Genomics: Towards a More Comprehensive View on Human Life

Hub Zwart

What is genomics?
This is by no means a trivial or academic question but an issue that has serious implications for the way in which the societal debate about genomics has to be defined. Basically, two answers can be given. The first answer stresses the newness of genomics. The neologism genomics is used to emphasise the basic difference between traditional genetics and biotechnology on the one hand, and genomics on the other. Whereas in traditional genetics and biotechnology the focus is on detecting, transferring or deleting single genes, the objective of genomics is to understand complexity, to make visible complex patterns of interaction between large numbers of genetic and environmental factors. Thus, genomics research is said to exemplify a paradigm shift or quantum leap in the history of the life sciences. We have entered a post-reductionistic era.

1 Prof Dr H.A.E. Zwart, Centre for Society & Genomics, The Netherlands.
Others, however, stress the continuity between genetics, biotechnology and genomics. Genomics is basically regarded as a set of tools used in the context of research programmes that remain reductionistic and deterministic in orientation. Genomics as a neologism was introduced for strategic reasons in order to open up new avenues of funding and to get away from undesirable connotations associated with biotechnology in the public realm. Up to a certain extent both views are viable, and the difference between genomics and traditional genetics or biotechnology is a fluid one. But if we wish to take genomics and its challenges seriously, the focus should be on its novelty. Or, to put it differently, in this contribution I will discuss genomics in so far as it differs from traditional genetics and biotechnology.

The basic objective of biotechnology as it emerged in the 1980s and 1990s was to change, to modify organisms. In the context of agriculture for example, biotechnology aimed at the introduction of new sets of products, such as crops containing certain additional ingredients. Genomics, however, is basically about knowledge. It generates information about the ways in which genetic and environmental factors interact. How do certain genes respond to certain ingredients, how will certain ingredients affect my health? Rather than producing new sets of products, genomics will basically produce new forms of information. The focus will shift from the question what kind of novel food products consumers will accept to questions such as: ‘To what extent will individuals use genomics knowledge in order to adapt their lifestyle and diet?’ In a general way we all know, for example, that smoking cigarettes is bad for our health. We also know, however, that smoking is not equally bad for everybody. Some smokers remain healthy until old age. Genomics will probably clarify the genetic basis for these individual differences. For some people, a moderate use of alcohol is part of a happy and productive life. To others, the use of alcohol poses a serious threat. Or, to give yet another example, some people will flourish in a stressful environment, while others will develop serious health problems. Genomics is expected to shed some light on these individual dispositions.

This type of information will not only be of interest to individuals, however. It will have a much broader implication. To begin with, governmental organizations may become increasingly interested in this type of information. In the nineteenth century, national governments became increasingly interested in the physical conditions of the general population and in science-based methods to improve it, such as hygienic living conditions and making available healthy but inexpensive food products (bread, meat, butter, vegetables) for the working classes in the urban centres. It was recognised that the economic and military power of a nation was determined by the general physical condition of its population. Subsequently, during the first decades of the 20th century, governmental organizations developed a growing concern for
the psychic wellbeing of the population. Intelligence tests and other tools for large-scale testing programmes were developed. And now the genomics era can be expected to provide governments with information on the genetic condition of the population. In the near future, contemporary society can expect some challenges. For example, we are confronted with an ageing population. More people will have to stay healthy and active for a longer period of time, notwithstanding the ever-increasing pace of technological innovation. Shall we (will they) be able to cope with that?

In addition to individuals and governments, other stakeholders may well be interested in genomics information, not only insurance companies, but also companies (employers) in a more general sense. The possibility of genetic pre-employment screening is not entirely fictional. A genetic factor has been identified that increases susceptibility to SARS. In the future, a hospital in the vicinity of an international airport may argue that hospital personnel, notably in an emergency room setting, should be subjected to a genetic susceptibility test for SARS and similar infectious diseases, in their own interest as well as that of others. It is not entirely unthinkable that in the near future genomics will provide us with information concerning the likelihood for individuals to develop stress, burn-out, and other life-style related problems. Will it be possible or objectionable to use this kind of information when it comes to selecting candidates for a job? Maybe a new type of expert, the career consultant, will emerge, providing career advice on the basis of a combination of genetic and psychic testing?

