Rethinking **Science** Curricula in the Genomics Era

> Edited by Dirk Jan Boerwinkel Arend Jan Waarlo

**Proceedings of the Invitational Workshop** 

4-5 December 2008, Utrecht, the Netherlands

## **Rethinking Science Curricula**

in

## the Genomics Era

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These proceedings are the result of a two-day invitational workshop as part of the research project 'DNA labs for Citizenship' of the Cancer Genomics Centre and the Centre for Society and Genomics, funded by the Netherlands Genomics Initiative and based at Utrecht University, Freudenthal Institute for Science and Mathematics Education. www.cancergenomics.nl www.society-genomics.nl www.genomics.nl www.fisme.uu.nl



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#### Rethinking Science Curricula in the Genomics Era

Editors: Dr. Dirk Jan Boerwinkel & Prof.dr. Arend Jan Waarlo

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### Preface

Advances in genomics research not only result in important changes in scientific practice, but also widens the gap between this practice and school science education. This is a serious problem, as an important task of science education is to prepare students for the 'knowledge society', including dealing with socio-scientific issues arising from applications and implications of genomics research.

In the Netherlands, genomics research is for the large part financed through the Netherlands Genomics Initiative (NGI), which coordinates the activities of 16 genomics centres (www.genomics.nl). A substantial part of this funding is earmarked for communication and educational activities through the Centre for Society and Genomics (www.societygenomics.nl). One of these activities is the development of five mobile DNA laboratories by five of the genomics centres, each with content related to the research of that centre. The mobile DNA laboratories visit secondary schools and offer free-of-charge, handson experience using advanced equipment to both students and teachers. The practical work is taught by trained students studying for a Bachelor degree at the participating universities. Accompanying teaching materials help teachers to introduce the practical work and to reflect afterwards with students on scientific and societal issues related to the experiments.

The link between research and education is one of the strong elements in this educational innovation, and mobile laboratories clearly help to bridge the gap between scientific practice and school science. However, the mobile laboratories are not part of the official curriculum, and questions arise as to which parts of the content can be embedded in future science curricula and how this can be carried out. This is not an easy decision to make, as the curriculum is already overloaded. This problem is not specific to education in The Netherlands, but has been reported worldwide. Therefore, during the 2008 Conference of the European Researchers in Didactics of Biology (ERIDOB), an invitational workshop was announced to discuss the problem of curricular embedding of genomics. This workshop was organized in Utrecht on 4–5 December 2008 and hosted by the Cancer Genomics Centre (www.cancergenomics.nl) and the Freudenthal Institute for Science and Mathematics Education (www.fisme.uu.nl). Speakers were invited to respond to the keynote article, which offered a framework of questions about curriculum innovation. Presentations were grouped in sessions, with each session followed by a

discussion. In the final discussion, all presentations and discussions were combined in an attempt to propose more specific changes in the curriculum.

These proceedings contain the presentations and reports of the discussion. Furthermore, conclusions were drawn up from each session, and a final article was written by one of the editors in which the questions formulated in the keynote article were answered based on the results of the workshop.

Although many questions remain that need further research and discussion, we hope that these proceedings are a step forward in curriculum innovation based on scientific, societal and pedagogical arguments.

Our special thanks go to Ragna Senf for taking observational notes during the workshop and for reporting the discussions afterwards, and to Jane Hoyle for copy-editing this book.

#### Annelies Speksnijder

Managing Director, Cancer Genomics Centre

#### Dirk Jan Boerwinkel & Arend Jan Waarlo

Freudenthal Institute for Science and Mathematics Education Project 'DNA Labs for Citizenship' Utrecht, October 2009

## Workshop programme

Chair: Arend Jan Waarlo, Freudenthal Institute for Science and Mathematics Education

#### Thursday December 4

08:30-09:00	Registration, coffee				
09.00-09.15	Annelies Speksnijder Welcome Cancer Genomics Centre, Education				
09.15–09.30	Dirk Jan Boerwinkel Freudenthal Institute, Utrecht University	Introduction			
Session A. Why	y rethink science curricula?				
09.30–10.00	Andrew Moore Editor-in-Chief, BioEssays, Wiley- Blackwell	Leave the molecular stuff till university? An overview of the problems and opportunities for secondary-level biology education in Europe			
10.00–10.30	Michiel van Eijck Eindhoven School of Education, Eindhoven Technical University				
10.30-11.00	11.00 Discussion and conclusions				
11.00–11.15 Coffee break					
Session B. What discriminates genomics from genetics?					
11.15–11.45	Jenny Lewis School of Education, University of Leeds	Genetics, genomics and the curriculum			
11.45–12.15	Roald Verhoeff Freudenthal Institute, Utrecht University	Genomics and biology education: complex stuff and curricular overload			
12.15-13.00	D Discussion and conclusions				
13.00–14.00	13.00–14.00 Lunch break				
Session C. Pedagogical approaches					
14.00–14.30	Ralph Levinson Institute of Education, University of London	Genomics and teaching of risk			
14.30–15.00	Catherine Naepflin & Stefanie Sapienza Department of Education, University of Fribourg	Genomics and moral reasoning			
15.00–15.30	Coffee and tea break				
15.30–16.00	Paul van der Zande IVLOS Institute of Education, Utrecht University	Health-related genomics in classroom practice			
16.00–16.45	Discussion and conclusions				
17.00–18.00	Walking tour of Utrecht				
18.00–19.30	Speakers' dinner				

#### Friday December 5

Session D. Implementation of genomics education				
09.00-09.30	Anat Yarden Weizman Institute of Science, Rehovot	Genomics in the curriculum in Israel		
09.30–10.00	Martina Cornel Community Genetics, VU University Medical Centre Amsterdam	Genomics in health-related education		
10.00–10.30	Discussion and conclusions			
10.30–11.00	Coffee break			
Session E. Overall conclusions and recommendations from sessions A-D				
11.00–12.30 Combining conclusions from sessions A–D Concept proposals for curricular change Proposals for further research and collaboration				
12.30–13.30	Lunch with the speakers			

## A framework for rethinking science curricula in the genomics era

**Dirk Jan Boerwinkel, Roald Verhoeff and Arend Jan Waarlo** Freudenthal Institute for Science and Mathematics Education, Utrecht University, The Netherlands

Only a few years after the publication of the human genome, genomics research is generating a steady stream of large and complex data sets of molecular information that have transformed the study of virtually all life processes (Collins, 2003). Major changes are apparent in a diversity of practices such as medicine, forensics, the production of biofuels, the development of vaccines and cleaning of polluted soil (NGI, 2007). Curricula always lag behind scientific innovations, and conceptual and practical changes related to genomics have not yet found their place in science curricula in the Netherlands. Outreach programs like the 'Mobile DNA laboratories' in the Netherlands offer a temporary solution (van Mil, 2007), but a more systematic analysis of genomics and its applications and implications is needed to study the possible consequences for the science curriculum. In this introductory paper, the central question is whether and how genomics should be embedded in science education.

Several questions must be answered in order to decide which changes in the curriculum are necessary. These questions concern the target group, the content, the justification and the pedagogical approach of the subject (Bayrhuber & Brinkman, 1998): in short, the Who, What, Why and How of genomics education.

Starting with the Who question: this workshop will focus on students of upper secondary education because teaching about genomics presupposes basic knowledge of DNA and cell processes. Within this group of students, educational goals will differ. All students will have to deal with genomics applications and implications in society, but only a few will go on to use genomics research in advanced studies. Thus, there is a need to differentiate between a core curriculum for all students at upper secondary level, and an advanced curriculum for those who are being prepared for a possible career in science.

In addition to the questions of who, what, why and how, another range of questions involves the consequences for the existing curriculum. Do the changes mean that new elements should be added, that elements can be replaced or that the conceptual structure or emphasis of the subject matter should be drastically changed?

The first part of this contribution will deal with the content, the What question of genomics education. The Why and How questions will then be addressed. In each part, questions will be formulated concerning the curricular consequences. Finally, questions will be formulated concerning the existing curriculum. In this workshop, these questions will be answered, as far as possible, in the presentations and following discussions. Finally, all of this should result in substantiated ideas for curriculum revision, teacher training and curriculum research.

# The What question: genomics education for science, students and society

Relevant science education takes into account what is needed to understand, use and evaluate scientific statements, the needs and interests of the student, and the competences required for participating in society (Figure 1) (Robinsohn, 1967). Genomics is likely to impact on each of these so-called curriculum determinants; in other words, we need to ask:

- What changes has genomics brought about in the life sciences?
- What changes has genomics brought to society?
- Are these changes relevant to and understandable by the student?

In the next three paragraphs, these questions will be elaborated.



Figure 1. Curriculum determinants of science education.

#### What changes has genomics brought about in the life sciences?

Changes in scientific practice can refer to the process and/or product of research. Changes in the process include changes in research tools and methods, and in the composition of research communities. Changes in the product include changes in research questions, concepts and relationships between concepts. With regard to the changes in process, molecular technologies and bioinformatics have resulted in a shift from a single geneoriented approach (gene hunting) to genome-wide studies (fishing for genes in a data pool). This entails the analysis of large and complex data sets to find the characteristic molecular alterations (biomarkers) that determine either functional characteristics such as risk of disease and susceptibility to treatment (Balmain et al., 2003), or markers that can be used in the identification of genes (e.g. in the development of genetic tests), individuals (e.g. in forensic science), species (e.g. in metagenomics; see http://omics.org/index.php/ Metagenomics) or the analysis of migratory patterns in mankind (Wells, 2006). Molecular alterations include changes on many levels, for example chromosome structure, DNA sequences, levels of mRNA (DNA expression profiles), proteins, metabolites and posttranslational modifications and methylation patterns in DNA. Research on these different levels has led to the use of a number of different terms such as transcriptomics, proteomics and metabolomics (Bork, 2005). Programs to compare novel genome sequences with previously characterized genes are now publicly available on the internet and allow both evolutionary (interspecies) and functional analyses. Nucleotide and protein databases can

also be searched. Understanding how large networks of genes and gene products are related to the behaviour of the system under study is the topic of systems biology, in which the interaction between components is studied by a combination of modelling and testing. The enormous complexity of this task demands collaboration between different scientific disciplines ranging from biology and chemistry to mathematics, informatics and physics.

Changes in concepts and relationships include more complex relationships between DNA, the environment and the expression of traits in organisms. For instance, many diseases are not caused by a single gene mutation but originate from a complex interplay between environmental factors and multiple 'low-penetrance' predisposition gene variants (Balmain *et al.*, 2003). Predisposition by a combination of weak genetic variants and environmental factors may be of much greater significance to public health than the individual risks of rare monogenic diseases (van Rijswoud *et al.*, 2008). Another conceptual change is that the genome itself can no longer be described as an unchangeable chain of genes, but instead is considered a complex system that interacts in many different ways with the environment. Furthermore, new methods cause many changes in insight into evolutionary patterns (Moore, 2007), species diversity (especially in microbial ecosystems) and variability within species. In short, genomics has caused many changes in the top of the 'curriculum triangle' shown in Figure 1. Questions regarding the curricular consequences are:

- **Question I:** Has genomics changed research methods and results in life sciences in a way that makes changes in the curriculum desirable?
- **Question 2:** If yes, how can these changes best be described and structured to be of use in a curriculum discourse?

#### What changes has genomics brought to society?

As a result of the changed research practices, new technologies have influenced medical, administrative, industrial and agricultural practices. These in turn lead to new societal questions. A few examples are described below.

New methods in genomics research make large-scale storage and use of genetic information possible. This plays a role in forensic practices and in storage of patient tissue,

genetic data and health data (biobanking). Issues in these practices are the protection of privacy and ownership of the stored information (Godard *et al.*, 2003; Levitt, 2007).

The discovery of many low-penetrance/high-frequency genes correlated with health risk causes changes in the concepts of health and disease, because genetically there is no clear distinction between the two. A high proportion of the general population is carriers of at-risk genotypes (KNAW, 2006). This means that communication about genetic information becomes more complex. Phenotypically healthy people become genotypic 'protopatients', which can lead to overconsumption of medical services (Sense about Science Trust, 2008). Another outcome of genomics research is that genetic information can be used in more individual prognosis and treatment (tailored medicine). Healthcare professionals are often not well prepared to deal with this kind of information (McInerney, 2002; Guttmacher *et al.*, 2007).

Technological innovations have made gene sequencing ever faster and cheaper, which makes it possible to offer test facilities on a commercial basis. Commercial enterprises have entered the market with direct-to-consumer products such as genetic tests, mostly via the internet. The regulation concerning these tests is often much less strict than regulation about medication (Gezondheidsraad, 2007).

Another commercial aspect of genomics is the patenting of genes and related discoveries. This influences the development and dissemination of both agricultural and medical innovations (Nuffield Council on Bioethics, 2002).

The issues described above include both societal and personal choices, for example in genetic testing a personal choice is about ordering a test and acting on the results, and a societal choice is whether genetic testing should be better regulated by the government or medical institutions.

Returning to Figure 1, several changes in society caused by genomics can be distinguished that could be used to argue for curricular change. This leads to the following questions:

- **Question 3:** Has genomics raised new societal issues in a way that makes changes in the curriculum desirable?
- **Question 4:** If yes, how can these changes best be described and structured to be of use in a curriculum discourse?

#### Are these changes relevant to and understandable by the student?

Even when the answers to questions I and 3 are positive, there can be two important reasons not to propose new curriculum content. When, for example, societal issues cannot be linked to student experiences or interests, it becomes hard to motivate students to study these issues, even if it is clear that in the future they will be confronted with them. Health insurance, for example, is a very relevant issue for adults, but normally doesn't play a role in student life. So relevance for the student is one of the criteria to propose or reject content. This does not mean that only topics that play a role in student life should be included, but students must be able to identify with people who are confronted with situations in which he or she would be confronted with genomics issues as a patient, consumer or citizen. When considering an advanced curriculum on top of the core curriculum, the question of relevance is also influenced by the ideas of the student about his or her future career.

Another reason not to include new content is when concepts and relationships are too complicated to understand, given the knowledge base of the students. This is again connected with the question of whether one has a core curriculum for all students in mind or an advanced curriculum for some. For example, understanding the use of bioinformatics may require too many new concepts and skills to be included in the core curriculum, but can be understandable by students with more science background. So from the student perspective of the triangle in Figure 1, the following questions arise:

- Question 5: Are genomics methods, concepts and issues sufficiently relevant to students in upper secondary education to make changes in the curriculum desirable?
- **Question 6:** Are genomics methods, concepts and issues understandable by students in upper secondary education?

#### The Why question: genomic literacy and the curriculum

The What question about the possible content of genomics education has now been elaborated. But curricula are not decided on content alone. In particular, when changes in the existing curricula are proposed, the arguments must be very strong to convince everyone that in the limited time available new topics should be included and even replace existing ones. So in this discussion, the question of why students should learn about genomics becomes important.

The combination in one curriculum of scientific literacy for all and pre-professional training for some is problematic (Millar & Osborne, 1998). Therefore, in several curricular models, these two goals are divided into separate curricula: a core curriculum for all students and an advanced curriculum for pre-professional training.

Roberts (1988) analysed the different justifications of science content in curricula and distinguished seven categories. Each category can be considered as an answer to the student question, 'Why are we learning this stuff?' Curricula can differ in their emphasis on one or more of these categories.

- 1. Everyday coping: content is needed for understanding and therefore controlling everyday objects and events.
- 2. Structure of science: content is needed to develop a conceptual system for explaining objects and events.
- 3. Science, technology and decisions: content is needed to inform decisions about societal issues.
- 4. Scientific skill development: content is needed to be able to participate in inquiry.
- 5. Correct explanations: content is needed to learn the truths of scientific knowledge.
- 6. Self as explainer: content is needed to understand how the development of ideas is influenced.
- 7. Solid foundation: content is needed to prepare for the next level of scientific knowledge.

The emphases on 'everyday coping' and 'science, technology and decisions' are in line with current ideas about citizenship education, in which the student is empowered to participate in decision-making about both his or her personal life and societal issues (Ryder, 2002; Levinson, 2003; Lewis & Leach, 2006).

When we apply these categories to a core curriculum for all and an advanced curriculum, we get a matrix for analysing the importance of genomics in science curricula, as shown in Table 1. Some elements of the table are left open to indicate that this function is not relevant for this kind of curriculum.

Table 1.	Legitimation of	genomics e	education in	the core	curriculum	and	advanced	curriculum
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Roberts' categories (Roberts, 1988)	What is the relative importance in science education <i>for all</i> ?	What is the relative importance in <i>advanced</i> science education?
Everyday coping	To learn to cope with personal issues influenced by genomics.	See core curriculum.
Structure of science	-	To develop genomics- informed conceptual systems in biology.
Science, technology and decisions	To learn to understand and participate in societal decisions influenced by genomics.	See core curriculum.
Scientific skill development	-	To develop genomics- informed inquiry skills.
Correct explanations	To develop a correct image of the genome and its relationships to use in personal and societal decision-making.	To develop a correct image of the genome and its relationships to understand how organisms function.
Self as explainer	To understand how scientific ideas about the genome are developed.	See core curriculum.
Solid foundation	-	To prepare for advanced studies in which genomics play a role.

It should be realized that students who follow the advanced curriculum also participate in the core curriculum. The questions in the matrix can be considered as subquestions of the following:

- **Question 7:** What is the importance of genomics education in the core curriculum?
- **Question 8:** What is the importance of genomics education in the advanced curriculum?

#### The How question: structures and strategies

The What and Why questions precede the How question. Not all curriculum documents contain information about how the proposed content can or should be learned, and often this is left to the teachers and the textbook writers. However, there are many principles to choose from, and many research data have been gathered about effective ways of teaching and learning. Many different curricula can be built around the same content, depending on the chosen teaching and learning strategy. Learning about genomics can, for example, be embedded in authentic practices, in which the genomics concepts are learned in contexts such as medical diagnosis (van Mil, 2007). Genomics can be treated as a specific topic in the curriculum, but another option is to include genomics in many different topics such as physiology, evolution and heredity. Genomics education could be embedded in a systems approach (Knippels, 2002;Verhoeff *et al.*, 2008). Several strategies can be used in the learning and teaching of concepts, skills, the nature of science, coping with uncertain information and moral reflection (Sadler & Zeidler, 2003).

This means that curricular decisions can be made about the structuring of genomics education, and about the learning and teaching strategies of different aspects of genomics. In short, two questions again arise:

- **Question 9:** How can genomics education be structured most effectively in science education?
- Question IO: How can genomics concepts and issues be learned and taught most effectively?

#### Changing the existing curriculum

In the end, many decisions about curriculum changes will depend on the existing curriculum and the existing practices in science education. Do the desired changes require adding new elements, replacing existing elements and/or a restructuring of the curriculum? How can the curriculum be adapted without increasing the conceptual load? Who will participate in the discourse about the curriculum?

Going back to the triangle in Figure 1: the science teacher is the one whose commitment is crucial to successful implementation of curricular change (Ben-Peretz, 1990). This means that teacher involvement not only includes updating knowledge and skills, but has to start early in the process of curricular discourse.

This brings us to the final questions in this article:

- **Question II:** How can the current curriculum be adapted without increasing curricular overload?
- **Question 12:** How can teachers and other stakeholders be involved in the adaptation of the curriculum?

#### Conclusions

Genomics is an important pillar of the life sciences in the 21st century. Sometimes, the media create a hype or false expectations. Curricular reform cannot be based on hypes. A thorough analysis is needed before curricular proposals can be made. This workshop aims to make a thoughtful step forward in science curriculum innovation by answering the questions put forward in this introductory paper.

