Genomics Education for Decision-making

Proceedings of the Second Invitational Workshop on Genomics Education

Genomics Education for Decision-making

Proceedings of the Second Invitational Workshop on Genomics Education

2–3 December 2010
Utrecht, The Netherlands

These proceedings are the result of a two-day invitational workshop as part of the research project 'Embedding Genomics Literacy in Science Education' 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
http://www.cancergenomics.nl
http://www.society-genomics.nl
http://www.genomics.nl
http://www.fisme.uu.nl

Genomics Education for Decision Making

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

Lay-out: Communications & Design, Faculty of Science, Utrecht University

First published in 2011 by the Freudenthal Institute for Science and Mathematics Education, Utrecht University, The Netherlands (FIsme Scientific Library, No 67)

ISBN 978-90-70786-99-1

Contents

Preface

Advances in genomics research and technology generate new personal and societal choices. As science education has the task of preparing students for decision-making on socio-scientific issues, research is needed to develop genomics education aimed at empowering students in the decision-making process.

At the Freudenthal Institute for Science and Mathematics Education in Utrecht, a research project is running to inform education for decision-making using knowledge on genetic testing practices, decision-making, technological change and student reasoning. This educational research is financed through the Netherlands Genomics Initiative (NGI, http://www.genomics.nl), which coordinates the activities of 16 genomics centres. A substantial part of this funding is earmarked for communication and educational activities through the Centre for Society and Genomics (CSG, http://www.society-genomics.nl). Among these outreach activities are six mobile DNA laboratories run by six of the genomics centres, each with content related to the research of that centre. The mobile DNA laboratories visit secondary schools free of charge and provide hands-on experience to both students and teachers using advanced equipment. The practical work is taught by trained students studying for a Bachelor or Masters degree in life sciences 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 genomics research, educational research and educational design is one of the strong characteristics of this educational innovation, and mobile laboratories clearly help to bridge the gap between scientific practice and school science. Research on genomics education is closely linked to these DNA laboratories, and new strategies are tested in lessons following the laboratory practice and in teacher training related to the laboratories.

As a part of this research project, an invitational workshop was held in Utrecht on 2–3 December 2010, hosted by the Cancer Genomics Centre (http://www.cancergenomics.nl) and the Freudenthal Institute for Science and Mathematics Education (http://www.fisme.uu.nl).

Speakers were invited to respond to the keynote article, which offered a framework of questions about decision-making in the context of genetic testing. Presentations were grouped in sessions, with each session followed by a discussion. These proceedings contain the key note article, the presentations and reports of the discussions. Conclusions were drawn up from each session, and a final chapter was written in which the results of the workshop were summarized in terms of guidelines for curriculum reform, teacher preparation and further research.

Our special thanks go to Alexander Brandenburg for taking observational notes during the workshop and for reporting the discussions afterwards.

Annelies Speksnijder
Managing Director, Cancer Genomics Centre

Dirk Jan Boerwinkel and Arend Jan Waarlo
Freudenthal Institute for Science and Mathematics Education

Utrecht, June 2011

Workshop programme

Thursday December 2

09.00–09.30	Registration, coffee
09.30–09.45	Welcome
	Theme: Decision-making on what?
09.45–10.15	Genomics issues: what needs to be decided? Tsjalling Swierstra Maastricht University, Maastricht, The Netherlands
	Theme: How are decisions made?
10.15–10.45	Decision-making in the context of genetic risk Lidewij Henneman VU University, Amsterdam, The Netherlands
10.45–11.00	Coffee break
11.00–11.30	Demanding users and genomics decisions Ellen Moors Utrecht University, Utrecht, The Netherlands
11.30–12.30	**Discussion: For what kind of genomics-related decisions should students be prepared?** Chair: Jenny Lewis University of Leeds, Leeds, UK
12.30–13.30	Lunch
	Theme: How do students reason about socioscientific issues?
13.30–14.00	Moral reasoning and ethical discourse in socioscientific issues: implications for polymorphism and heterosis in genomics education Dana Zeidler University of South Florida, Tampa, Florida, USA
14.00–14.30	Research on argumentation about genetics and determinism Maria Pilar Jiménez-Aleixandre and Blanca Puig Universidade de Santiago de Compostela, Santiago de Compostela, Spain
14.30–15.00	Students' reasoning on socioscientific issues and socially acute questions Laurence Simonneaux Ecole Nationale de Formation Agronomique, Toulouse, France

15.00–15.30	Tea break
15.30–16.30	**Discussion: What criteria can be deduced from research on student reasoning for designing genomics education aimed at decision-making? What research should be done next?** Chair: Jenny Lewis University of Leeds, Leeds, UK

Friday December 3

	Theme: Dealing with risk and uncertainty
09.00–09.30	Understanding the numbers behind risk predictions from personal genome tests Cecile Janssens Erasmus University, Rotterdam, The Netherlands
09.30–10.00	Towards personal models of risk: what lessons from Deborah's dilemma? Ralph Levinson University of London, London, UK
10.00–10.15	Coffee break
	Theme: Genomics education in practice: what are the effects?
10.15–10.45	Measuring the impact of instruction about argumentation and decision-making in high-school genetics Vaille Dawson Curtin University of Technology, Perth, Australia
10.45–11.15	Raising awareness of pre-symptomatic genetic testing Dirk Jan Boerwinkel Utrecht University, Utrecht, The Netherlands
	Theme: Teacher education: how to empower teachers
11.15–11.45	Empowering teachers to teach socioscientific issues: the role of teacher identity in teaching Paul van der Zande Utrecht University, Utrecht, The Netherlands
11.45–13.00	**Discussion: What kind of learning activities should be developed and tested? How should teachers be prepared?** Chair: Jenny Lewis University of Leeds, Leeds, UK
13.00–14.00	Lunch

Introduction

Genomics education for decision-making: research on socioscientific learning and teaching
Dirk Jan Boerwinkel and Arend Jan Waarlo

Theme: Decision-making on what?

Genomics issues: what is there to decide? The 'gestalt' of a socioscientific issue
Tsjalling Swierstra

Theme: How are decisions made?

Decision-making in the context of medical genetics
Lidewij Henneman

Demanding users and genomics decisions
Ellen Moors

Discussion 1: For what kind of genomics-related decisions should students be prepared?

Chair: Jenny Lewis

Genomics education for decision-making: research on socioscientific learning and teaching

Dirk Jan Boerwinkel and Arend Jan Waarlo
Utrecht University, The Netherlands

Introduction

One of the main conclusions of the first invitational workshop, 'Rethinking Science Curricula in the Genomics Era', was that dealing with uncertainty and complexity is central to genomics education (Boerwinkel, 2009). These concepts could be misunderstood as temporary qualities of genome knowledge due to insufficient research. However, uncertainty and complexity will remain linked to genome knowledge, exactly because the links between the genome and all that surround it are not linear and unidirectional but form networks of influences to and from the genome. Applications of genomics research impact on citizens and society, and generate or transform socioscientific issues (SSIs). The uncertain and complex nature of genome information complicates decision-making on these issues. How can we use information that is both uncertain and complex in matters of life and death? How can science education prepare students for decision-making on genomics-related issues? Preparing future citizens to use scientific knowledge in societal and personal decisions is broadly accepted as a task of science education (Ryder, 2002). Thus, the question is not whether genomics education should contribute towards learning how to make informed decisions but how this should be done. This is the subject of this workshop, which aims to formulate research-informed guidelines for designing, developing, implementing and testing SSI-based science education, and to identify research needs.

The following questions are meant to frame and integrate the research findings:

- How should we decide which genomics-related issues have educational potential to empower students for informed decision-making in general?
- What knowledge is needed to make informed decisions on these issues?
- How are personal decisions on genomics-related issues made?
- How are societal decisions on genomics-related issues made?
- How do students reason about genomics-related issues?
- What can we learn from our experiences with current (genomics) education for decision-making?
- What competencies do teachers need for education aimed at decision-making?

Each of these questions will be elaborated below.

1. How should we decide which genomics-related issues have educational potential to empower students for informed decision-making in general?

Why should we know this?

Developing genomics education includes choosing between many possible issues and clarifying selected issues to teachers and students. Will genomics-related issues have a limited life span, as with many other socioscientific issues (Ratcliffe & Grace, 2003)? Or do these issues repeat earlier discussions and should we look for a general framework that can be applied to new technoscience? How do 'personal issues' and 'societal issues' relate? Is there a hierarchy in the importance or complexity of these issues that could help us to sequence SSI-based education? This section addresses some of these questions, and we hope that the workshop will help in articulating and answering them.

New knowledge leads to a variety of new issues

Biomedical genome research has found many gene variants associated with disease and behaviour. This generates questions on the definition of health, disease and normality, and on personal and familial risk and reproductive choices (Clarke *et al.*, 2009). Other genetic variants are associated with geographical and historical origin and play a role in ethnic identity (Bandelt *et al.*, 2008) and even in immigration politics (Nature editorial, 2009). Still other parts of the genome are used in determining individual DNA profiles for forensic use. These developments are also linked with societal questions, for example the question of who should be included in databanks (Lynch & McNally, 2009). Property rights of genes and genomes can be claimed, either by corporations or by countries. Situations where biotechnological corporations take advantage of the genetic resources and traditional knowledge and technologies of developing countries are often referred to as biopiracy, and developing countries argue a claim on this knowledge (Hamilton, 2008). On the other hand, biotechnical corporations claim patents on the genome sequences and methods used in their research (Parthasarathy, 2007).

These examples illustrate that genome research raises or redefines a variety of issues that people are confronted with. The issues differ in complexity; for instance, many discussions concerning agricultural genomics are part of a wider discussion on sharing benefits between developed and developing countries. Its societal complexity can be an argument not to use this type of issue in science education.

Another complexity has to do with the status of knowledge on these issues. Levinson (2006) formulated a typology of controversial issues based on the kind of disagreement and the role of evidence in discussing the differences, varying from issues that can be solved by more or better information to issues where the disagreement is on whole frameworks of interpretation, such as in the evolution versus creation debate.

Are these issues really new?

Although the techniques used are new, many of the issues generated by them are not. Ethical debates on new technologies often have a common pattern, while only parts of the debate are issue-specific (Swierstra & Rip, 2007). Concerns about the privacy of biomedical and personal information existed before the use of genetic databanks. Issues concerning the use of risk information in genetic counselling and reproductive decisions have a history that started long before genomics. The access to new plant varieties has long been an issue before details of the genomes of important crop plants were known. However, known issues can be changed by the introduction of new technologies. One of the changes has been brought about by the comparatively cheap and simple ways that genetic information can be obtained and compared. This has led to the growth of several economic activities based on genetic information in biological samples. Commercial exploitation of genetic knowledge contrasts with knowledge for the public good. This issue played an important role in the Human Genome Project. Another specific characteristic of genomic knowledge is that most gene variants are only loosely correlated with certain characteristics such as diabetes. Results of genetic tests often indicate only a higher or lower risk/chance. This kind of result creates the dilemma of whether to take a risk knowingly or to take preventive measures that might not be needed and might even be harmful.

Personal and societal issues are often linked

Regulation of reproductive technology by the government or by medical authorities can limit personal choices. Commercial firms provide the possibility of making a personal choice about whether or not to buy a genetic test, but the regulation of these tests requires societal discussion and decision-making (Beaudet, 2010; Javitt, 2010). Whether you buy genetically modified food depends on your personal choice, the retailer's policy and government decisions. Therefore, science education for citizenship should address both personal and societal issues. A personal choice often influences another person's choice, which makes many personal choices implicitly also societal.

What kind of decisions have to be made?

SSIs in society can question the desirability of a certain development, or question the conditions under which a certain development should take place. Decisions of the first kind are, for example:

- Should genetic testing be a part of examinations for insurance or employment?
- Should everybody be included in forensic databanks?
- Should patents on genes be allowed?

Decisions on the conditions can include, for example:

- Who should decide on genetic testing?
- Who should have access to genetic information?
- How should participants in a population screening be informed?

Both types of decision-making include weighing up the advantages and disadvantages, determining the relative interests of the different stakeholders and assessing the risks or chances.

Values such as respect for autonomy and non-maleficence ('do no harm') influence the weight of arguments in the decision-making process (Beauchamp & Childress, 2001).

2. What knowledge is needed to make decisions on these issues?

Why should we know this?

Genomics education is not just for future professionals in the life sciences. All students should be prepared for making genomics-related decisions, and proposals should be made for both advanced and general science education (Boerwinkel *et al.*, 2009). Therefore, it is important to know what conceptual understanding is essential for an informed decision (Lewis & Leach, 2006).

Genetic knowledge is not only about genes

The examples of issues given in the section above, 'New knowledge leads to a variety of new issues', illustrate that the required genetic knowledge is diverse in nature. Genetic information holds different messages with different degrees of certainty. Short tandem repeats (STRs) used in forensic DNA research are not genes but can provide profiles that allow highly likely conclusions about someone's identity. Single-nucleotide polymorphisms (SNPs) used in genetic testing are not genes either but can indicate the position of genes correlated to some extent with certain characteristics. Biopiracy questions concern whole genomes. This diversity adds to the complexity of genetics education, which until now has been mostly limited to the role of genes.

Nature of science knowledge

Using scientific knowledge in decision-making requires not only a basic conceptual understanding but also a notion of the way scientific knowledge is produced (Ryder, 2002). Media coverage of science often undoes the findings of the research context and their inherent uncertainty. As uncertainty and complexity are central to genomics education, this part of science knowledge is essential. The discussion in the Netherlands on pre-implantation genetic diagnosis (PIGD) illustrates this. Among the arguments put forward to prohibit the expansion of PIGD to genes only indicating a risk was the statement that testing for these genes should wait until research enables certain predictions to be made for these genes. This indicates that uncertainty is often seen as a temporary status that can be removed by more research.

A specific aspect of the nature of science, especially in biomedical issues, is the concept of risk information. Both in the media and in test results, information is often presented in a form that requires a conceptual understanding of risk (see also section 5).

Before deciding whether or not to have a medical test, students should also be aware of the risks of the medical test itself. 'Medical' should not be equated with 'healthy', and students should also be aware that test results may give a false-positive or false-negative result.

Social knowledge

As mentioned above, decisions often include weighing up the interests of different stakeholders. This means that, in dealing with SSIs, students should be informed about who the stakeholders are and what their interests are. This requires some societal understanding, for example about how decisions are made and by whom, the media impact and an understanding of how the regulations work. This kind of knowledge is also necessary to prepare students for social participation but is generally not a part of science education. In section 4, the societal aspect will be elaborated further.

Personal knowledge

Engaging in decision-making demands being in touch with yourself. Who am I? What do I feel? What do I like or dislike? What does life mean to me? Am I self-governing or am I inclined to conform to the views of my peers or to social norms? Students differ considerably in self-reflexivity; value clarification exercises may be helpful in enhancing self-understanding. Practising decision-making should include a final reflection phase to identify crucial factors in the process of opinion-forming so as to acquire metacognition (Waarlo, 1999).

3. How are personal decisions on genomics-related issues made?

Why should we know this?

If personal decisions could simply be made by comparing and weighing up the advantages and disadvantages, education could limit itself to listing and prioritizing the pros and cons of an issue. However, from experience and research, we know that personal decision-making is a complicated process with non-rational aspects. In addition, many personal decisions are the result of shared deliberations, for example in doctor–patient communication or after consultation with friends, family members or clergymen. The principle of non-directiveness in genetic counselling is much disputed.

Neuropsychological research provides new insights

Recent research has shown that emotion and intuition play an important role in decision-making. It has even been stated that arguments are often added in hindsight to defend a choice made intuitively (Greene & Haidt, 2002). This does not mean that decision-making is irrational or that arguments are meaningless, rather that, in discussing issues, it is important to realize that rational arguments are not the only factors to include. Education aiming at decision-making should therefore include an awareness of intuitive and emotional aspects (Sadler & Zeidler, 2005).

Informed decision-making

Other research has analysed how people use genetic risk information in personal decisions on, for example, preventative breast amputation or reproduction. Why do others prefer not to be informed about risks? Genetic counselling on risk for diseases such as cancer is complicated by the difficulty of correctly estimating the risk. For this reason, decision aids have been developed (Wakefield *et al.*, 2007). In genetic counselling, the timing, amount and tailoring of information is crucial in order to optimize decision-making instead of confusing it. Basic conceptual understanding should not be confused with factual overload.

4. How are societal decisions on genomics-related issues made?

Why should we know this?

Societal decision-making on genomics-related issues has been studied in many fields such as the development of genetic tests and new medicines. Students should be prepared for several societal roles such as consumer or professional. How can education prepare future citizens and professionals for collective decision-making processes? What should be included in education and how can research on societal decision-making inform this?

Societal discussions

Students often do not realize how decisions are made on issues such as the availability of tests and medicine, let alone how they can influence these decisions. Only rarely are these decisions discussed publicly, for example with regard to PIGD in the Netherlands. Citizenship education should raise awareness about how these decisions are made and how stakeholders are involved. This means that students should know something about the relevant institutions, the levels (local, national and international) at which decisions are made and the accompanying societal debate. Some illustrative cases are outlined below.

Local decisions, national responses

In the Netherlands, prescription of the cancer medicine Herceptin was decided through negotiations between hospitals and insurance companies at regional levels, which led to regional inequalities. Cancer patient organizations successfully interfered. This example shows that decisions are not always made at the national level, and that patient organizations can be influential stakeholders.

Personal decisions, national discussion

In the Netherlands, PIGD is used to check and select embryos with regard to serious hereditary diseases. When an expansion of this practice was proposed for genes with incomplete penetrance, such as BRCA1 and BRCA2, the then-Christian government decided against it. The argument used was that expansion would lead to more use and therefore more loss of embryos, although the test only indicates a risk. Another argument was the 'slippery slope' argument, saying that this could be the first step to exclude any unwanted characteristic from being passed on. This led to a societal and political discussion, in which many stated that this kind of decision should be taken case by case, by parents and medical professionals together. This was also the advice of the National Health Council; such advice will generally be taken over by the government.

This example illustrates that sometimes, albeit seldom, fundamental issues enter the political arena, and that there can be tension between individual and collective decisions.