Therefore, I agree with Frans van Dam\(^2\) that, in order to confront individuals in a meaningful way with genomics, we must approach them as citizens rather than as consumers. Genomics is not about particular products but rather about new forms of knowledge and information. Who will use this information and how? These are questions to be addressed in the public domain rather than in the supermarket, by citizens rather than by consumers. I do not expect genomics to lead to fierce disputes whether or not a certain product should or should not be developed or introduced. On the contrary, I agree with Swierstra [Swierstra, 2004] that genomics will trigger new sets of ethical questions such as ‘What do we expect from life?’ and ‘How do we wish to live?’ Societal debate will shift to other forums, in particular to ‘genres of imagination’, such as films, novels and plays. This means that genomics issues will not be addressed in the same way as biotechnological issues were in the past. Typically, in the context of a dispute over biotechnology, proponents and opponents of a certain innovation were invited by the media to explain, in two or three sentences, why they were in favour or against a particular innovation (modification). Genomics is a much broader issue. It will have an impact on a much broader scale. The societal and cultural impact of genomics will be addressed in other ways and by other media, such as literature, cinema and

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\(^2\) See article of Van Dam ‘Genomics for consumers?’ in Part II of this book.
theatres. The question will be: ‘How will genomics information influence our views on health, on personal responsibility, on personal autonomy, on reproduction, on old age?’

Genomics is not about monogenetic diseases, but rather about multi-factorial health problems. Therefore, genomics information is not only interesting for specific risk groups, it is relevant for everybody. In other words, the genomics era will involve a shift from single genes and specific genetic defects to persons as a whole. It will allow them to gear their lifestyles to their genetic profiles. Genomics challenges us to develop a more comprehensive view on human health. This will obviously have consequences for policies as far as screening and prevention are concerned.

Will this stimulate or reduce medicalisation? In order to answer this question, we have to briefly review the history of the medicalisation debate. During the 1950s and 1960s, science and technology dramatically changed medicine as a field. This was exemplified by the sudden emergence of transplantation medicine (the first kidney transplantation took place in 1954, the first heart transplantation in 1967), but also by the fact that more and more people came to die in hospitals instead of at home. This development was both applauded and criticised. There was a general concern among critics that the emergence of a scientific and technological approach to medicine would undermine a more holistic view on man. Rather than seeing the patient as a person, the new, science-based medicine would reduce him or her to a particular condition or disease. Patients would no longer be seen as human beings with worlds of their own, but rather as objects, to be talked about in terms of symptoms, treatment options and prognostics. In the 1950s, the Hippocratic ethic was still very much alive. The doctor-patient relationship was seen as a very personal relationship. The physician was something of a friend, someone who knew his patient personally. A patient was to be approached as a human being leading a social and cultural life apart from a physiological one. The new science-based medicine seemed to change that. Attention seemed to shift from people to X-rays and lab results.

Around 1970 the field of bioethics came into existence. The Hippocratic era was definitely over and medicine had finally become a science. How to reaffirm and re-establish the personhood of patients, now that medicine had become a high-tech, science-based field? There was a sense that the triumph of medicine was accompanied by a crisis of medical ethics. How could be made sure that a patient would be more to a physician than his or her X-ray? Those were the typical concerns voiced by bioethicists in the 1970s.

In the genomics era, this is likely to change. The focus will be on a more comprehensive view on individuals and human wellbeing. Genomics is not about specific monogenetic or moncausal health problems. Rather, in the genomics era, we will once again be invited to study the interaction between the
physiological, the social and cultural dimension of human life. I expect, for example, that genomics will be particularly helpful when it comes to furthering our understanding of the so-called new diseases that emerge on the borders between physiology, psychology and sociology, such as burn-out or the chronic fatigue syndrome.