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# Session A Why rethink science curricula?

## Leave the molecular stuff until university?

Andrew Moore

## Genomics and scientific literacy

Michiel van Eijck

## Discussion

### Conclusions

### Leave the molecular stuff until university?

#### Andrew Moore

Editor-in-Chief BioEssays, Wiley-Blackwell

The presentation title was inspired by a not uncommon question from secondary school teachers as to whether 'molecular stuff' cannot rather be left to university study. This is quite worrying, given the rapid advances in our understanding that result from the development of molecular techniques, their application to disease diagnosis, research and therapy, and the (potential) impact that these have on society. The starting thought of this presentation was therefore that, although genomics might change many things, a key problem in science education continues to be the pedagogy. The way in which science is taught determines whether science teaching is successful.

In addition to this observation, in 2007, the European Molecular Biology Organization (EMBO) conducted an informal survey asking how well certain aspects of science, such as genomics, are represented in the curriculum. The results showed that the principles of bioinformatics are almost absent and that molecular evolution (phylogeny) is covered in at most 30% of all secondary curricula. However, the UK did embed the latter recently in the curriculum. As for the principles of molecular medicine, only one in seven countries explain such approaches to disease study and treatment.

Let us give some examples of molecular medicine and molecular evolution. Gleevec, often called the leukaemia pill, is a drug designed to avoid the severe side-effects of chemotherapy. With the use of molecular genetics, the Bcr-Abl homodimer was identified, which is continuously active and activates a cascade of cell-cycle proteins leading to uncontrolled proliferation and thus cancer. Gleevec, pioneered by Brian Druker, is a chemical agent that selectively inhibits the kinase activity of BCR-Abl (BCR-Abl is a specific chromosomal abnormality that is associated with chronic myelogenous leukemia (CML). It is the result of a reciprocal translocation between chromosomes 9 and 22). Another example lies within the field of pharmacogenomics. This field uses genotyping to correctly prescribe medicines and develop patient group-specific drugs. In the USA, annually over 100,000 deaths occur due to adverse reactions to FDA-approved drugs. Individual differences in liver detoxification enzymes are an important factor in toxicity and efficacy in many drugs. The cytochrome P450 genotyping test has been developed to determine whether patients have a mutation in their CYP450 2D6 gene affecting

their ability to metabolize certain groups of drugs. A last example of molecular medicine refers to the genotyping of mosquitoes to enable an understanding of the genetic origins of differential resistance to the malarial parasite. By genotyping individuals in African populations, molecular genetic variations in the ABO blood alleles were found, providing the opportunity to identify people at much greater risk of severe infection with *Plasmodium falciparum*. Knowing the *P. falciparum* genome sequence significantly accelerates the search for new targets for therapeutics, and antigens for vaccine development.

The field of molecular evolution has had a major influence on the classification of primitive kingdoms and other phylogenies. The primitive kingdoms of life – namely bacteria, archaea and eukarya – were reclassified when, instead of the traditional comparison of intracellular architecture and cell-wall structure, a molecular comparison of the 16S rRNA gene sequences was used. A new DNA sequence-based animal phylogeny was also made, differing greatly from the original phylogeny, which was based on morphology and embryology.

Gene sequence comparison does not necessarily give an unequivocally correct phylogeny (it has its problems too), but it has often proved extremely useful, or even decisive, when combined with other phylogenetic approaches (e.g. fossil records and comparative anatomy). Lastly, evolutionary genomics provides us with the opportunity to compare genomes among species, leading to the knowledge that there is only a 1.7% and 1.2% difference between the DNA of humans and gorillas, and humans and chimpanzees, respectively.

The above examples demonstrate the importance of mathematics to modern biology: many of the above results would not have been obtained without the aid of maths. Nowadays, there is much data involved in producing insights into and understanding of biological fields such as bioinformatics, genomics, proteomics, metabolomics and transcriptomics. For example, systems biology is becoming increasingly popular as a way of understanding large data sets for complex systems, and of understanding the behaviour of these systems and predicting the kind of components that constitute them. Mathematics, however, is not currently incorporated enough in biology education. This statement is supported by the following two quotes (from presentations at the EMBL/EMBO joint conference on Science & Society, 3–4 November 2008):

We need much better training of biologists in mathematical tools. Otherwise, we will end up leaving biology to engineers. Biology is too important to leave it to engineers. Biology is seen by people as a way of doing science without doing mathematics...and maths is used as way of 'sorting out' the ones who can't deal with the more numerical aspects of biology...

Marvin Cassman, former head of the California Institute for Quantitative Biosciences (QB<sub>3</sub>).

Computational methods give us biological knowledge on individual components and interactions, but we need better mathematical models to integrate this and produce real understanding of the system...

Uwe Sauer, Swiss Federal Institute of Technology, Zürich.

The above citations also refer to the following problem of systems biology. There are around 25,000 genes in the human genome, coding for over 100,000 proteins. We know the function of a very small proportion of genes and proteins. However, most biological functions depend on a multitude of interacting genes and proteins. Even supercomputers, which have helped generate all the data, cannot solve the problem of interpreting it, as they cannot calculate all the possible functions in a time-scale relevant to human life spans. For example, if you assume that there are 100 genes involved per function  $(10^{289} \text{ possibilities})$ , the fastest computer would currently take  $10^{282}$  seconds to test all possibilities. Considering that the age of the universe is about  $4.3 \times 10^{17}$  seconds, it is clear that we need bright human minds to develop hypotheses and models in order to reduce the number of possibilities to test.

Many recent reports comment on the need for new pedagogy in science education that fosters critical, independent, imaginative and creative thinking, and educates students to ask good scientific questions and understand what doing science means. Students, especially if planning to go into tertiary study of science, need to be resourceful and independent and to have the ability and curiosity to investigate scientific topics. There needs to be less attention on learning mere facts, and more attention on these skills in the science curriculum. However, in the process of organizing a stakeholder forum for curricular change, EMBO found out that it is very hard to identify and engage the people in the ministries who actually make the decisions and write the new curricula. If it is possible to change a curriculum to get new material into it, this is the 'easy' solution. However, it is virtually impossible to change a curriculum to get all the new material into it (there will be small wars in the process). Besides, the curriculum is only part of the picture. The harder but more effective solution is to train and equip teachers better – to provide in-service training for all and implement assessments that test whether new concepts and skills are being taught effectively. Finally, as with the view from systems biology, the division between the hardware and software of the system is necessarily blurred: teachers are the hardware and the curriculum is the software. But the hardware must, itself, be capable of independent response/adaptation to circumstances as well as 'reprogramming'.

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The following are reports that note the need for an overhaul of science education pedagogy:

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- *New Biology for New Curricula*. Report on representation of molecular genetics and genomics (and related disciplines) in European secondary education systems. EMBO. http://www.embo.org/documents/teachers\_wko7report.pdf
- Science Education in Europe: Critical Reflections. A consultation report
  from the Nuffield Foundation and Kings College London. http://www.
  nuffieldfoundation.org/fileLibrary/pdf/Sci\_Ed\_in\_Europe\_Report\_Final.pdf
- Science Education Now: A New Pedagogy for the Future of Europe. European Commission. http://eesc.europa.eu/lisbon\_strategy/backgroundsdocs/ RapportRocardFinal.pdf.

### Genomics and scientific literacy

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Scientific literacy, which citizens require in a scientifically sophisticated society, entails many aspects, such as understanding science as a process (Dehart Hurd, 1998). Genomics itself is a highly dynamic process in science and is large scale, reflexive, transdisciplinary and heterogeneous. Understanding the term 'genomics literacy' thus means we need to find out which definition of scientific literacy appropriates understanding sciences such as genomics as a dynamic process.

Figure 2 shows a common model of the dynamics of science. This model is grounded in the actor-network theory (ANT), a theory that resulted from attempts to reveal the dynamics of the infrastructure that constitutes the often-static accounts of scientific and technological achievements (Latour, 1987; Callon, 1991). It provides tools to understand how science is kept alive and how it develops dynamically over time.

The model departs from the notion that a science is the result of a set of interconnected dynamic loops or flows. The first loop corresponds to instruments that scientists use to bring the 'outside' world in their laboratories, such as a DNA sequencers and DNAchips. Every science needs its instruments to stay alive. The second loop represents autonomization, that is, the way in which a discipline maintains itself as an independent science. This loop includes the institutionalizing of scientific enterprises and the inherent formation of what are called 'epistemic cultures' (Knorr Cetina, 1999). An exemplary institution for the science of genomics is the academic journal *Genomics*, which is entirely devoted to the discipline. The third loop symbolizes the alliances that have an interest in the discipline, such as medicine and industry in the case of genomics. The fourth loop stands for public representation: terms such as 'DNA' enter the public domain through the media, and once they do, it is easier for scientists to explain their work. The central and fifth loop encompasses the links and knots that hold together the other four flows. These signify the basic concepts and the disciplinary formal knowledge of a scientific discipline. However, according to ANT, they are not things that can be 'contained' by individuals. Rather, they should be seen as containers for the other loops that are as such interconnected and dependent on each other - if one of the knots gets loosened, the whole system falls apart and no longer exists. Textbooks usually focus on the core loop,



Figure 2. The dynamics of science (after Latour, 1999).

the basic concepts of a science. However, in understanding the dynamics of a science, we need to move away from thinking in concepts only, as this makes the link between the different aspects of science unclear.

Nevertheless, thinking of a science in terms of concepts and formal knowledge is rather common with regard to definitions of scientific literacy. Take, for instance, the following definition of scientific literacy:

Science classes should give students the knowledge and skills that are useful in the world of work and that will enhance their long term employment prospects in a world where science and technology play such a large role. DeBoer (2000, p. 592).

Although this definition of scientific literacy illustrates an honourable aim of science education, it focuses mainly on knowledge as the aim of science education, rather than the process of becoming scientifically literate. Moreover, by referring to scientific knowledge mainly as something to be 'contained' by individuals, it does not appropriate the dynamics of science. In addition to such definitions in terms of aims, other definitions attempt to illustrate scientific literacy in discursively associated terms like knowing and learning:

People have to construct their own meaning regardless of how clearly teachers or books tell them things. Mostly, a person does this by connecting new information and concepts to what he or she already believes. *Rutherford & Ahlgren (1989, p. 198)*.

Here, scientific literacy is rooted in a constructivist notion of knowledge and students need to be engaged more actively in constructing scientific knowledge. Again, this is an honourable aim. But none the less, even in this definition, there is still a focus on formal scientific concepts as things to be 'contained' by individuals, which does not appropriate the dynamics of science.

In response to the above two types of definition of scientific literacy, we can rethink scientific literacy in terms of practices rather than formal scientific knowledge. This rethinking informed a research project in the discipline of environmental education (van Eijck & Roth, 2007). The project centred on a polluted creek, as a result of which students were not allowed to swim in a nearby pond. In collaboration with teachers, a curriculum on water sheds, pollution and environmental issues was designed without prior established goals in terms of formal scientific knowledge. In the unfolding curriculum, teachers, environmentalists and other community members were brought together with students who could set their own goals and choose their own instruments. The module turned out to be highly successful. The students were not only doing science in a lab and learning about it as a concept, but they also discovered that science can be made public and relevant for the community. As one of the students said:

I worked very hard on the map and proceedings. During this course I learned about fieldwork: I learned how to collect samples of the creek and take temperatures and speed. I also did some work with the community. [This unit] taught me about working with others and working in the community. I noticed that ever since our Henderson Creek article was published in the *Peninsula News Review* that the public has begun to notice the creek.

van Eijck & Roth (2007, p. 2768).

This example from environmental education has led us to define scientific literacy as an emergent feature of collective human activity. In such a definition, scientific literacy is practice-focused and concerns useful scientific knowledge that is collective and distributed over activity. More so, knowledge is understood in terms of a dynamic process in which concepts are related to the public, allies and instruments.

To conclude, scientific literacy can be defined in terms of the aims of science education, as individually constructed knowledge or as an emergent feature of collective human activity. However, so far, only the latter definition has allowed us to appropriate understanding science as a dynamic process. In regard to genomics education, this implies that scientific literacy is inherent to activities in which students engage. At a minimal level, such activities should bear some family resemblance to scientific activities. However, recent research on authentic practices in school science have revealed that the problem of fostering scientific literacy does not lie with the level of agreement between school science and laboratory science, but with the levels of control, authority, mastery and authorship that students are enabled to exercise and by which they are allowed to co-determine how such activities unfold over time (Roth et al., 2008). Thus, even experiences in highly sophisticated DNA laboratory settings may deprive students of scientific authenticity, while less sophisticated classroom-based science may provide opportunities for doing science in an authentic manner, that is, with high levels of control over the learning environment, authority, master and authorship. This is a major challenge, but one that is essential to allow scientific literacy to emerge during genomics education.

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### Discussion

The discussion in this session concentrated on authentic learning, defined in three different ways:

- 1. Learning concepts in a situation in which they are relevant and useful for the practices that follow.
- 2. Acquiring scientific method: how do scientists think and how do they obtain their data?
- 3. Discussing problems that are meaningful to students.

#### Which knowledge is necessary?

Andrew Moore first compared molecular topics with astrophysics, stating that students cannot understand the big picture unless they know a bit about the fundamentals. However, there is a difference between understanding things and appreciating them. For instance, students may not fully understand the concept of a single-nucleotide base difference, but they can appreciate the influence it has on someone's life. To him, it is about appreciating, rather than understanding the details.

Michiel van Eijck mentioned that it depends on the practices you want to engage students in. Bring the students into a situation where concepts are relevant and useful for these practices. This also applies to the molecular topics; there must be a need to start talking about molecules. Andrew added that it is important for people to know about things such as single-nucleotide differences, because they are important for their healthcare. They need to understand that we are all genetically different and the possible influences this may have.

#### Should students learn how knowledge is achieved in science?

Anat Yarden mentioned that she sees authenticity as acquiring scientific method: how do scientists think and how do they obtain their data? Find topics that are of interest to students and let them practise the way of scientists. Bring authenticity into the schools. Let them solve authentic problems such as scientists are doing. In bioinformatics, students can choose their own tools and path, when they know the methods and the databases are available.
Anat also reacted to Andrew Moore's remark that students do not necessarily need to know the methods of science. How will they understand how science actually works if they do not have this knowledge? Andrew responded that he was talking about the technical methods of science, not about the approach of scientists to obtaining data. In the EMBO workshops, they aim to bring teachers and scientists together. A presentation last year demonstrated two classroom experiments. One was about collecting data and doing so correctly. The other was about a real problem, which, according to Andrew, is a clever approach.

Ralph Levinson appreciated Michiel van Eijck's talk about producing knowledge rather than consuming and using it. However, he would argue that there is a whole methodology about how science operates, and there is a distinct difference between how scientists are involved with science compared with the general public. Therefore, it is problematic tying these two together. Science is also deeply political, so how does one actually convey this to students? Ralph perceived a huge problem there.

Michiel discussed why you should let students understand the scientific process. He stated that if you think in terms of concepts only, students learn 'scientist' science. If you focus on the process, on the other hand, they may ultimately learn their own 'student' science. No one will become scientifically literate if you teach them 'scientist' science, because only scientists think 'scientist' science.

Andrew continued by saying that we do not want to scare people away with the maths, and that maybe we should separate students into those who are more interested in science and mathematics and those who are more interested in societal science in the curriculum. Ralph mentioned that this separation has disadvantages. Scientists also have to be citizens; they need to be deeply sensitive to the societal aspects and issues of their work.

#### Present problems or provide tools?

Klaas van Hees raised the question of whether we should present science problems to the students or let them find their own problems. He gave an example of a DNA laboratory about bioinformatics in which the story of a murder by poison was used. The students in his class could not identify with the given problem, but liked the fact that they were given tools and could use them to answer their own problems. They liked comparing gene sequences and the methods they learned that could be used to do so.

Arend Jan Waarlo mentioned that students' interest depends very much on the context and the way you introduce the problem. The narrative introduction of an authentic issue is very important. For instance, the makers of the 'It's in the genes' educational video spent much time talking to people who had to decide on genetic testing and their findings informed the docudrama. The video evokes empathetic involvement and is helpful in grasping what is at stake.

Andrew Moore mentioned that he sees the students through the eyes of the teachers. He noticed that there is a big difference between what interests the teachers and what interests the students. This does not mean that we should only pay attention to what interests the students; they do need to become part of a larger community.

## Conclusions

The conclusions reached were as follows:

- Important advances in molecular medicine and molecular evolution are not yet represented in most science curricula.
- Systems biology cannot be studied without mathematics.
- Training teachers could be more effective than finding and engaging government officials who make decisions about curricula.
- Scientific literacy can be defined as individual knowledge or as an emergent feature of collective human activity. The latter definition means understanding science as a dynamic process.
- Fostering scientific literacy depends more on the levels of control, authority, mastery and authorship by students than on sophisticated DNA laboratory settings.

Authentic learning can be defined in different ways:

- 1. Learning concepts in a situation in which they are relevant and useful for the practices that follow.
  - The selection of conceptual knowledge should be based on the need for this knowledge in certain practices.
  - Discussing real problems is a part of science education for citizenship. Scientists also have to be citizens; they need to be deeply sensitive to the societal aspects and issues of their work.
- 2. Acquiring scientific method: how do scientists think and how do they obtain their data?
  - There is a whole methodology about how science operates, and there is a distinct difference between how scientists are involved with science compared with the public's involvement. Therefore, it is problematic tying these two together.
  - How much detail is needed to appreciate the approach of scientists towards obtaining data?
  - Science is also deeply political; how does one convey this to students?
  - Current genomics practice uses a lot of maths, and this could scare students away.
  - Genomics practice offers chances: access to databanks with genomic information offers an opportunity to students to work with the same data as scientists do.

- 3. Discussing problems that are meaningful to students.
  - An important question is whether we should select science problems for the students or let them find their own problems. There is a big difference between what interests the teachers and what interests the students. Finding suitable problems is of special importance in designing narratives to introduce issues to students.
  - An argument for authenticity can be that the student experiences more ownership. If you think in terms of concepts only, students learn 'scientist' science. If you focus on process, on the other hand, they may ultimately learn their own 'student' science.

# Session B What discriminates genomics from genetics?

## Genetics, genomics and the curriculum

Jenny Lewis

## Genomics and biology education: complex stuff and curricular overload

**Roald Verhoeff** 

## Discussion

Conclusions

## Genetics, genomics and the curriculum

#### Jenny Lewis

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The distinction between genomics and genetics is not clear cut. The polygenic, multifactorial nature of genetics is well established, even though it is rarely addressed within the traditional school curriculum, and at one level the outcome of genome sequencing can be seen as an extension of this awareness, providing the data to inform our developing understanding of the nature of this complexity. The thing that is distinctive about genomics is the extent to which this new knowledge changes the emphasis from single-gene characteristics to multiple effects and interactions, and the implications of this change in emphasis – both for science and for society.

The possible implications of these changes for the school curriculum will be considered by looking at the current situation in England. In particular, the potential for an increased emphasis on genomics and related societal issues will be explored, taking account of the problems this might raise in relation to curriculum content, pedagogy and teacher development.

#### Curriculum content

In England, in the lower secondary school (age 11–16), all students study core science (a 'science for all' curriculum) and those who wish to can take additional science modules or courses. In the core curriculum (Department of Education and Science, 2004), genetics content relates both to content knowledge and to applications of that knowledge. There is also an expectation that, in teaching this genetics content, the 'How Science Works' element of the curriculum, including implications of that knowledge, will be addressed (see Table 2).