National decisions, international differences

Another issue that was decided at a national level is the possible use of genetic information by insurance companies and employers to exclude people with a genetic predisposition from insurance or employment. Government decisions vary, but many restrict or even forbid the use of genetic data for this purpose (Rothstein & Joly, 2009). This raises new questions, for example whether a ban on genetic information also includes the longstanding and common usage of information about the medical history of family members (De Vries & Horstman, 2008). In the Netherlands, insurance companies themselves made a moratorium decision on the use of genetic information. These examples illustrate that decisions sometimes lead to new questions. Even a longstanding practice, such as national screening for genetic diseases, can be confronted by new issues, as certain diseases have been found to be more frequent in certain ethnic groups (Lakeman *et al.*, 2008).

International claims, worldwide opposition

Some decisions are made in court. Biotechnical companies make many patent claims on the use of identified DNA sequences and techniques developed by them. Myriad Genetics claimed a patent on the use of BRCA1 and BRCA2 sequences, which would mean that any test for this gene would fall under this patent. Oppositions were filed against the European patent (EP 705902) on the isolated BRCA1 gene by many European countries and non-governmental organizations. The opponents challenged the patent on the basis of the European Patent Convention's patentability criteria, arguing that the claimed invention lacked novelty, an inventive step and industrial application, and that the patent failed to disclose the invention sufficiently for a person skilled in the art to carry it out. In the USA, this claim was handed down by a district court in March 2010 (Conley & Vorhaus, 2010).

5. How do students reason about genomics-related issues?

Why should we know this?

Education on decision-making did not start with genomics. Much research has been done on student reasoning about SSIs and the role of education in improving student reasoning. Genomics education aimed at decision-making can build on the results of research carried out on moral reasoning, argumentation and interpreting risk information.

Research on argumentation

Argumentation has different meanings, two of which are relevant for science education: argumentation as knowledge construction and argumentation as persuasion. The first definition refers to inviting students to express and exchange their knowledge in order to co-construct new knowledge. When societal issues enter the discourse, other meanings of argumentation become relevant, which are *'related to the development of citizenship, of educating citizens that are critical thinkers, in the sense not only of a commitment to evidence, but also of an empowerment to critical rationality, the capacity to reflect on and influence social issues of relevance of their lives'* (Jimenez-Aleixandre & Erduran, 2008). Argumentation as critical thinking is also important in evaluating the sense or nonsense of a statement and confronting pseudoscience.

Empowering students for decision-making requires more than discussing rational arguments. Most, if not all, genomics-related issues include normative judgements. Zeidler and Sadler (2008) argued that moral education remains in a vacuum if not linked to a sense of conscience, which also includes the search for what one considers as 'crossing the line'. In this search, rational, emotional and intuitive arguments are all used in discussing an SSI. This needs a new framework that helps students in their understanding, communication and integration of these different kinds of reasoning.

Several researchers have studied the effect of education on improving argumentative skills (Zohar & Nemet, 2002). Factors of influence were, among others, the chosen strategy, for example debate versus role-play, the place in the spectrum from more to less 'value laden', cultural and religious values, and the ability to recognize key issues (Simonneaux, 2008).

Using risk information in decision-making

The fact that many people have trouble interpreting risk information in health-related issues is rooted in the difficulty students have with the concept of risk (Levinson, 2009). Absolute and relative change is difficult to distinguish, and media communications often also fail in this respect. Should a risk increase from 4 to 8% be represented as a 4% increase or a 100% increase? Not only is risk information often difficult to interpret, but students also differ in the way they use risk data in decision-making. Kolstø (2006) distinguished in students several types of reasoning in which risk knowledge and values were weighed in decision-making in a socioscientific context.

6. What can we learn from experiences with current (genomics) education for decision-making?

Why should we know this?

Societal issues such as sustainability and living together in a multicultural society are often addressed by the development of educational material aimed at informing and educating people. Evaluation of the impact of these materials is difficult, especially when it concerns informal educational settings such as expositions, TV programmes and brochures. Educational measurement of learning outcomes related to decision-making is a complicated endeavour, because effects may be long-term and unpredictable. Yet educational testing is a main concern of teachers and we cannot leave them empty-handed.

Informal genomics education

Topics such as embryo selection and cloning have been the subject of novels and cinema productions. This influences societal discourse; for example, many references to the film The *Boys from Brazil* have been made in the media when the theme of cloning is in the spotlight.

This can have negative effects on opinion-forming but also offers educational opportunities. Scenes from the film *Gattaca,* presenting a future scenario in which a genetic counsellor discusses with the parents which parts of the genome of the future baby should be improved before birth, proved effective in stimulating students to formulate arguments to support their opinion (Knippels *et al.*, 2008). In the UK (www.geneticfutures.com) and the Netherlands (http://www.pandemonia.nl/english.html), special theatre productions were developed and some are available online. The scripts enabled us to introduce various sides of a current or future issue in a narrative setting and thus contribute to empathetic involvement with the issue. Several websites include decision-making tools on SSIs. The German website Genethix, for instance, offers students arguments from experts for and against sociogenetic issues such as the introduction of a genetic passport (http://www.bioethik-diskurs.de/genethix_e/genethix.html). Finally, many educational opportunities are offered by internet sources that are not designed for education but offer interesting and authentic topics for discussion, such as personal genome tests and public genetic databanks.

Formal genomics education

In the Netherlands, the project 'DNA Labs on the Road' was started in 2006 as an educational outreach project aimed at informing students about genomics research and its applications (van Mil *et al.*, 2010). In this project, bachelor life sciences students visit upper-secondary schools with mobile DNA laboratories. Evaluation of this project at an early phase showed much appreciation by school students and teachers. However, the learning results and attention to societal issues proved to be less than had been hoped for. This shows that a positive user evaluation should not be confused with measuring effectiveness.

Evaluation of the effect of the process of argumentation on both quality of argumentation and conceptual understanding has been carried out by Dawson and Venville (2010). In a comparison of an argumentation group with a reference group, the argumentation group showed better results in terms of the structure and complexity of students' arguments and in conceptual understanding. The quality of arguments was measured using an instrument with levels derived from the components of Toulmin's framework, a structural tool for analysing argumentation. Such scales, which have also been developed to measure levels of moral sensitivity (Clarkeburn, 2002), can be adapted for classroom use by teachers.

7. What competencies do teachers need for education aimed at decision-making?

Why should we know this?

Teachers are the most important factor in the implementation of an educational innovation. Success depends on the role teachers have in the process (Lieberman & Pointer Mace, 2008). Teachers can develop educational material, trial and report on new approaches, coach fellow teachers, and discuss innovations in national and regional conferences. They are the ones who present the innovations to their students. This means that involving and training teachers always has to be part of any innovation (Waarlo, 1989).

The questions above about the personal knowledge of students also apply to teachers. Who am I as a teacher? What is my personal opinion on an SSI and how does this relate to how I communicate about values in my classroom? Self-reflexivity and dialogical competence seem to be required for discussion of SSIs (Waarlo *et al.*, 2002).

Pedagogical content knowledge

The National Science Teachers Association (NSTA) in the USA recently published a positional statement to promote the teaching of science and technology within the context of personal and societal issues (NSTA, 2010). This document specifies in great detail what this entails for both students and teachers, and for teachers this means many things. The necessary components of teachers' knowledge such as knowledge of subject matter, of student learning and conceptions, of representations, and of learning and teaching strategies are indicated as pedagogical content knowledge (PCK) (van der Zande *et al.*, 2009). van Driel *et al.* (2001) specified this concept for science teachers and summarized research on science teachers' PCK. With regard to subject matter knowledge, science teachers in general possess limited knowledge of aspects of the nature of science. This is a problem, because this was indicated earlier as an essential part of genomics education. A larger problem is that science teachers in general feel uncomfortable leading discussions (Bryce & Gray, 2004) and prefer to stay in control by dominating the discussion. Combined with new subject matter resulting from genomics research, PCK for genomics education is a real challenge for teacher training.

Communities of practice

Teacher learning may effectively be combined with developing educational material and strategies by organizing a Community of Practice (CoP). Within the concept of CoP, learning is viewed as a dynamic social and participation process in which professionals share information and develop new solutions. This approach is being developed and researched in different forms (Akkerman *et al.*, 2008).

Conclusion

The scope of topics related to genomics education for decision-making is huge. This workshop with invited expert speakers and a motivated audience should help us to discuss and articulate research-informed guidelines for designing, developing, implementing and testing genomics-related sociocientific learning, and to identify research needs. Our hope is that this keynote paper will contribute to opening minds and starting dialogue from common ground.

References

Akkerman, S., Petter, C. & de Laat, M. (2008). Organising communities-of-practice: facilitating emergence. *Journal of Workplace Learning* **20**, 383–399.

Bandelt, H.J., Yao, Y., Richards, M.B. & Salas, A. (2008). The brave new era of human genetic testing. *BioEssays* **30**, 1246–1251.

Beauchamp, T.L. & Childress, J.F. (2001). *Principles of Biomedical Ethics.* Oxford: Oxford University Press.

Beaudet, A.L. (2010). Which way for genetic test regulation? *Nature* **466,** 816–817.

Boerwinkel, D.J. (2009). Back to the framework: the what, why and how of genomics education. In: Boerwinkel, D.J. & Waarlo, A.J. (eds) *Rethinking Science Curricula in the Genomics Era.* FIsme series on Research in Science Education No. **62.** Available at: http://igitur-archive.library.uu.nl/bio/2009-1208-200117/UUindex.html. Utrecht: CD-β Press, pp. 122–133.

Boerwinkel, D.J., Verhoeff, R. & Waarlo, A.J. (2009). A framework for rethinking science curricula in the genomics era. In: Boerwinkel, D.J. & Waarlo, A.J. (eds) *Rethinking Science Curricula in the Genomics Era.* FIsme series on Research in Science Education No. **62**. Available at: http://igitur-archive.library.uu.nl/bio/2009-1208-200117/UUindex.html. Utrecht: CD-β Press, pp. 13–25.

Bryce, T. & Gray, D. (2004). Tough acts to follow: the challenges to science teachers presented by biotechnical progress. *International Journal of Science Education* **26**, 717–733.

Clarke, A.E., Shim, J., Shostak, S. & Nelson, A. (2009). Biomedicalising genetic health, diseases and identities. In: Atkinson, P., Glasner, P. & Lock, M. (eds) *Handbook of Genetics and Society.* London: Routledge, pp. 21–40.

Clarkeburn, H. (2002). A test for ethical sensitivity in science. *Journal of Moral Education* 31, 439–453.

Conley, J. & Vorhaus, D. (2010). *Pigs fly: Federal Court invalidates myriad's patent claims.* Genomics Law Report, 30 March 2010. Available at: http://www.genomicslawreport.

com/index.php/2010/03/30/pigs-fly-federal-court-invalidates-myriads-patent-claims/.

Dawson, V. & Venville, G. (2010). The impact of a classroom intervention in grade 10 students' argumentation skills, informal reasoning, and conceptual understanding of science. *Research in Science Teaching* **47**, 952–977.

De Vries, G. & Horstman, K. (2008). Learning from the work that links laboratory to society. In: De Vries, G. & Horstman, K. (eds) *Genetics from Laboratory to Society.* Basingstoke, UK: Palgrave MacMillan, pp. 171–190.

Greene, J. & Haidt, J. (2002). How (and where) does moral judgment work? *Trends in Cognitive Sciences* **6**, 517–534.

Hamilton, C. (2008). Intellectual property rights, the bioeconomy and the challenge of biopiracy. *Genomics, Society and Policy* **4**, 26–45.

Javitt, G. (2010). Assign regulation appropiate to the level of risk. *Nature* **466**, 817–818.

Jimenez-Aleixandre, M.P. & Erduran, S. (2008). Argumentation in science education: an overview. In: Jimenez-Aleixandre, M.P. & Erduran, S. (eds) *Argumentation in Science Education*. Dordrecht: Springer, pp. 3-27.

Knippels, M.C.P.J., Severiens, S. & Klop, T. (2008). Education through fiction: acquiring opinion-forming skills in the context of genomics. *International Journal of Science Education* **31**, 2057–2083.

Kolstø, S.D. (2006). Patterns in students'argumentation confronted with a risk-focused socio-scientific issue. *International Journal of Science Education* **28**, 1689–1716.

Lakeman, P., Plass, A.M., Henneman, L., Bezemer, P.D., Cornel, M.C. & Ten Kate, L.P. (2008). Three-month follow-up of Western and non-Western participants in a study on preconceptional ancestry-based carrier couple screening for cystic fibrosis and hemoglobinopathies in the Netherlands. *Genetics in Medicine* **10**, 820–830.

Levinson, R. (2006). Towards a theoretical framework for teaching controversial socioscientific issues. *International Journal of Science Education* **28**, 1201–1224.

Levinson, R. (2009). Genomics and teaching of risk. In: Boerwinkel, D.J. & Waarlo, A.J. (eds) *Rethinking Science Curricula in the Genomics Era.* FIsme series on Research in Science Education No. **62.** Available at: http://igitur-archive.library.uu.nl/bio/2009-1208-200117/UUindex.html. Utrecht: CD-β Press, pp. 72–76.

Lewis, J. & Leach, J. (2006). Discussion of socioscientific issues: the role of science knowledge. *International Journal of Science Education* **28**, 1267–1287.

Lieberman, A. & Pointer Mace, D. H. (2008). Teacher learning: the key to educational reform. *Journal of Teacher Educatio*n **59**, 226–234.

Lynch, M. & McNally, R. (2009). Forensic DNA databases and biolegality. In: Atkinson, P., Glasner, P. & Lock, M. (eds) *Handbook of Genetics and Society.* London: Routledge, pp. 283-301.

Nature Editorial (2009). Genetics without borders. *Nature* **461**, 697.

NSTA (2010). *NSTA Position Statement: Teaching Science and Technology in the Context of Societal and Personal Issues.* Available at: http://www.nsta.org/about/positions/societalpersonalissues.aspx.

Parthasarathy, S. (2007). *Building Genetic Medicine.* Cambridge: MIT Press.

Ratcliffe, M. & Grace, M. (2003). *Science Education for Citizenship: Teaching Socioscientific Issues.* Maidenhead/Philadelphia: Open University Press.

Rothstein, M.A. & Joly, Y. (2009). Genetic information and insurance underwriting. Contemporary issues and approaches in the global economy. In: Atkinson, P., Glasner, P. & Lock, M. (eds) *Handbook of Genetics and Society.* London: Routledge, 127-144.

Ryder, J. (2002). School science education for citizenship: strategies for teaching about the epistemology of science. *Journal of Curriculum Studies* **34**, 637–658.

Sadler, T.D. & Zeidler, D.L. (2005). Patterns of informal reasoning in the context of socioscientific decision making. *Journal of Research in Science Teaching* **42**, 112–138.

Simonneaux, L. (2008). Argumentation in socio-scientific contexts. In: Jimenez-Aleixandre, M.P. & Erduran, S. (eds) *Argumentation in Science Education.* Dordrecht: Springer, pp. 171–199.

Swierstra, T. & Rip, A. (2007). Nano-ethics as NEST-ethics: patterns of moral argumentation about new and emerging science and technology. *Nanoethics* **1**, 3–20.

van der Zande, P., Brekelmans, M, Vermunt, J.D. & Waarlo, A.J. (2009). Moral reasoning in genetics education. *Journal of Biological Education* **44**, 31–36.

van Driel, J., H., Beijaard, D. & Verloop, N. (2001). Professional development and reform in science education: the role of teachers' practical knowledge. *Journal of Research in Science Teaching* 38, 137–158.

van Mil, M.H.W., Boerwinkel, D.J., Buizer-Voskamp, J.E., Speksnijder, A. & Waarlo, A.J. (2010). Genomics education in practice: evaluation of a mobile lab design. *Biochemistry and Molecular Biology Education* **38**, 224–229.

Waarlo, A.J. (1989). *Biology teaching and health education. Initiation of educational innovation by means of in-service education of biology teachers.* Utrecht: Utrecht University (PhD thesis).

Waarlo, A.J. (1999). Biology students' forming and justifying of opinions on predictive genetic testing. Towards a practicable and effective teaching strategy. In: Bandiera, M., Caravita, S., Torracca, E. & Vicentini, M. (eds) *Research in Science Education in Europe.* Dordrecht/Boston/London: Kluwer Academic Publishers, pp. 41–48.

Waarlo, A.J., Visak, T., Nieuwendijk, G.M.T., Meijman, F.J. & Brom, F.W.A. (2002). *Towards competence-oriented genomics education and communication. Interdisciplinary scientific essay.* Den Haag: NWO/Netherlands Genomics Initiative.

Wakefield, C.E., Meiser, B., Homewood, J. *et al.* (2007). Development and pilot testing of two decision aids for individuals considering genetic testing for cancer risk. *Journal of Genetic Counseling* **16**, 325–339.

Zeidler, D.L. & Sadler, T.D. (2008). The role of moral reasoning in argumentation: conscience, character and care. In: Jimenez-Aleixandre, M.P. & Erduran, S. (eds) *Argumentation in Science Education*. Dordrecht: Springer, pp. 201–216.

Zohar, A. & Nemet, F. (2002). Fostering students' knowledge and argumentation skills through dilemmas in human genetics. *Journal of Research in Science Teaching* **39**, 35–62.

Genomics issues: what needs to be decided?

The 'gestalt' of a socioscientific issue

Tsjalling Swierstra
Maastricht University, Maastricht, The Netherlands

Introduction

Developing genomics education includes choosing between many possible issues and clarifying selected issues to teachers and students. But how do we decide which genomics-related issues are best suited to engage students in the process of informed decision-making about new technologies?
Two conditions are of importance here:

- It has to be clear that the technology really affects the students. This is easily overlooked, but, as a teacher, you have to demonstrate how the technology actually changes their lives.
- It has to be clear that the students, in turn, can affect this technology. This is not self-evident, as people often think they have little or no control over the development of new technologies.

Obstacles in assessing the impact of technology

Instrumentalism and free choice

The main obstacle in teaching the ethics of a type of technology is the combination of an instrumentalist vision of technology, with a (neo-)liberal stress on individual free choice. If students believe this, they assume that technology is a tool, a passive servant of our will. From this point of view, there is no agency in the technology itself. A discussion in the classroom between students will soon be ended with the argument, 'If you don't like the technology, nobody forces you to use it. So please respect my freedom of choice to use it if I want to.' This means that an effective educational case study (or socioscientific issue, SSI) is capable of undermining this instrumentalist vision and the belief that personal decisions are only made by individual free choice.

