 10, 2010).
- 44 The University of Utah: Learn.Genetics, Genetic Science Learning Center. 2011. <http://learn.genetics.utah.edu/> (accessed September 2010).
- 45 Smerecnik CM, et al: Applying a theory-based framework to understand public knowledge of genetic risk factors: a case for the distinction between how-to knowledge and principles knowledge. *Public Health Genomics* 2010, E-pub ahead of print.
- 46 Ashida S, et al: Age differences in genetic knowledge, health literacy and causal beliefs for health conditions. *Public Health Genomics* 2010, E-pub ahead of print.
- 47 Condit CM, Shen L: Public understanding of risks from gene-environment interaction in common diseases: implications for public communications. *Public Health Genomics* 2010, E-pub ahead of print.
- 48 Carpenter MJ, et al: Does genetic testing result in behavioral health change? Changes in smoking behavior following testing for alpha-1 antitrypsin deficiency. *Ann Behav Med* 2007;33:22–28.
- 49 Brand A: Integrative genomics, personal-genome tests and personalized healthcare: the future is being built today. *Eur J Hum Genet* 2009;17:977–978.