There is no requirement for students to study science at upper secondary school. Students following the traditional route choose four or five subjects to study in their first year (leading to an AS qualification) and in preparation for university entrance reduce these to three specialist subjects in their second year (leading to a full A level qualification). Many students opt to study biology in the first (AS) year, even when they have no interest in

**Table 2.** Genetics content in the core curriculum (lower secondary school). KS3: key stage 3:11–14 year-olds; KS4: key stage 4: 14–16 year-olds

#### Content knowledge

- Basic knowledge of DNA, genes and cell processes
- Single gene inheritance including single gene disorders
- Variation and its causes genetic and environmental

#### Applications of that knowledge

- Genetic engineering
- Cloning

#### Implications of that knowledge ('How Science Works')

- How the creative application of scientific ideas can result in technological developments and changes in the way that people think and behave (KS3 1.2a)
- The use of contemporary scientific and technological developments (benefits, drawbacks and risks) (KS4 4a)
- How and why decisions about science and technology are made (ethical issues; social, economic and environmental consequences) (KS4 4b)
- There are some questions that science cannot answer/address (KS4 1d)

specializing in science in their second year, because it is considered good to demonstrate a breadth of knowledge at AS level. Students who do not wish to follow the traditional route have a wide range of vocational options, some of which include biology, but these are too diverse to consider here.

Since at least 2000, genetics in the specialist biology curriculum has included gene technology and related issues, but in most cases this has been set in the context of single-gene disorders and characteristics. In September 2008, a revised upper secondary curriculum was implemented. Within the new specialist biology curriculum, the content is still focused on 'traditional' genetics, but this is beginning to change. For example, content may now include less traditional topics such as totipotency, small interfering RNA (siRNA), epigenetics, the human genome, comparison of genomes, regulatory genes and apoptosis. There is a strong emphasis on gene technology, mostly focused on developing an understanding of basic techniques such as gene sequencing, genetic engineering, the polymerase chain reaction (PCR), gene therapy and genetic testing, and a consideration of societal implications. The context for this is usually a single-gene characteristic or disorder, but it may also include a more complex example such as genetic engineering for xenotransplantation.

A major change to this new upper secondary biology curriculum has been the introduction of 'How Science Works'. This is intended to provide continuity with the lower secondary core curriculum with the expectation that, as in the core curriculum, these ideas about science are integrated into the biology curriculum and developed through appropriate contexts. Elements of the 'How Science Works' strand that may be relevant to the genetics/genomics context include (AQA, 2008; OCR, 2007a, b; Edexcel, 2007a, b):

- Explaining how scientific theories are supported, refined or refuted as new data/ interpretations become available
- Appreciating the tentative nature of (some) scientific knowledge
- Evaluating activities in terms of applications, implications, benefits and risks of science
- Identifying ethical issues that arise from applications of science
- Discussing scientific solutions from a range of ethical viewpoints
- Appreciating the ways in which science is used to inform decision-making.

#### The potential to include genomics

In considering the potential to include genomics (the science and/or the social implications) within the English secondary science curriculum, two questions need to be addressed. These relate to purpose and justification: why might we want to include genomics and can this purpose be justified within the school science curriculum? Two main purposes – the development of science specialists and engagement with social issues related to genomics – will be considered.

Genomics is the basis of all biological processes, so if the purpose is to develop specialist biology students, then it would seem essential, at some point, to provide these biology specialists with some teaching about genomics. The question then becomes: how much (what) knowledge is needed, and when? We do not know the answer to this at present, but it might be suggested that sufficient knowledge is needed to develop some coherent understanding of basic principles at upper secondary level that could be applied or developed as required at degree level. The specialist biology curriculum in England does now provide some space for teaching about genomics at upper secondary level, and although the current selection of content appears to be fragmented and arbitrary, there is clearly potential to use this curriculum space to develop a basic but coherent understanding of genomics. It is difficult to know if this will be sufficient space. If not, there will be difficult decisions to make (and justify) relating to the selection of content. There is very limited potential to teach about genomics in the core (lower secondary) science curriculum, and if preparation of biology specialists is the main purpose for such teaching, it is difficult to see what the justification for inclusion (and potential exclusion of some other topics) would be.

If the purpose is to prepare young people for future engagement with social issues relating to the use of genomics – whether as scientists or citizens – then clearly whatever teaching is provided needs to reach all students, not just specialist biologists. In this case, the question becomes: what is it that needs to be taught and where? In England, there has been extensive discussion of the place of socio-scientific issues within the school curriculum, often linked to arguments about the need for a 'science for all' curriculum (Millar, 1996; Jenkins, 1999; Millar & Osborne, 1998; Levinson & Turner, 2001; Donnelly, 2004, 2005; Osborne, 2005). Arguments have related to:

- The extent to which it is possible to prepare young people for such future eventualities
- The extent to which any knowledge of science is required for a consideration of such issues
- The appropriateness of including social issues within a science curriculum
- The capacity of science teachers to address such issues
- The capacity of lower secondary students to engage in reasoned discussion of such issues.

Research (Lewis & Leach, 2006) shows that young people aged 14–16 can engage in reasoned discussion of such issues and that, although they rarely draw on the science to support their arguments, some basic knowledge of the science is essential if they are to engage in reasoned discussion in the first place. Although the amount of knowledge that was needed seemed to be quite limited, relating to an understanding of basic concepts relevant to the particular context, misunderstanding of this basic knowledge could make it difficult for students to recognize key issues. Humanities teachers, with limited knowledge of science or how to teach it, are unlikely to be able to explain the basic science content or to recognize the science-related issues that may be important. In addition, a view of science as a body of uncontested facts sometimes made it difficult for students to argue about social issues in a science context in the way that they might in some other contexts. – they need more experience of questioning ideas and evidence within a science context.

For these reasons, it could be said that, if the purpose of including genomics in the school curriculum is to prepare young people for future engagement with related social issues, then at least some of this teaching must take place in the science classroom and must include the development of some basic understanding of genomics. In England, this would mean inclusion of genomics within the lower secondary core science curriculum. While the 'How Science Works' element of this curriculum provides potential for such discussions, it is not clear what understanding of genomics would be needed or where/ how this might be developed. Establishing this would require research similar to that already carried out for more traditional genetics. Given the complexity of genomics, this research would also need to establish the extent to which students of this age are capable of developing this knowledge (this is likely to depend, in part, on how such knowledge is taught).

In summary, although it is clear that a justification for the inclusion of genomics within the secondary school curriculum can be made, and that there is some potential for inclusion of genomics within the existing curriculum (both lower and upper), inclusion raises a number of issues relating to content:

- What knowledge of genomics is needed for engagement with socio-scientific issues relating to genomics and will it be accessible to students aged 14–16?
- Is it possible to define a basic but coherent conceptual framework for genomics that could be extended as needed in the future, and would students in either age group be able to develop this?
- What additional knowledge and skills may be needed (for example, skills of argument within a science context)?
- How can space be made for additional content within the existing curriculum? For example, could we justify taking the 'kidney' out and putting 'genomics' in its place?

# Other considerations (supporting the inclusion of genomics within the curriculum)

Adjusting any curriculum leads to issues of pedagogy (how to achieve the intended teaching goals, within a changing context) and practice (the extent to which the intended changes are implemented in the classroom). For genomics, in England, the impact in the classroom (the extent to which these new components of the curriculum are actually

addressed in the classroom) and the outcomes (the effectiveness of the teaching and resulting learning gains) are not yet known – there is no relevant research data and the first exams have not yet taken place.

Genomics is a completely new topic for most science teachers and requires them to change, quite fundamentally, the way they have traditionally thought about genetics. If they are to teach genomics effectively, they will first need to develop their own understandings – of the science; of the curriculum expectations (the purpose of the teaching and where it fits within the broader curriculum); of the potential difficulties and barriers to learning that their students will experience; and of the teaching approaches that can help students to overcome these difficulties. In short, they will need to develop new 'pedagogical content knowledge' (van Driel, 1998). This applies to their teaching of the science, but also to the consideration of resulting societal issues – an area of the science curriculum that many science teachers find particularly challenging (Levinson & Turner, 2001). Previous research on the implementation of an innovative biology curriculum for upper secondary level (Lewis, 2006) suggests that until teachers have developed this knowledge they are reluctant to make the intended changes to practice, and that developing this knowledge (and the confidence that goes with it) takes time.

Other factors can also affect the extent to which teachers will change their usual practices. Currently (at least in England), most teaching is driven by assessment. The new curriculum provides opportunities to consider the societal implications of genomics through the 'How Science Works' strand and provides some specific contexts in which such considerations could take place, but assessment of 'How Science Works' seems to focus almost exclusively on data collection and interpretation. This provides teachers with little guidance on the purpose (intended learning outcomes), making it difficult for them to decide on an appropriate teaching approach or to evaluate the effectiveness of the resulting teaching/learning, and little incentive to try. Teachers' personal attitudes and beliefs also play a part. If they view science as a body of (mainly) uncontested facts, they may believe that consideration of societal issues, where there are no definite right or wrong answers, is inappropriate within the science classroom. They may also struggle with the uncertainty and complexity of our developing understanding of genomics. The extent to which genomics and related societal issues are taught by a biology specialist (who may be expected to have some understanding of the complexity of biological systems), rather than a general or other science specialist, might have some impact on this. Students also have an impact on how teachers work in the classroom, and they will also

need to develop their understanding of how science works if they are to engage with the uncertainty and complexity of genomics.

#### Conclusions

In summary, there is a sound justification for including genomics within the school science curriculum. If the purpose is to prepare students for engagement with societal issues relating to genomics, then in England it would need to be included in the science curriculum at lower secondary level. This might present some problems in relation to the science content that would need to be taught and the capacity of students at this level to understand the relevant content. It would be very helpful to have some research data on this – similar to the data that already exists for more traditional aspects of genetics – that would allow us to identify the key ideas that students need at this level. If the purpose is to prepare specialist science students for future work as biologists, then there is a need to define a core conceptual framework for genomics that is basic and coherent, which is accessible to biology specialists at upper secondary level and provides a sound basis for further development as the need arises.

If genomics is integrated into the school curriculum, there will be a need for some teacher development to support this, particularly in relation to subject knowledge, pedagogy and pedagogical content knowledge. It will also need to be reflected in the assessment regime.

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## Genomics and biology education: complex stuff and curricular overload

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Over the last four decades, researchers have made much progress in acquiring insight into the genetic background of cancer. Research has shifted from traditional (clinical) genetics research, typified by the hunt for genes that cause monogenic diseases, to multidisciplinary genomics research. Nowadays, it is realized that cancer is the result of a mismatch in complex cellular signalling networks involving large numbers of genes and proteins. To determine risks, prognosis and therapies for cancer patients, single biomarker tests have been replaced by characterization of tumours by several biomarkers (DNA, RNA, proteins). The first steps towards more individual diagnosis and treatment of cancer patients have also been taken, such as Herceptin and Glyvec (see for example Strausberg *et al.*, 2004), based on molecular markers, e.g. using microarrays. In short, cancer researchers and physicians have moved from concentrating on the organ of the primary tumour to focusing on biomarkers that reflect the underlying cellular processes.

Another change in genomics research is the attention paid to the relationship between science and society. Since the announcement of James Watson that the Human Genome Project would devote a significant amount of its funding to the ELSI (Ethical, Legal and Social Implications) Research Program of the full human genome sequence, many research programmes and technological advances have been accompanied by studies of their potential ethical, legal and social impact (Kitcher, 2001).

But which of these trends in genomics should be included in new educational materials? Interviews with cancer genomics professionals (n = 6) suggest the following list of learning goals:

- Students should:
  - 1. Have a fundamental knowledge of genetics
  - 2. Be aware of future developments, such as the \$1000 personal genome
  - 3. Comprehend the nature of science, including understanding:

- The time span between laboratory and clinic
- Dealing with uncertainty in science (and society)
- Complexity and multifactoriality of diseases
- Risk assessment and perception.

Fundamental knowledge of genetics refers mainly to a basic conceptual understanding of DNA, RNA, the process of protein synthesis, i.e. transcription and translation, and the relationship of these cellular processes with phenomena at higher levels of biological organization. In addition, awareness of future societal implications and understanding the way science works are important learning goals for secondary students. Genomics studies the relationship between large networks of genes and/or gene products, and the behaviour of complex systems at higher levels of organization, e.g. metabolic pathways, cellular responses, development, etc. Genomics professionals regard it as important for future citizens and scientists to be aware of the complexity of these systems, including the notion that simple cause–effect relationships in disease development are the exception. This evidently has consequences for cancer risk prediction and the development of (individual) treatments.

The learning goals described by genomics professionals indicate that genomics education should prepare students for different communities of practice and different roles. Genomics education should empower students for individual decision-making in their personal lives and also for partaking in societal decision-making. Some students will be the scientists and doctors of tomorrow, so students should also be prepared for future professions in science or medicine.

Five genomics centres of excellence in the Netherlands have jointly developed a series of mobile DNA practicals that can be taken to secondary schools to give students a realistic impression of genomics research and the implications for society. These so-called DNA laboratories are offered free of charge to all Dutch upper secondary schools, and each laboratory focuses on a different field of genomics research. The DNA laboratory that focuses on cancer genomics is called 'Tumour Talk' (see also van Mil, 2007; and www. cancergenomics.nl – Societal Aspects). The practical takes two lessons and the teacher is expected to give an introductory and a concluding lesson, resulting in four lessons in total. Students learn how cancer can be diagnosed and how treatment may be tailored to the genetic make-up of a certain tumour (personalized medicine). The hands-on experiments of students consist of DNA isolation, copying DNA in a small portable PCR apparatus and running it on an agarose gel. Students then search for mutations in

three different genes and have to choose an adequate therapy. For example, a mutation in the HER2NEU gene means that administration of Herceptin is an adequate therapy. The intended learning outcomes of the various DNA laboratory topics include the 'learning goals' put forward by genomics experts, with particular focus on preparing students as future citizens, i.e. consumers of genomics information taking personal decisions and critical democratic citizens participating in societal decisions:

- Realistic views on science and technology
- Viewing knowledge as tentative
- Willingness to seek more information
- Critical reflection
- Gaining insight into their own and other people's values
- Substantiation of their own position
- Preparation for any future decisions: opinion-forming competence.

Overall evaluation of the five DNA laboratories has revealed that they are successful in terms of reach and user satisfaction (Knippels *et al.*, 2006). Teachers and students were enthusiastic and expressed a positive attitude towards genomics research. The success of the initiative is most obviously reflected in the number of schools that have visited the website and have ordered the DNA laboratory 'Tumor Talk'. Since September 2005, 'Tumor Talk' has been fully booked and more than 17,000 students in 700 classes have been involved. However, the perceived learning outcomes were modest; students commented that they were able to grasp the how and why of genomics research, but seem to learn little about the functioning of and relationship between DNA, genes, proteins and phenomena at higher levels of organization. In addition, the initiative's aim to encourage the formation of opinions about genomics research, as well as to stimulate the discussion of societal issues in the classroom, has not yet been achieved.

These findings were the reason for a revision of the DNA laboratories programme directed at enhancing students' insight into the complexity of cellular interrelations, and at fostering each student's competence to deal with genomics-related socio-scientific issues. An additional challenge is to embed the DNA laboratories in the existing biology curriculum, i.e. institutionalizing genomics education, without adding to the problem of curricular overload. For both challenges, the adoption of 'systems thinking' in upper secondary school biology education might be an important step towards a solution.

Systems thinking is linked with but not identical to systems biology. The latter focuses on the systematic study of complex and dynamic interactions in biological systems. Genomics contributes to this relatively new field of biology. In genomics, molecular technologies and bioinformatics are integrated to understand and predict complex cellular functions in relation to phenomena at higher levels of organization, e.g. concerning health and disease, agro-food and sustainability.

A survey of 22 countries indicated that systems biology is not explicitly mentioned in any science curricula in Europe (Moore, 2007); in addition, the principles of bioinformatics – an important discipline within genomics – are mentioned in very few. However, the exclusion of systems biology is not a unique oversight; the introduction of new scientific concepts and techniques into science education is hampered in general by the problem of curricular overload. Current European biology curricula cover many themes in a descriptive manner, each of which brings a large number of new concepts used at various levels of biological organization. In the Netherlands, for example, an average school textbook introduces no less than 577 new concepts related to cell biology alone, which illustrates that the curriculum is extremely heavy on factual content.

To investigate the extent of this information overload, the contents of two Dutch textbooks entitled 'Biologie voor jou' ('Biology for you') were analysed. These textbooks are used to teach pre-university biology by approximately 40% of biology teachers (Smits & Waas, 2000). The first chapter introduces biology as an empirical discipline and explains the structural organization of organisms in terms of organs, tissues and cells. In addition, the submicroscopic structure of plant and animal cells is elaborated in detail. Subsequent chapters focus on topics such as reproduction and development, genetics, DNA, homeostasis, behaviour and the immune system. As a focus for our analysis, the topic of cell biology was selected and all cell biological concepts – concepts connected to the theme of 'the cell' – were classified according to three main categories representing the molecular, cellular and organism levels (Verhoeff, 2003). Each new cell biology concept mentioned for the first time in the text or in the legends of figures was scored and checked for whether it was simply mentioned or whether it was also explained to the reader in terms of his or her prior knowledge.

Table 3 presents the results of this analysis. At the molecular level, the concepts presented in the textbooks covered topics including chemical compounds, chemical reactions – such as phosphorylation and polymerization – and molecular characteristics such as fat

Categories of cell biological concepts ( <i>n</i> = 544)	Number of new concepts	Concepts coupled with explanation (%)	Concepts used after introduction and explanation (%)
Molecular level (e.g. compounds, chemical reactions, characteristics)	141	70	9
Cellular level (e.g. substances, processes, structures, functions, cell types	357	77	19
Organism level (e.g. processes, structures, characteristics)	79	61	14

**Table 3.** Introduction and use of biological concepts related to the topic of 'cell biology' in Dutch schoolbooks entitled 'Biologie voor jou', classified by level of biological organization

solubility and oxidation. At the cellular level, the concepts ranged from substances – hormones and nutrients, for example – to processes such as diffusion or active transport, as well as cellular structures and their functions. At the organism level, the concepts related to bodily processes, structures – both organs and artificial replacements – and organism characteristics within the context of cell biology such as phenotypes, zygosity and trophism.

Professional biologists like biology teachers and genomics researchers often implicitly link certain concepts or phenomena to a specific level of organization and have acquired a coherent understanding of biological processes. Secondary students do not do this, i.e. many problems with acquiring a coherent understanding of cell biology can be typified as difficulties in interrelating different concepts at the cellular level, and interrelating concepts at the cellular and organism level (Verhoeff *et al.*, 2008). To cope with these difficulties, a learning and teaching strategy that features the intentional use of systems thinking was developed (Verhoeff, 2003; Verhoeff *et al.*, 2008). This means that systems thinking is considered not only as a tool for developing coherent biological knowledge, but also constitutes a desired learning outcome of the strategy. The main outcomes referring to systems thinking competence are outlined in Table 4. **Table 4.** Four elements of a systems thinking competence to be acquired in biology education (Verhoeff *et al.*, 2008)

- 1. Being able to distinguish between the various levels of biological organization, i.e. cell, organ and organism, and to match biological concepts with specific levels of biological organization.
- **2.** Being able to interrelate concepts at a specific level of organization (horizontal coherence).
- 3. Being able to link biology concepts from different levels of organization (vertical coherence).
- 4. Being able to think back and forward between abstract visualizations (models) to real biological phenomena.