One way of doing so is to point out possible 'positional' goods provided by the technology under debate. Positional goods are goods with a competitive edge: they enhance users so that they can be better than their competitors. Pointing out positional goods is an effective way to discuss the issue of free choice. Students can be presented with the choice not to use the enhancing technology, but when taken to a societal perspective, it becomes clear that, if many people start enhancing themselves, others no longer have the choice to refuse to do so, except if they are willing to pay an increasingly higher price.

Another way is to point out changing norms, laws and regulations, or, in contrast to the instrumentalist vision, 'technomoral change' (Swierstra *et al.*, 2009). From an instrumentalist point of view, new technologies will keep emerging to serve the old, common goals (for instance, fighting a disease). In the instrumentalist perspective, new technologies can cause revolutions but have no effect on a moral level. A good case study will show that technology does have agency: it can change laws, norms and values, and as a consequence the available space for free choice is also modified.

The 'hype–horror cycle'

Another obstacle in teaching the ethics of technology is that this includes talking about future technologies or future consequences of technologies. This is in the domain of speculation, and those in favour of a specific technology are often as speculative as those who are against it.

Students have to be aware that the technological promise itself is an expectation and is, in that sense, speculative. Human beings cannot act without speculating about the future, because we are goal-setting beings. Generally, an emerging technology is born in a cradle of inflating expectations and promises that can be described as the 'hype–horror cycle'. Scientists have to inflate the promises of a technology (hype) to attract (financial, political) support for their research. Sooner or later, 'priests and ethicists' will wake up and challenge these possibilities by creating fear. The hype becomes horror. After a while, the cycle will even out (Swierstra & Rip, 2007).

The consequences for education are that students should be made aware of this cycle and be warned not to become part of it. If you look back at the genomics debate over the last 10 years, many our efforts were ill-directed and within the 'hype–horror cycle' or in utopian/dystopian future scenarios. These are grand, large and ethically very interesting to discuss. However, as a teacher, you have to keep your case studies and discussions mundane, and based on daily life, and train students to become technological citizens and to be as realistic as possible.

Educational objectives

The first objective of demonstrating to students how technologies affect them is a thorough stakeholder analysis to show students how the lives of different stakeholders are changed by the technology. An effective way to demonstrate societal impact is to bring some unforeseen stakeholders into the discussion. For example, when diagnostic technologies provide us with ever more information about the fetus and how environmental factors influence its well-being and development in a myriad of ways, few people realize that this puts even more responsibilities on the shoulders of the mother. To what extent can we ask them to radically alter their behaviour because, according to the latest insights, this might avoid risks to the unborn child or help it develop better? How can the interests of the fetus be balanced against those of the mother?

Secondly, and of key importance, we must teach that technology is not only destructive (hard impacts) but also creative (soft impacts). The hard impacts are generally well known; they are the typical risks of technology and are used to show how a new type of technology can harm stakeholders. Hard impacts (risks) refer to well-established values that are considered to be objective and non-controversial; for example, if there is a direct link between the technology and a given health outcome, and the impact is quantifiable in terms of risk or chance. For instance, if the new technology will cause a risk of 4% instead of 2%, this is a rise of 100%, but it is still only 4% as a whole. How does that affect insurance practices? What does that mean in technomoral terms? These kinds of discussions can be used effectively to keep an SSI practical. Soft impacts are much broader: the ELSI/A studies on biotechnology and genomics made us aware that technological developments are not just poisonous or explosive. In the case of genomics, they may affects our lives in many unforeseen ways that are less tangible than the aforementioned clear instances of harm, such as our right to not enhance ourselves, and our right 'not to know'. Currently, when the technology is still at an emerging stage, the right not to know is not yet an issue (as the technology is not yet 'real' and available), but as development of the technology progresses, this right will become a real issue.

Most values at stake in these issues are controversial. Is it harmful to claim your right not to know? Is it harmful to be forced by society to live more healthily?
The harm or risk is qualitative rather than quantitative, and it is technology-mediated rather than technology-caused. It facilitates and changes our range of actions and our power relationships but does not really force us to do anything; it is a bit more 'fuzzy', causally speaking.

Discussions about soft impacts help to broaden students' minds about the many ways that different technologies affect their lives.

Obstacles in assessing the impact of society on technology

We live in a technological culture, and technology is affecting our lives. Therefore, there is a good case to be made that citizens should have democratic control over the development of technology. However, it is hard to teach this in the classroom. Students will argue that you neither can nor should control technological development. Four forms of objection are often mentioned:

- Technology development is autonomous.
- Technology development cannot be influenced by ordinary citizens. *'What can a citizen do against big corporations?'*
- Technology development cannot be influenced by small countries. *'We are in Holland, a small country. We can't change what the UK does!'*

- Technology development is already influenced by the market mechanisms. *'We don't need control because we are already in control, as consumers rather than citizens. We determine whether we use the technology or not.'*

Education should make visible the fact that technology is not autonomous but is man-made, as a result of human choices, and therefore it can be steered in a particular direction and can be influenced. Thus, a good SSI for students to explore is one in which they are allowed to give input into how the design/development/use has to turn out, and what (conflicting) interests prevail. However, a teacher should also be honest, and point out that citizens are not all-powerful. Many aspects cannot easily be changed because of the following:

- Sociotechnological path dependencies, e.g. switching from a combustion-driven car to an electronic car is not easy because we made the 'wrong' choice (to use petrol) 100 years ago and we now have to live with the consequences.
- Technology development is not a one-person process. Who is actually doing the steering is a rather complex question.

One way to include these elements into education is to convey a picture of technology development as 'reflexive sociotechnical Darwinism'. There is evolution and contingency, there is competition (of technologies) and there are unforeseen directions. However, the development is also sociotechnical: both man-made and technical. Education should also teach students to be reflexive: as citizens in a technological culture, you should know how technical development broadly works, so you have a realistic (neither too optimistic not too pessimistic) idea of how the course of technology can be influenced. This is a key skill for life in the 21st century and to control the evolution of technology.

The 'gestalt' of a well-chosen SSI for genomics

The following criteria should be used to choose a case study:

- The case study contradicts instrumentalist visions and the belief that personal decisions are made only by individual free choice by pointing out that the technology can change laws, norms and values, and that the available space for free choice is also modified.
- The impacts of the technology in the case study include both hard and soft impacts and are preferably mundane rather than of the 'hype–horror cycle' type.
- There are various (preferably also unforeseen) stakeholders.

The technology in the case study should allow imaginable alternative courses of actions:

- Alternative problem definitions/goals (often we start from the technology, but we can talk about the goal or problem first and then about how we can solve the problem using the technology).
- Alternative means.

- Alternative designs (we want this technology, e.g. enhancement, but it has negative side effects. Is there an alternative technology or a way to regulate the technology to avoid this?).
- Alternative uses.

Good candidates that fit the 'gestalt' include:

- Genetic susceptibility tests. There may or may not be some free choice and instrumentalism.
- Enhancement: this works well in terms of technomoral change, i.e. how are our values and aspirations (what we hope for in life) changed by the technology?
- Biobanking: this is very political and addresses the question of how to regulate access to a biobank, and democratic control of the regulations. It is a very clear example to show the political dimensions of technology.

References

Swierstra, T. & Rip, A. (2007). Nano-ethics as NEST-ethics: patterns of moral argumentation about new and emerging science and technology. *Nanoethics* **1**, 3–20.

Swierstra, T., Boenink, M. & Stemerding, D. (2009). Exploring techno-moral change: the case of the obesity pill. In: Sollie, P. & Düwell, M. (eds) *Evaluating New Technologies. Methodological Problems for the Ethical Assessment of Technology Developments.* Dordrecht/ Heidelberg: Springer, pp. 119–138.

Decision-making in the context of medical genetics

Lidewij Henneman
VU Medical Center, Amsterdam, The Netherlands

Introduction

In terms of genetics and healthcare, two major domains/settings can be distinguished where decisions are made: clinical genetics and genetic screening. A major difference is that only a few people will be confronted with clinical genetic services, whereas screening will affect many, if not all, of us.

Clinical genetics versus screening

Clinical genetics is concerned with individuals, couples or families who have or fear a health problem, usually because there is 'something', such as cancer, running in the family, or because a child does not develop fully. In the Netherlands, people are usually referred to one of the eight specialized clinical genetics centres by the general practitioner or midwife. People who have or who may be at risk of developing a genetic disorder are told about the consequences of the disorder, the probability of developing or transmitting it, and management options (Godard *et al.*, 2003). The possibilities and consequences of genetic testing may also be discussed, which may also have consequences for other family members.

Screening clearly differs from clinical genetics activities by its pro-active character and its orientation towards large numbers of people. Screening involves the *'medical examination of individuals who are not known to have any health problems with the aim of detecting disease, or an hereditary predisposition to disease, or risk factors that can increase the risk of disease'* (Health Council of the Netherlands, 2008). Screening can take the form of large-scale programmes for a particular group of people but can also entail individual examination by, for example, a physician or by people responding to a website that offers a health check within a clinic.

Screening programmes in the Netherlands

Well-known screening programmes are those for cervical cancer and breast cancer. Genetic screening programmes may take place in different phases in life, and three large programmes have been implemented in the Netherlands. Firstly, neonatal screening, which is offered to newborns in their first week of life to test for treatable disorders (heel prick) and hearing loss. The heel prick started in 1974 for detection of one disorder, phenylketonuria (PKU). Nowadays, newborns are tested for 17 disorders, mainly metabolic diseases. From May 2011, cystic fibrosis will also be included. Secondly, the Netherlands has a countrywide unique programme for familial hypercholesterolaemia

(FH, hereditary high cholesterol), where close relatives of patients already diagnosed with FH are actively traced and offered testing for FH (http://www.stoeh.nl). FH patients have an increased risk for cardiovascular disease and, knowing their risk, they can take risk-reducing measures, e.g. cholesterol-lowering medication. The third programme is pre-natal screening, i.e. testing for conditions in a fetus before birth. Since 2007, a pregnant woman and her partner are informed about non-invasive screening (ultrasound scan and maternal blood test) for Down syndrome (DS) at 10 weeks' gestation. When screened, an individualized risk estimation of having a child with DS is calculated and when this exceeds a specified threshold, the couple is offered invasive diagnostic testing that provides certainty. This invasive test has the disadvantage that it may induce miscarriage. If DS is detected, the couple can choose to terminate the pregnancy or prepare for the birth of a child with DS. At 20 weeks, pregnant women are also offered an ultrasound scan to detect major structural abnormalities, such as heart defects or neural tube defects. Every pregnant woman (and partner) thus faces decisions about whether they want to know if their unborn child has DS or other fetal abnormalities, and they have to think about the possible consequences when accepting screening (e.g. invasive testing, termination of pregnancy or not).

The purpose of screening

The purpose of screening can be twofold: (i) *health gain* through timely treatment because of early detection of disease (e.g. neonatal screening) or disease risk (e.g. FH screening), or (ii) *informed reproductive decisions* (e.g. pre-natal screening). Almost all screening programmes also have drawbacks. People may receive false-positive results (a false alarm) or false-negative results (leading to false reassurance). In neonatal screening, the numbers of false-positive results are relatively high. For example, in 2008, ~186,000 newborns were screened in the Netherlands (uptake 99.8%); 230 (real) patients were detected, but 461 false-positive results were also obtained (TNO Evaluation Report, available at http://www.rivm.nl), which causes anxiety and uncertainty, especially if the final confirmation takes a long time. In pre-natal screening, around 5% of women and their partners initially receive a high-risk estimate for DS that turns out to be a normal after a follow-up test (Alfirevic, 2004).

Expansion of screening

More screening programmes are expected in the future, partly because of new technologies, which may raise debate about the desirability of these screening programmes. There has also been debate on the expansion of existing programmes, for example, whether or not neonatal screening should be expanded to untreatable childhood-onset disorders such as Duchenne muscular dystrophy, a genetic disorder causing a progressive loss of muscle function. (This is an interesting example to use in an educational debate.)

For screening for a disease to be acceptable, several screening criteria must be met, and the benefits must outweigh the disadvantages of screening. Key criteria are that the disease must be a significant health problem (in terms of prevalence and/or severity), that a valid and reliable screening test is available, and that people have practical courses of action after screening. Moreover, the Population Screening Act (WBO) dictates that some screening tests that involve a significant degree of risk must first be subjected to independent quality testing.

A screening programme that has been debated for quite some time is screening for carrier status for autosomal recessive disorders such as cystic fibrosis (CF) and haemoglobinopathies (HbPs; e.g. sickle-cell disease, thalassaemia). In Caucasian populations, 1 in 30 people is a carrier of CF; in populations of African or Asian ancestry, carrier frequencies of HbPs range from 5 to 40%. These types of programme are not aimed at finding disorders in children, but rather screen the parents-to-be before pregnancy (pre-conception). If partners of a couple are both carriers of the same disease, their risk of having an affected child is 1 in 4 in each pregnancy (Figure 1). Offering pre-conception carrier screening enables informed reproductive decision-making among identified carrier couples before pregnancy, which includes not only pre-natal diagnosis followed (or not) by abortion but also refraining from having children, using donor sperm/eggs or pre-implantation genetic diagnosis. Despite positive results in pilot studies, meeting genetic screening criteria and constructive debates about ethical, technical and financial aspects, in most European countries a systematic healthcare offer of pre-conception carrier screening for the general population is lacking. Meanwhile, uncontrolled commercial private testing is available online. For example, a company called Counsyl offers a Universal Carrier Test including over 100 diseases (Figure 2). Is this development desirable in terms of informed consent, counselling and medical supervision? In addition, it is debatable whether every condition included in this panel could fulfil the screening criteria (Borry *et al.*, 2011). In the absence of a healthcare offer, the Clinical Genetics Department of VU University Medical Center in Amsterdam recently started to offer a pre-conception CF carrier screening test on the hospital website, accompanied by sufficient medical information, without commercial goals and with the availability of counselling (Figure 3). Is this the ideal answer in the diversifying contexts of screening?

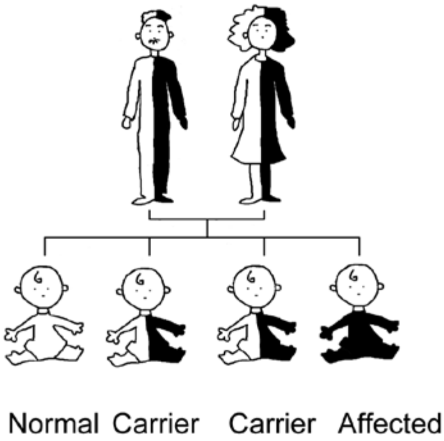


Figure 1. Autosomal recessive inheritance

Figure 2. Commercial offer of a Universal Carrier Test for more than 100 diseases (http://www.Counsyl.com, accessed 11/02/2010)

Figure 3. CF carrier testing offered to couples planning a pregnancy through the hospital website of VU University Medical Center, Amsterdam, the Netherlands (http://www.vumc.nl/CFtest, accessed 11/02/2010)

Neonatal screening can also result in incidental findings of carrier status. Although neonatal screening is aimed at finding sufferers to prevent serious harm, it also detects healthy carriers of diseases such as sickle-cell disease. Knowledge of a child's carrier status and its implications may be helpful as this can have reproductive implications for parents and their wider family. However, it also raises many questions, not only among parents but also about the competence of healthcare professionals to address this issue (Parker *et al.*, 2007).

Decision-making in the context of genetics

Where medical choices or decisions have to be made, three models of patient–doctor communication can be distinguished:

1. Paternalistic model: the doctor decides what is good for the patient.
2. Shared decision-making: the doctor and the patient share information on the basis of which decision is to be made.
3. Informed-decision model: the choice is made entirely by the patient based on full understanding of all advantages and disadvantages, in accordance with the individual's values and beliefs, and the doctor is only seen as a source of information.

As has been shown in the above-mentioned examples of reproductive genetic screening, and in particular in clinical genetics, decisions are often very difficult and complex, e.g. whether to have children, whether to undertake pre-natal diagnosis, whether to terminate a pregnancy, whether to have predictive genetic testing for a late-onset disorder. Counsellors in clinical genetics strive for a non-directive way of counselling, which means that they help the counsellees facilitate their decision-making process, for example in the case of genetic testing, based on their own moral considerations and/or what they think is important in life. In the end, the counsellees themselves have to make the choice (informed-decision model). Non-directive counselling is, however, not always considered the best choice in some circumstances. There are cases where a doctor could be more directive, for example, in clinical recommendations in hereditary breast cancer to detect the disease at an early stage, or in informing family members who may also be at risk. This calls for more shared decision-making (Elwyn *et al.*, 2000).

In screening, informed choice is recognized as important in supporting free choice and ensuring that people are not coerced. This does not apply only to reproductive genetic screening (pre-natal screening and pre-conception carrier screening) but is also now increasingly seen in traditional cancer screening programmes, where screening used to focus mainly on population outcomes such as reduced mortality and high participation rates (Jepson *et al.*, 2005). However, in organized screening programmes, informed choice raises many challenges. The question here is how to strive for informed choice when a physician or midwife, who has less understanding of genetics, has little time and also requires complex communication skills, or where there is no counsellor (e.g. testing offered through websites). One way to help people make decisions is to use decision aids to support informed value-based decision-making (e.g. online decision tools; see, for example, http://decisionaid.ohri.ca/). These are not meant to replace counselling but are an addition. An example for pre-natal screening can be found at http://www.kiesbeter.nl/medische-informatie/keuzehulpen/prenatalescreening/.

One exception in terms of striving for informed choice is seen with neonatal screening where the health of the child is at stake. In the Netherlands, participation in the voluntary neonatal screening programme is now almost 100% (http://www.rivm.nl). Paternalism may be considered better in neonatal screening because it is based on benefit to the child. In the USA, neonatal screening is mandatory. The reporting of carrier status in neonatal screening is, however, considered a decision that has to be made by the clients themselves.

