

CHAPTER THREE

THE HUMAN GENOME PROJECT: JUSTIFICATION, PROMOTION, AND ACCESS TO RESULTS

1. SUMMARY AND APPLICATION: RESPONSIBLE GENETICS

What should responsible geneticists do? This is the key question in this and coming chapters. 'Responsible geneticists' are those who actively take moral responsibility for their research and its consequences. The term may include individuals and research teams, as well as the genetics community at large.

In answering this key question, we should keep in mind the distinction between the domain of responsibility (the crossing of a stage of research and a party involved in or affected by research), content of responsibility (the obligations and virtues), and form of responsibility (the means of implementing the normative content).

With regard to the domain of responsibility, I have suggested that scientists in general should assume responsibility for all the different stages of research. This view is also applicable to geneticists. They should take moral responsibility for the choice of subject (topic), the research process in the narrow sense (empirical and theoretical work), publication, and application. What geneticists do affects other people. Their research has consequences in the short run and in the long run. The idea that geneticists should assume responsibility for the choice of subject, the research process in the narrow sense, and publication, is uncontroversial. But that they should take responsibility for the applications of their findings is not. I have argued that scientists, including geneticists, should assume responsibility for the applications in the sense that they should try to affect applications of their findings made by other people. My main arguments are that scientists have a duty to respond to the needs and fears of the general public, because their research has a social impact, and that scientists owe this concern to society, because they have received from society education, resources, and access to the general infrastructure. 'Responding' and 'owing' correspond to the two metaphors constituting the concept of responsibility. To these arguments can be added two further arguments that are particularly applicable to genetics. Geneticists can often anticipate what possible applications might be made, and possible applications are often referred to as a justification when applying for financial grants to basic research.

In this and subsequent chapters, however, I shall not discuss these questions about the domain of responsibility any further. Instead I shall focus on the content and, to some extent, form of responsibility. I have already suggested certain general prescriptions: that scientists including geneticists should use their moral imagination to envision different consequences of their research and different ethical arguments with regard to these consequences, that they should learn from historical cases such as the eugenics movement and the recombinant-DNA debate, that they should take part in a dialogue with various parties on research and application, and finally that they should integrate ethical reflection with scientific practice, i.e. find an appropriate form of responsibility. I shall now apply these rules of thumb to different kinds of human genetics research and applications.

It should be noted, however, that the attention given to each of these general prescriptions may vary among different sections and chapters. The prescription of moral imagination will get attention throughout the book, explicitly and implicitly. It is the key idea of imaginative casuistry. Dialogue will also be central in most sections. Many of the ethical problems raised by human genetics have to do with communication of genetic knowledge and information. For instance, there is a need for dialogue in the research process between geneticists and human subjects, but also a need for dialogue between the genetics community and society at large on the consequences and applications of genetics research. Historical cases, however, will be discussed occasionally, most importantly in Chapter 5 in relation to the topic of eugenics. Integration should be viewed as a general suggestion to the geneticists to find appropriate forms of taking responsibility. For example, should the genetics community try to formulate a common professional policy on certain issues or stay content with governmental regulations? Such questions of integration will also be touched upon in a few sections.

There are, of course, many different views on what responsible geneticists should do and it is obvious that geneticists must find their own answers. They have to carry out their own interpretation, application and ranking of different ethical principles and values. However, I will propose certain suggestions about what they should reasonably take into consideration when taking responsibility. For instance, I will present different arguments in favor of and against certain kinds of human genetics research and applications. I shall also occasionally reveal my own standing on specific issues; not that my views would be particularly interesting as such, but as a contribution to dialogue.

2. DIALOGUE AND THE HUMAN GENOME PROJECT

The Human Genome Project (HGP) is of key importance to many different branches of human genetics. In this chapter, I shall discuss some of its ethical aspects. Of particular importance is dialogue. Dialogue was needed before the project started and it is also needed now when it is almost completed. Geneticists have to take part

in a dialogue with other scientists, politicians, and the general public about the justification of the project. Dialogue is also an integrative part of the promotion of the project. How are other scientists, politicians, and the general public informed about the project? How is the project described and what communicative methods are used in fund-raising? Finally, dialogue is essential within the scientific community regarding the results of the project. Does the prescription of dialogue imply open access for all to the results or can restricted access in terms of gene patents be accepted in the short run?

Some Characteristics of the HGP

I shall start by giving a short description of some of the characteristics of the international Human Genome Project coordinated by HUGO. These characteristics will indicate why the HGP is such a 'hot' subject in research ethics and worthy of a thorough dialogue from an ethical point of view. In the dialogue, responsible geneticists would do well to have these characteristics in mind. What is an everyday reality to geneticists may stick out as controversial to other people.

Big science. In magnitude and costs the Human Genome Project is sometimes thought to stand in the tradition of the Manhattan Project of developing the atomic bomb and the Apollo Project of placing a man on the moon. This is clearly an overstatement but, to be sure, it is a large scale project.

Controversial. The HGP is rather controversial, but perhaps more so at the start than now when it is almost completed. Criticisms have come both from within science itself and from outside science. Some critics have questioned the scientific value of sequencing the whole genome and argued that the money should be spent on other projects instead. Others have objected to its anticipated social and medical value. If social and medical benefits are the real goals, the money could have been spent in more efficient ways, they argue.

The result of a struggle for power. Since the project is big science it is not strange that its start is characterized by a struggle for power between different interests in society. In this way the origins of the HGP illustrate perfectly the contextual interaction model proposed in Chapter 2. Clear examples are the US project and the European Community project.