In contemporary research, systems biology refers to the integration of experimental and computational approaches to understand and predict complex cellular functions (Alberghina, 2007). One important characteristic of systems biology is that it is an iterative process of data-driven model building and model-driven data gathering. The fourth element of a systems thinking competence (Table 4) reflects this central role of the use of models. Although systems thinking gets little attention in secondary education, textbooks used in secondary education contain many two-dimensional and three-dimensional models that focus, for example, on different aspects of cells. The functionality of using models in science education has been widely acknowledged (see, for example, Gilbert, 1993; Coll & Taylor, 2005). In science education literature, an important distinction is made between idiosyncratic mental models and analogical scientifically accepted consensus models (Gilbert & Boulter, 2000) or symbolic models (Harrison & Treagust, 2000). In our study, students engaged in an active 'model-based learning trajectory' starting with their idiosyncratic mental models, via intermediate models, towards a systems theoretical target model (see Figure 3) (Verhoeff 2003; Verhoeff *et al.*, 2008).

By going through the process of systems modelling, students were introduced to the scientific practice of developing and using models as tools for observation, exploration and the prediction of biological phenomena. In this way, a systems approach not only helped students to learn about biological systems at different levels of organization, but also fostered an understanding of the nature of science that is largely concerned with extending and refining systems models. Indeed, although educational or student models vary in many respects from scientific genomics models, we nevertheless see that



**Figure 3.** A model-based learning trajectory starting with students' naïve models based on their prior knowledge and moving towards a systems theoretical target model (Verhoeff *et al.*, 2008).

an iterative process of modelling and testing is possible in education, and can prepare students for a strategy that they will later encounter in studies in which systems biology has a role.

The question of how systems thinking can diminish the curricular overload has not yet been completely answered. The answer is to be found in the attention that needs to be paid to coherence in students' understanding of biological phenomena, starting at the concrete organism level. Phenomena like cancer or eating/digestion can act as a plot by which all details and characters of the story can be remembered. By building models of horizontal and vertical relationships related to a phenomenon, students construct a framework in which they can place new concepts (see, for example, a framework built by students around the phenomenon 'cancer' in Verhoeff *et al.*, 2009). The use of such a framework as a so-called 'advance organizer' improves retention (Ausubel, 1968): it provides organizational cues and helps to connect the known to the unknown.

Systems thinking also means separating central concepts from peripheral ones, implying that fewer concepts need be learnt by heart because the framework indicates how and

where information can be found. In genomics, for example, the gene is a central concept that will appear many times. As Knippels (2002) has shown, tuning the genetics vocabulary to the specific level of organization that students are dealing with at any given moment prevents confusion. Explicitly distinguishing levels of organization therefore helps to prevent the often-reported difficulties that students have with cytological concepts, chromosome structure and the homologous chromosome concept.

Systems thinking allows students to frame their knowledge in a matrix that includes a broad range of distinct organizational levels from the molecular up to and including the societal or population level. Inserting genomics in science curricula in this way might break what has been called the central dogma of biology – the primacy of DNA as the originator and primary ruler of cellular function – and help students to realize the influence of environmental stimuli on the proteins that turn on our genes, and therefore shape organisms' ability to adapt and evolve. With this in mind, issues on the societal level concerning (public) health or sustainable use of resources can be discussed as well. Clearly, a gap exists between knowledge produced in academic research practices and the knowledge disseminated by our pre-university education system. In the light of this, a rethinking of the 'essential' biological concepts might actually reduce the cognitive load of the curriculum, which could then provide space for updating school curricula. However, the inclusion of genomics would also imply the introduction of another conceptual focus - one that gives credit to both the complexity of the topic and the societal implications of contemporary research practices. As we have argued, acquisition of a systems thinking competence should be a central focus for secondary biology education that helps students to acquire a coherent understanding of biological phenomena from the molecular level up to and including the societal level. In the Netherlands, the mobile DNA laboratories incorporate scientific practices of genomics in classroom practice and relate these to societal implications. Within the context of these educational laboratories, an educational research project has been started, funded by the Centre for Society and Genomics, that takes up the challenge of developing a model-based learning trajectory for genomics (www.society-genomics.nl). It explores how genomics experts use imagery to handle the dynamic nature of molecular processes and how this might inform 'minds-on' education accompanying the 'hands-on' DNA laboratories.

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## Discussion

#### **Teaching uncertainty**

Dirk Jan Boerwinkel started the discussion by stating that it is hard for teachers to not only convey scientific knowledge to the students, but also talk about the uncertainties of science, the probabilities and so on. Students tend to say, 'If you are not sure about these things, then why am I learning it? Come back when you are more certain about what you are saying.' And many teachers may also think in that way – they want to teach students knowledge that will help them understand phenomena, not knowledge that makes them uncertain.

Ralph Levinson wondered whether it would make sense to split the curriculum, so that we would have science lessons that deal with extensive genomics and then lessons dealing with the problems that arise from this. In Northern Ireland, many teachers teach more subjects, such as science and religious education. When there was a discussion in a science class about ethical subjects, it was impossible to get the discussion going, because the students did not want to talk about it in a science class. The moment the religious class started, they wanted to talk about it and raised their hands and were active. Paul van der Zande replied that he does not recognize Ralph's problem at all. When he was observing a classroom of a religious school, students were talking about the ethical implications of genomics in science class. They actually liked to talk about it, because they felt related to the problems. Jenny Lewis mentioned that people sometimes need to be helped to understand that it is okay to discuss these things in a science class.

Next, Michiel van Eijck wondered how to move away from the concepts. Why are teachers so concept focused? Because firstly it allows them to cover a domain and secondly, it allows them to test for a specific concept and to provide marks. In this way, it is clear for teachers: in this class we discuss this concept, and in the following class we discuss the following concept. But there is tension between the more practical aims of providing marks, and science education for life after science education. Paul added that this is exactly the problem he is working on at the moment: how much space do we have to address these controversial issues?

Angela Legierse mentioned that she followed a workshop of Jonathan Osborne, who had done research on teachers of physics, biology and chemistry. It was noticeable that the physics teachers never allowed any questions from students and that they had an attitude of much authority. The biology teachers, on the other hand, were different. There was more opportunity for the students to ask their own questions, thus allowing a good discussion to happen. This might be explained by the nature of biological phenomena: there are always exceptions in biology, so there is never one correct answer.

#### What is the best way to determine the core curriculum?

Marc van Mil asked who is going to define the core knowledge of science and genomics. Jenny Lewis thinks that it should be done with experts who are highly knowledgeable about genomics, as well as with teachers, and that they should think about the aims of the curriculum. However, in the end, a small number of people are going to have to sit down and ask, 'What are the key ideas and why do we want them to know this?' There needs to be a reason why you are asking students to learn it.

Michiel van Eijck asked Jenny whether she wants the students to learn 'scientist' science or 'student' science. When you are designing a curriculum, you are talking about owning knowledge, so do we want the 'scientist' science in school, or do we also want the science that produces new knowledge by which students are empowered to participate in the discourse around science? Because with the latter we get citizens who will also participate in determining the contents of the curriculum.

Jenny explained that what she did with genetics was to start with an analysis of the key ideas that may be needed. She started with a very simple and short piece of teaching of about ten minutes in a small class and gave the students the opportunity to talk about it and ask questions. In this way, it is possible to see what they understand, what knowledge they still need and what the obstacles are.

Arend Jan Waarlo mentioned that Jenny talked about coherent basic knowledge and a conceptual framework. He believes that a combination of methods may provide the answer: first you can ask the experts, then you can analyse the school books, as Roald Verhoeff did, and then you can see how the students talk about it and which gaps in their knowledge occur. You have to relate all of these data sources in order to produce a basic conceptual framework. For instance, the school book analysis of Roald is very impressive, but what are the implications? The analysis alone will not tell us what we should do with the results. Roald added that talking about a core curriculum should also take into account the different roles students may have later on in life. Which activities or competencies are needed to fulfil their roles in different communities of practice? Perhaps it is not necessary to teach students 300 concepts, because they are not used later on. So maybe we need to totally reframe our thinking: as Michiel said, do we ever think about the roles of different practices? Arend Jan brought up the fact that you need a certain number of specific concepts to develop a framework of key concepts. Some of these specific concepts may become obsolete later, but we cannot just jump to a reduction of concepts without reflection.

#### What should be in the core curriculum?

Marc van Mil asked whether Jenny Lewis had basic ideas about what the core of the curriculum should be. We are raising this question for genomics, which extends and evolves from genetics. Is the basis fundamentally changed or can we still learn from your lessons in genetics? Jenny was sure that the basics for genetics are still a good starting point. She also mentioned that we need to look at interactivity, the multifactorial aspects of genomics and a model explaining how these things can interact. It is about understanding the fluid nature, the multiple interactions, which may also be the obstacle. Dirk Jan Boerwinkel agreed that the core curriculum should entail a good image of what your genome means and the role your genome plays in your life. Genomic research highlights the flexibility of genes, whereas students often think that your genes are a recipe that shows what you can and cannot do. Anat Yarden added that it is important that the curriculum also reflects the dynamics of science and that students grasp the uncertainty of science. It should not be a large part of the curriculum, but it should be there. One of the questions is whether we want to put this in the core curriculum or the advanced curriculum? We should also ask ourselves the question of whether the curriculum for advanced secondary school classes should be a preparation for university or for citizenship. Anat believes it should be for citizenship, because you do not need high-school biology to go to university.

Dirk Jan suggested that Andrew Moore gave us a nice example of dynamic changes in biological knowledge in his case of the new classification of organisms. The older classification was not unscientific, i.e. it was based on sound comparative anatomical and embryological research. However, due to the changes in research methods, our ideas about descent have changed. In this way, you can show students that facts can change by taking a different perspective. Arend Jan Waarlo adds that the history of the gene concept is a very illustrative example of this, which could be included in genomics education.

Roald Verhoeff warned that more space for the dynamics of science means less space for the concepts themselves. When he was a mentor for first-year university students, they complained that they lacked sufficient conceptual knowledge and the right way of thinking. Therefore, university teachers should explain the basics concepts before actually starting their lectures. Michiel van Eijck thought this was an interesting comment, because it got him wondering whether scientists are then deciding what is important for the students' future. Should students not also have an influence on the discourse and what they think is important?

#### Constructing knowledge together

Ralph Levinson said that genomics changes perceptions about ourselves and our ideas of health and sickness. We can perceive all of us as being sick, because we all have different dispositions. But in spite of these changing perceptions, the teaching–learning method is still in many ways like it was in the 19th century. At home, young people can generate and introduce new knowledge themselves, through technological and digital advances such as Facebook, but in schools and education we hardly use these. Perhaps one of the problems is that we are out of synch. There are huge advances being made in science and learning technologies, and yet we are barely making use of those technologies. Dirk Jan then wondered what Ralph's idea about a curriculum would be. Would he throw out all of the concepts and say that students should be able to construct their own knowledge? Ralph replied that knowledge is fractured and split in some ways. There is a way in which academic knowledge is part of learning, but there is also a part of knowledge that is actually about engaging with each other, building knowledge, politicizing and taking action. And these two can actually live side by side with each other and occasionally they may interact.

Michiel van Eijck added that he thought it was an important aspect of this discussion to distinguish how we think of knowledge. On the one hand, we can think of knowledge that is individual and in our minds: this restricts us to some kind of transmission model. On the other hand, knowledge is collective and distributed over different people, who all have their own way of thinking about a concept. So we can think about a layperson and a scientist and use their collective knowledge to learn, rather than transferring knowledge from the scientist to the layman. With respect to students and teachers, the students can also inform their teachers about what kind of knowledge is important for their current activities or their future life.

Ralph mentioned that he thinks knowledge can be a number of different things. For example, when I tell my three-year-old child, 'Don't cross the road when a car comes!', I am not engaging them in a discourse. But I can also have more of a discussion with them on a topic that is important to them. There are simply various different types of knowledge and ways of communicating knowledge. Maybe we should just accept that there is no one right or wrong way of interacting and communicating.

#### Citizen science

Arend Jan Waarlo asked how we define 'citizen' science. Is it the 'science' of the citizen (folk wisdom)? Or is it the knowledge of the sciences that is embedded in their own life-world and then perhaps transformed? Ralph Levinson gave an example of people with hereditary conditions having linked up as lobby groups and becoming informed about the kind of problems they face. The problem is that the way medical professionals approach the problems is not satisfactory, because this approach does not deal with the kind of issues they meet in their personal lives. These groups seek the knowledge they need and try to use this to deal with the problems they have. They become politicized and state that the science they have is different from the 'scientist' science. The patients need to share their knowledge and say, 'These are the kind of things we need in order to deal with our problems.' For example transgender individuals, who feel they are neither male nor female, argue that modern medicine deals in a very gender-focused way: you are either a male or a female. But for them it is totally different, and 'scientist' science does not address their problems.

Roald Verhoeff linked this with his experiences in connecting the different knowledge modes of patients and medical professionals at the 'Cancer Genomics Markt Plaza'. The Markt Plaza was held two years ago, and 1400 patients or so participated in this public event. One of the purposes was to facilitate a dialogue between different practices: academic, professional and life-world. Unfortunately, the moment workshops started, patients took on their traditional role: the patients were asking questions of the experts and no real dialogue arose. So now for the second Markt Plaza, a specific workshop will be organized to explore to what extent patients can participate in setting a research agenda by contributing their own life-world experiences. Because experts tend to dominate, the patients will be empowered in a session that precedes the workshop with the health professionals. Michiel van Eijck added that it is not only a matter of empowering the patients, but also of preparing the experts to take responsibility here. Perhaps then a real dialogue can start.

## Conclusions

#### What is the best way to determine the core curriculum?

- Students should have some influence on what is being taught and teachers should give ample opportunity for asking questions in order to inform themselves about students' interests and knowledge levels.
- A coherent knowledge base (conceptual framework) should be informed by:
  - Asking the experts
  - Analysing school books
  - Analysing how students talk about genomics-related topics to probe their initial understanding.
- Different roles students may have later on in life should be taken into account: which competencies are needed to fulfil these roles in different communities of practice?

#### Content

- What is new in genomics is not the polygenic, multifactorial nature of genetics, but the extent to which this new knowledge results in a move from single-gene characteristics to multiple effects and interactions, and the implications of this emphasis shift – both for science and for society.
- Interviews with cancer genomics professionals reveal that, from their perspective, students should:
  - Have a fundamental knowledge of genetics
  - Be aware of future developments, such as the \$1000 personal genome
  - Comprehend the nature of science, including:
    - Being aware of the time span between laboratory results and clinical use
    - Being able to deal with uncertainty in science (and society)
    - Understanding the complexity and multifactoriality of diseases
    - Understand risk assessment and perception.
- The amount of knowledge that is needed to discuss socio-scientific issues related to genetics is limited but essential. Students should also develop an attitude of questioning ideas and evidence within a science context, and this requires a basic understanding of genomics.

- The core curriculum should include:
  - The concept of interactivity: the multifactoriality of genomics and a model explaining how these factors interact
  - An adequate meaning of genome: the role your genome plays in your life
  - The dynamics of science: advancing science and uncertainty of knowledge,
    e.g. the new classification of organisms and the history of the gene concept
  - Different knowledge modes (academic, professional and life-world; 'scientist' science and 'citizen' science; individual and collective knowledge) serving different purposes, and how interaction and dialogue can contribute to co-construction of new knowledge.

#### Core and advanced curriculum

- The concept of three communities of practice (academic, professional and everyday life practices) can be translated into two different streams in upper secondary education:
  - Preparation for careers in life sciences: research scientist, health professional
  - Preparing future citizens: informed personal and democratic collective decision-making in practice in everyday life.

This would require recontextualizing genomics concepts and teaching the students in such a way that they will 'learn for life' rather than 'learn for school'.

- The new specialist biology curriculum in England (September 2008) now includes topics such as totipotency, siRNA, epigenetics, the human genome, comparison of genomes, regulatory genes and apoptosis.
- Both core and advanced curricula entail the strand 'How Science Works'. This strand includes:
  - Explaining how scientific theories are supported, refined or refuted as new data/interpretations become available
  - Appreciating the tentative nature of (some) scientific knowledge
  - Evaluating activities in terms of applications, implications, benefits and risks of science
  - Identifying ethical issues that arise from applications of science
  - Discussing scientific solutions from a range of ethical viewpoints
  - Appreciating the ways in which science is used to inform decisionmaking.

#### Pedagogical approaches

- Embedded DNA laboratories have the potential to integrate:
  - Hands-on and minds-on experiences
  - Research, professional and life-world contexts
  - Various levels of biological organization.
- The profusion of terminology in (cell) biology education can be tackled by introducing systems thinking, including being able to:
  - Distinguish between the different levels of organization, i.e. cell, organ, organism and community, and to match biological concepts with specific levels of biological organization
  - Interrelate concepts at a specific level of organization (horizontal coherence)
  - Link biology concepts from different levels of organization (vertical coherence)
  - Think back and forward between abstract visualizations to real biological phenomena (modelling).
- Information technology and new media offer educational opportunities.

#### **Teacher preparation**

- Genomics education demands new 'pedagogical content knowledge' (PCK) including the science and its applications and implications. Teacher confidence plays a key role in any change in classroom practice. Developing this knowledge and building confidence takes time.
- Teaching 'uncertainty' may encounter resistance. Teachers want to teach students knowledge that will help them to grasp phenomena; disputable knowledge may bring about the opposite effect.
- There is a tension between producing marks in school and preparing for life. Genomics will need to be reflected in the assessment regime.
- It is advantageous to biology teachers that they are familiar with individual differences (exceptions), so there is never one correct answer.

#### Research

- Research is indicated to inform the knowledge base required for recognizing and appreciating social issues related to genomics. This knowledge base should differentiate between ability/age groups and type of school.
- The potential of systems thinking in reducing conceptual overload and in improving coherent understanding should be elaborated and tested further.
- A pedagogical framework for the teaching of genomics-related controversial socio-scientific issues should be elaborated and tested in classroom practice.
- Curriculum research is indicated to reconsider curriculum content and to reduce curricular overload.
- Empowering teachers for contemporary and relevant genomics education requires practice-oriented research on the development of expertise/PCK.

# Session C Pedagogical approaches

## Genomics and teaching of risk

**Ralph Levinson** 

## Genomics and moral reasoning

Catherine Näpflin and Stefanie Sapienza

## Health-related genomics in classroom practice

Paul van der Zande

## Discussion

Conclusions
### Genomics and teaching of risk

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The House of Lords Science & Technology Report (2000) claimed that people have different and diverse concerns with regard to uncertainty and risk in publicly contested areas of science. Measurement of risk commonly draws on two combined variables: the chance of an event happening and the seriousness of the consequences if it does.

Risk entails concepts such as probability, uncertainty, impact and trust in public policies. An example that depicts all of these factors perfectly is the development of the cowpox vaccine by Edward Jenner, particularly at the very moment at which James Phipps received the jab from Dr Jenner. (Figure 4). The mother (and child) need to trust the doctor, because the consequences would be calamitous (the death of James) if something goes wrong with the vaccination. But the vaccination was successful and its impact is that it has arguably led to millions of lives being saved. Therefore, risk incorporates both hoped-for benefits and possible harm. But how do you quantify an impact factor? You cannot simply multiply the impact factor by the probability. For instance, it is difficult to comparatively quantify a fall from a slippery unsafe bridge into a shallow river (high probability of falling into the river, low impact factor) compared with falling from a safe yet very high bridge (low probability, high impact factor). The risk of certain events can be judged from either a public policy or a personal perspective. For example, there have been public consultations and meetings about the desirability and constituent risks of making genetic testing kits available on the open market. They might, for example, increase public anxiety, impose unnecessary strain on medical services and create a social divide between those who can afford the kits and those who cannot. Should such kits be regulated? From a personal perspective, a particular genetic testing kit might be inaccurate and raise unnecessary fears, or people might need to learn how to judge the risk factors associated with the information in the kits. Real problems are extremely complex in their context dependence, and generally depend in reflexive ways on the subjective perceptions of different participant groups.