Decision-making in a medical genetic context

It is important to know how people make decisions in the context of clinical genetics and screening in order to meet their needs with regard to information and counselling. There are many factors that may influence decisions. For example, for couples at increased risk of having a child with a genetic disease, the decision to have (more) children may depend on whether the couple already have a child with the disease (familiarity with the disorder), the desire to have children, the perceived family burden, etc. (Frets *et al.*, 1990). Another important factor shown to influence decisions is the perceived risk, more than the actual risk (Dommering et al., 2010). A small risk (<3%), which in 'normal' situations would be acceptable, can take on more importance in pregnancy and may influence, for example, the decision of a couple to undergo pre-natal diagnosis (Dommering et al., 2010) or screening (Marteau et al., 1991). This aspect also relates to the fact that people often have trouble understanding risk. Many people have a global sense of risk: it will happen or it won't, which is not always influenced by risk communication or counselling. This also applies to diseases that directly affect people. For example, many people with a family history of cancer overestimate their risk of getting cancer themselves, even after counselling (Michie et al., 2003), and even after negative (favourable) predictive genetic test results (Sivell et al., 2008). As yet, it is not known how risks should best be presented to people, although there are some thoughts on how to help people be more well informed about risks, as the understanding of risks is considered important in decision-making (Paling, 2003).

Future of genetic testing

Traditionally, genetic tests are not given without medical supervision or support, but this is about to change. The rapidly increasing knowledge of molecular genetics has created new possibilities for testing (e.g. http://www.genetests.org). There is an increasing number of tests offered online, in particular in commercial setting, where people can order tests to see whether they are at risk for so-called multifactorial diseases, such as diabetes or cardiovascular disease. These susceptibility tests are offered by commercial companies who will test a sample of your saliva and send you a risk profile and advice to reduce your risks. So far, these tests have been considered unsound, mainly because of limited clinical utility (Janssens & van Duijn, 2010), but also because they may induce anxiety and requests for unnecessary follow-up diagnostic tests in regular healthcare. This raises the question of how we should inform people about which tests may be good and which tests are useless or may even cause harm.

What we are thus seeing is a change from reproduction decision-making to more personal risk reduction (living more healthily), from monogenic to multifactorial disease, and from families/small settings to large health populations. Thus, genetics will in the end affect most, if not all, of us.

Questions that can be raised and discussed with students

The following questions and topics, as addressed in this article, are especially interesting to discuss with students and also raise good cases for debate:

- How can we facilitate informed decision-making?
- How can we convey genetic risk information?
- How can the public find reliable information on genetics?
- How will the public know which (online) genetic test is useful and which is not?
- How can we educate health professionals about genetics?
- How can we deal with a shift from a complaint-orientated society to a more risk-orientated society?

References

Alfirevic, Z. (2004). Antenatal screening for Down's syndrome. Nuchal translucency plus biochemical tests has the lowest false positive rate. *British Medical Journal* **329**, 811–812.

Borry, P., Henneman, L., Lakeman, P., Ten Kate, L.P., Cornel, M.C. & Howard, H. (2011). Preconceptional genetic carrier testing and the commercial offer directly-to-consumers. *Human Reproduction* **26**, 972–977.

Dommering, C.J., van den Heuvel, M.R., Moll, A.C., Imhof, S.M., Meijers-Heijboer, H. & Henneman, L. (2010). Reproductive decision-making: a qualitative study among couples at increased risk of having a child with retinoblastoma. *Clinical Genetics* **78**, 334–341.

Elwyn, G., Gray, G. & Clarke, A. (2000). Shared decision-making and non-directiveness in genetic counseling. *Journal of Medical Genetics* **37**, 135–138.

Frets, P.G., Duivenvoorden, H.J., Verhage, F., Niermeijer, M.F., van de Berge S.M. & Galjaard, H. (1990). Factors influencing the reproductive decision after genetic counseling. *American Journal of Medical Genetics* **35**, 496–502.

Godard, B., Kääriäinen, H., Kristoffersson, U., Tranebjaerg, L., Coviello, D. & Aymé, S. (2003). Provision of genetic services in Europe: current practices and issues. *European Journal of Human Genetics* **11** (Suppl. 2), S13–S48.

Health Council of the Netherlands (2008). *Screening: between hope and hype.* Publication no. 2008/05 E. The Hague: Health Council of the Netherlands,.

Janssens, A.C.J.W. & van Duijn, C.M. (2010). An epidemiological perspective on the future of direct-to-consumer personal genome testing. *Investigative Genetics* **1**, 10.

Jepson, R.G., Hewison, J., Thompson, A.G.H. & Weller, D. (2005). How should we measure informed choice? The case of cancer screening. *Journal of Medical Ethics* **31**, 192–196.

Marteau, T.M., Kidd, J., Cook, R., Michie, S., Johnston, M., Slack, J. & Shaw, R.W. (1991). Perceived risk not actual risk predicts uptake of amniocentesis. *British Journal of Obstetrics and Gynaecology* **98**, 282–286.

Michie, S., Smith, J.A., Senior, V. & Marteau, T.M. (2003). Understanding why negative genetic test results sometimes fail to reassure. *American Journal of Medical Genetics A* **119A,** 340–347.

Paling, J. (2003). Strategies to help patients understand risks. *British Medical Journal* **327**, 745–748.

Parker, H., Qureshi, N., Ulph, F.& Kai, J. (2007). Imparting carrier status results detected by universal newborn screening for sickle cell and cystic fibrosis in England: a qualitative study of current practice and policy challenges. *BMC Health Services Research* **13**, 203.

Sivell, S., Elwyn, G., Gaff, C.L. *et al.* (2008). How risk is perceived, constructed and interpreted by clients in clinical genetics, and the effects on decision-making: systematic review. *Journal of Genetic Counseling* **17,** 30–63.

Demanding users and genomics decisions

Ellen Moors
Utrecht University, Utrecht, The Netherlands

Introduction

The main question addressed here is how education can prepare future citizens and professionals for collective decision-making processes. Both are users of technology (in this case, the development of drugs), but what exactly is their role in these innovation processes? Decision-making and genomics education are viewed here from a more social/innovative point of view, with drug innovation as the example. The societal goal of drug innovation can be formulated as: *'Developing and delivering efficacious, safe, affordable products to market, while at the same time addressing public needs and emerging threats, taking consumer/patient perspective into account.'*

The research discussed in this article started with the observation that there seems to be a lack of social/clinical uptake of some emerging medical innovations. This is partly due to the nature of medical knowledge, but also and mainly because social shaping of technology is an important point to get a good understanding. Although many new technologies carry high expectations and promises in the laboratory, these are often hard to fulfil in practice. There are two possible explanations for this phenomenon:

- Science oriented: there is a lack of proof of safety and functionality (e.g. gene therapy).
- Societally oriented: there is a lack of uptake even when the technology actually reaches the clinic/society (e.g. cell-based therapies, pharmacogenomics).

This poses the question of whether there is a lack of demand by professionals and end-users. To answer this question, we will look at the drug development process.

The nature of medical knowledge: the linear model of innovation

The old but still predominant way of thinking about (drug) development depicts the innovation process as a linear model (Figure 1).

Figure 1. Innovation as a linear model

A 'technology push' ensures that the process will automatically follow the right path, from a good idea to research to an invention that will eventually find its ways into society. The policy implication of this logic is that when research and development is well funded, everything will turn out right. This is a clear example of 'technology determinism'. This linear model can be translated into a drug development pipeline as shown in Figure 2.

Figure 2. A drug development pipeline, with the developmental stages on the left and healthcare stages on the right

Although this pipeline of events also seems linear, the reality is different. The left side of the model represents the most linear parts of the process: the developmental stage, consisting of the following elements: clinical trials, diagnostics, registration, intellectual property rights issues, reimbursement and post-marketing monitoring. These elements take place in a certain order, because it is a regulated process. On the right side, however, there is the domain of healthcare. This domain also has elements and participants such as economic impacts (of firms), ethical and social impacts, legal impacts, utilization in clinical practice and role of the government. These elements are not linear, which can have consequences for influencing decision-making by citizens and professionals.

Decision-making in drug innovation

The decision-making processes in the stages of drug innovation can be divided into internal and external decision-making.

Internal decision-making consists of decisions that have to be made by organizations in the developmental stage, e.g. scientific and technical organizations. However, these decisions are not just scientific; operational and strategic factors also have to be included.

External decision-making is more societal. Drug innovation is a complex interaction between science, institutions and the market, rather than a linear pipeline. All the participants make decisions based on their own point of view. Clinical practice is not a free market where an end-user can choose freely; it is often the general practitioner or pharmacist who chooses the product for you.

Medical work is deeply embedded in a sociotechnical system that is shaped by:

- Management of complexity and uncertainty (about the body and disease).
- Established routines and interventions (a path-dependent way of doing things).
- Existing technical infrastructures (therapies, diagnostics).
- Organization of services and care.
- Rationed access to resources.

Medical knowledge is much more than the 'bare' appliance of science. Other forms of knowledge are key and are only produced in particular clinical settings, e.g. experience of disease, routines and protocols, practice style, complementary technologies and assessment of cost–benefit.

The nature of medical knowledge: the innovation systems approach

To replace the linear model in drug innovation, a model is needed that takes complexity, participants and institutions into account. The innovation process is not linear but is an iterative process in which feed-forward and feed-back processes are important. All the building blocks influence each other. In addition, the concept of 'demand' is an important part of the system. These factors lead to the systems approach as seen in Figure 3.

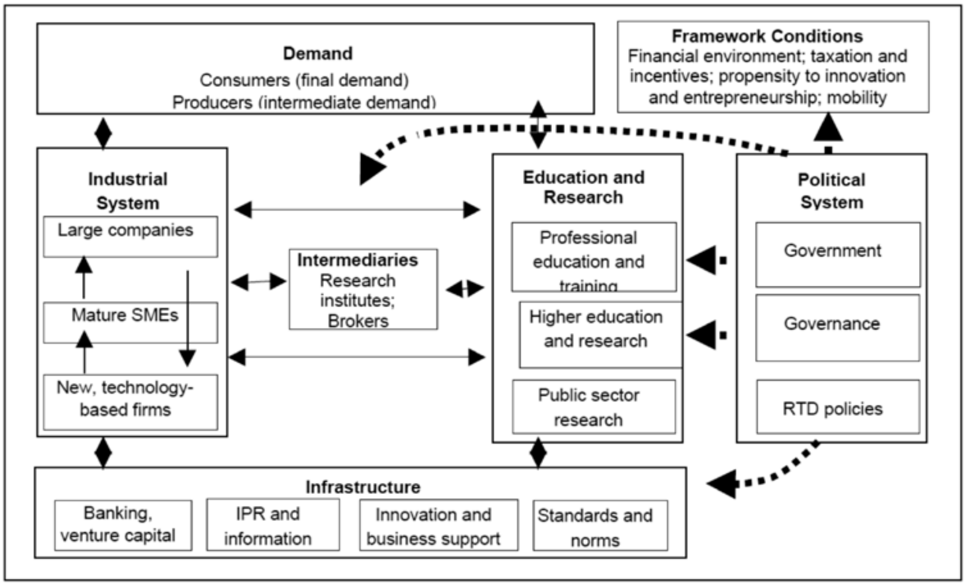


Figure 3. The systems approach (Arnold & Kuhlmann, 2001)

The utility or usability of a new product is often framed by the context. How severe is the disease? Are alternatives available? Is it cost-effective? Utility is also constructed within existing work practices. Products and technologies emerge from demands: in clinics there are demands, questions and shortcomings that could be fulfilled by new technologies. Preliminary data on the development of first-generation genomics products suggest that there is a lack of producer–user interaction. Therefore, these demands are not clear enough. Firms that are producing or developing technologies tend to use rather linear models for innovation processes and have a poor understanding of what the user needs.

Smits and Den Hertog (2007) distinguish five general dimensions in which producer–user interaction could improve the quality of innovation processes:

1 More effective articulation of social needs.

2 Enhanced competitive strength of enterprises.
3 Improved acceptance and social embedding of knowledge and technologies.
4 Improved learning capacity of society as a whole.
5 Enhanced democracy.

Demand articulation in emerging pharmacogenomics technologies

The role of a patient organization in the development of the drug Herceptin shows an example where users (in this case, a patient organization) had an influence on the innovation process. The problem is this case was the high price of Herceptin and low access, while there were no clear data on the needs. In this study, it was hypothesized that the involvement of organized users (patient groups) would be beneficial.

There were three theoretical entrance points (Figure 4):

- Emerging drug innovations (genomics).
- Articulation of demands from users (what are the user needs?).
- Organized (patient) groups as stakeholders.

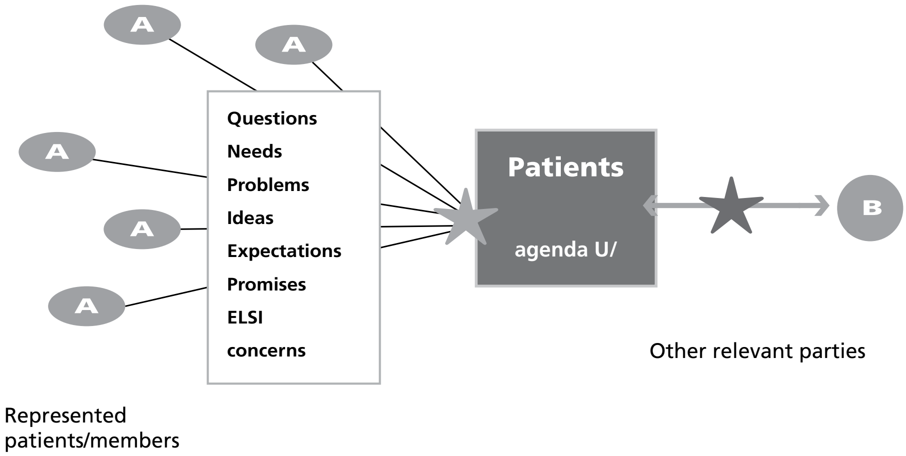


Figure 4. Theoretical entrance points in the fight for Herceptin

The patient groups served as the central focus of the research. This group consists of many representative members. Their ideas, questions, needs, etc. are denoted 'A' in the figure and influenced the patient group agenda. The demands that were articulated by the group as a whole were the demands that were most frequent.

Demand articulation as a theoretical concept is an inherently creative process. The users try to unravel preferences and what they perceive as important aspects of an emerging innovation. Demand articulation is also a learning process, in which first- and second-order learning can be distinguished.

The question in this research was: *How can we understand the demand articulation processes of patient groups in the context of emerging pharmacogenomics technologies?*

Herceptin (trastuzumab) is a medicine that treats metastatic breast cancer. It is a monoclonal antibody, produced by Genentech/Roche. Herceptin came relatively quickly to the market in the development stage. It was invented in 1986, subsequent clinical trials were done in the 1990s, and in 1998 Herceptin was approved for clinical use.

The Dutch Breast Cancer Association was highly involved in the approval procedure, and later on also in the reimbursement procedure, because the drug was not available in all hospitals. The patient organization lobbied hard to ensure nationwide availability.
In the demand articulation, the first- and second-order learning processes in this case can be summarized as in Figure 5.

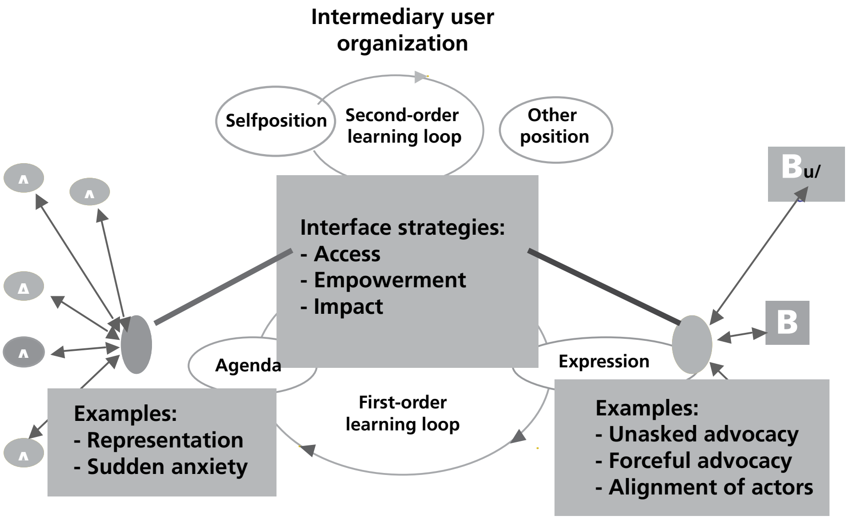


Figure 5. First- and second-order learning processes in demand articulation

The individual patients had their needs put on the agenda by the (intermediary) Breast Cancer Organization. First-order learning of the patients produced: agenda setting, evaluation and expression. Second-order learning produced knowledge about their own position compared with that of others.
Examples of what representatives did in this community included representing other patients and giving negative examples about unequal reimbursement, which was producing anxiety in individual patients.

Conclusions

Users have influence over innovation processes in terms of boundary conditions and user conditions but not much influence on the science itself. Their influence can be studied using a model of first- and second-order learning and the mechanisms thereof.

Using a more dynamic perspective:

- Successful clinical development involves establishing clinical utility or usability.
- It is important to negotiate between product specification and design with users (what do they actually want from it?) to embed different forms of knowledge into artefact.
- Unlike other technologies, users are constrained in their ability to adapt technologies as they are used.

References

Arnold, E. & Kuhlman, S. (2001). *RCN in the Norwegian Research and Innovation System.* Technopolis, Brighton, UK.

Smits, R. & den Hertog, P. (2007) Technology assessment and the management of technology in economy and society. *International Journal of Foresight and Innovation Policy* **3**, no. 1.

Further reading

Moors, E.H.M., Enzing, C., van der Giessen, A. & Smits, R. (2003). User–producer interactions in functional genomics innovations. *Innovation: Management, Policy & Practice* **5**, 120–143.

Moors, E.H.M., Boon, W., Nahuis, R. & Vandeberg, R. (2008). User–producer interactions in emerging pharmaceutical and food innovations. *International Journal of Innovation Management* **12**, 459–487.

Verhoeff, R., Moors, E.H.M. & Osseweijer, P. (2008). Interactive communication in pharmacogenomics innovations: user–producer interaction from an innovation and science communication perspective. *Journal of Genomics, Society and Policy* **4**, 53–69.

Discussion 1: For what kind of genomics-related solutions should students be prepared.

Chair: Jenny Lewis, University of Leeds, Leeds, UK

How can we engage students in genomics decision-making?

