



Genetics and Health – Visions Of The Future

Summary of a joint meeting held by the Wellcome Trust and the Royal Society in February 2003

Introduction

This is a report of a meeting held by the Wellcome Trust and the Royal Society in London on 3 February 2003. The purpose of the meeting was to brainstorm and debate what the field of genetics might deliver in 20 years time and to identify what the policy implications of developments in this area might be. This document summarises the ideas expressed at the meeting and does not necessarily represent the views of the Wellcome Trust or the Royal Society.

Key conclusions

- Overall, the clear consensus at the meeting was cautious but optimistic about the progress in the field of
 genetics and its application to healthcare. The next 20 years will see an increase in our ability to understand
 biology and the mechanisms of disease. However, participants were more circumspect about how many
 healthcare benefits could be realised in this timescale. Moreover, they considered it likely that improving our
 understanding of diseases and how they are treated will not occur in a uniform manner; there will be major
 developments in some areas but not in others.
- Now that we have the sequence data for the human genome, the next major challenge is to discover what
 each gene does. Model systems, particularly those based on animals, will be vital in fully understanding the
 function of genes. The hope is that in 20 years we shall have some idea about the function of every single
 gene through the study of these models, but some scepticism was expressed about the realism of such a
 hope.
- In the next 20 years, advances in genetics are likely to improve our ability to diagnose and treat disease, although working out the genetic contribution to many common diseases is likely to take a long time. Nonetheless, genetic analysis may lead to better classification of diseases, for example some cancers, and this may allow a practitioner to administer better, more effective, targeted treatments. Already, different types of leukaemia are increasingly classified in this way, enabling the most effective clinical treatment to be used. We will see much more research into the therapeutic potential of stem cells, in particular in the areas of haematopoietic (blood) stem cell and embryonic stem cell research. However, in most cases, useable clinical applications are likely to take longer than 20 years.
- The usefulness of genetic screening was a matter of much debate in the meeting. Some participants contended that screening should only be performed when treatment was already available for the particular disease or disorder, or where people could make informed lifestyle decisions that would reduce their risk of developing the condition. Others questioned how such tests would be interpreted in terms of risk and probability, and whether they would cause unnecessary anxiety where no treatments were yet available. This debate is likely to intensify in the next 20 years, as more tests become available while interpretation of their meaning and therapies continue to lag behind.

- Some participants believed that in 20 years time, technological advances would mean that it will be feasible in terms of cost and speed to sequence the entire genomes of individuals on a routine basis. Not everyone could see what the merits of a total genome scan for everyone would be and there was much discussion about the potential pros and cons of this. A number of significant social and ethical questions were raised, including: who would have access to the information; how informed consent could be given if the scan was routinely performed at birth; and what other implications it might have for society (for example, the ability to establish paternity more readily).
- The pharmaceutical industry will have a key role in the advance of future therapies. Genetics will be applied in research, drug discovery and development of therapies. In the next 20 years, a better understanding of genetics is likely to enable the development of new uses for old drugs and the wider use of pharmacogenetics (where drugs will be targeted to individuals on the basis of their individual genetic makeup). However, many treatments arising from the advances in genetics, in particular where new drugs are involved, will have development times beyond the 20 year time span. In recent decades, fewer new drugs have been released onto the market each year, partly because of the increasingly rigorous safety tests that are performed before drugs can be approved for use. Society will have to continue to weigh up this balance between the benefits of extensive testing and the faster delivery of drugs (with the associated potential risks).
- Understanding the genetic basis of many diseases will require extensive collaboration across the different scientific disciplines, for example, between individuals in fields as diverse as genetics, molecular biology, epidemiology, bioinformatics, mathematics and computer science. There was recognition that attracting and retaining suitably qualified individuals across a wide range of fields would be vital to maximising our understanding of genetics research.
- Participants highlighted how, in 20 years time, scientists, health professionals and the public will need a
 much better understanding of the roles played by genetics, by the environment and their interactions in
 causing disease if we are to interpret genetic tests and suggest preventive strategies for individuals to avoid
 illness. The success of this increased understanding is also likely to depend on the extent to which people
 are willing to change their behaviour as a result of the outcome of such tests, where assessment of risk and
 probability will play a large part. Responding to new genetic advances and the possibilities they present will
 take time, education and the involvement of scientists, medical practitioners, health and genetic counsellors,
 policy-makers and the public.

Meeting programme

Approximately 50 people, including life scientists, members of the policy community and representatives from the clinical and social sciences attended the meeting and our thanks go to the participants of the meeting. A list of participants is available on request from Dr Josephine Craig, Science Advice Section, The Royal Society, 6-9 Carlton House Terrace, London SW1Y 5AG or e-mail: josephine.craig@royalsoc.ac.uk.

Against the background of current scientific progress, predictions were made about where genetics and healthcare will be in 20 years time. Presentations on five key areas were given by experts in the field, who provided their perspectives on how genetics research will progress over the next 20 years and the impact that this research may have on health. The topics covered were: translating gene sequences to gene function; the complexities of regulation of gene expression; how genetics will impact on treatment and prevention of common diseases; possibilities for pharmaceutical intervention and population screening.

Following these brief scene-setting presentations and a general discussion, the meeting broke into four different groups and each group was asked to consider one of the following questions:

- What are the policy, infrastructure and educational implications of advances in genetics?
- What are the likely clinical and non-clinical applications of the predicted advances in genetics? What is practically achievable?
- How far will the field of genetics move on over the next two decades? Can genetics deliver our expectations? How will people use an increased knowledge of their genetic make-up?
- What is the likely value of genetics relative to other factors, such as environmental influences, in determining and treating disease?

Each group reported back to all the participants of the meeting and this was followed by a general discussion.

A full report of the meeting will be available shortly on the website of the Royal Society (www.royalsoc.ac.uk).