While the concept of risk does not appear in the Dutch curriculum, Harrie Eijkelhof from the Netherlands has researched the understanding of risk in connection with ionizing radiation and proposed an approach for teaching this concept as early as the 1980s. In the





USA, project SEPUP (Science Education for Public Understanding Program) for grades 7–12 incorporates risk, although its emphasis is on understanding probability. In England, GCSE 'Twenty-first Century Science' for 14–16-year-olds and 'Science in Society' for those aged 16+ devote a substantial part of the courses to risk in science. In Table 5, the acquired competences from the Twenty-first Century Science course with respect to risk are shown.

There are many contexts in which risk plays an important factor. For instance, gene therapy may have benefits, but also causes side effects and (unknown) latent effects. Genetic screening tests can result in false-positive and false-negative outcomes, and there is always the influence of the interpretation of probability and resulting anxiety.

Funded by the Welcome Trust, the TURS Project ('Promoting Teachers' Understanding of Risk in Socio-scientific Issues') was recently started. It will run until February 2010. This project is important, as teachers need to understand risk themselves before they can properly teach it. The aim of the project is that the researchers will work with maths and science teachers to enhance the teaching of risk by developing:

- Pedagogical principles
- Software tools/simulations that support reflection, sharing and perturbation of teachers' knowledge about the teaching and learning of risk.

With this project, they want to bring the quantitative and mathematical perspective incorporating informal inferential reasoning (drawing uncertain conclusions from data) together with the socio-scientific, through teachers' interdisciplinary working and novel software designs. They aim to capture teachers' knowledge about risk and about teaching and learning of risk, and the processes of how these change, through the iterative design

Торіс	Acquired competences
Nothing is risk free. New technologies and processes based on scientific advances often introduce new risks.	Can identify examples of risks that arise from new scientific or technological advances.
To make a decision about a particular risk, we need to take account of both the chance of it happening and the consequences if it did.	Can discuss a given risk, taking account of both the chance of it occurring and the consequences if it did.
If you are not sure about the possible results of doing something, and if serious and irreversible harm could result from it, then it makes sense to avoid it (the 'precautionary principle').	Can identify, or propose, an argument based on the 'precautionary principle'.
Our perception of the size of a risk is often very different from the actual measured risk. We tend to overestimate the risk of unfamiliar things (like flying as compared with cycling), and things whose effect is invisible (like ionizing radiation).	Can suggest reasons for given examples of differences between actual and perceived risk.
Reducing the risk of a given hazard costs more and more, the lower we want to make the risk. As risk cannot be reduced to zero, individuals and/ or governments have to decide what level of risk is acceptable.	Can explain what the ALARA ('as low as reasonably achievable') principle means and how it applies in a given context.

Table 5. Risk topics in the Twenty-first Century Science course and the respective competences

of software. Their first impressions of the interdisciplinary potential of the project are that most science teachers do not attempt to quantify probability or risk as part of socioscientific issues; the perceived authority of the data influences its perceived reliability. For most mathematics teachers, risk is a topic on the horizon of the revised National Curriculum that has not yet had an impact on practice. The project deals with the scope of interdisciplinary collaboration in order to develop models that bring mutual benefits to the teaching of both science and maths and illuminate the role of risk in the teaching of socio-scientific issues, including those that are based in a knowledge of genomics. Several problems that they are encountering are as follows:

• Quantifying risk (probability and impact): can risk be measured? The Royal Statistical Society has devised a one-dimensional riskometer to illustrate relative risk factors (Royal Statistical Society, 1996). As understandings of risk are mediated by social, psychological and cultural factors (Pidgeon, 1992), a

riskometer oversimplifies reasoning about risk. Furthermore, it fails to take into account population characteristics when calculating probabilities (Adams, 2000). For example, car accidents are estimated in terms of probabilities for the whole population, but the probability of a 17-year-old being injured in a car accident on a Saturday night is very different from the probability of a middle-aged man being injured in a car accident on a Tuesday afternoon.

- Personal, cultural, social, ethical and historical factors that influence risk perception. For instance, in a pilot study reported by Levinson, a maths teacher said he would not travel to Nigeria with his children because of the risk of malaria. On the other hand, a young Nigerian teacher did not see the risk as serious, as she had had malaria three times and it was simply part of what living in West Africa entails.
- Lay and scientific views of risk: they have different rationalities, but they are both authentic (Stilgoe, 2007). Experts and lay parties work from different assumptions and focus on different data, but their arguments have similar validities in their own descriptive contexts.
- Inter-relationships of risk, trust and participative democracy: for instance, the perception of risk diminishes with increased trust and grows with decreased trust (O'Neill, 2002).

As the TURS Project has just started, two additional questions relevant to this research as well as to the workshop may be posed:

- What approaches or conceptualizations of risk are appropriate to high-school studies of genomics?
- What issues in genomics lend themselves both to a discussion of risk and to interest and curiosity in young people?

Given this particular approach, the research best addresses questions 3 and 4 formulated in the introductory keynote paper, 'A framework for rethinking science curricula in the genomics era'. Genomics has raised societal issues that have been clearly outlined. The problem with the curriculum is that issues are in a state of flux and there needs to be a framework that can focus on political, social and ethical commonalities in a wide variety of circumstances. A theoretical pedagogical framework for socio-scientific issues (Levinson, 2006) has been described, which outlines different criteria for making decisions on socio-scientific issues from examination of evidence to exploration of different world views. There is a role for risk in this framework and this is especially important for developments in genomics, which has generated new areas of risk, e.g. through genetic screening, pharmacogenomics, bioinformatics and environmental aspects. Rather than incorporate new genomics-related issues specifically into the curriculum, students could investigate how these issues can be examined through a study of risk. Stirling (1999) proposed a range of attributes for the scientific appraisal of risk. These include transparency where all relevant information is made available, use of systematic methodologies, scepticism over knowledge claims, extent of quality control through expert peer-review, independence from interest groups such as commercial enterprises, professional accountability, and understandings open to change through the continuous process of learning. Is it reasonable to incorporate reflection on such attributes in the curriculum in studying risk factors from any techno-scientific development?

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## Genomics and moral reasoning

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Ethical discourse is an important constituent of a Swiss societal debate on genetically modified food. How can students who will have different future roles in society develop their moral judgement? An educational intervention study has been started aimed at a change in moral consciousness/sensibility, moral character, moral judgement and moral motivation with respect to the genetic manipulation of plants. In addition, any changes in knowledge level, attitude and interest towards this new technology, as well as readiness to assume a risk and to take on responsibility, will be monitored.

The intervention consists of the following:

- First laboratory day
- Two teaching modules of 4 hours each (M1 and M2 over 4 weeks)
- Second laboratory day
- One module of 4 hours (M3 over 4 weeks)
- Final module of 4 hours (M4 over 4 weeks).

The classes will be given by teachers of philosophy, biology and ethics.

During the first laboratory day, the students will get an introduction to the cloning of DNA, plasmids, transformation, selection, restriction and polymerase chain reaction (PCR) through the context of bacterial transformation. On the second laboratory day, they will learn to identify a transgenic crop and are taught about Agrobacterium, regeneration of plants, selection, antibiotic resistance, isolation of plant DNA, PCR, gel electrophoresis, analysing plants and application areas. The goals of these two laboratory days are that the students enhance their technical knowledge and that they experience working in a laboratory. The laboratory days are possible in just one day each, because an expert will already have prepared and grown the plants, and the students will only actually do the fingerprint. After the first and second laboratory days, the students will learn how to deal with their experiences in an ethical and moral way during the modules.

These teaching modules aim to stimulate moral judgement, consciousness/sensibility, character and motivation (the Four-component Model by Rest, 1986, in Bebeau, 2002). Students will search for answers to important questions concerning, for example,

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responsibility and care. The students will get to know different possibilities of philosophical argumentation. Furthermore, the students will be taught Kohlberg's stages of moral development (Kohlberg, 1981, 1984) and will discuss authentic situations concerning the genetic engineering of plants.

They will learn the four philosophical positions of Jonas (1979), Spinoza (2007, first published 1677), Rawls (2005, first published 1971) and the Swiss Ethic Commission (2008), respectively. For instance, the Swiss Ethic Commission asks whether plants have the right to be treated and protected as creatures, with their own need to live and reproduce. On the other hand, Jonas states that you should look at the results or consequences of genetic engineering of plants at different levels. For example, 'Biopol' is biological plastic, which is produced by a genetically modified plant. On a societal level, this type of genetic engineering is good, as it produces biological plastic. At the level of nature, this production method needs less CO2, which is also a good result. However, at the plant level, the consequences are severe: the plant dies after it has been used once.

The intervention will last about 3 months and is partially randomized. There will be 12 classes in total with high-school students aged 18–19: four control groups, four experiment 1 groups and four experiment 2 groups. The control group will have no intervention and the experiment 1 groups will have the complete intervention. The experiment 2 groups will only participate in the laboratory days. The researchers decided in favour of 'laboratory days only' groups rather than 'modules only' groups, because they believe that interest and motivation is very important for learning, and that students would not be able to develop abstract concepts without gaining laboratory experience, so they would be less good at the modules.

The hypotheses are that the experiment I groups (complete intervention) will show no difference with respect to all dependent variables at t<sup>o</sup> of the intervention, in comparison with the control group and the experiment 2 groups (laboratory days only). The experiment I groups will show the highest gain in biotechnology competence after the intervention. After the intervention, compared with the control group and the experiment 2 groups, experiment I groups are expected to show:

- A higher ethical sensitivity.
- A greater amount of moral motivation.
- A slight change in the moral judgment level.
- A higher moral character.
- A more complex ethical knowledge system in each student.

What they measure	Description	Origin
Moral motivation	The relative importance that someone attaches to a specific value related to the gene technology and plants theme.	Self-constructed hierarchy of values.
Moral character	The moral character towards gene technology in plants.	Adapted from the scale by Schwarzer & Jerusalem (1999).
Moral judgement	Moral judgement, both general and specific for gene technology in plants.	Defining Issues Test (Rest, 1979). Two dilemmas are specifically constructed for this theme (to enable international comparison).
Ethical sensitivity	Perspective change in plant gene technology. Generate and identify options for action.	Adapted from Tirri & Nokelainen (2007).
Apperception test of ethical situations	The perception of ethical problems during genetic engineering of plants.	Adapted from Hébert e <i>t al.</i> (1992).
Ethical argumentation skills	Ethical argumentation skills.	Self-constructed.
Interest	Acceptance and fears towards green gene technology.	Todt & Götz (1994).
Attitudes	Attitudes towards green gene technology.	Todt & Götz (1994).
Moral engagement/ indifference	Moral 'exclusion/inclusion'.	Adapted from Opotow (1990).
Conceptual change	Conceptual change in plant gene technology.	Self-constructed.
Knowledge	<ul> <li>Knowledge test about:</li> <li>Genetic technology (module by Bergmüller).</li> <li>Ethical positions (Jonas, Rawls, Spinoza, Hare and Swiss Ethic Commission).</li> <li>Kohlberg.</li> </ul>	Self-constructed, based on the Life Sciences Learning Center (LSLC) module and the ethical modules.

Table 6. The qualitative measuring instruments of the study.

A qualitative measuring instrument based on the Four-component Model from Rest (Rest, 1986, in Bebeau, 2002) will be used to analyse the data including moral motivation, moral character, moral judgement and moral/ethical sensitivity (see Table 6). Other measurements such as the ethical argumentation skills of students are also mentioned in this table.

Currently, the project is in the stage of improving the modules and preparing the actual intervention. In the first term of 2009, the intervention will take place, and in 2010 the final report should be finished.

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## Health-related genomics in classroom practice

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As part of a PhD study, teachers' expertise needed for teaching controversial genetic issues in high-school biology, in particular issues raised by genetic testing for personal health, has been mapped. This mapping was informed by exploring, through individual interviews, the clinical genetic testing practice and the educational practice of expert biology teachers. The former should reveal relevant concepts and issues, and the latter the required pedagogical expertise.

The clinical genetic group consisted of four clients who underwent genetic counselling, four medical professionals (two physicians of whom one was also an ethicist, a clinical geneticist and a genetic counsellor), and four medical ethicists. Nine experienced teachers from eight different schools were interviewed. They had an average teaching experience of 20.7 years. Two teachers worked at vocational schools, two in pre-university classes and five at schools with both vocational and pre-university education. Five of the teachers worked at a school with a religious denomination and four at public schools.

#### **Results: concepts and issues**

With regard to conceptual knowledge, a number of concepts were identified that are currently lacking in the Dutch examination syllabus (see Table 7). However, not all interviewees held the same opinion on whether all of these concepts should be included in the curriculum. They did agree on the belief that students should be taught more general notions of genomics, and that you need concepts to fully grasp the meaning of notions such as uncertainty, complexity and probability.

For example, regarding uncertainty, many clients expect straightforward answers and clear-cut solutions when they consult a physician or genetic counsellor. Patients think that everything is possible and that anything can be explained with the help of genetics. Tempering of high expectations held by future patients should be one of the educational goals according to the respondents. Students should also be taught the complexity of genomics: quite often numerous genes are involved in diseases; in addition, genetic

Table 7. Conceptual knowledge in the context of genetic testing for health

testing can be emotionally overwhelming (Wilfond, 1995; Decruyenaere, 2003; Evers & Swenne, 2005). Lastly, the probability or genetic risks can be quite unclear or confusing. For instance, it sounds less frightening when a physician tells you that I in 2000 people with the same genetic predisposition gets a disease compared with being told that your risk of getting the disease is four times higher than average.

According to the professionals, making responsible decisions concerning genetic testing requires both genetic and ethical knowledge. As one of the medical ethicists stated: 'In school, students must constantly learn to connect information and knowledge with emotions and values.' Therefore, both rational and emotional considerations are important in education (Sadler & Zeidler, 2005). Patients should be aware of what they want to know, why they want to know it and what they will do with the knowledge, prior to a consult. In relation to this, four different stages were distinguished during the process of genetic testing. In the context-based genetics education, students could be asked to play the role of a future patient and to go through the four stages.

#### Stage 1: Preparation phase, gathering information

The first decision a client has to make is whether he or she wants to know the test results (Wilfond, 1995). There are different arguments for wanting or not wanting to know, such as:

- Medical reasons: is the disease treatable or not?
- Ethical reasons: religious arguments or arguments of care; can you avoid harm and sorrow?
- Legal reasons: is it legal; is the 'right not to know' applicable?
- Socio-psychological reasons: aspects to consider are for instance dealing with reassurance, (un)certainty, relief, anticipating decision regret, (in)dependency, responsibility, taboos, complexity and timing.

After this part of the preparation phase, clients need to gather relevant information:

- Medical information: clients must know something about the cause of the disease, heredity, probability, symptoms, consequences, different treatments and their side effects, and lifestyle influences.
- Ethical information: mostly the four principles of biomedical ethics are at stake: patient autonomy, beneficence, non-maleficence and justice, together with the principle of privacy (Beauchamp & Childress, 2001; Nyrhinen et al., 2004). Which values are important for the client? Is there a conflict of interests?
- Legal information: what are the consequences for work, loans and insurance?
- Socio-psychological information: who is involved? Can the client cope (emotionally) with a change of perspective? What about the carrying capacity of the family?

#### Stage 2: Weighing information and decision making

Before making any decisions, the client has to examine for example whether he or she understands all of the complex information, what it means to him or her, and whether the patient and her or his environment can handle it emotionally. How are the involved values balanced? Are all of the different interests met and is help needed?

#### Stage 3: The laboratory, analytic phase

This is the phase during which the actual genetic test is done.

#### Stage 4: Interpretation and processing of the results, and consequences

Finally, the client must learn to live with the outcome of the test, whether it is positive or negative. In all cases, emotions are involved and there will be follow-up questions of

responsibility and social consequences. Who else must be notified: children, other family members, parents, brothers and sisters? Some questions are still unanswered: When will it happen? How serious will it be? How fast will it affect me?

It is important to realise that this process can be quite confusing from the perspective of clients. Also, the process is under pressure from and influenced by the outside world. The outside world includes not only relatives and friends (who can each hold different opinions on the topic leading to further chaos) but also the medical professionals and the way they treat a patient.

#### **Results: pedagogical expertise**

The teachers focused on the concepts mentioned in the Dutch examination syllabus. Only one teacher mentioned an extracurricular concept, namely epigenetic factors. With regard to the content perspective, the teachers underlined the difficulty students have in understanding probability in genetics. All teachers referred to complexity, which is known as one of the main characteristics of teaching genetics (Knippels, 2002), and most of the teachers reported the implicit or explicit use of Knippels' so-called yo-yo strategy to meet this complexity. On the other hand, the teachers made no mention of the uncertainty connected with the context of genetic testing. And although they all reported the difficulty students, in particular those in vocational education, have in understanding probability in genetics, they did not mention that students have problems with understanding the relevance of chance for themselves as individuals.

In general, it can be stated that teachers did not have a complete picture of the moral dilemmas and questions linked to genetic testing. Because the teachers had a lot of life and teaching experience, they were all familiar with some moral dilemmas and questions. However, this familiarity differed among the teachers, although the teachers were capable of recognizing moral questions and dilemmas when they were confronted with them during their lessons.

One problem teachers encountered was that the context-based education requires a reshuffling of the biology curriculum. Due to a tight time schedule, teachers may not be able to elaborate on controversial topics such as genetic tests.

The teachers all mentioned a good pedagogical environment as a conditio sine qua non for this kind of education. They mentioned safety (all nine teachers) and a safe environment (four of the nine). On being asked how they tried to bring about this, they mentioned for instance open communication (seven times), mutual understanding and acceptance (seven times), comfort and order, clear rules about manners (seven times), and making interventions when students say or do something that does not fit within the rules, i.e. being a good pedagogue or a sharp coach (eight times). A pleasant classroom, e.g. walls decorated with materials made by the students, was also mentioned. In addition, good interpersonal relations were considered important for this kind of education. Open communication, shared goals and mutual understanding, and acceptance were all mentioned seven or eight times by the nine teachers.

On being asked about their responsibilities as pedagogues, the teachers were aware that they are role models for their students. During discussions and role play, three of them chose the role of 'absent leader' (sometimes 'neutral facilitator') and six of them were mostly the 'committed instructor' (Harwood, 1998; Waarlo, 2003). All experienced teachers took the stance of value development and value communication (Ritzen, 2004), but sometimes, when thinking from a biblical point of view, religious teachers may take up the position of value transfer (two of the nine).

The teachers used narratives (films, documentaries or personal stories) to start their lessons with to arouse empathetic involvement. In their eyes, empathy is a motivational factor. The teachers indicated the importance of problem-based approaches. Concerning moral reasoning, they mostly reported class discussions based on rational argumentation. Although personal valuation was reported to be important, they did not mention many teaching and learning activities to reach that goal. Two teachers used learning activities that were selected explicitly to enable reflection on different kinds of considerations, such as 'opinion-writing in gender-related small groups' and 'yes/no, agree/disagree or 0/10 scale. Here, students physically position themselves on a line and explain their positioning. Considerations based on ratio and feelings are both accepted. Reflection on moral reasoning is still uncharted territory: none of the teachers had experience with these kinds of activities, but most of them indicated that new teaching and learning activities on reflection with regard to moral reasoning would be welcome.