Tsjalling Swierstra acknowledged that teaching ethical issues in genomics comes with motivational difficulties. Not every area in genomics translates to an interesting subject in the classroom. Students seem to think they are immortal: they don't think about preventing diseases. Using genomics to enhance the body is a good educational context to catch their interest. And as competition seems to be a major theme in the lives of students, the way technology affects competition may lure them into biotechnology. Paul van der Zande has interviewed students about this topic, and mentioned that most of them are very interested in, for instance, their future children. Many students have family members with genetic diseases, a history of cancer, etc. These students want to bring this out into the open; they want to know what is happening in their family and to discuss this. Vaille Dawson added to this that, when appropriate subjects are being used, genomics can be very appealing to students. For her research, she observed several teachers and classroom practices. Students are fascinated with themselves in terms of their bodies and health. Combining genomics and reproduction is a fruitful area. Students know that they may become parents in a few years and are genuinely interested from a personal perspective. In every class, there is a student who says, 'I'm a carrier for a gene. The disease runs in my family, and I want to understand it!'

Dana Zeidler mentioned the teachers' perspective: how much content can you offer in a limited time span? Teaching moral issues in genomics sounds like a good idea, but it takes time away from the rest of the curriculum. Dana showed teachers examples of how they can implement moral issues in their daily classroom routines. The teachers began to realize that students can learn the content more deeply and at a higher conceptual level when you really engage them. Students will let you know what constitutes an interesting topic for them. Issues that are in their personal interest appeal to them, and a good teacher knows how to make this connection.

Tanja Klop also pointed to the teachers. She thinks that identifying appropriate topics is not the main problem for teaching socioscientific issues (SSIs) but rather the level of knowledge in teachers. Do they have enough knowledge of genomics and risk to teach SSIs?

Marcus Grace added that the age and abilities of students are important factors, in response to Dana's points. SSIs are equally important for all students, including students of low academic ability. As a teacher trainer, Marcus works with teachers who find it hard to teach genomics to students with learning difficulties. In genomics education, there is a need for differentiation, so every student will be able to learn about this, especially because it is likely that they will never formally learn more about it after they leave school. The 'hype–horror cycle' that was addressed earlier by Tsjalling Swierstra seems to cause a dilemma. You don't want students to get sucked into the cycle by the media, but, on the other hand, some of the ridiculous newspaper headlines serve well to engage students in the issue. As teachers, we need to engage with the media and then dismantle the media reports for what they really are.

Key issues in genomics teaching

Jenny Lewis asked how you can prepare students as users of new technologies. What basic knowledge do they need? What are the key issues that every student should be exposed to?

Interdisciplinarity

Ellen Moors called for an awareness of interdisciplinarity in genomics. In school, genomics is not taught as an interdisciplinary subject. The complexity and uncertainty surrounding genomics is then lost. Laurence Simonneaux suggested that education of SSIs is always interdisciplinary. It involves science but also the humanities and social science. It is too important to leave it only to the biology teachers. Henk van Netten, a biology teacher himself, recognized the lack of interdisciplinarity but thought that biology teachers are the only teachers that are able to tackle the complexity of genomics. Genomics is part of biology, so it is natural to speak about it in the biology classroom. Laurence did not agree with Henk, because complexity is not limited to biology. In economics, for example, there is a high level of complexity. In genomics issues, there are also political and economical factors. Biology teachers cannot always know how to deal with these issues.

Risk, fear and realism

Tsjalling Swierstra wanted to see a better understanding of the concept of risk. People generally do not understand risk, but we have to learn this as a society, because we are a risk society. Also, the difference between monogenic and multifactorial diseases needs to be explained better. Cecile Janssens noted that genomics cannot solve every problem. SSIs should be realistic, to help students consider realistic applications. In addition, some examples of potential (and controversial) genomics applications that are used in healthcare are already becoming outdated. Lidewij Henneman added that students have to realize that genomics is already based on everyday life, whether they like it or not. It needs to become more common knowledge that everyone is a carrier for some diseases. You can then start the discussion with the question, 'Would you like to know?' Students will then start to see the multidisciplinarity of genomics and how to deal with genomics issues. Laurence Simonneaux thought that discussing carrier status would frighten students. Dirk

Jan Boerwinkel wanted to take carrier status in education to a deeper level. Discussing carrier status depends on what you think you are carrying. The concept that every gene links to a certain disease may indeed be threatening, but this concern can be reduced by discussing genetic variation and the concept of multifactorial causation of disease.

Carin Cruijssen trains university students who have to discuss these issues with pupils. In the training, students practice the same discussions. It always strikes her that, even with university students, you can discuss genomics issues on two different levels: a personal intuitive level and a more scientific argumentative level. You can ask them, 'Do you want to know?' and they will discuss whether they want to know. Then the discussion is narrowed down to the criteria that form their opinion. This can be done independent of age, but you always have to break down the discussion to find the criteria they base their decisions on.

Pushing the moral button

Dana Zeidler narrowed the students' life down to their social circles – their family level or their friends. At these levels, you can see what affects them individually. The students care mostly about themselves and what their friends think of them. Dana found that a good teacher knows how to create dissonance, making them rethink how they perceive the world. This is a moral button, and a good teacher knows how to push that to provoke a reaction.

Students' estimation of influence

In his presentation, Tjalling Swierstra put forward two obstacles that have to be prevented when discussing genomics with students: overestimation of free will and underestimation of influence. Students tend to underestimate their influence on emerging technologies and their position in society. They do not feel responsible for choices in genomics. On the other hand, they overestimate their own free will because they think they can always choose for themselves whether they want to do something with a new technology. This poses difficulties in teaching. Ralph Levinson reacted to the point about students underestimating their influence in society. Students go to school not because they want to but because they have to. In the teaching system, the interests of students are not valued enough. When we ask ourselves why students underestimate their influence, this is because we have so little political education in schools. The problem is that we do not give students much of a chance to understand what they might find interesting. If they want to change something, how can they do that? Certainly in genomics, with its high uncertainty, you have to give young people more political self-confidence to act, to know how they can handle this question. This brings us back to interdisciplinarity. Dirk Jan Boerwinkel added to this that Ralph made interesting remarks about the 'hidden curriculum', which touches on what a student can learn gradually from the complete system of lessons. When students are not in a position to learn about the process of decision-making, they will never experience the complexity underlying decisions. It would be interesting to investigate the outcomes in schools where this issue is handled properly.

Complexity and narratives

In genomics education, two factors of complexity play a role. The genome itself is complex, but this complexity is multiplied by the complexity of the societal and decision-making aspect. The solution to deal with this double complexity is to use (sometimes write) narratives. In a good narrative, the complexity is present or can be built in. Discussing the narrative with the students produces the complexity in a natural way. Ralph Levinson also appreciated the use of narratives in education because they allow the subliminal, hidden interests to emerge, which is crucial. Tsjalling Swierstra mentioned another use of narratives. Many students only see the outcome of science when it comes to moral judgement and scientific literacy; they have no idea how science 'works' and how it is produced. We have to teach them, for example using shaped narratives based on ethnographic studies.

Summary of Discussion 1

Prevention of diseases might for some students be a topic that does not appeal to them, but as soon as a personal history is involved, many students want to discuss this topic. Perhaps surprisingly, they are often interested in the fate of their future children. This engagement is not only a way to motivate students but has also a positive effect on learning, and teachers should be aware that attention to SSIs can contribute to a higher conceptual level. The contexts in which genomics is related to prevention are demanding for teachers, as these contexts have their own concepts (such as risk) together with the genetics concepts. Another challenge for teachers is to adapt genomics education to students of different learning abilities. Engagement can also be helped by media reports, but special attention is needed as to how to interpret these reports.

Genomics issues are interdisciplinary, and the question is whether science/biology teachers are willing and able to handle this interdisciplinarity in their lessons, or whether these issues should be treated by a team of teachers from different disciplines. One of these interdisciplinary aspects is how societal decisions are made. In choosing genomics issues for education, two checks are necessary:

- To what extent is the issue already reality? If the issue is already part of everyday life, it is more valuable to discuss how to deal with the issue than to discuss whether it is desirable.
- How is the issue developing? Some hype–horror scenarios quickly become outdated or changed by lack of interest by the stakeholders/buyers.

Genomics developments show on the one hand a genetic influence on every part of life and disease, and on the other the unpredictability due to the many genetic and environmental factors involved. In this way, genomics education can also be reassuring, but there needs to be specific attention to risk. However, independent of genomics knowledge, students at every level seem to have an intuitional decision mode next to a more argumentative mode, which offers extra challenges to the teacher. The teacher in turn should challenge the students by exploring the moral limits of the students.

The problem that students underestimate their influence on technology may be caused by the lack of political education. Students have no idea how to influence societal decisions and are often rather fatalistic. By making this a recurrent point in SSIs, students might learn gradually how to deal with these questions when they arise in their lives.

Narratives can be very helpful in many ways. They can contain and illustrate the many complexities of decision-making in genomics-related issues, and can also be used to illustrate how science is produced and used.

Theme: How do students reason about socioscientific issues?

Moral reasoning and ethical discourse in socioscientific issues: implications for polymorphism and heterosis in genomics education
Dana Zeidler

Research on argumentation about genetics and determinism
Maria Pilar Jiménez-Aleixandre and Blanca Puig

Students' reasoning on socioscientific issues and socially acute questions
Laurence Simonneaux

Discussion 2: What criteria can be deduced from research on student reasoning for designing genomics education aiming at decision-making? What research should be done next?

Chair: Jenny Lewis

Moral reasoning and ethical discourse in socioscientific issues: implications for polymorphism and heterosis in genomics education

Dana Zeidler
University of South Florida, FL, USA

Introduction: scientific literacy and the curriculum

Any curriculum can be divided into subcategories. For example, it is clear that there is an explicit curriculum that aligns with our purported objectives and goals. We may find these aims stated in mission statements, brochures, websites, lesson plans and the like. There is also an implicit curriculum, one that is unofficially communicated but is implied during the enactment of the explicit curriculum. For example, policy-makers may advocate one aim in clever slogans but fail to fund schools in a manner that ensures the realization of those slogans. The message is subtle – education takes a backseat to other causes. This may also come in the form of teacher expectancy effects – how teachers respond to particular questions or students, but not others, carries with it implicit messages as to what are important. And yet, there may be said to be another component, the null curriculum. Administrators and teachers alike make decisions as to what gets excised from the curriculum. What aspects are intentionally or unwittingly left out? It is this latter part that needs more attention. A major part that has historically been left out of science classrooms is related to ethical concerns and moral reasoning. Ironically, these are the very parts that are needed most to achieve scientific literacy. It is not enough to be technically competent in the subject matter. To be functionally scientifically literate, decisions must be made using subject matter (evidence-based reasoning) that considers the moral consequences for the biological, physical and social worlds that we live in.

Challenging epistemological belief systems

What does teaching entail? Most of us have been taught within traditional paradigms. Accordingly, we tended to accept the authority of teachers and printed books without serious questioning and reflection. Such classrooms were teacher-centred and produced dogmatic viewpoints. In recent years, more progressive views of education have been realized. The focus in this kind of classroom is more on developing student responsibility, engagement and compassion in a student-centred environment. In this progressive paradigm, teaching is equated with challenging students' epistemological belief systems, rather than simply pouring new information into passive vessels. A major goal is to create dissonance with prior belief systems that allow the brain to become permeable enough to allow new thoughts to enter through the protective layers for serious consideration and reflection (Figure 1). This allows students to make decisions for themselves and to develop character, conscience and scientific enquiry though the use of socioscientific issues (SSIs). The fatal flaw held by many teachers is their own pedagogical belief that concepts can be taught using sufficient explanations and tidy analogies and will then magically alter the students' core beliefs. For students to change their epistemological beliefs about scientific data (about what good knowledge constitutes), the educational experience must be personal and relevant. If we as science educators wish to cultivate future citizens and leaders that care, serve the community and provide leadership for new generations, then we have a moral imperative to delve into the realm of virtue, character and moral development.

What the typical 17-year-old student's brain looks like. The protective coat protects the brain's core beliefs against new ideas that challenge their epistemological framework

Research on moral reflection using SSIs

We have reported various outcomes relative to using SSIs in classroom contexts. Selected outcomes of (past) research most relevant to moral reasoning on SSIs include the following:

1. Students develop (increased) epistemological sophistication (reflective judgement). This is important because higher levels of reasoning can help them to resolve issues of fairness more effectively in competing claims. Higher levels of reasoning, then, are associated with developmental sophistication, and increasingly fulfil the moral form of the philosopher by striving for impersonality, ideality, universalizability and pre-emptiveness during the decision-making process.
2. Students have been shown to increase their degree of empathy after utilizing SSIs in science classrooms.
3. Students increase their level of sophistication in argumentation strategies. There are, of course, many ways to think about what constitutes higher or lower forms of argumentation. Through our research, we have evidence that SSI approaches increase the level of sophistication of using relevant arguments, counterarguments and evidence-based reasoning.

4 Students develop a more sophisticated understanding of aspects of the nature of science. An article that will be published soon by us suggests that students become more aware of the creativity, the tentativeness and the process of science and how it works.
5 Students are able to contextualize scientific content in more personally relevant and meaningful ways, revisit it (transfer it to novel learning situations) and really use it to make sense out of scientific data. A good teacher knows how to facilitate this process so that positive outcomes can be ensured.

What questions need further research?

Several key questions, also referred to as 'core issues' in our research programme, have been developed and proposed previously. Those most germane to genomics education and scientific literacy are discussed below.

How can argumentation best play a role when implementing SSIs aimed at developing scientific literacy?

There is a need for better conceptualization of transactive discussions and group discourse around social norms. A heterogeneous group of students will facilitate better discussions and challenge the individual's thinking. But what degree of difference among students is sufficient? What is ideal? What is counter-productive?

We also need to identify an issues-driven curriculum where a natural point of critical discourse will arise. Not every issue is appropriate for a given group of students or necessarily contributes to the proper elements for a good discussion.

How can cognitive, moral and social developmental frameworks inform our understanding of cultivating scientific literacy?

There exists a need for better conceptualization and understanding of the nature of sociomoral discourse, and the epistemological bases of the nature of science in SSI contexts, as well as how to assess reflective judgement more effectively.

We also need to plan experiences and provide opportunities to create cognitive and moral dissonance to take students out of their comfort zone.

What does scientific enquiry look like within an SSI (genomics) context?

We need to identify and examine scientific enquiry strategies that students can best use to evaluate empirical data and other forms of claims. Not all strategies are equally effective. Students need to know how to discover data and how to reason effectively about issues involving complex dilemmas with undetermined solutions. Every individual has their own perspective. What is the influence of these perspectives? Related to this is the importance of investigating how forms of socioscientific reasoning (complexity, perspectives, enquiry, scepticism) are enacted, or can be realized better, during contextualized learning of the subject matter.

'Slip and slide' as a model for SSIs

A 'slip and slide' is an item where kids run and slide on a long sheet of wet plastic when it is warm outside. This is not only a fun thing to do but can also be used to enquire about concepts related to the physics of motion. The students were engaged and happy in this activity. After the students had got some notion about the concept of 'speed', they sought to do calculations about speed, velocity force and so on. Afterwards, they were engaged in a discussion about whether it should be obligatory to use safety helmets in specific conditions (such as riding a bike) and whether there should be more severe restrictions in speed laws. The students now had a context for understanding the scientific concepts, and were personally engaged in reasoning about factors related to the variables under consideration, as well as the consequences of adopting different positions on the issue. After that, more discussion followed on whether or not they (the students or their parents) should be fined for not wearing a safety helmet when they ride their own bikes. Thus, the students transferred their understanding to new situations and issues – this all started with a 'slip and slide' activity. They enjoyed the investigation and felt personally connected to the SSIs that were meaningful to their own lives.

Metacognition

The area of metacognition, while not a novel construct, is nevertheless fundamentally important to SSIs and socioscientific reasoning in general, and to genomics education in particular. This is because, in relation to genomics understanding, the ability to evaluate and reflect on decisions that impact on students and the world they inhabit is central to inciting democratic values. The ability to apply metacognition and contrast one's reasoning with that of others necessarily leads to traits of a collective *polymorphism* (acquiring or at least recognizing multiple viewpoints and perspectives) and the expression of *heterosis* (increased fitness in the social and physical world having derived knowledge and meaning-making based on enquiry and experience). However, metacognition has an even more purposeful feature to the individual, as it plays an important role in acquiring moral competence. Some elements connected to this point include the notion that metacognition entails the following:

1 The ability to identify and evaluate potential fallacious reasoning. This is important for students as they evaluate the efficacy of their own reasoning, as well as for their teachers so that they can better challenge the arguments of their students.
2 The practice of thinking turned back on itself to gauge one's virtue (excellence).
3 Students need some sort of meta-reflection to be aware of the limits of their own thinking.
4 Developing a sense of prudence (looking forward and looking backward – the 'yin and yang' of prudence) as students anticipate potential future consequences and attempt to understand the historical contexts related to those decisions, so they

can try to ameliorate historical 'wrongs' as they arrive at decisions about genomics and SSIs. Students will generally do what is in their own interest, or at least what they think is in their own interest. They will not always choose the most efficient strategy and they may be clumsy in executing the process. However, they do not need to be taught to pursue their own interests. This is where moral education comes in. Good teachers develop pro-active strategies to provide the opportunity for students to plan ahead and consider contextual historical factors, and to begin to negotiate with others so the best decision after considering all competing claims can be realized.

5 Consistently holding one's actions up for internal scrutiny – this is a fundamental feature of conscience (i.e. reflexive thinking).

A prerequisite of scientific literacy for the cultivation of scientifically literate citizens is that students must first have a sense of conscience. In its absence, moral education becomes merely a well-intended exercise in a vacuum devoid of virtue. This is because any type of moral argument is lost on those who have not adequately established a sense of conscience inasmuch as such discourse presupposes the existence of conscience.

Zeidler & Sadler, 2008, p. 204.

Further reading

Dolan, T.J. & Zeidler, D.L. (2009). Integrating argumentation into elementary classrooms. *Science and Children* **48**, 20–23.

Fowler, S.R., Zeidler, D.L. & Sadler, T.D. (2009). Moral sensitivity in the context of socioscientific issues in high school science students. *International Journal of Science Teacher Education* **31,** 279–296.

Sadler, T.D. & Zeidler, D.L. (2004). The morality of socioscientific issues: construal and resolution of genetic engineering dilemmas. *Science Education* **88**, 4–27.

Sadler, T.D. & Zeidler, D.L. (2004). Negotiating gene therapy controversies: an activity to help students explicitly consider the ethics of genetic engineering. *American Biology Teacher* **66,** 428–433.

Sadler, T.D. & Zeidler, D.L. (2005). The significance of content knowledge for informal reasoning regarding socioscientific issues: applying genetics knowledge to genetic engineering issues. *Science Education* **89**, 71–93.