This means that in the future a completely new role will be played by general practitioners. In the high-tech science-based medicine as it emerged in the recent past, the place of the general practitioners in the health system became an increasingly marginal one. But this may well change. In the genomics era the question will be how to interpret genomics information, how to connect it with developments in a person’s social or professional life. And the general practitioner may well be the one who is best-fitted to assist individual patients in building a comprehensive view of their health status on the basis of genomics information. How to translate genomics information into concrete everyday choices? In other words, general practitioners will play a prominent role in this whole process. In their professional life, a shift of emphasis is likely to occur from intervention towards information management. Are they ready to play this role? On the one hand, health care workers in general will have to be educated in order to be able to deal with the new forms of knowledge and information that will influence both the health domain and our understanding of illness and health. On the other hand, general practitioners are experts in their own right, of course. They are experts of illness and health in daily life and in this position they will no doubt be able to play an important role as intermediaries between genomics science and society, between scientific innovations on the one hand and societal urgencies and developments on the other. Patient organizations will also increasingly function as intermediaries between science and patient (in two directions). They will educate their interests groups, participate in research programmes and stimulate particular lines of genomics research.

Against the background of these developments, I consider the scenario study by Theo Verrips about the virtual health agent quite credible. Such an agent can monitor our health situation. Besides measuring body weight, a health practice many people are already involved in on a daily basis, it can give us information on blood pressure and other parameters, depending on the individual’s condition and genetic profile. The focus will be on prevention, on gearing lifestyles to genetic risks and on tailor-made pharmaceuticals and special food products. General practitioners will be called upon to assist their patients in interacting with such a device. A virtual health agent will not replace the physician. On the contrary, patients and physicians will have it at their disposal as a reasonably reliable tool for monitoring the patient’s condition (notably for example during periods of drug use), generating input for consultations. The virtual agent can integrate genetic and other types of infor-

\[^3\] See article of Verrips ‘Genomics 2030: Part of Everyday Life’ in Part II of this book.
mation into a comprehensive assessment of the person’s physical condition and health options.

For the larger part, genomics is still a laboratory phenomenon. The 1990s are known today as ‘the years of controversy’, but they also constituted an era of optimism. Life scientists promised their societal audiences that chronic problems of long-standing, such as cancer and global inequality, would finally be addressed. The basic message of genomics, however, is that life is much more complicated than life scientists in the 1990s were willing to realise. More research is needed in order to appreciate and understand nature’s extremely complicated and intelligent designs. The trajectory from basic research to applications is complicated and time-consuming. As is indicated by Peter Streng, the production of new pharmaceuticals, for example, is a costly process. During the 1990s the ‘commercialization’ of biotechnology took place. Scientists migrated in large numbers from university laboratories to private companies. In the genomics era, however, we witness a dramatic resurgence of large-scale public forms of funding, for example in the context of the Human Genome Project. It is simply not true that politicians or the public are unwilling to make funding available for basic scientific research. The problem is, rather, that whereas the scientific objectives of research activities are often articulated in a very precise and accurate way, the societal prospects of these programmes tend to be addressed in rather vague and general terms. In order to convince society of the importance of long-term public funding of genomics research, the promises of genomics have to be toned down to realistic proportions and the societal agenda of genomics has to be formulated in a more concrete and, above all, less noncommittal way, in terms of definite milestones. This should be the basis of a new social contract between society and genomics. Genomics research has increasingly to be willing to orient itself towards goals and objectives that really are of substantial societal importance. In other words, the problem is not that the public suffers from a lack of information (a knowledge deficit). The problem is rather how to produce a robust and convincing societal agenda for genomics. This calls for more intimate forms of dialogue between science and society. Genomics researchers can no longer afford to postpone or restrict societal communication to the dissemination phase. The societal arena of genomics research has become a complex setting in its own right.

In short, genomics is not about the modification of organisms or the introduction of specific products. Genomics will rather add a new dimension to our knowledge about ourselves. This will have an impact on the way we interact with our bodies, our general practitioners, our insurance companies, our careers. In a knowledge society, scientific and technological innovations are of essential importance, but we have to move beyond a view that sees the public

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4 See article of Streng ‘Living the Future’ in Part II of this book.
as epistemologically deficient and reduces science communication to ‘public relations’. We have to invest in genomics, but we have to invest in developing innovative forms of societal interaction as well.

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