Students understand that a decision based on genetic testing is under time pressure, as reported by the client-respondents:

When I was pregnant for 13 weeks, the triple test indicated it wise to puncture my placenta. That test outcome could be ready within one or two weeks and then I had exactly one week left to decide to have an abortion or not. How could I decide in two weeks time over life or death of my child?

Preparation for this time pressure is one of the arguments the respondents of the genetic health practice had for teaching genetics in this context:

Imagine a positive test, so with a negative outcome, but in medical language that is called positive. Then, in a very short period of time, you have to make a decision that has consequences for the rest of your life. Suppose you decide to abort your child: you can never undo that; you will live the rest of your life knowing that you have aborted a child on genetic grounds. Suppose you do not abort it. Then you have a comparable situation; you have to live with the fact that a child is born that will probably require help and care the rest of its life. In a timeframe of two weeks, you'll have to decide something that encloses the rest of your life. I think that is far too radical. That is why I support your research so much, because I think that in your pubertal period or adolescence, you have to be trained to deal with this kind of dilemma. These vital questions cannot be postponed until the moment you are confronted with them.

#### Conclusions

There are several aspects of expertise necessary to teach genetics in the context of genetic testing. Some of these aspects are present in education, and some are present in genomics practices (see below). These aspects of expertise are:

- Genomics practices expertise:
  - Conceptual knowledge (high-/low-risk genes, SNPs)
  - Notions such as uncertainty, complexity and probability
  - Knowledge of most of the relevant moral dilemmas.
- Educational expertise:
  - The genetic concepts of the curriculum
  - Knowledge of some relevant dilemmas
  - o Knowledge of how to discuss moral issues with students
  - What is needed for a moral and interpersonal perspective

• Some teaching and learning activities, such as narrative starts and problembased approaches.

The teachers appeared to have several aspects of the expertise needed to teach genetics in the context of genetic testing, such as knowledge of most of the genetic concepts and some of the relevant dilemmas. The teachers also seemed aware of the pedagogical necessities and interpersonal perspectives, and had some ideas about appropriate teaching and learning activities. However, teaching and learning activities concerning moral reasoning, personal valuation and reflection on moral reasoning still need to be developed.

Research will continue with a focus on the design, implementation and evaluation of teaching and learning activities for teaching genetics in the context of genetic testing for health. A team of ten biology teachers will work together in a 'community of practice' and translate the reported findings into their own educational practices. These teachers will be monitored in order to describe the expertise they develop during the learning process and the kinds of activities that contribute to their learning outcomes. Attention will be paid to interpersonal perspectives and the pedagogical environment, as these were indicated by the teachers as important perspectives.

The classroom practice of the 'community of practice' teachers will include a narrative start (such as a film or documentary), a problem-based approach and (reflection on) moral reasoning.

Finally, the question will be raised as to how biology teachers can acquire the expertise to teach genetics in context. How can the development of expertise within the different perspectives be stimulated (content, moral, learning activities and interpersonal perspective)?

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## Discussion

# What knowledge is needed for moral discussions on genetic subjects?

The first question was raised by Anat Yarden about the Swiss intervention study: whether or not the students need a solid knowledge base. Knowledge was considered to be of relative importance, but during the two laboratory days, the students would get enough theoretical background. The moral modules are not very technical; the students should know what happens to the plants, but they don't need that much theoretical background to be able to argue in a moral way. In any case, they took biology classes before the intervention study.

Anat Yarden responded that she believes students do need knowledge about science and genomics to make decisions, next to philosophical knowledge. Paul van der Zande said against this that people base their reasoning more on intuition than on facts, and if we really want to teach students moral reasoning, there should be room for emotional and intuitive reasoning. Furthermore, we should prepare students for coping with uncertainty, because often there are no clear answers. This requires a safe class environment, especially when students are starting to question their initial position and express their doubts.

The next question was raised by Angela Legierse. She explained that many teachers are not aware of ethical frameworks, and she asked Paul van der Zande whether they need knowledge of ethics to lead the discussions. Paul responded that, although not all of his teachers know the ethical frameworks, they do know the values related to the topics, such as privacy and preventing harm. They can pinpoint the feelings of students, but they do not use ethical frameworks, for example about the question of how to weigh values. Paul tries to avoid a discussion on 'this value is the best'. Arend Jan Waarlo stated that the principles of ethics can be used to reduce a moral discussion to a conflict of underlying principles and thus making it transparent. Paul doubted whether the students should use ethical theories like deontology and consequentialism. Arend Jan answered that it may depend on the nature of the case and the personal background of the discussants, for instance, whether someone is religious or not. Ralph Levinson agreed to a certain extent that the teachers need to know ethical frameworks, but more importantly they should have thought through the issues themselves. To him, that is the most crucial thing. Of course, some people have strong religious views, but sometimes you do not have any clear ground on which to base your decisions. For instance, should we have a utilitarian view or a deontologist view? Paul mentioned that it is because of this 'thinking through the issues themselves' that the teachers in his research project practice the lessons twice themselves. The teachers' concern is not whether they have an ethical framework; their main concern is how to respond when there is an emotional response from the class.

#### What are the goals of moral education?

Dirk Jan Boerwinkel inquired about the standpoint of the Swiss Ethic Commission. Catherine Näpflin replied that, according to the Swiss Ethic Commission, the plant is a creation and has dignity. It should therefore be treated as a moral subject. Many people say they do not care about plants, but when you have a plant in your living room and you let it die, occasionally you do feel guilty. They are living things and we should also consider them in our ethical discussions.

Another question with regard to the Swiss study was asked by Marc van Mil: what change is intended and why is this change needed? Catherine and Stefanie Sapienza replied that they are aimed at enhancement of moral judgement and moral motivation. Paul van der Zande joined in by saying that he also felt a bit confused by the term 'change', which suggests that they have a criterion for moral reasoning. Catherine and Stefanie explained that they want young students to be able to recognize moral problems. Initially, the students may not even be thinking about ethics in relation to plants, but when they discuss it from different perspectives, they may begin to see that there is also an ethical problem with plants and the environment. And with regard to their moral motivation, their values may change. So the researchers want to measure whether there is a change in value and moral judgement. For instance, Kohlberg defines different stages where at a higher stage you have a more autonomous judgement. An example of this would be that students are independent of their parents in moral reasoning.

Arend Jan Waarlo brought up the difference between transfer of values, value clarification and value communication, and asked for characterization of the Swiss and the Dutch studies accordingly. Catherine and Stefanie responded that, in their project, the teacher should not push the students in one direction; they should accept the different arguments, but also suggest another point of view from a philosophical position. In this way, the students learn to incorporate this different point of view into their own or reject it because they cannot accept it. In one module, the students do a role play: one student acts out the story and another records what is happening. Afterwards, they have to discuss it and look at it from the outside, so they take on a different perspective. During this process, the teacher should observe and help them, and find arguments but not push them. So it is value communication and value clarification.

Paul explained that his answer would depend on the age group. The younger the children, the more the teaching leans towards value transfer, because students need to know and understand values before they can develop argumentation skills about them.

#### How do we discuss risk with students?

Ralph Levinson's presentation on risk did not mention examples of risk suitable for our age group of students. He added that it is important to pay attention to statistical knowledge, for example the difference between relative and absolute risk. These do occur in the media, even though they might be wrongly rated. For instance, when you drink a lot of coffee, the risk of a stroke is doubled. However, for some people, drinking a lot of coffee actually lessens the risk of a stroke. So there is always uncertainty, because risk can differ in different people. In addition, the doubling of a risk is not necessarily bad, e.g. doubling a chance of one in a million to two in a million.

According to Ralph, it is important to analyse how values and knowledge contribute towards risk judgement. Do you need scientific knowledge to make a decision? This depends on the decision you need to make. For some decisions it is essential, while for others it may be useless. Scientific knowledge often has to be resituated or reclassified: how does that knowledge make sense in a specific situation? Much of the knowledge is inert, because it does not really help us to make decisions.

Another thing is that young people think that they are immortal, and they think this because of a change in physiology. Therefore, young people worry less about risks and adults tend to estimate risks as higher. So how do we discuss these things with students, if they estimate risks differently? Ralph admitted that he does not really know how to do this.

Klaas van Hees put forward the point that he recognizes the perceived immortality of students. For example, when they read about the risks of eating red meat and so on, they think 'Everything is lethal, so I might as well eat it; it does not matter anyway.' However,

when it comes to making a judgement for someone else, they are able to take risk into account.

#### Choosing contexts for moral education

The last topic of discussion was on the concepts and contexts of teaching. Paul van der Zande stated that it is advantageous to choose your own context. Instead of genetic screening for health, CSI (crime scene investigation or DNA forensics) provides an appealing context. The important thing is that you keep in mind what the context means to your students. Marc van Mil wondered how the use of contexts can cover all of the concepts you are expected to teach.

Ralph Levinson explained about 'Perspectives on science' (see http://www.wellcome. ac.uk/stellent/groups/corporatesite/@msh\_publishing\_group/documents/web\_ document/wtxo53188.pdf). This is a discussion-based course for students aged 16+. Students produce a 6000-word essay of their choosing that explores historical, philosophical and ethical issues. It turns out that this course raises their level of philosophical and ethical reasoning enormously. When students say, 'I just happen to believe that' and teachers say, 'I want you to justify it. Everyone should respect that, but you do need to justify your beliefs', the students took that on board and it enhanced the quality of their moral thinking.

# Conclusions

#### The essential elements of genomics education are:

#### Risk

The teaching of risk should include the following:

- Concepts such as probability, uncertainty, impact (both benefits and harms) and trust.
- Raising awareness: nothing is risk-free, reducing risk is costly, in some cases it is better to avoid risks (the precautionary principle) and there is a difference between perceived risk and measured risk.
- Differences in risk perception: young people tend to think they are immortal.
- Drawing uncertain conclusions from data and analysing the way data are presented (for example, absolute and relative risk).

Furthermore, risk should be incorporated into the science curriculum and applied to topical issues. Cooperation between science and maths teachers could have added value.

#### Moral education and moral reflection

- Moral education on genomics issues could include learning and applying philosophical positions.
- Promoting moral development and moral argumentation can be studied in different ways.
- Teachers should think through issues themselves and be aware of the values at stake rather than having extended knowledge of ethical frameworks.
- Moral education can lead to change and moral development, but should not prescribe values or opinions.
- Moral argumentation can be enhanced by assignments in which students study in-depth historical and ethical issues.
- Emotional considerations are important in decision-making and should therefore be addressed in education.
- The phases in the process of genetic testing raise different issues and emotions and offer a useful framework for educational design.
- A safe class environment is essential for expressing and reflecting on emotions when teaching decision-making.
- Teaching strategies for moral reflection put high demands on teachers; consequently, they need to develop the appropriate expertise.

#### Concepts and notions

- Experts in medical health genomics indicated that the following concepts should be included in the science curriculum:
  - Genetic testing.
  - Genetic variation (e.g. genetic polymorphisms, SNPs).
  - The relationship between genes and disease (high-/low-risk genes, multifactorial and polygenic disorders).
  - Techniques such as microarrays, sequencing and whole-genome screening.
  - Risk assessment.
- These concepts are needed to build notions such as uncertainty, complexity and probability.
- There are different opinions concerning the extent of conceptual knowledge required for decision-making on genomics issues.

# Session D Implementation of genomics education

# Genomics in the curriculum in Israel

Anat Yarden

# Genomics in health-related education

Martina Cornel

# Discussion

Conclusions

## Genomics in the curriculum in Israel

#### Anat Yarden

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In Israel's national system, students are taught genetics in the 9<sup>th</sup> grade in the course of their Science & Technology classes, a multidisciplinary topic. During the 10<sup>th</sup> grade, they usually have three hours each of biology, chemistry and physics. Subsequently, they can select one of these disciplines, or Science & Technology in the Society, which combines all of the aforementioned topics. We tend to treat students as future citizens rather than future scientists. During the biology majors programme in the 11<sup>th</sup> and 12<sup>th</sup> grade, students receive 300 hours of biology per year. The course is composed of a theoretical part consisting of six topics, and a practical part consisting of laboratory training and a research project. Both components include the development of scientific literacy skills, including reading scientific articles. The theoretical part consists of:

- Three core topics: The living cell, Systems in the human body and Ecology.
- Two elective topics from: Genetics, Evolution, Animal behavior, Energy flows, Transport systems, Communication, Microbiology or Reproduction.
- One research topic on: Developmental biology, Biotechnology or Biodiversity.

The teachers choose the elective courses, including the research topic. We are currently investigating how to integrate genomics into the genetics elective. The aim of this course is to make the student acquainted not only with knowledge of the principles and facts of heredity, but also how the science of genetics has been and is being developed, and to provide elementary knowledge of the modes of genetics research (following Hutchinson, 1922). We believe it is important for students not only to accumulate facts, but also to comprehend the uncertainties of science and the way in which knowledge is acquired. About 10 years ago we started a project in which we developed an educational genetics website on which students can decipher the secrets of the genome by making use of bioinformatics tools. The genetics module is 30 hours, and this web-based environment is integrated at the end. The module is very different from assignments developed previously, as students have to actively solve a complex problem using these bioinformatics tools. Our research was based on two theoretical frameworks: authenticity and challenges in learning modern genetics. Table 8 describes different aspects of these two frameworks.

In this study, our research question was, 'How does learning to use the simulation influence students' understanding of genetics?' Our results showed that the simulation promotes

Table 8. Theoretical framework of our research

#### Authenticity

A model based on a research project actually being carried out by scientists rather than a school project (Chinn & Malhotra, 2002).

Provide a real-life problem-solving context with high degrees of complexity (Lee & Songer, 2003).

Let the students have first-hand experiences: employ authentic tools and procedures as used by scientists (Edelson, 1998).

Let the students have first-hand experiences: use a simulation of complex multistep research that could not be conducted in school due to lack of time and equipment (Chinn & Malhotra, 2002).

#### **Challenges in learning modern genetics**

Forming a coherent continuum between phenotype and genotype (Marbach-Ad & Stavy, 2000; Lewis & Kattmann, 2004; Duncan & Reiser, 2007).

Linking the molecular level and the determination of the heredity pattern (Knippels et al., 2005; Stewart *et al.*, 2005).

Students should be given experiences with the practice of genetics, to understand how the specific subject-matter knowledge has been generated and justified through the research process (Cartier & Stewart, 2000).

understanding of the relationships between molecular mechanisms and phenotype, as well as an understanding of the research heuristics used by geneticists in revealing the function of a gene (Gelbart & Yarden, 2006). We also found that the students' ability to respond correctly to 12 true/false statements in genetics increased, as did their capacity to provide an explanation for their choice of either true or false (see Figure 5).

In our more recent research, we asked, 'How do students' approaches to learning influence their learning outcomes?' In this qualitative study, the learning process of two pairs of students who used the simulation in laboratory settings was documented. The four students were 12<sup>th</sup> grade biology majors, who had almost finished their genetics elective, were known to be high achievers and who volunteered to participate in this activity. The analysis of the results was carried out in two steps. The analysis of the students' learning approach (step 1) served as the perspective for the analysis of genetics understanding (step 2). The two students using a research-oriented approach were paired, as were the other two students using a task-oriented approach (see Table 9).



**Figure 5.** The scores of the students of the true/false statements (A) and their scores of the explanations of their answers (B). exp, experimental group; con, control group; pre, before the simulation; post, after the simulation.

Next, we divided the learning processes into recognition of the research practices of the genetics discipline, and expansion of the students' genetics knowledge. The results are shown in Table 10.

From these results, we concluded that the learning environment provides learners with the opportunity to expand their genetics knowledge through the recognition of genetics

Table 9.	The	learning	approaches	of the	four	students	(from	Gelbart	et al.,	2008)
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Research-oriented	Task-oriented
The students were constantly involved and attempted to cope with the scientists' steps.	The students made limited efforts to understand the scientific steps and gave little attention to the research sequence.
The students made efforts to understand the scientific tools and procedures.	The students focused on a procedural level in each assignment.
The students were engaged in interpreting the data and generated explanations spontaneously when introduced to the data.	The students used the tools superficially to find correct answers, with no further interpretation of the data.

	Learning approach			
	Research- oriented	Task- oriented		
Recognition of the research practices in genetics				
Understanding the research goal	+	+/-		
Using tools and procedures of the discipline	+	+/-		
Interpreting data presented in each of the assignments and generating inferences and explanations	+	+/-		
Answering the research question	+	+/-		
Generalizing from a particular problem	+	-		
Coordinating results from different stages of the study	+	-		
Referring to each of the research steps in the framework of the genetics problem, and understanding the explanatory power of that framework	+	-		
Predicting the next research question	+	-		
Understanding the heuristics	+	+/-		
Expansion of genetics knowledge				
Referring to various organizational levels (connecting phenotype and genotype)	+	+		
Forming a link between classical and molecular genetics models	+	-		
Connecting genetics concepts to genetics-research practices	+	+		
Examining critical characteristics of genetics concepts	+	-		
Recognizing gaps in prior knowledge	+	-		
Referring to the normal and mutated versions of the gene	+	+		

Table 10. The results of the learning processes (from Gelbart et al., 2008)

research practices. This has two educational implications. First, we suggest that, in a classroom setting, learners should be encouraged by their teachers to follow the scientists' steps in the context of the genetics research while learning using simulation. Secondly, the teachers' involvement is particularly important for students with a task-oriented approach to learning science. The module with the simulation may therefore not easily

be transferred to the classroom and it may be particularly challenging for teachers with students who have a task-oriented approach.

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### Genomics in health-related education

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Almost the entire human genome was sequenced at the beginning of this century, and it was claimed by many that this would rapidly result in considerable changes in the practice of medicine. Indeed, the Online Mendelian Inheritance in Man (OMIM) database currently displays a large number of genetic diseases: over 19,000 genes or Mendelian disorders are described. However, the number of diseases for which both phenotype and DNA sequence are known is only about 400, so there remains much work to be done. In the past, genetic diseases for which you visited a doctor were monogenic disorders: rare but usually very serious. Nowadays, when we speak of genetic diseases we often mean chronic diseases in which more than one gene is involved and that usually have less serious consequences. In the years to come, we expect that the greatest health benefit of advances in our understanding of the human genome will be realized for common chronic diseases such as cardiovascular disease, diabetes mellitus and cancer (Scheuner et al., 2008). A problem related to this development is that physicians lack insight into genetic testing and its social implications, and do not understand the concerns regarding privacy and discrimination. Furthermore, they report that they do not know exactly when to use genetic services. Thus, physicians currently lack the knowledge of genetics relevant for their daily practice.

In a study by Baars *et al.* (2005), medical departments were requested to provide insight into the questions asked during a genetics examination for medical students, and this information was put into a database. Subsequently, experts from non-genetic healthcare fields were asked to indicate what they considered to be essential, desirable or 'too specialized' knowledge based on the information in the database. The cut-off scores for passing according to the non-genetic healthcare providers were 85, 65 and 48% for essential, desirable and 'too specialized' knowledge, respectively. When medical students about to graduate were asked to take the test, the results were disappointing: only 50% of the answers were correct, and only 3% of the students answered 85% or more of the questions about essential knowledge correctly (see Figure 6). On the other hand, they had a lot of 'too specialized' knowledge. The conclusion was therefore that medical students nearing graduation lack the genetic knowledge essential for clinical practice. Thus, changes need to be made to the medical curriculum.