Zeidler, D.L. & Keefer, M. (2003). The role of moral reasoning and the status of socioscientific issues in science education: philosophical, psychological and pedagogical considerations. In: Zeidler, D.L. (ed.) *The Role of Moral Reasoning on Socioscientific Issues and Discourse in Science Education*. The Netherlands: Kluwer Academic Press, pp. 7–38.

Zeidler, D.L. & Nichols, B.H. (2009). Socioscientific issues: theory and practice. *Journal of Elementary Science Teacher Education* **21**, 49–58.

Zeidler, D.L. & Sadler, T.D. (2008). The role of moral reasoning in argumentation: conscience, character and care. In: Erduran, S. & Jiménez-Aleixandre, M.P. (eds) *Argumentation in Science Education: Perspectives from Classroom-based Research*. The Netherlands: Springer Press, pp. 201–216.

Zeidler, D.L. & Sadler, D.L. (2011). An inclusive view of scientific literacy: core issues and future directions of socioscientific reasoning. In: Linder, C., Ostman, L., Roberts, D.A., Wickman, P., Erickson, G. & MacKinnon, A. (eds) *Promoting Scientific Literacy: Science Education Research in Transaction*. New York: Routledge/Taylor & Francis Group, pp. 176–192.

Zeidler, D.L., Sadler, T.D., Applebaum, S. & Callahan, B.E. (2009). Advancing reflective judgment through socioscientific issues. *Journal of Research in Science Teaching* **46**, 74–101.

Research on argumentation about genetics and determinism

Maria Pilar Jiménez-Aleixandre and Blanca Puig
Universidade de Santiago de Compostela, Santiago de Compostela, Spain

Question and focus

The question we addressed was, what criteria can be derived from research on student argumentation for the development of genomics education aimed at decision-making? The basis of this presentation is formed by our research about students' argumentation on genetics (Jiménez-Aleixandre *et al.*, 2000) and on gene expression and determinist claims (Puig & Jiménez-Aleixandre, 2009, 2010), and about teaching gene expression (Puig & Jiménez-Aleixandre, 2011a) in a series of classroom studies. By argumentation, we mean the evaluation of knowledge claims in the light of evidence.

Reasoning about gene expression in the context of genomics

What changes might genomics bring to the controversies about biological determinism? Biological determinism maintains that individual traits and performance, including intelligence, criminality and academic achievements, are determined entirely by genes. It has an expression in racist and sexist statements. It attributes social differences among different races or genders to heredity. It is important to acknowledge that these views were part of mainstream science and present in the works of Linnaeus and Cuvier (Puig & Jiménez-Aleixandre, 2009). In the 18th century, scientists employed the concept of 'race'. In his 'Systema Naturae' in 1859, Linnaeus divided humans into four groups according to physical and 'behaviour' features. For instance, *Europeanus* were characterized as gentle, acute and governed by law, while *Africanus* were indolent, negligent and governed by caprice.

We didn't have to wait long for genomics to dismantle this determinist reasoning. In the middle of the last century, scientists addressed determinism as a fallacy. For example, Lewontin *et al.* (1984) showed that the majority of genetic differences in the human species occur within populations, and that determinist views are related to particular ideologies.

Genomics lends more support to the now common view that phenotype is not only a matter of gene expression but is also determined by the environment. The genome itself is now considered a complex unit that interacts with the environment. As Boerwinkel *et al.* (2009) pointed out when discussing the changes brought about by genomics in the life sciences, *'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 ways with the environment'.* Findings from the Human Genome Project have supported the notion of genetic similarity: humans are 99.9% identical in our genes. A concluding paragraph in the *Science* paper reporting the human genome sequence states: *'There are two fallacies to be avoided: determinism, the idea that all characteristics of a person are "hard-wired" by the genome; and reductionism'* (Venter *et al.*, 2001).

Social representations, social decisions, argumentation and critical thinking

Why is reasoning about gene expression relevant for social representations and decisions? Despite scientific consensus about interactions between the genome and the environment, the views (representations) circulating in society may be different and still determinist. These views correspond to representations, characterized by Moscovici (1961) as notions that are socially constructed. Social representations about gender and race grounded in determinism continue to be present in the media, literature (e.g. Warner, 1994), films and jokes. In a travel book, *The Masque of Africa, the Nobel laureate V.S. Naipaul writes, 'It was hard to arrive at a human understanding of the pigmies, to see them as individuals. Perhaps they weren't'.*
Biological determinism is related to the use of these determinist perspectives to support particular political agendas challenging the notion that all humans are equal. Determinist claims are not targeted to the scientific community, and its political agenda is illustrated in James Watson's interview for the *Sunday Times,* 14 October, 2007: *'All our social policies are based on the fact that their intelligence [Africans] is the same as ours – whereas all the testing says not really.'* This may be used as a justification for the reduction of financial support for Africa and against policies of equal opportunities, or for challenging policies for equal opportunities.

How do we frame this issue in the relationship between argumentation and critical thinking? In this context, critical thinking is not only about summing up evidence, but also needs to take into account an *emancipatory* dimension: to support marginalized sectors of the population, for instance women and blacks, in seeking equality.

Jiménez-Aleixandre & Puig (2011) have proposed a characterization of critical thinking that combines evidence evaluation, a central feature in argumentation, and social emancipation components (Figure 1). In this model, critical thinking is characterized as the capacity to develop independent opinions, even if that implies challenging the ideas of one's own group or community, and to critically analyse arguments that justify inequalities. One of these arguments justifying inequalities is the determinist discourse.

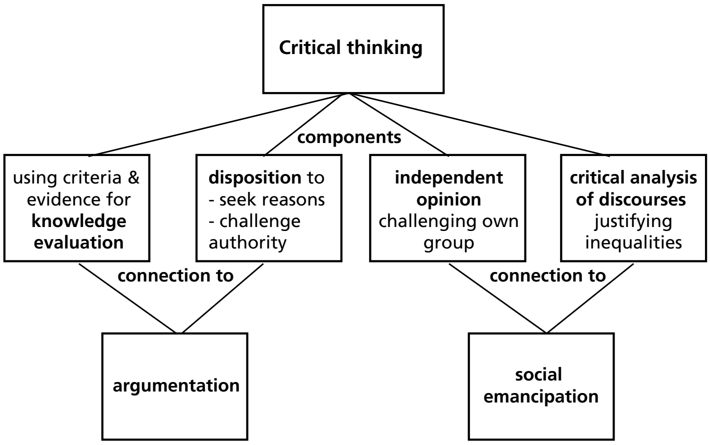


Figure 1. Characterization of the components of critical thinking (Jiménez-Aleixandre & Puig, 2011)

Students' argumentation about genetics and determinism

What have we learnt from research about students' argumentation so far and what questions need further research? How transferable is issue-specific argumentation?

Firstly, we found that determinism was not explored in science education. It is assumed that, because the notion of race as a hierarchy has disappeared from the textbooks, the underlying social representations of biological determinism have also disappeared from students' notions.

In our work, argumentation is framed in *scientific practices* (theory) and *scientific competence* (policy). Within the perspective of scientific practices, learning science involves, besides understanding scientific concepts ('what'), participating in scientific or epistemic practices ('how'). Learning the 'how' supports students' enculturation in scientific practices. Scientific practices are defined as *'the specific ways members of a community propose, justify, evaluate and legitimize knowledge claims within a disciplinary framework'* (Kelly, 2008). Kelly proposes three practices in scientific knowledge construction: producing knowledge, communicating knowledge and evaluating knowledge (argumentation). Therefore, argumentation involves students' engagement in scientific practices.
Argumentation and the use of evidence is one of the three dimensions in scientific competence, according to PISA (OECD, 2006) and the EU recommendations (European Union, 2006), which have been translated into policy documents in European countries, as shown by the S-TEAM report (Jiménez-Aleixandre *et al.*, 2010). These three dimensions are as follows:

1 Identify scientific questions.
2 Use scientific explanations to explain or predict phenomena.

3 Use scientific evidence to draw and communicate conclusions.
The third dimension corresponds to argumentation, a process of weighing scientific evidence to draw conclusions, or to criticize claims by others.

To these frameworks, grounded in theoretical approaches and in policy, we need to add another, a methodological tool to analyse argumentation, which was developed by Toulmin (1958). According to Toulmin, the components of an argument are:

- Claim: the statement that has to be supported or disproved (explanations are a sort of claim).
- Evidence (data for Toulmin): observations, facts or experiments used to evaluate a claim. We consider that what differentiates evidence from data is its role in the discourse.
- Justification: a statement that relates the claim to the evidence (Toulmin).
- Background knowledge (or backing): supports the justification, appealing for instance to theories.
- Rebuttal: in the sense of a criticism of the evidence of an opponent (Kuhn, 1991); this is different from Toulmin.
- Modal qualifiers: express the degree of certainty.

In order to evaluate argument quality, according to Kuhn (1991), a good argument, besides being supported by evidence, should take into account the arguments of the opponent, or consider alternative hypotheses. This is a relevant criterion, but it assumes a scenario with two contrasting sides. We suggest that there are other contexts for dialogic argumentation: cooperative contexts, for instance when students are discussing solutions to a problem.

We are currently working on a paper (Jiménez-Aleixandre, Puig & Bravo, in preparation) in which we challenge the idea that rebuttals are the only criterion for quality. We argue that it is just one of the indicators for quality. What we have found is that, in discussing authentic issues, arguments do not necessarily have to be oppositional. For instance in Jiménez-Aleixandre *et al.* (2000), in a context of dialogic argumentation, students cooperate in proposing an explanation for the yellow colour of farm chickens: one student proposes a claim and another supports it with a justification.

Therefore, we propose other quality criteria, besides rebuttals, for instance types of evidence, existence of justifications, coherence among lines of reasoning and persuasion strategies. All these would contribute to the quality of the argument (product) or of the argumentative process.

In summary, with regard to the content specificity of argumentation competence, the research points to a development that may be transferable to other issues, although the context of the task needs to be taken in consideration, as it may require different operations. An example of this work is students' interpretation of evidence, discussed below.

Interpreting evidence

How do students use evidence about gene–environment interactions to evaluate a determinism claim? Are they able to connect evidence and claim through justification? We illustrate these issues with an example drawn from a classroom study discussed by Puig and Jiménez-Aleixandre (2011a, b) (Figure 2).

Olympic games	Gold medal	Born in/skin colour	Trained/raised in
LA 1984	Carl Lewis, USA	Alabama, USA, black	USA
Seul 1988	Carl Lewis, USA	Alabama, USA, black	USA
Barcelona 1992	L. Christie, UK	Jamaica, black	UK (since 7)
Atlanta 1996	D. Bailey, Canada	Jamaica, black	Canada (since 13)
Sidney 2000	M. Greene, USA	Kansas, USA, black	USA
Athens 2004	Justin Gaitlin USA	NY, USA, black	USA
Beijing 2008	Usain Bolt, Jamaica	Jamaica, black	Jamaica

Figure 2. Information about athletics performances from the teaching sequence (Puig and Jiménez-Aleixandre, 2011b)

In this task, fourth-grade students (15–16 years old) were asked to discuss why all nine gold medal winners in the Olympic Games had black skin colour. They could choose between three possibilities: genetics, environment or a combination of both. The table reproduced in Figure 2 was one of eight pieces of information provided for the task.
For the researchers, the questions that could be asked were: What is there? What do we interpret as missing? Is there evidence for a genetic influence on the athletes' performances? Is there evidence for an environment influence on the athletes' performance?

In order to answer these questions, the last column was relevant. It showed that every winner had trained in the USA, UK or Canada (except for Usain Bolt, who was trained in Jamaica). What was missing was athletes who were trained (or born) in African countries. But how do students interpret this? For some of them, this means that environment is not important, because the athletes have been raised in different countries. Thus, some of the students concluded that it was all about the genes: it was only because the athletes were black that they won.

Students' problems in building justifications

As experts, we interpret that there are no African-born or -trained athletes in the list. If this question could be explained only by gene influence, Africa would have won some medals. However, some of the students did not analyse the data with this perspective. This is a problem of justification, of connecting the data to the claim.

The implications are that interpreting evidence, drawing conclusions, and connecting evidence and conclusions through justifications are not easy processes for students to develop without support. There is a need for learning tasks targeted at these processes.

What can we learn from research about students' argumentation?

In summary:

- Implications for argumentation quality: as discussed above, we challenge the idea that better quality is evaluated only through the presence of rebuttals. We need to take into account co-construction of arguments, the capacity to cooperate in building arguments and the coherence.
- Implications for research: understudied topics include (i) the relevance of contexts (Jiménez-Aleixandre, Puig & Bravo, in preparation), and (ii) the students' difficulties in building justifications. In our work, we explore argumentation, which is understood as the evaluation of knowledge claims in the light of available evidence. This process may involve different operations, depending on the context, for instance:
    - Choosing among *competing explanations* for a phenomenon and supporting them with evidence (Jiménez-Aleixandre *et al.*, 2000).
    - *Selecting data* and integrating them with theoretical claims (Puig & Jiménez-Aleixandre, 2011a, b).
    - *Evaluating others'* claims on the basis of evidence (Puig & Jiménez-Aleixandre, 2009, 2010).

Recommendations for curriculum innovation, teaching and teacher education

The following recommendations for curriculum innovation, teaching and teacher education are suggested from these approaches:

- Argumentation is part of scientific competence and should be an integral part of science education, contributing to students' engagement in scientific practices.
- The current model of gene expression, in terms of interactions of genes and the environment, should be given more attention in genetics curricula and, within them, biological determinism should be addressed explicitly.
- Argumentation and the use of evidence are competences that need to be practised; therefore, a learning environment where students are required to justify their

claims supports their development (Jiménez-Aleixandre & López Rodríguez, 2001).

- For substantive arguments, a threshold knowledge is necessary (Sadler & Donnelly, 2006), and in some topics students need to construct and apply complex models in order to produce quality arguments (Bravo & Jiménez-Aleixandre, 2011). We studied the design and implementation of a teaching sequence in five high-school classrooms (Puig & Jiménez-Aleixandre, 2011a). The influence of the didactical contract (students' expectations about the role, teachers' expectations about students) and communicative approach is essential in the development of the sequence. This didactical contract was different in the different classrooms: in one class, students were asked to play an active role, to elaborate their answers, to work in groups and to justify their answers, while in others their role was different. All these issues are relevant for the development of argumentation competence. In the first class, argumentation was embedded in enquiry: in this class, all students had designed and carried out enquiry projects in small groups. This meant that they were used to this type of practice (Jiménez-Aleixandre & Fernández López, 2010).
- Teachers (in both initial training and professional development) need to practice argumentation in order to be able to support its development in the classroom (Jiménez-Aleixandre *et al.*, 2010).
- In the curriculum, besides including argumentation in competences, there has to be room for engaging in enquiry.
- We believe that when teachers ask their students to justify why they give a particular answer or interpretation, they are introducing argumentation, even if they do it implicitly.
- Whenever teachers have goals of supporting students in constructing explanations and relating them to evidence, they should have argumentation in mind.
- The purpose of our professional teacher development workshops and classroom resources is to support teachers in introducing argumentation in a more structured and explicit way than they are currently doing.

Recommendations for research

- Research is developing new lines, for instance, how to support argumentation in classrooms, from examining argumentation to the design and testing of teaching approaches for supporting it.
- How should we use Toulmin's model? In our opinion, this model is useful for teacher education and for educational research (useful for us), although not necessarily for the students. We believe that they do not need to be taught the model, or at least not in every context. It is more effective for them to practice argumentation and the use of evidence.

Acknowledgements

This work was supported by the Spanish Ministry of Science and Innovation, code EDU2009-13890-C02-01.

References

Boerwinkel, D.J., Verhoeff, R. & Waarlo, A.J. (2009). A framework for rethinking science curricula in the genomics era. In: Boerwinkel, D.J. & Waarlo, A.J. (eds) *Rethinking Science Curricula in the Genomics Era.* FIsme series on Research in Science Education No. **62.** Utrecht: CD-β Press, pp. 13–24.

Bravo, T.B. & Jiménez-Aleixandre, M.P. (2011). Progression in complexity: contextualizing sustainable marine resources management in a 10th grade classroom. *Research in Science Education* (in press).

European Union (2006). Recommendation of the European Parliament and of the Council of 18 December 2006 on key competences for lifelong learning. *Official Journal of the European Union* 30.12.2006, L 394/10–18. Available at: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2006:394:0010:0018:en:PDF.

Jiménez-Aleixandre, M. P. & Fernández López, L. (2010). *What are authentic practices? Analysis of students' generated projects in secondary.* Paper presented at the NARST Annual Meeting, Philadelphia, PA, 21–24 March.

Jiménez Aleixandre, M.P. & López Rodríguez, R. (2001) Designing a field code: environmental values in primary school. *Environmental Education Research* **7**, 5–22.

Jiménez-Aleixandre, M.P. & Puig, B. (2011). Argumentation, evidence evaluation and critical thinking. In: Fraser, B., Tobin, K. & McRobbie, C. (eds) *Second International Handbook of Science Education* (in press). Dordrecht: Springer.

Jiménez-Aleixandre, M.P., Bugallo Rodríguez, A. & Duschl, R.A. (2000). "Doing the lesson" or "doing science": argument in high school genetics. *Science Education* **84**, 757–792.

Jiménez-Aleixandre, M.P., Puig Mauriz, B. & Gallástegui Otero, J.R. (2010). *Report on Argumentation and Teacher Education in Europe.* Trondheim: S-TEAM (Science Teacher Education Advanced Methods)/NTNU.

Kelly, G. (2008). Inquiry, activity and epistemic practice. In: Duschl, R. & Grandy, R. (eds) *Teaching Scientific Inquiry: Recommendations for Research and Implementation.* Rotterdam, The Netherlands: Sense Publishers, pp. 99–117.

Kuhn, D. (1991). *The Skills of Argument.* Cambridge: Cambridge University Press.

Lewontin, R.C., Rose, S. & Kamin, J. (1984). *Not in Our Genes. Biology, Ideology and Human Nature. New York:* Pantheon Books.

Moscovici, S. (1961–1976). *La Psychanalyse, son Image et son Public,* 2nd edn. Paris: PUF.

OECD (2006). *Assessing Scientific, Reading and Mathematical Literacy: a Framework for PISA 2006.* Paris: OECD.

