
Summary, conclusions and recommendations

Public awareness about genetics deserves our attention on account of the wide-ranging applications of this branch of science within our society and the speed at which it is developing. Such developments as the discovery of disease genes, the cloning of animals, DNA research by officers of the law and genetically modified (GM) food are increasingly confronting citizens with decisions and choices that require some degree of information. It is expected that the number of applications of genetic technologies will experience a further substantial increase as a result of the unravelling of the human genome. In the past, government White Papers and Health Council advisory reports have advocated public information campaigns aimed at enabling citizens to make informed choices.

The main focus of this ‘alerting’ advisory report is on the nature of the information that is required. This leads on to a discussion of what we know about the current level of public awareness and what initiatives are of relevance in this context. The report is based on a discussion of these issues that took place at a symposium organised by the Health Council in November 2001.

This advisory report does not discuss which psychological and sociological factors influence public opinion with regard to genetics. Nor does it consider which forms of (mass) information are most effective. These issues warrant closer attention.

The question of what level of public awareness about genetics is desirable receives a two-part answer. As far as the content of this knowledge is concerned, we are talking about an understanding of the large number of differences in genes and of the interaction between genes and the environment. The many genetic differences that exist between

individual human beings also apply in the case of the 'disease genes'. All human beings have genes that can trigger disease processes in themselves and in their offspring. Increasingly often, it is possible to provide specific counselling on those processes. It is also important for the public to know that the effect of genes is almost always influenced by other factors, which are referred to collectively as "the environment". These factors include diet and lifestyle. Awareness of these issues underlines the individual responsibility of the citizen. Besides possessing certain specific knowledge, it is desirable that people should know how to go about asking for genetic counselling.

The question of what knowledge the public actually has of genetics is not an easy one to answer. Research in this area is not only scarce, but it is also open to criticism with regard to the methodology employed. Experience gained in the field of clinical genetics teaches us that the heritability of disease is a misunderstood concept. Thus it appears that some people do not seek counselling in spite of the fact that there is a history of a particular disease in their family.

As far as the initiatives that are needed in order to raise public awareness are concerned, the focus is placed on education, general information and the position of the general practitioner. An obvious dichotomy arises in the sphere of education. Only a proportion of pupils – i.e. those who opt to take a course in biology – are informed about genetics. However, adequate public awareness demands that the others must also gain an insight into this issue – something which could probably be accomplished through the use of simple examples. This requires consultation between educational experts, geneticists and officials from the relevant ministries.

Furthermore, the public at large needs to have access to general information. As far as hereditary diseases are concerned, it is possible to consult a general practitioner. Discussion between clinical geneticists and GPs could improve this process. Information can also be provided via the internet, which entails making the public aware of informative websites. One such site is the Erfocentrum, a genetic resource and information centre to be found at www.erfelijkheid.nl. The dissemination of information to ethnic minorities is an issue that warrants special attention. Research has shown that child mortality within this population group is substantially higher than the national average in the Netherlands, with hereditary diseases being an important contributory factor.

Conclusions

- The rapid advancement of scientific knowledge in the field of genetics is constantly giving rise to new applications for these technologies (in areas such as health care and food production). Citizens are required to make an ever-increasing number of choices in this area. Nevertheless, little is known about the level of awareness, and about possible misconceptions, in relation to genetics within the public at large.
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- A substantial proportion of the students in secondary education receive no instruction on genetics.
 - Owing to a lack of knowledge and misconceptions, people sometimes fail to seek counselling about genetic problems in situations where such advice is, in fact, required.
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Recommendations

- Further research needs to be conducted into public awareness and attitudes in relation to genetics.
- All students should, as part of their education, be familiarised with the fundamental principles of genetics. Consideration should be given to the possibility of starting this process in primary schools.
- Key elements of genetics that merit thorough consideration are the enormous range of genetic variation and the interaction between genes and environmental factors such as diet and behaviour.
- General information and adequate referral to clinical genetics centres are important components of genetic counselling. This ideally requires an information service of the type provided by the Erfocentrum, and raising of GP awareness with regard to referral.