**Figure 6.** Results from a test given to medical students about to graduate. (From Baars et al., 2005.)

For genomics to have an effect on clinical practice that is comparable to its impact on research, an improvement in the genomic literacy of healthcare providers (Guttmacher *et al.*, 2007) is needed. For example, midwives, who generally show low confidence with genetic issues, consider the psychosocial, screening and risk assessment issues to be more important than the technical aspects of genetic services (Benjamin *et al.*, 2009). Considering the changes genomics has brought to society and medicine in particular, these are unfortunately still few. An example is the Mammaprint®, a recent development from the Netherlands. This test provides gene expression profiles of breast cancer tissues, which can be used to predict the recurrence of disease. If the prognosis is good, the woman may not need chemotherapy. The Mammaprint® has already been approved by the FDA and is used in clinical practice. This was possible because the test fits nicely within the existing diagnostic and therapeutic channels. However, it would be much more difficult for a test designed for the prevention of disease, for instance.

An example is a diabetes risk test, which can be bought via internet (van Ommen & Cornel, 2008). The test is based on one gene for which the unfavourable variant gives an additional risk with an odds ratio of about 1.5. In the Netherlands, the risk of getting diabetes is about 13%; with the unfavourable version of the gene the risk increases to between 17 and 19%. But what does that mean? It will not change the practical advice

you get from your physician: you still need to eat healthily and exercise. Thus, you pay about \$300 to get advice to do what you already might or should be doing anyway. Therefore, many medical professionals believe that these tests are a waste of money. Nowadays, you can also buy tests for monogenic disorders – such as for certain subtypes of cancer – from a commercial company without first consulting a clinical geneticist or receiving psychological help to deal with the results. Furthermore, the quality controls of these tests are highly dubious.

Regarding the question 'What is new?', my answer would be that the methods of research have changed, for instance due to the development and application of genome-wide association studies. Such studies are hypothesis-free: we collect a lot of genomics data, put them in a database and see whether we can correlate some of these data with, for example, disease susceptibility. Thus, the medical curriculum should be adapted such that genetic susceptibility is included in the discussion on the causes of common diseases. Furthermore, the roles of patients and physicians are changing because of the advance of 'consumer genomics'. More and more, patients are likely to visit their physician announcing that they have ordered a genetic test via the internet. Often, such a test will not have any clinical utility, so physicians may need to protect patients against their (unfounded) hopes and fears. In the medical curriculum, these issues should be included by discussing the pros and cons of (commercially available) screening tests. Regarding upper secondary education, the hypothesis-free approach of doing research is highly relevant, as it is an entirely new approach. Here also, direct-to-consumer tests should be included, as they are available for everyone and thus relevant for all (future) citizens. A question to consider is whether you can interest students in these issues, as they tend to think more about current issues rather than what may happen in the future. That is why prevention programmes, for example to stop smoking, do not really appeal to them. An additional example regarding the medical curriculum can be given: about 20 years ago, researchers in Canada asked patients what physicians should know and how a doctor should be trained. This resulted in the CanMEDS Physician Competency Framework, which was launched by the Royal College of Physicians and Surgeons of Canada in 1996 (http://rcpsc.medical.org/canmeds/index.php). This framework includes different roles for a physician, not only that of medical expert, but also of communicator and health advocate, as patients considered these competencies to be important for physicians (see Figure 7). Doctors should be able to communicate, collaborate and refer patients to other physicians; they should be thinking in terms of prevention or health advocacy; they should keep up with new information ('scholar'); and they should know and follow the





professional guidelines. The VU University Medical Center added the term 'reflector', which was implicitly present in the original CanMEDS model.

Since the introduction of CanMEDS, many curricula for medical students have become problem-based and patient-centred, and attainment targets mention core competencies rather than specific topics. For example, in the Dutch end-of-term examinations for medical students, words such as 'genetics', 'anatomy' and 'genomics' are not mentioned explicitly.Therefore, as Guttmacher *et al.* (2007) has stated, for most clinicians the genomic era has not yet arrived. As mentioned previously, for advances in genomics to have an effect on clinical practice, advances in the genomic literacy of healthcare providers are needed.

Another point to consider is that genomics is special in that it is a young and rapidly evolving domain. In order to understand and incorporate this domain, one therefore needs to become a lifelong learner. Thus, we will need to teach our students the knowledge, skills and attitudes that will make them lifelong learners of genetics and genomics. With regard to the core competencies, in my opinion the following list embraces the most important aspects of genomics:

- Identify patients who require further investigation or specialist referral.
- Understand and communicate the disease risk to facilitate and support the patient's informed decision-making.
- Understand modes of inheritance: the concept of multifactorial inheritance as well as awareness of rare Mendelian disorders.
- Have a low threshold for discussion with a genetics specialist.
- Understand genetic tests, both the results of molecular genetic tests to identify Mendelian disorders and the results of more common diseases, such as breast cancer.
- Understand information in laboratory reports, including the limitations.
- Understand risk calculation and when to refer patients.
- Use pre-symptomatic testing for Mendelian disorders only in association with genetic counselling.
- Be aware of the specific genes that contribute to specific disorders, the clinical significance, the distinction between an abnormal genotype/phenotype and the implications.

The skills that are required of a physician with regard to genomics may change even more, and more quickly, than the knowledge content. Such skills include assistance in making informed decisions, talking to patients about ethnicity with respect to genetic tests, and dealing with the personal experiences of patients and family dynamics. Therefore, students and future physicians must be able to frame genomics in a practical clinical context. An inclusion of clinical examples to illustrate the fundamental principles of genomics as they relate to common diseases is needed, as common diseases will be a main focus in their later careers. Such examples will serve to develop a genomics way of thinking, not necessarily to cover all relevant disease conditions. We need to bridge the gap between basic science courses and clinical perspectives, and to teach our students to use a genomics approach in their thinking. Furthermore, it is important to integrate diagnosis, treatment and prevention of common diseases in the medical curriculum. Table II shows some recommendations for integrating genomics into education as formulated by Guttmacher *et al.* (2007).
**Table 11.** Recommendations for integrating genetics into education (from Guttmacher *et al.*,2007)

Recommendations
Integrate genetics across the pre-service curriculum
Increase the amount of content that is related to genetics and common diseases, as opposed to rare Mendelian diseases
Build bridges between basic sciences and clinical instruction
Ensure that instruction is care-based and reflects practical examples that demonstrate genetic matters on a daily basis and can improve patient outcomes

Develop continuing-education programmes in conjunction with representatives of the target audience

To conclude, first, we should combine new conceptual views of genomics with the practice of genetic counselling. Secondly, it is obvious that teachers need continuing education, as do the multidisciplinary teams in which physicians collaborate. Thirdly, the number of people needing genomics training will continue to expand and individual training may therefore not be feasible. The internet may increasingly play a key role as a teaching medium.

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### Discussion

#### The aims of genomics education

Marc van Mil perceived an inconsistency between the content and the aim of genomics education in the curriculum in Israel. This curriculum is aimed at citizenship, but includes an assignment in which the students have the role of genetic counsellors. In addition, he doubted whether the content of this assignment is in accordance with what genetic counsellors need to learn according to Martina Cornel. Martina answered that the module in the Israel curriculum may be based more on what is required for researchers than for counsellors, and that these students are already very involved. Genetic counsellors get extensive communication training, such as finding out whether the patient has understood them and understanding the emotions of their patients. What might still be needed for first-year medical students is a basic understanding of genetics, but this does not fit well into their future practice.

AnatYarden explained that the education that students need is very different for secondary school students compared with medical students. We should ask ourselves the question what is of interest to the students, and let them solve the problems by themselves with the appropriate tools. Anat really wants them to learn how scientists think, the way they use tools and the way they reach their conclusions. The course itself is a bit of a teaser. Marc wondered why it is so important for Anat that the students are prepared for citizenship. Anat replied that she does not think that secondary school should be a preparation for university - she thinks they should choose later on whatever they want to study. Jenny Lewis wondered whether the political situation in Israel might affect this gap between school and study: when students graduate in secondary school, many go into the army first and only decide afterwards whether they want to go to university. Anat asked whether the university preparation is really an aim for Dutch teachers. Paul van der Zande answered that it is one of the aims. Dutch teachers also want to prepare students for citizenship. Martina added that she really wants 16- and 17-year-olds to be able to think, 'What does it mean when a doctor offers me a DNA test? What will be the consequences for the rest of my life, in terms of health, work and insurance?' She would like students to understand this line of thinking. Questions such as, 'Do I buy this DNA test?' will be important for every citizen. This context is quite different from understanding how scientists build their knowledge.

Paul considered it very important for students to have an inquiring attitude and to ask questions such as, 'Why is this happening?' Martina agreed that the research attitude is important, but that the consequences for you personally should be a part of education as well. Otherwise, it may teach you academic thinking and how to be critical and so on, but it will not teach you what to consider when offered such a test. Everyone agreed on this. Arend Jan Waarlo asked what kind of activities students need in order to learn 'genetic thinking' and for which group of students this would be appropriate. Are we aiming at a core curriculum, a scientist career or a citizen career?

#### Bioinformatics in the curriculum

Robbie Joosten remarked on the data-driven science and hypothesis-free research mentioned by Martina Cornel. He believes this is typical for genomics, and wondered what her views are on implementing it in high schools. Martina answered that you can still keep asking questions about relationships between genes and disease, but it is less specific. We can show students the power of bioinformatics. An approach to implement this in secondary school teaching is by showing examples of how this is done in science. Robbie replied that going from data to a question or hypothesis is already a very difficult step. You have to find certain ways of pattern matching, which means that students need more mathematics to be able to understand the data. That problem was raised in a previous session: there is too little mathematics in biology. Therefore, he believes there should be more to it than just a few examples. Martina responded that she was not sure about that. Medical students are not very good at mathematics, but they are able to interpret the results of data from pictures without knowing what a relative risk is, or understanding the mathematics. So maybe it is not always necessary to understand the mathematics completely. Robbie added that science teachers should of course not teach mathematics in depth. Pattern matching is something you can do by visually inspecting your data; it is relatively simple. But that is not the way it works in genomics. In genomics, you look at many data and it is harder to understand how to get from data to information. It is more of a mathematical or informatics way of thinking. You do not have to know the formulas, but you do have to know that there is some form of pattern involved or recognition. Martina replied that it is not a new concept for a doctor to use pattern matching. They use it every day, by establishing which symptoms a patient has and linking it to a disease.

#### Authenticity in genomics education

Michiel van Eijck then raised the issue of authenticity: Anat Yarden explained in her presentation that she tried to produce an authentic programme and we saw the results in the form of research- and task-oriented students. Michiel wondered whether this programme really stimulated authentic learning, because there was no attention given to problems defined by the students. In addition, authenticity is not so much a matter of the programme in itself, but how students experience it.

Anat responded that it is true that the problem was already solved, so in that way it is not really authentic. It is a simulation of research, but it is authentic in the way the tools are used. It is more a complex problem-solving activity. However, we have to compromise, because doing real research in school is not possible. Marc van Mil asked how to involve students who are by nature not so research-oriented: how do we make it truly problematic for all of them? Anat explained she did not mention this in her presentation, but that this is done by the teachers. They ask questions and make it a real problem for the students.

#### The role of the teacher in metacognition

Dirk Jan Boerwinkel suggested that there is a specific role for the teacher, and perhaps also in the design of an activity like this. The students are learning a lot, but what they should be learning according to Anat Yarden is not the factual information, but an idea of how genetic research is done. Dirk Jan doubted whether students are aware that they are also learning this general view, so after the assignment other activities should be planned to transfer the general view of thinking to other problems. The teacher plays a key role in this. After the assignment, you have to spend time on discussions, so that students can reflect on what they have learned. Anat agreed with Dirk Jan. She believes that students are getting familiarized with the tools much faster than the teachers, so they have to think carefully about teacher development. It is not a teacher-free environment and the role of the teachers is essential in the classroom.

Klaas van Hees agreed with Dirk Jan that teachers should discuss this with the students afterwards. It is very important to make students aware that they are being taught to use a certain way of thinking that is transferable to other situations, and that they should not focus only on procedures or factual knowledge. Klaas's experience with students doing the bioinformatics laboratory – one of the mobile DNA laboratories – has been as follows: the students pointed out that there were shortcomings in the bioinformatics programme and expressed the wish to use their procedural knowledge in another way. Only when Klaas pointed out that they were already able to do that they realized that they had indeed learned to do this. Klaas added that his students really enjoyed working independently with the bioinformatics tools.

Anat mentioned that this kind of evaluation and reflection with the students was exactly what her teachers also did.

#### **Risk and probability**

As a final question, Ralph Levinson asked Martina Cornel whether she thinks it is important to distinguish between risk and probability. The outcome of genetic tests depends on many things. Probability can be measured, but risk has to do with various factors beyond chance and probability. Martina answered that she prefers not to stress the distinction between risk and probability, but rather that physicians so far have thought of genetics as 'determining' what is going to happen. For example, if you have the gene for Huntington's disease, then you will get Huntington's. Nowadays, many physicians' practices have to do with gene and environment interactions, and with factors that you can influence. So, if you know that you have an increased probability of a disease, you should adjust your lifestyle, because it might decrease the risk. The advice physicians give nowadays is related to lifestyle and medication, and these are all related to those probabilities that genomics tells you about. So probability is not such a different concept from risk.

## Conclusions

#### General

- Students should be given experiences with the research practice of genetics to understand how the specific subject-matter knowledge has been generated and justified through the process of inquiry.
- It is important for students not only to accumulate facts, but also to comprehend the uncertainties of science and the way in which knowledge is acquired.

#### Research on genomics education

- Research on a project in which students actively solve a complex problem using various bioinformatics tools shows the following:
  - Simulation promotes an understanding of the relationships between molecular mechanisms and phenotype, and promotes understanding of the research heuristics used by geneticists in revealing a gene function.
  - The learning approach (research-oriented versus task-oriented) seems to be an important factor in determining the learning outcomes in an open-learning situation, both in recognition of the research practices of the discipline of genetics and in expansion of the students' knowledge of genetics.
  - Teachers should encourage students to follow the scientists' steps in the context of the genetics research, while learning through simulation.
  - Teachers' involvement is especially important for students with a taskoriented approach to learning science.

#### The need for attention to genomics in health-related education

- The greatest health benefit of advances in understanding the human genome will be realized for common chronic diseases such as cardiovascular disease, diabetes mellitus and cancer. Education of healthcare workers should illustrate the fundamental principles of genetics as they relate to common diseases, because these are the diseases that they will spend most time on in their later careers.
- Physicians lack the knowledge of genetics relevant for their daily practice and do not know exactly when to use genetic services. They lack the oversight of

genetic testing and the social implications, for example the concerns about privacy and discrimination.

- For genomics to have an effect on clinical practice that is comparable to its impact on research, an improvement in the genomic literacy of healthcare providers is required.
- There are serious doubts concerning the value of commercial genetic tests.

#### Contents of genomics education in health-related education

- Upper secondary education should pay attention to research methods such as genome-wide association studies because they are fundamentally different from earlier methods, for example in the fact that they are hypothesis-free.
- Direct-to-consumer tests should be included in the curriculum, because they are relevant to all citizens, as these tests are available to everyone.
- In the medical curriculum, the changes in genomics should result in the inclusion of genetic susceptibility when discussing the causes of common diseases. Physicians may need to protect patients against their (unfounded) hopes and fears.
- We will need to teach the knowledge, skills and attitudes that will make students lifelong learners of genomics, as it is a very young and rapidly evolving domain.
- The following list contains the core competencies of health-related genomics:
  - Identify patients who require further investigation or specialist referral.
  - Understand and communicate the disease risk in order to facilitate and support the patient's informed decision-making.
  - Understand modes of inheritance: the concept of multifactorial inheritance as well as an awareness of rare Mendelian disorders.
  - Have a low threshold for discussion with genetics specialist.
  - Understand genetic tests, both the results of molecular genetic tests to identify Mendelian disorders and the results of more common diseases, such as breast cancer.
  - Understand information in laboratory reports, including the limitations.
  - Understand risk calculation and when to refer patients.
  - Use pre-symptomatic testing for Mendelian disorders only in association with genetic counselling.

- Be aware of the specific genes that contribute to specific disorders, the clinical significance, the distinction between an abnormal genotype/ phenotype and the implications.
- The skills physicians need with regard to genomics may change more, and more quickly, than the required knowledge. These skills include making informed decisions, talking to patients about ethnicity with respect to genetic tests and dealing with the personal experiences of patients and family dynamics.
- We need to bridge the gap between the basic science courses and the clinical perspectives, and teach students to 'think genetically'. It is important to integrate the diagnosis, treatment and prevention of common diseases in the curriculum.

#### Questions concerning genomics education in secondary education

- The aims of genomics education:
  - Are we aiming at a core curriculum, a scientist career or a citizen career?
  - How much time should be devoted to university preparation in comparison with preparing students for citizenship?
  - Is empowerment for understanding the consequences of genetic tests more important than developing a research attitude?
  - What kinds of activities do students need in order to learn 'genetic thinking' (the What?) and for which group of students (the Who?)?
- Bioinformatics in the curriculum:
  - How much mathematics do students need to be able to understand bioinformatics data?
  - How many examples are needed to understand how such knowledge is used?
- Authenticity in genomics education:
  - Is the room for students to formulate their own questions the hallmark of authenticity?
  - Alternatively, is the hallmark of authenticity using the tools that are used by scientists?
- The role of the teacher in metacognition:
  - To focus students on 'genomic thinking' rather than concepts and procedures, specific activities have to be planned to enable the transfer of the general thinking pattern to other problems. The teacher plays a key role in transfer learning.

- Risk and probability:
  - Are risk and probability different concepts or can they be treated the same? (Probability can be measured, but risk has to do with many factors beyond chance and probability).

# Session E Overall conclusions and recommendations from sessions A–D

Conclusions

# Back to the framework: the what, why and how of genomics education

Dirk Jan Boerwinkel

## Conclusions

In this small group work session, conclusions and recommendations with regard to the biology curriculum in secondary education were formulated by three subgroups. The statements contain specifications of:

- The goals: what do we want to achieve?
- The concepts: what should therefore be taught?

The following is a summary of the suggestions from these three subgroups.

#### 1. Uncertainty and the nature of science

- Students should be able to understand science as an ongoing process with inherent uncertainties. The development from genetics to genomics can be used as an example to describe the constant development of science. This means that the curriculum should combine 'ready-made science' with 'science in the making'.
- Students should understand that science does not have all the answers and evidence. This applies especially to the context of genomics, as brought forward by the issues of determinism: genomics undermines genetic determinism; it provides freedom, but also responsibility with regard to your lifestyle. Generally, there is a negative connotation of uncertainty, but on the other hand this also provides freedom!
- This means that uncertainty is also a key concept. In genomics, this concept appears in two ways:
  - Science is an ongoing process and knowledge will continue to change through the development and application of novel technologies.
  - In most biological phenomena, the interaction between genes and the environment is complex and genetic information will generally provide indications of risk rather than certainty.
- Important concepts linked with uncertainty are monogenic versus multifactorial, risk and genetic information.