Puig, B. & Jiménez-Aleixandre, M.P. (2009). *Use of evidence and critical thinking about determinist claims on race and intelligence.* Paper presented at the European Science

Education Research Association (ESERA) Conference, Istanbul, 31 August–4 September.

Puig, B. & Jiménez-Aleixandre, M.P. (2010). What do 9th grade students consider as evidence for or against claims about genetic differences in intelligence between black and white "races"? In: Hammann, M., Waarlo, A.J. & Boersma, K.T. (eds) *The Nature of Research in Biological Education*. Utrecht: University of Utrecht, pp. 137–151.

Puig, B. & Jiménez-Aleixandre, M.P. (2011a). Different music to the same score: teaching about genes, environment and human performances. In: Sadler, T. (ed.) *Socio-scientific Issues in the Classroom: Teaching, Learning and Research*. Dordrecht: Springer (in press).

Puig, B. & Jiménez-Aleixandre, M.P. (2011b). From our Genes and Something Else: *Teaching Sequence about Genetics and the Use of Evidence.* S-TEAM (Science Teacher Education Advanced Methods) (in preparation).

Sadler, T.D., & Donnelly, L.A. (2006). Socioscientific argumentation: the effects of content knowledge and morality. *International Journal of Science Education* **28**, 1463–1488.

Toulmin S (1958). *The Use of Argument*. Cambridge: Cambridge University Press.

Venter, J.C., Adams, M.D., Myers, E.W. *et al.* (2001). The sequence of the human genome. *Science* 291, 1304–1351.

Warner, M. (1994) *From the Beast to the Blonde. On Fairy Tales and their Tellers. London:* Chatto & Windus.

Students' reasoning on socioscientific issues and socially acute questions

Laurence Simonneaux
Ecole Nationale de Formation Agronomique, Toulouse, France

The SAQ approach

A 'socially acute question' (SAQ) (Legardez and Simonneaux, 2006) is a controversial issue and raises social implications. SAQs are the object of controversies between specialists from different disciplinary fields and between experts from associated professional fields. SAQs challenge social practices and reflect social representations and value systems that society believes it is important to discuss. Consequently, they have the potential for debate in classrooms.

In relation to socioscientific issues (SSIs), SAQs have in common that they are open-ended questions involving ill-structured problems. They integrate knowledge in the humanities and sciences. They are complex and raise uncertainties. Zeidler *et al.* (2005) showed that SSI education was a better way than the science, technology and society (STS) movement to integrate the nature of science, arguments, values and moral judgement.

The SAQ approach emphasizes the degree of acuteness of the question in the world of research and/or society. Teaching SAQs contributes to scientific literacy. Risk analysis, analysis of patterns of political and economic governance, decision-making and action are central to teaching SAQs. This approach has in common with the STS(E) (E for environment) model of Hodson (2003) the aim encouraging the commitment of students to make responsible decisions with regard to SAQs.
This article describes different aspects of the SAQ approach:

- Learning and teaching strategies.
- Contextualization.
- Complementarity between analysis relying on different frameworks or previous surveys.
- Using a grid to analyse socioscientific reasoning in the perspective of sustainability.

Learning and teaching strategies

I have analysed different types of learning strategies such as role play and debate, or combinations of debate or role-play with another strategy, such as:

- Combinations of debate and epistemological disturbances.
- A contextualized problem situation and debate.
- Role play and modelling, often called 'serious games'.

Most of the findings on these strategies are relevant for genomics education.

Role-play and debate

We compared the arguments of students in a role-play and in a classic debate on an SSI/SAQ (Simonneaux, 2001). It appeared that the arguments in the role-play were less justified and that students used more destabilizing strategies (provocation, irony, etc.). Students' statements were shorter and they sought to give the arguments of the characters they played as quickly as possible (arguments with which they sometimes did not agree). This finding questions the situations implemented in the classroom. Role-play encourages students' participation and may lead them to use deceptive strategies to 'win' at the expense of a strong exploration of the controversy. It seems to us important to equip students with the ability to analyse the expertise and controversial scientific results and to identify deceptive strategies (fallacies) in the claims of the researchers and/or the media.

Debate and epistemological disturbances

Our objective was to develop the ability to question the way in which scientific knowledge is constructed. To do this, we used a series of didactic games, based on the impact that providing food has on the environment. The games were designed to expose individuals to disconcerting 'evidence' taken from different scientific studies (glass packaging impact, energy cost of local meat compared with meat from New Zealand, etc.). These studies raised questions about the methodologies and indicators used, and at the same time revealed that evaluation of the food–environment relationship is only possible in specific contextualized cases and cannot be generalized. This strategy enabled the individuals to improve their capacity for critical analysis. They questioned the hypotheses and indicators chosen for the scientific demonstration. They understood that, because reality is complex, it is necessary to remain cautious. It is impossible to reduce the complexity of reality to the 'artefacts' selected for the different studies (Simonneaux & Simonneaux, 2009a, 2010).

Serious games: modelling issue

Companion modelling associates simulation using a multi-agent system, a Geographical Information System and role-playing in order to create a model and to simulate the dynamics of eco-sociosystems. A computer model takes into account the interactions between the stakeholders and the different elements of the actually given territory, and of the sociological, economic, ecological processes and vagaries likely to interfere in the system; it helps to map out the evolution of the territory according to the choices made by the stakeholders. The use of companion modelling in the classroom is the subject of research being carried out within the framework of Education for Sustainability. Students, participating in a role-play, use the modelling approach to understand several aspects: the sociological, economic and ecological dynamics at issue; interplay between activities linked to farming, forestry and biodiversity protection; and the importance of dialogue between stakeholders. A computerized simulation enables them to be confronted with the impact of their decisions.

This helps students to understand the socioecological system. This kind of strategy can also be used for genomics issues. It raises the interest of the stakeholders. The main problem with this type of serious game is that students discuss the relevance of the model itself: they often consider it not to be realistic or to be too complex (Vidal & Simonneaux, 2010; Vidal *et al.*, 2010).

A case of gene therapy

We tried to determine the reasoning behind the positions taken by a group of 19–21-year-old students on the unsettled and controversial issue of feasibility and acceptability of human gene therapy. The students were in training at a biotechnology institute. We organized debates in class, punctuated by phases of epistemological 'disturbances'. During the course of these activities, we set up small discussion groups. We used a variety of resources and authentic gene therapy cases combining gene therapy already undertaken and gene therapy in progress. We also worked on the reconsideration of Crick's model on the basis of recent results in molecular genetics and genomics. By using authentic examples, the students were faced with a real picture of scientific practice in the knowledge-building phase and with the limits of this knowledge when applied to problem-solving. We used two analytical tools: Gauthier's (2005) categorization to measure the intensity of the argumentation and to determine its origins, and Habermas's (1987) theory of communicative action to identify the different types of action used by the students.

The presentation of texts on the failure of gene therapies stimulated critical analysis. It also engaged the students in the evaluation of empirical evidence by mobilizing current data in the field of molecular biology that challenge Crick's central dogma. We observed an increase in the intensity of argumentation. Forms of communicative action were used the least, whereas forms of strategic action were used the most. However, we saw that during the final discussions, the students' discourse was more in keeping with communicative action than in the first discussions (Simonneaux & Chouchane, 2010).

Contextualization

In various studies, four different issues have been used as the topic of a so-called contextualized problem combined with a debate:

1. Reintroduction of bears in the Pyrenees and the presence of wolves in the Mercantour National Park (Simonneaux & Simonneaux, 2009b).
2. Pesticides and invasive pests: the case of the corn rootworm (Diabotrica virgifera virgifera Le Conte) (Morin & Simonneaux, 2010).
3. Ali's case: the above gene-therapy issue (Simonneaux & Chouchane, 2010).
4. Currently in progress: a comparison between Australian and French territorial/ cultural contextualization.

In the last study, we are analysing whether online exchanges on SAQs embedded in different cultural contexts can improve the socioscientific reasoning of students.

Affective and/or cognitive mobilization

In our first research, we compared students' reasoning on several issues related to sustainability: two local issues connected to bioconservation (reintroduction of bears in the Pyrenees and the presence of wolves in Mercantour National Park), and a global one (global warming) (Simonneaux & Simonneaux, 2009b). In this piece of research, we observed that the greater the 'proximity' between the question considered and the students (e.g. a local issue in which they are involved because of their sociocultural origins), the lower the level of scientific learning (critical analysis of their ideas, knowledge appropriation, socioepistemological thinking about the knowledge involved, reasoning). The overexpression of the effect won over the rest. However, sometimes mobilizing the effect actually encourages the search for scientific counterarguments in order to refute the differing opinions. This was the case in the analysis carried out by Jiménez-Aleixandre (2006) on the scientific learning of Galician pupils confronted with the sinking of the *Prestige* and the resulting oil slick. In these apparently contradictory results, we can see the imprinting of values on learning. If the situation presented to the students contradicts their system of values, the effect can hinder critical reasoning, effectively 'blinding' them and building resistance; if, however, it allows them to defend sociocultural positions, it stimulates critical analysis.

How can we achieve the correct distance to foster motivation, the emergence of a need for scientific and 'social' knowledge to which it is appropriate to apply a critical analysis, and a detachment from the *a priori* beliefs? On the local question – the one that was 'closest' to the students – there was a rejection of the differing arguments presented. On the global question, we saw an often very fine analysis of contradictory arguments and a detachment from prior conceptions.

Although contextualization is supposed to improve situated cognition and encourage scientific learning by giving a meaning to scientific knowledge, we saw here the limits of a local contextualization that involved the students too much.

The findings of the three initial pieces of research suggest that although contextualization is supposed to improve situated cognition and encourage scientific learning by giving a meaning to scientific knowledge, there are limits. Contextualization can be counterproductive. Thus, we need to achieve the correct distance to foster motivation, the emergence of a need for scientific and 'social' knowledge to which it is appropriate to apply a critical analysis, and a detachment from the *a priori* conceptions. To find the correct distance is a question of research in itself.

Analytical frameworks

Several researchers have investigated the ways people differ in their perception of science, nature and risk, for example Boltanski & Thévenot (1991), Beck (1986), Douglas (1992) and Haste (2004). These typologies can be adapted to describe and categorize student attitudes, and the types they distinguish can be compared, as shown in Table 1.

Table 1. Articulation and coherence among various frameworks

<table>
<tr><th>Douglas' cultural types</th><th>Beck's rationalities</th><th>Epistemological postures</th><th>Haste's typology</th><th>Cities of Boltanski & Thevenot</th><th>Science/ technology perception</th></tr>
<tr><td>Individualist</td><td rowspan="2">Techno-scientist</td><td>Positivist</td><td>Science oriented</td><td>Trade</td><td>Science = progress</td></tr>
<tr><td>Hierarchist</td><td>Utilitarist</td><td>Techno-investor</td><td>Industrial</td><td>Science, then technology application</td></tr>
<tr><td>Egalitarian</td><td rowspan="2">Reflexive sciencitization</td><td rowspan="2">Critical realist</td><td rowspan="2">Green</td><td rowspan="2">Civics</td><td rowspan="2">Responsible science</td></tr>
<tr><td>Fatalist</td></tr>
</table>

A tool for evaluation of SSI reasoning

We first considered Grace's work (2009), which provides a quality gradient of the argument based on the combination of three criteria: (i) the justification or otherwise of the decision; (ii) the choice of arguments; and (iii) the consideration of alternatives. We then reworked the chart developed by Sadler *et al.* (2007). They identified four aspects of socioscientific reasoning: (i) examining the situation from different points of view; (ii) the perceived need for further research; (iii) the expression of scepticism with regard to information being potentially biased; and (iv) consideration of the complexity. Unlike them, we did not reduce the examination of the complexity in one step of reasoning; rather, we believe that complexity emerges from reasoning about the conjunction of the different operations. Fourez (1997) defined an 'island of rationality', which corresponds to knowledge in a specific authentic situation, whose main characteristic is to be explicitly linked to a context and a project.

Audigier (2004) highlighted the consideration of different scales when he proposed specific indicators of the contribution of social science lessons in citizenship education. Changes of scale should be spatial and temporal but also connected with a reflection on social regulations at the individual and collective levels. Indeed, sustainable development invites us in its founding documents to 'act locally and think globally'.

We pursued the transformation made by Simonneaux & Simonneaux (2009b) of the chart of Sadler *et al.* (2007), adding identification of risks and uncertainties, and research and evaluation of knowledge produced by non-academic producers of knowledge, taking into account the values, analysis of governance and power relationships (Figure 1). Kolstø (2001) emphasized the need to train students to work on the reliability of advanced knowledge, especially as the personal interests of stakeholders are involved.

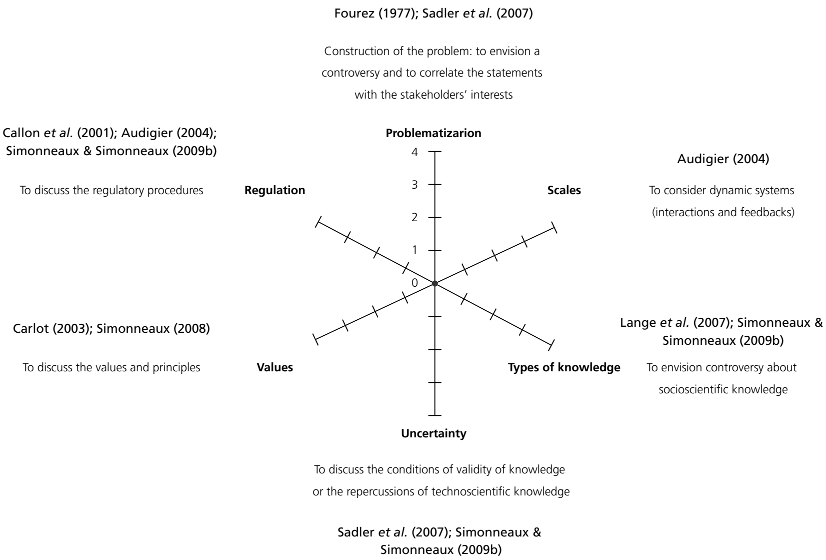


Figure 1. Evaluation of SSI reasoning

In our various studies, we noticed that students' commitment to reasoning was linked to:

- Their rationality (scientific, social or technoscientific).
- Their personal conviction (environmental in the field of education for sustainability, ethical in the field of health).
- Their epistemological position (expressing doubt or 'blind' confidence in science).

A new curriculum in genomics education

The conceptual, technical and methodological genomics and post-genomics fields provide new opportunities both in terms of practical applications and in terms of research.

The possibilities for practical applications affect all areas related to life: medical, pharmaceutical, veterinary science, agronomy, food, agrochemicals, cosmetics, control of the environment and ecology. Current links between genomics and post-genomics medicine are numerous. They focus on understanding and detection of diseases with a genetic component. However, the paths leading to therapeutic applications are more complex than expected. Genomics and post-genomics are also areas of application in the study of biodiversity, the study of evolution and mechanisms involved in genomic evolution.

Some ethical questions

The use of genetic knowledge in medical and social contexts raises numerous ethical questions. Some of the most frequent are:

- Equal opportunities for access to genetic services (e.g. individual, social, cultural and political inequalities).
- The right to abortion, while respecting the choices of parents either to abort or to continue the pregnancy with an abnormal foetus.
- Confidentiality, although not absolute when the patient refuses to communicate with others who may be implicated.
- Protection of privacy against intrusion by third parties by establishing effective legal standards that prevent discrimination in hiring workers and the impact of genetic information on premiums for life insurance or health insurance.
- Arrangements for disclosure of genetic information: who and how?
- An indication of when pre-natal diagnosis should be used (e.g. only when the life of the fetus is at risk).
- Conditions for mass genetic screening (of large populations), either voluntary or compulsory, linked with the existence or not of a clinical treatment available to the general population.
- Methods of genetic counselling and the dangers of interventionism.

References

Audigier, F. (2004). La formation du citoyen aux prises avec les échelles de temps et d'espace. Communication au 15ième Simposio internacional de didáctica de la ciencias sociales. *Formación de la ciudadania: las TICs y los nuevos problemas.* Université d'Alicante (Espagne), pp. 359–376.

Beck, U. (1986). *La société du risque, sur la voie d'une autre modernité.* Paris: Flammarion, traduction française 2001.

Boltanski, L. & Thévenot, L. (1991). *De la justification Les économies de la grandeur.* Paris: Gallimard.

Callon, M. Lascoumes, P. & Barthe, Y. (2001). *Agir dans un monde incertain: essai sur la démocratie technique.* Paris: Le Seuil.

Carlot, Y. (2003). Quelques réflexions sur la géographie scolaire. In: *Itinéraires de Géographe.* Lyon: Le Clos, pp. 11–23.

Douglas, M. (1992). *Risk and Blame: Essays in Cultural Theory.* London: Routledge.

Fourez, G. (1997). Qu'entendre par 'îlot de rationalité'? et par 'îlot interdisciplinaire de rationalité'? *Aster* **25**, 217–225.

Gauthier, G. (2005). Argumentation et opinion dans la prise de position éditoriale. In: Burger, M. & Martel, G. (eds) *Argumentation et Communication dans les Médias.* Québec: Édition Nota bene, pp. 131–152.

Grace, M. (2009) Developing high quality decision-making discussions about biological conservation in a normal classroom setting. *International Journal of Science Education* **31**, 551–570.

Habermas, J. (1987). *The Theory of Communicative Action: a Critique of Functionalist Reason,* vol. 2. Translated by T. McCarthy. London: Polity Press.

Haste, H. (2004). *Science in my Future: a Study of the Values and Beliefs in Relation to Science and Technology Amongst 11–21 year olds.* London: Nestlé Social Research Programme.

Hodson, D. (2003). Time for action: science education for an alternative future. *International Journal of Science Education* **25,** 645–670.

Jiménez-Aleixandre, M.P. (2006). Les personnes peuvent-elles agir sur la réalité? La théorie critique et la marée noire du Prestige. In: Legardez, A. & Simonneaux, L. (eds) *L'École à l'Épreuve de l'Actualité – Enseigner les Questions Vives.* Issy-les-Moulineaux: ESF, pp. 105–118.

Kolstø, S.D. (2001). To trust or not to trust…– pupils' ways of judging information encountered in a socioscientific issue. *International Journal of Science Education* **23**, 877–901.