The fight over the US project had to do with exactly what kind of research should be conducted and who should direct it. With regard to the first issue, it is clear that all the important scientists from whom the idea of the project originated in 1985-86—Robert Sinsheimer, Walter Gilbert, Charles DeLisi (Department of Energy), Renato Dulbecco—shared the vision of a sequencing project. However, the project was to be redefined by the National Research Council (NRC) of the National Academy of Sciences (NAS). In 1988, NRC issued a report stating the intention of mapping first and sequencing later. Sequencing should be the ultimate goal, but would require advanced technological developments. It would be wiser to start with

genetic mapping and physical mapping. A pilot project for sequencing could be initiated, however. The report also stressed the importance of studying the genomes of other organisms. This revised view was embraced by the National Institutes of Health (NIH), and eventually also by the Department of Energy (DOE). Consequently, in the final joint NIH/DOE Human Genome Project three scientific goals are stated, namely physical mapping, genetic mapping, and sequencing. The second issue of controversy had to do with what agency or agencies should direct the project. As indicated, DeLisi at DOE early proposed a sequencing project. DOE wanted this kind of research as a part of its study of heritable mutations due to radiation and as a way of using its laboratories in solving nationally important problems. NIH, on the other hand, came to support the idea of a genome project somewhat later, and primarily for the reason of finding disease genes as a part of biomedical research. Eventually, DOE and NIH joined and proposed both mapping and sequencing with the justification of finding disease genes. These two agencies still have separate project directorates but cooperate rather well, for instance through certain common committees.¹

The fight over the human genome project in the European Community had a different character. A key issue was how to characterize and justify the project. While the US struggle concerned the scientific value of sequencing, the European struggle had to do with the social value of the project. In 1988 a proposal appeared from the European Commission entitled 'Predictive Medicine: Human Genome Analysis'. The aim of this 'health measure', as it was characterized, was summarized as follows: "Predictive Medicine seeks to protect individuals from the kinds of illnesses to which they are genetically most vulnerable and, where appropriate, to prevent the transmission of the genetic susceptibilities to the next generation."² The genome program was expected to make Europe more competitive by slowing down the rate of increase in health costs and by making its scientific and technological base stronger. This proposal was criticized in a report by the 'reader' Benedikt Härlin, a member of the West German Green Party. He warned against the genome project as an enterprise in preventive medicine. In his interpretation, the proposal included eugenic elements. The application of genetic information to protect people from transmitting genetic diseases or conditions would almost always involve eugenic decisions about what is normal and abnormal, desirable and undesirable. As a result of this report there appeared a new proposal from the European Commission without regard to predictive medicine and simply called 'Human Genome Analysis'. It was formally accepted in 1990 by the European Community Council of Ministers, authorized for three years. The genome program then became part of the 'BIOMED' programs.³

¹ See Cook-Deegan, 1994, for the most detailed and authoritative account of the origins of the project.

² Commission of the European Communities, 1988. Quoted in Kevles, 1994, p. 20.

³ See Commission of the European Communities, 1988; Commission of the European Communities, 1989; European Community, 1989; Official Journal of the European Communities, 1990; Kevles, 1994.

Big business. Great commercial expectations are linked to the HGP. Many academic geneticists are directly involved in biotechnology companies. They serve as board members, as consultants, or even as investors. A large part of the genome research is carried out by private companies. Important examples are Celera Genomics and Incyte Pharmaceuticals.⁴

Advanced technology. The HGP uses very advanced instruments. To a large extent this technology is a product of the project itself. This is especially true of sequencing technology and data handling.

Tight links between basic research and applied research. A significant feature of the HGP are the tight links between basic research and applied research. New discoveries are rapidly put to practical use. This is true both of genetic knowledge and of the technology being developed. Knowledge of new genes is rapidly translated to clinical and other applications. Mapping and sequencing technology is transferred to and used in other kinds of research.

Teamwork. The HGP deviates distinctly from the old picture of the lonely scientist seeking the truth. Genome research is a well-organized teamwork.

International cooperation. The teamwork is carried out not only at a national level, but also at an international one. The HGP is an international project. As mentioned above, the cooperation is directed by the Human Genome Organisation (HUGO). This organization aims at coordinating the work in order to avoid overlap and making the knowledge generally available in data bases.

Competition. However, there is also competition, within nations as well as between nations, between publicly funded research teams and private companies. The cooperation is only partial. 'Gene hunting' is not a far-fetched metaphor. 'Gene wars' is another, but probably adequate only for the years preceding the start of the HGP in the US.

High scientific status. Due to its character of big science, genome research enjoys high scientific prestige. Some critics maintain that other equally important fields of investigation become second-rate, at least in the eyes of the funding agencies.

Far-reaching medical and social consequences. It already appears quite obvious that the HGP will generate knowledge and applications with great impact on society. The project can be anticipated to lead to improved human self-knowledge as well as great medical advancement. Some critics argue that some of these anticipations are unfounded. The results will not be as important as is often proclaimed. That might be, but on the whole the consequences are massive and cannot be ignored. The problem is how to avoid harmful consequences and promote good ones.

Ethical reflection as part of the project from the very beginning. Above I mentioned the comparison made by some between the HGP and the Manhattan Project. Both projects could be viewed as examples of big science. But, of course, there are differences as well. One important difference concerns ethical reflection. Right from

⁴ See URL: www.celera.com, and URL: www.incyte.com.

Responsible Genetics

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Consequences of Human Genetics Research

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