#### 2. Complexity and the genomics perspective

- Students should learn about the interactions of genes: their functions on many different levels and in many different ways, for example in lifestyle choices.
- Students should be able to describe how things 'act out' at different levels. Students should be able to connect genetics to everything, not just to monogenic diseases, but also to heart disease and so on.
- Students should integrate and inter-relate biological concepts by using a genomics perspective; they should understand genome expression on different levels of biological organization, also known as systems thinking. Systems thinking is the main goal, whereas genomics is a tool to stimulate systems thinking. When studying the heart in biology, students should realize how the structure and function of the heart are represented in the genome and how the genome interacts with the development and functioning of the heart. In education, one should search for practices in which this relationship is important, for example in medical testing for sports professionals.
- We should avoid the image that genomics is a medical phenomenon; it should also be applied to evolution (students frequently ask, 'Are we still evolving?'), agriculture and industrial technology.
- Students should also inter-relate products and processes on different levels. A gene cannot be defined simply as a sequence of nucleotides; the description needs to include processes such as expression, transcription, mutation, regulation, and so on.
- Complexity is another key concept and forms a pair with uncertainty. Related concepts are, for example, genome structure, systems biology and bioinformatics. It is important to specify complexity further in order to include this concept in formal curricula.

#### 3. Learning for life

- Students must be prepared for life-long learning.
- Students must be able to evaluate the impact of genomics and form their own opinion on societal issues. This means that, in one way or another, morality must be included in the curriculum. Students should learn to think about the impacts of genomics from a personal perspective, as well as from a democratic perspective.

# Back to the framework: the what, why and how of genomics education

#### Dirk Jan Boerwinkel

In this section, the conclusions from sessions A–E are used to answer the questions put forward in the introductory keynote paper 'A framework for rethinking science curricula in the genomics era'.

#### Question 1: Has genomics changed research methods and results in life sciences in a way that makes changes in the curriculum desirable?

It is not a new revelation that most traits of man and other organisms are determined by the complex interaction of genes and the environment. What is new is that the research focus has shifted from studying monogenic traits to collecting and interpreting genomewide data on complex relationships. High-throughput screening techniques and the use of bioinformatics make it possible to study the influence of many 'low-penetration' genes on the phenotype. Research methods include techniques to study differences in gene activity, for example between healthy people and patients. In turn, the identification of groups of patients with different gene expression leads to the development of targeted therapy for these patients.

Many genes that appear to be correlated with the phenomenon under study (for example, metastasis) are not found as a result of a hypothesis-testing research, but as an unpredicted result of screening techniques. Sometimes the function of these genes is not even known. This 'hypothesis-free' type of research provides many starting points for further investigations.

The complexity of the relationships within the cell requires a strategy in which the results of research lead to the development of a model for interaction of the different molecular components. These models explain the activity of these components as part of a system with a specific role in the cell. The models are tested by generating and investigating new research questions. This type of research in which many disciplines cooperate is known as systems biology.

Research on molecular evolution has led to new theories on the phylogeny of organisms and the migration of mankind. This illustrates that new techniques can create new knowledge that replaces former theories. These important advances in molecular medicine and molecular evolution are not yet represented in most science curricula.

## Question 2: How can these changes best be described and structured to be of use in a curriculum discourse?

This question will be answered in the section on content at the end of this article.

## Question 3: Has genomics raised new societal issues in a way that makes changes in the curriculum desirable?

In the past, the study of monogenic diseases resulted in many medical and administrative measures, such as testing of newborn infants for phenylketonuria (PKU) and other afflictions, and prenatal testing for Down's syndrome. Patients with a serious monogenic disease such as Huntington's and their relatives are assisted in their decisions by genetic counsellors. Uncertainty in these decisions often means that the person in question does not know whether he or she (or the embryo/foetus) carries the gene.

This practice is now complicated by the possibility of testing for many other genetic variants that increase or decrease the risk for a certain affliction. This means that, even when the presence of the variant is established, there is no certainty about the future, because the variant is only one of a range of factors. Some gene variants have a strong predictive value, such as the BRCA genes for the risk of breast cancer. Other variants indicate only a slightly higher risk. An example of a societal issue connected with this uncertainty is pre-implantation genetic diagnosis, in which embryos are tested before implantation. In the Netherlands, the question of who decides which genetic variants are included in this test has become a political issue.

Methods to distinguish these variants have become simple and cheap. As a consequence, many commercial enterprises offer these tests for a limited price directly to the public, without the need to consult a medical professional. There are many doubts concerning the value of these commercial genetic tests. Other issues concern the fact that test results may cause unnecessary worry in people and may lead to further unnecessary, expensive and possibly harmful medical investigations. It is possible that, in the future, genetic testing will be a normal procedure, for example in medical testing for certain professions or sports. The '\$1000 genome' is often discussed in the media. Therefore, is it necessary to introduce students to these issues.

Changes are needed not only in secondary education, but also in medical training. In order for genomics to have an effect on clinical practice that is comparable to its impact on research, it requires an improvement in the genomic literacy of healthcare providers.

During the workshop, the emphasis was on biomedical applications of genomics. Applications in agriculture and industry are also connected with societal issues, such as gene patenting and biosafety and biosecurity of the products of synthetic biology. These issues were not discussed in the workshop.

# Question 4: How can these changes best be described and structured to be of use in a curriculum discourse?

This question will be answered in the section on content in the end of this article.

# Question 5: Are genomics methods, concepts and issues sufficiently relevant to students in upper secondary education to make changes in curriculum desirable?

#### and

#### Question 6: Are genomics methods, concepts and issues understandable by students in upper secondary education?

As there is little experience on this matter, most of the answers come in the form of research proposals. The experience that is available, like the experience with bioinformatics simulation in Israel and with mobile DNA laboratories in the Netherlands, shows that most students find genomics and contexts like cancer research interesting. However, these are students who have chosen to study biology at an advanced level.

Research is required to study what knowledge is necessary to recognize and appreciate social issues related to genomics. This research should include the extent to which students of this age are capable of developing this knowledge.

Examples of research questions would be:

- What knowledge of genomics is needed for engagement with socio-scientific issues relating to genomics?
- Is it possible to define a basic but coherent conceptual framework for genomics that could be extended as needed in the future, and would students in either age group be able to develop this?
- What image do students have of the genome and its impact on their lives?
- Are research methods in genomics understandable by students in this age group?
- What is the attitude of students towards socio-scientific issues such as genetic testing?

# Question 7: What is the importance of genomics education in the core curriculum?

Why should genomics form a part of the curriculum of all students? The categories formulated by D.A. Roberts and mentioned in the keynote article are elaborated below.

#### Everyday coping

It is probable that, in the future, genetic testing will be a normal part of medical procedures, and that part of this testing will be offered outside the medical system. This means that students should be empowered to value genetic information in personal decision-making, especially when coping with risk information and uncertainty.

#### Science, technology and decisions

In some cases, government decisions will influence the autonomy of citizens concerning genetic information, for example in databanks of forensic or medical genetic information and in decisions about which gene variants will be included in pre-implantation genetic diagnosis. This means that students should also be prepared for such societal decisions. Societal discussion may include ethical questions on the acceptance and value of life with a potentially avoidable genetic affliction, and questions about the ownership of genetic information, for example in patenting genes and genotypes.

#### **Correct explanations**

In these discussions, a correct image of the genome is essential. This is not necessarily a detailed molecular image, but it should avoid genetic determinism. Linked to this, the principles of how data are collected and what information can be gained are important.

The image of the genome should therefore include a basic idea of how genomic information is collected and used.

## Question 8: What is the importance of genomics education in the advanced curriculum?

It has been stressed that future researchers and professionals should be aware of the personal and societal issues related to genomics. Therefore, the advanced curriculum should build on the core curriculum or include it. The other roles of genomics in an advanced biology curriculum are again linked to the categories formulated by Roberts.

#### Structure of science/correct explanations

An advanced curriculum should develop coherent biological conceptual systems. Genomics pervades all biological concepts and has brought significant change to some of them. The image of the genome has changed in such a way that much current textbook information about the functioning of genes is incorrect or mainly describes exceptions to the rule.

#### Scientific skill development

Genomics research is interdisciplinary and uses bioinformatics as a basic tool. Students should at least have an image of this kind of research, and experience shows that it is possible to introduce students to working with official databanks that are also in use by researchers.

#### Self as an explainer

In academic studies, it is part of a general university curriculum to study the development of the science under study and its relationship with society. The history of the gene concept is a perfect illustration of how scientific and societal ideas interact and are still under development.

#### Solid foundation

Genomics is essential as a base for all further studies in life sciences and also within medical curricula. The greatest health benefit of advances in understanding the human genome will be realized for common chronic diseases such as cardiovascular disease, diabetes mellitus and cancer. Training of healthcare workers should illustrate the fundamental principles of genetics as they relate to common diseases, because these are the diseases that they will spend most time on in their later careers. In addition, although not mentioned during the workshop, genomics will be at least as relevant in agricultural studies as in medical studies.

## Question 9: How can genomics education be structured most effectively in science education?

In order to decide on changes in the curriculum, we should look at the different roles students may have later on in their life. Which activities or competencies are needed to fulfil the roles in different communities of practice? Furthermore, in order to design a coherent knowledge base and a conceptual framework, it is necessary to ask the experts, to analyse school books and to assess how students talk about the subject and find the gaps that occur in their knowledge. At the classroom level, students should have an influence on what is taught and teachers should give ample opportunities for questions. This also informs the teachers about the interests and questions of the students. The concept of three communities of practice (research, professional and everyday life practices) can be translated into two different streams in upper secondary education:

- 1. Advanced curriculum: aimed at preparation for careers in the life sciences, such as research scientists and health professionals.
- 2. Core curriculum for all: preparing future citizens for informed personal and democratic collective decision-making in practice in everyday life.

## Question 10: How can genomics concepts and issues be learned and taught most effectively?

#### Systems thinking

There is a need for new pedagogical approaches that stimulate systems thinking in students. Examples of these are 'yo-yo learning' and modelling for coherent understanding of cell biology. Systems thinking competencies include being able to:

- Distinguish between the different levels of organization, i.e. cell, organ, organism and community, and match biological concepts with specific levels of biological organization.
- Inter-relate concepts at a specific level of organization (horizontal coherence).
- Link biology concepts from different levels of organization (vertical coherence).
- Think back and forth between abstract visualizations to real biological phenomena (modelling).

#### Authentic practices

The answers to Questions 7 and 8 indicate that it is important to learn how scientists think and how they obtain their data. It is important for students not only to accumulate facts, but also to comprehend the uncertainties of science and the way in which knowledge is acquired.

Mobile DNA laboratories are a way of bringing professional practice closer to the classroom. Other ways are guiding students to study primary literature and simulation of bioinformatics experiments.

It is not easy to give an honest image of scientific practice. Science is also deeply political, and explanation of this takes time, if indeed it is possible at all. Another difficulty is that current genomics practice uses a lot of maths. On the other hand, genomics practice offers chances: the open access to databanks with genomic information offers an opportunity to students to work with the same data as scientists.

#### Learning concepts in a situation in which they are relevant

An important question is whether we should think of science problems for the students or let them find their own problems. There is a big difference between what interests the teachers and what interests the students. Finding suitable problems is of special importance in designing narratives to introduce issues to students. Discussing real problems is a part of science education for citizenship. Scientists also have to be deeply sensitive to the societal aspects and issues of their work.

#### Using up-to-date technological advances in education

Students are often much more skilful than teachers in using technological and digital advances in education. In education, the content of many curricula may be new, but the communication and information technology is often outdated.

## Question 11: How can the current curriculum be adapted without increasing curricular overload?

The current (cell) biology curriculum is already overloaded. Students are supposed to learn hundreds of concepts, while only a few of these are used again later. Research has shown that the amount of knowledge that is needed to study socio-scientific issues related to genetics is limited but essential. The selection of conceptual knowledge should be based on the need for knowledge about the issues under study.

Decisions about including genomics imply that other subjects should make way for genomics. These are difficult discussions, and cannot be made individually but must be based on a coherent vision of the curriculum. As many issues discussed in this workshop concern citizenship education, cooperation with social studies should be explored.

We should not underestimate the importance of learning outside the curriculum. Students learn a lot from the media they are exposed to. To keep genomics in the spotlight might be a good strategy for generating interest.

# Question 12: How can teachers and other stakeholders be involved in the adaptation of the curriculum?

In order to involve teachers in the necessary changes in the curriculum, training is essential. Genomics education requires teachers to develop new 'pedagogical content knowledge': knowledge of relevant concepts and issues and pedagogical expertise. Until teachers have developed this knowledge, they are reluctant to make the intended changes to practice. This means that after training, some 'aftercare' is needed to promote the implementation.

A difficulty in teaching about genomics is that genomics knowledge is complex and uncertain. Teachers prefer to teach knowledge that will help students to understand phenomena, not knowledge that makes them uncertain. Even more difficult is the assessment of genomics knowledge. There is tension between the more practical aim of providing marks, and science education in terms of 'learning for'. However, genomics will need to be reflected in the assessment regime, otherwise it will be considered as a 'luxury theme' that can be omitted when time is limited.

Research is now in progress on how teachers can be prepared for moral reflection on issues related to genetic testing. This does not necessarily include knowledge of ethical frameworks, but teachers must have thought through the issues themselves and be aware of the values behind opinions. Development of training programmes should start with the concerns of the teachers themselves, and involve them in selecting topics and conditions of training.

Training teachers is also important as a strategic choice; in some countries, it could be more effective to train teachers with attractive new educational material than to find and engage the government officials who make decisions about curricula. Such a strategy should include the possibility of teachers themselves indicating what topics should be included in the training.

#### Content

This final part contains a first draft for the curricular content of genomics education. Two key concepts seem to cover the core of genomics education: uncertainty and complexity. These concepts form a pair with many relationships between them.

#### Uncertainty

Uncertainty as a concept has two aspects:

- Science is an ongoing process; understanding can change by using new methods, so knowledge is never certain.
- In most biological phenomena, the interaction between genes and the environment is complex, and genetic information will generally provide indications of risk instead of certainty (so complexity means uncertainty).

The first has to do with the nature of science in general. The second is more specific for genomics and can be considered as a major part of 'genetic thinking'.

#### Uncertainty as part of the nature of science

Students should be able to understand science as an ongoing process with developing theories and concepts. The case of the new classification of organisms and the history of the gene concept are good examples of the dynamic character of biological 'facts'. In the history of genetics, the scientific image of the genome has often had a profound influence on social practices and vice versa. This means that attention towards 'science in the making' is not limited to developments in research, but also to related developments in society. Knowledge about the genome is seldom neutral; it often has an implicit message about who you are and what choices you have. Today's message is that genomics undermines genetic determinism; it gives you freedom, but also responsibility with regard to your lifestyle.

The fact that science is never finished also implies that students must be prepared for life-long learning. This is especially true for the rapidly evolving domain of genomics and systems biology.

'Science in the making' does not only refer to the history of genetics, but also to recent developments in research. In particular, students in an advanced biology course need an image of research questions and methods in order to appreciate and interpret both the results of this research and the media communication about genomics. Students should be able to interpret popular headlines such as 'Criminality gene discovered'.

Another important aspect of the nature of science is that there are different kinds of knowledge. An example of this is experiential knowledge of cancer patients, which is different from the 'scientist science' of medical professionals. This indicates that 'citizen science' can be very different from 'scientist science' and that a dialogue may be necessary to construct knowledge together. In lessons about cancer, students often are interested both in how patients live with cancer (life-world practice), how cancer is studied (research practice) and how cancer is diagnosed and treated (professional practice).

#### Dealing with uncertainty and risk

Genomics education should include the teaching of risk, which entails concepts such as chance, probability, uncertainty, impact (both benefits and harms) and trust. In addition to these concepts, teaching about risk should make students aware that nothing is risk-free, that reducing risk is costly and that in some cases it is better to avoid risks (the precautionary principle). Students also should be aware that many factors influence risk perception, and that perceived risk and actual risk may differ. Teaching about risk includes drawing uncertain conclusions from data and analysing the way in which data are presented (for example absolute or relative risk; numeral or graphical). Study of risk is not limited to genomics education, but could be an inherent part of science education in the scientific/technological society and applied to topical subjects in the media. A special aspect in the teaching of risk is that young people tend to think that they are immortal and therefore have different views on risk compared with adults.

#### Complexity

Again, two aspects can be distinguished in this concept, although they cannot be separated in education:

- 1. The complexity of the relationships within the cell (internal complexity).
- 2. The complexity of the relationships between the genome, the environment and the organism (external complexity).

The first aspect has to do with questions such as, 'What is a gene?', 'How is it regulated?' and 'How do genes interact?' This part should lead to an adequate image of the genome.

The second aspect can be described as 'genetic thinking'. Students should integrate and inter-relate biological concepts by using a genomics perspective; they should understand genome expression on different levels of biological organization, also known as systems thinking.

When studying the heart in school biology, students should realize that the structure and function of the heart are represented in the genome and that the genome interacts with the development and functioning of the heart.

Both aspects should contribute to a balanced image of the interaction between genome and environment; on the one hand, genomic information mostly does not allow us to make a certain prediction, but on the other hand, there are no processes in a living organism that are not influenced by the genome. In the end, the image of the genome should inform students about the role their genome plays in their life so that they can make well-informed decisions later on.

#### Internal complexity

An important relationship that students should understand on different levels is between products and processes. A gene cannot be defined simply as a sequence of nucleotides; the description needs to include processes such as expression, transcription, mutation and regulation.

The *linear* image of a gene that codes for a protein with a specific function must be replaced with a *web-like* image of networks of genes that are activated or inhibited by many factors, of which the products again activate or inhibit other genes or proteins in the cell and in this way seldom do things alone and seldom do only one thing. We need new models to describe the genome; the 'recipe' metaphor is outdated. One method of reaching this goal is to introduce students to authentic practices, for example the use of bioinformatics and websites with genomic information. These sites contain information about many organisms and offer opportunities to compare the human genome with many other genomes. It is often a surprise to students to realize that the majority of genes have the same function in man as in many other animals.

#### External complexity

Students should learn about the interactions of genes: their functions on many different levels and in many different ways, for example in lifestyle choices. Students should be

able to describe how genes 'act out' at different levels and connect genetics to everything, not just to monogenic diseases, but also to sexuality, sporting ability, mental capacity and so on.

In the medical curriculum, the changes in genomics should result in the inclusion of genetic susceptibility when discussing the causes of common diseases. Furthermore, students should be aware of the influence of ethnicity with respect to genetic tests and the need to talk to patients about these aspects.

In secondary education, practices should be discussed in which genomic information is important. Genetic testing is one of these, for example medical testing for sports professionals. Direct-to-consumer tests should also be included in the curriculum, because they are relevant to all citizens as these tests are available for everyone. Important concepts related to genetic testing are:

- Genetic variation (genetic polymorphisms, single-nucleotide polymorphisms, short tandem repeats).
- The relationship between genes and disease (high-/low-risk genes, multifactorial and polygenic disorders).
- Techniques such as microarrays, sequencing and whole-genome screening.
- Risk assessment.

#### Moral education and moral reflection

Students must be able to evaluate the impact of genomics on societal issues and to form their own opinions. This means that, in one way or another, morality must be included in the curriculum. Students should learn to think about the impact of genomics from a personal perspective, as well as from a democratic perspective. Moral education can lead to change and moral development, but has no pre-determined goals like preferable values or opinions.

The phases in the process of genetic testing offer a useful framework for designing education and each offers a different type of issue and related emotions. Emotional considerations are important in decision-making and therefore also in education. Not many strategies are available for moral reflection on genomics-related issues; these require specific teacher competencies, both conceptual and pedagogical. A safe climate in the class is also essential for education on decision-making using emotions.

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