Lange, J.M., Trouve, A. & Victor, P. (2007). Expression d'une opinion raisonnée dans les éducation à…: quels indicateurs? *Actes du congrès international de l'Actualité de la Recherche en Education et en Formation, 28–31 August, Strasbourg.*

Legardez A. & Simonneaux L. (2006). *L'École à l'Épreuve de l'Actualité. Enseigner les Questions Vives.* Paris: Edition ESF.

Morin, O. & Simonneaux, L. (2010) Caractérisation de raisonnements socioscientifiques dans une perspective d'éducation au développement durable: apports et limites du traitement d'une controverse environnementale par le débat en formation professionnelle d'enseignants. *Actes du congrès international de l'Actualité de la Recherche en Education et en Formation. 13–16 September, Geneva.*

Sadler, T.D., Barab, S.A. & Scott, B. (2007). What do students gain by engaging in socioscientific inquiry? *Research in Science Education* **37,** 371–391.

Simonneaux, L. (2001). Role-play or debate to promote students' argumentation and justification on an issue in animal transgenesis. *International Journal of Science Education* **23,** 903–928.

Simonneaux, L. & Chouchane, H. (2010). The reasoned arguments of a group of future biotechnology technicians on a controversial socioscientific issue: human gene therapies. *ERIDOB Conference 2010, Braga.*

Simonneaux, L. & Simonneaux, J. (2009a). A la croisée des questions socialement vives et du développement durable: étude de la relation alimentation–environnement avec des enseignant(e)s. *Didaskalia* **34,** 67–104.

Simonneaux, L. & Simonneaux, J. (2009b). Students' socio-scientific reasoning on controversies from the viewpoint of Education for Sustainable Development. *Cultural Studies of Science Education* **4**, 657–687.

Simonneaux, L. & Simonneaux, J. (2010). The food–environment relationship: a socio-scientific issue in the perspective of sustainable development. In: Cakmakci, G. & Taçar, M.F. (eds) *Contemporary Science Education Research: Scientific Literacy and Social Aspects of Science.* Ankara, Turkey: Pegem Akademi, pp. 107–112.

Vidal, M. & Simonneaux, L. (2010). Using companion modelling on authentic territories in the teaching of biodiversity. *ERIDOB Conference 2010, Braga.*

Vidal, M., Simonneaux, L. & Simonneaux, J. (2010). Intérêts et limites de la valorisation des modélisations d'accompagnement pour une éducation au développement durable. *Colloque international Education au Développement Durable et à la Biodiversité: Concepts, Questions Vives, Outils et Pratiques.* 20–22 October, Digne les bains, France.

Zeidler, D.L., Sadler, T.D., Simmons, M.L. & Howes, E.V. (2005). Beyond STS: a research-based framework for socioscientific issues education. *Science Education* **89**, 357–377.

Discussion 2: What criteria can be deduced from research on student reasoning for designing genomics education aiming at decision-making? What research should be done next?

Chair: Jenny Lewis, University of Leeds, Leeds, UK

Guidelines for education

Jenny Lewis acknowledged that the three speakers in this session had quite a challenging task. They were expected to address a lot of questions in a small amount of time. The result was a huge amount of information. There were several good questions up for discussion. How do we help students? How do we know they are succeeding? What is the relationship between moral reasoning and decision-making? Should the focus be on the logical argument or on gut feelings? What is the role of the teachers? Should they start from the context and work up from there? Do we know the answers already or is there still a lot of research to do? What would the teachers in this room take from this session?

Dana Zeidler jumped in on these questions, and defined four criteria that are essential for good operational exercises in the curriculum:

1. Socioscientific issues (SSIs) need to be personal and relevant to students.
2. The topic or questions raised should be controversial. There are many issues and questions but they are not all appropriate SSI topics *a priori*.
3. Scientific positions in the SSI should ideally also be inconsistent, so that different forms of data can be presented.
4. There needs to be some form of ethical tension: a moral component.

Mieke Kapteijn accepted that these are criteria that describe the domain. But how are you going to do it in classroom? Jenny Lewis agreed that the discussion needed to focus on that. How we can use the presentations as a starting point to answer the question of how we use these criteria in a classroom?

Vaille Dawson noted that there is a broad range of approaches. You can start with content and go to the issue from there, but you can also intertwine them, or start with the issue and then work out the scientific content. However, in terms of overarching principles, you need to have an environment where it is safe to question, an environment where the scientific evidence is debatable. This has to be allowed in the classroom.

Maria Pilar Jiménez-Aleixandre revisited Dana Zeidler's criteria and supported these. The student role has to be active – they have to be active knowledge producers. Thus, there is a need for a curriculum that engages them in modelling knowledge and not just receiving a lecture. The teacher has to support this. In addition to Dana's criteria, there is another condition: teachers have to participate in generating resources. We have to be aware that SSIs need to be about scientific questions that have more than one answer. There are issues that do not have a single best answer, so to solve these, students have to be engaged in enquiry. Thus, students deal with the SSI not only by looking in a book but by doing something, like laboratory work. The teacher's approach in the curriculum should stimulate communication in order for students to feel free to say something without being corrected immediately.

Dirk Jan Boerwinkel mentioned that it would be fruitful if we looked at topics we already teach in biology and think about how we can enrich these topics. We can then teach the same topics but in a way that provokes argumentation and moral reflection. Building in genomics and argumentation several times in the existing curriculum is a better strategy than trying to create a whole new kind of teaching.

Educational goals

Miriam Ossevoort wanted to know how education on SSIs is evaluated. The goals to be implemented have not been clearly explained. What do we want the students to learn and how do we know they have learnt it? For Paul van der Zande, the goal is to improve the students' argumentation skills. They can demonstrate the arguments in tests and become better at argumentation. However, if the main goal is really to change their opinions and their behaviour in real-life situations, then that is a separate issue. Miriam summarized that these are two different goals within SSI education: improving argumentation, and changing opinions and behaviour. Laurence Simonneaux emphasized that the educational purpose should be the most important. Depending on the topic, there are different goals for the students. You have to be cautious when setting goals beforehand. Behavioural change is not automatically a goal for any topic. The goal can be decided at any time – it becomes situational. A more easily reached goal is to teach students about contexts, but this leaves another complex question unanswered: how to deal with uncertainty in this case. This is more difficult. You also have to deal with the level of commitment you want the students to achieve. Is this even possible? When training teachers, it is useful to start by raising all kinds of goals that can be reached with SSIs, and show the students that they have to be cautious with them.

Dana Zeidler commented on the overarching goals of scientific literacy. There are multiple ways to assess this, but these depend on what is considered to be the core of scientific literacy. Do you want a conceptual understanding? Does education have to change behaviour? Raise scepticism? Develop openness of mind? Enthusiasm?

Maria Pilar Jiménez-Aleixandre defined two main goals for science education. When we work on SSIs, they involve science, and sometimes the science is very complex. This relates to two types of goal. One has to do with scientific literacy, with learning science. This again implies two aspects: learning about science concepts and models, and learning about (or engaging in) science practices. The second type of goal relates to citizenship. This is why SSIs are very important and why we want students to develop critical thinking. Rather than the teacher telling them everything, they have to learn and form opinions for themselves. However, the teachers can give them the tools to enable them to decide. The involvement of the teacher in this process is contextual and depends on the theme.
Tanja Klop mentioned that there are three basic outcomes or changes that you want from students. You want to change their knowledge, their emotions and their behavioural intentions. If you want to measure the effect of your modules, these are the elements that can be used to determine effectiveness.

Ralph Levinson felt that the conversation was focusing perhaps too much on expected outcomes, on what we expect young people to do as a result of discussing SSIs. But is there a general theme here? The well-being of our fellow human beings is the ultimate justification of an SSI. The focus on measurement in terms of who profits and benefits might actually obscure what is really important in SSIs. Ultimately, the teachers make a judgement on students' values. Perhaps instead of looking for personal virtues, we should look for a society value, such as what it means to have a good society and what this says about the decisions we make.

Dirk Jan Boerwinkel wondered how the effectiveness of educational strategies can be evaluated. This question includes the idea that you can predict what students will learn from education. We have to move away from this and accept that when you present a complex issue such as genomics, the only thing you can predict is that different students will learn different things. For some students, this can be a new insight into how nature works, others will reflect on how the research is done, while yet others will realize that insurance companies play a part in these issues. The teacher has to allow for different kinds of reactions. It is important to give all these viewpoints the opportunity to develop during the discussion, instead of pinning the classroom activities down to just one learning objective.

Argumentation

Dana Zeidler argued that argumentation has to focus on students' ability to back up their claims and counterclaims. This goes hand in hand with more reasoning in the classroom. This is linked to elements of fairness, defined by justice, empathy and care, surrounded by social norms. These are distinct elements but they go together in the classroom. Maria Pilar Jiménez-Aleixandre thought that the importance of these elements depends on the context. There are contexts of argumentation where the ethical and value components are more important and there are others where the practices are more important. Thus, when we discuss SSIs, we have to take into account not just the rational arguments but also other components such as norms and emotions. The emotional role can be positive (e.g. care, empathy), but there are also some cases were emotion take precedence over the evidence. It is a very complex issue, but we have to take into account the reasons for argumentation. Laurence Simonneaux indicated that, in her eyes, the main thing is to increase the students' reflectivity on their own reasoning. Marcus Grace concluded with the statement that the importance of training children to discuss things within a meaningful debate must not be underestimated. There are many kinds of arguments, such as soap operas on television where people are shouting the entire time. If this is what students see, they may think that this is how interactions should be. Teachers have to teach them that there are more civilized ways to come to a decision.

Summary of Discussion 2

Several criteria have been formulated for the development of SSIs.

Criteria for choosing an SSI topic:

1 SSIs need to be personal and relevant to students.
2 The topic or questions raised should be controversial.
3 Different forms of data can be presented.
4 There needs to be some form of ethical tension; a moral component.

Criteria for the classroom environment:

5 Students should be active knowledge producers, engaged in enquiry.
6 Teachers should participate in generating resources.
7 The classroom environment should be a place where scientific evidence is debatable.
8 Teachers should focus not only on correct answers but also on relevant questions.

The goals that should be reached are described as forms of scientific literacy and citizenship, which appear to be closely related.

Scientific literacy:

- Using science concepts and contexts.
- Understanding use of models.
- Understanding science practices.
- An attitude of scepticism and openness of mind.

Citizenship:

- Critical thinking.
- Improving argumentation.
- Knowing how to deal with uncertainty.
- Changes in opinion and behaviour.

Some important caveats have been suggested in defining learning goals. We should be cautious in deciding on the learning goals beforehand. Themes differ in the relative importance of elements such as values, concepts and practices. Furthermore, it is difficult to predict learning outcomes in these complex issues, and perhaps we should allow for and expect different outcomes for different students. This also means that teachers should be prepared for different roles, depending on how the issue develops in the classroom. Another caution is that we should keep in mind that desired learning outcomes in SSIs have to be framed within the ultimate goal of being able to contribute to a 'good society' in which the well-being of our fellow humans is considered in decision-making processes.

Theme: Dealing with risk and uncertainty

Understanding the numbers behind risk predictions from personal genome tests
Cecile Janssens

Towards personal models of risk: what lessons from Deborah's dilemma?
Ralph Levinson

Theme: Genomics education in practice: what are the effects?

Measuring the impact of instruction about argumentation and decision-making in high-school genetics
Vaille Dawson

Raising awareness of pre-symptomatic genetic testing
Dirk Jan Boerwinkel

Theme: Teacher education: how to empower teachers

Empowering teachers to teach socioscientific issues: the role of teacher identity in teaching
Paul van der Zande

Discussion 3: What kind of learning activities should be developed and tested? How should teachers be prepared?

Chair: Jenny Lewis

Final reflections

Research-informed criteria for developing genomics education aimed at decision-making
Dirk Jan Boerwinkel and Arend Jan Waarlo

Understanding the numbers behind risk predictions from personal genome tests

Cecile Janssens
Erasmus University, Rotterdam, The Netherlands

Introduction

With current technologies, specialized companies can execute personalized genome tests that predict your risk of specific future diseases. But what do these results actually say? How predictive (deterministic) is our DNA?

In this presentation, I will illustrate what these results mean (and how you can form an opinion on this new approach) by sharing my own genetic test results.

Case: Reproductive lifespan

In October 2010, subscribers to the famous journal *Human Molecular Genetics* received an e-mail with the announcement: *'A relatively inexpensive test could predict a woman's reproductive lifespan, according to a study published in Human Molecular Genetics.'*

This is a claim that immediately increases the reader's curiosity. However, it also raises questions about the underlying scientific concepts. Predicting a reproductive lifespan – that must be a complex outcome. How can you make that into a test? And what is behind it?
For answers, I read the full article in the journal. As it turned out, the researchers found four genes that predict early menopause. In the conclusion of the article, they say that the predictive ability of the four genes is still limited. The conclusion does not resonate well with the claim that the journal made in the announcement.

This, however, did not prevent the news spreading very quickly. A Google search on the same day showed over 20 pages of results saying that there is a genetic test that predicts reproductive lifespan in women. FOX News, a popular medium in America, blew the news even further out of proportion, claiming that the test was already being developed for the market.

This example shows how science results can be translated into completely the wrong message to society.

Tailor-made genetics

The speed at which the news was picked up also indicated the curiosity and expectations that society holds towards genomics research. There are already hundreds of companies on the internet that are willing to satisfy this curiosity by offering you a completely personalized, predictive genetic test.

These companies (and their tests) can be divided roughly into two groups:

1. Tests that focus on monogenic diseases.
2. Tests that include genotype scans. Multiple genes are being tested here (sometimes even the whole genome), with risks calculated for many different, complex diseases.

For prediction purposes, it is essential to know whether a given disease is monogenic or multigenic. Monogenic diseases can be compared to an on/off switch. There is a relatively simple pathway when it comes to disease development. For example, in Huntington disease, there is a known mutation in a gene that will make you ill, with a risk of 100%. A more complex outcome is the question of the age at which you will get the disease and how severe the symptoms will become, but the pathway itself is simple.

This high genetic risk factor is a good reason for testing the patient's family members as well, to identify their genes and risk. There is a high risk that they are carriers of the gene themselves and will develop the disease. It is an informative test; nothing can be done against a positive test result (there is no cure), but it can help you plan your life.

It is different when it comes to complex diseases, which result from a complex interplay between many different genes and also non-genetic factors (e.g. smoking, diet, etc.) Complex diseases can be compared with the control panel of a space shuttle, with all kinds of different buttons and switches. Knowledge of the positions of all these buttons is needed to know how to launch the space shuttle. The same holds for the development of complex diseases; one needs to know the combination of risk factors to predict whether the disease will develop or not. In contrast to monogenetic disease risk factors, a specific genetic risk factor in complex diseases carries a small risk with respect to the health outcome. One faulty gene will not necessarily start the development of the disease. Therefore, it is not worth identifying such cases in a population.

For complex diseases, risk models consisting of gene profiles (with combined information) are developed for prediction purposes. This can be done by testing multiple genes alone (like companies do) or by adding multiple genes to traditional risk factors, as many diseases are not caused by genes but by lifestyle and environmental factors. Predictions should take these factors into account.

This is already done by many companies that try to predict health outcomes. However, these tests are not limited to health outcomes; there are even tests for finding an ideal partner, based on your genetics. It is striking that this test is based on one single gene: it is basically based on a study on tolerating sweat (odour) from your partner. Another example is the company Sciona, which recommends lifestyle choices based on your genetic profile (e.g. whether you exercise, your diet, etc.).

Evaluation

I studied seven of these examples to evaluate what they are predicting, which genes are being tested (and how this relates to the literature) and the evidence that the tested genes are actually associated (in multiple studies) not only with the disease that it tries to predict but with any given disease at all.

The findings were striking. Together, the seven companies tested 69 polymorphisms (mutations) in 56 different genes:

- For 24 of these genes, there is no scientific evidence that the genes tested are associated with any disease at all.
- For another seven genes, the association (with any disease) is not statistically significant.
- For 25 genes, associations were found but with so many different diseases (28) that the diseases cannot be predicted together in a risk profile, and furthermore the effect sizes were very small, with odds ratios ranging from 0.75 to 1.5, with only a few rare exceptions.
- The genes were often predicting diseases other than the ones they were actually meant to predict, e.g. a test in which genes are supposed to predict cardiovascular diseases, where the genes turned out to be a better predictor for non-cardiovascular diseases.

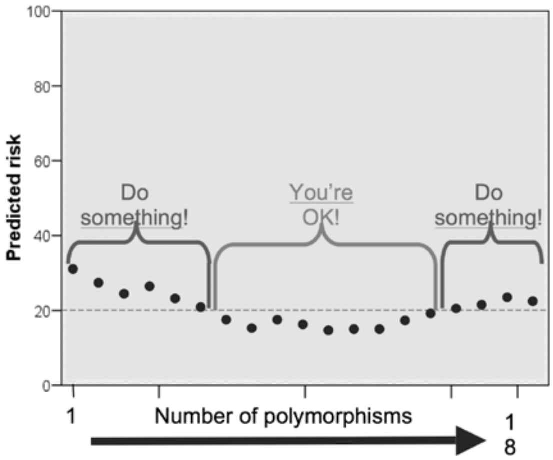
Genome-wide scans

Nowadays, you can get a prediction, based on your genotype, for many diseases rather than a specific one. The science behind these tests is better than in single-disease tests. Risk predictions are based on robust replicated single-nucleotide polymorphisms (SNPs) from many different genetic markers. These companies also give regular updates on risk predictions based on the fact that these risks change during ongoing genomic research and new inventions. However, these companies also claim that when you know your genetic risk, you can empower yourself in terms of prevention. In this way, they are no better than the older companies.

I had my genome checked by a company, and the results were presented in terms of risk numbers: for some diseases I had an elevated risk, while for some diseases the risk was decreased compared with the average risk. However, for most diseases, the risk levels were average. The reason for this is that most diseases are hard to predict. It is very likely that all people who buy the test will end up with average risks for most diseases.

Another unfortunate thing about the results is that you cannot do much with them. For most of the diseases listed, there are very limited intervention possibilities. Also, the risks are presented in terms of lifetime risks. But at the age of 42, for many diseases you would already have developed symptoms at that age, so it is highly likely that if you have not developed the disease yet, you will not develop it in the future.

The risk updates on these tests are also unclear. In Figure 1, the change in risk prediction for diabetes is shown over time. The figure shows that, when a 20% risk is considered average, your risk prediction can change from an increased risk to a decreased risk over time as more associated SNPs are found through diabetes research and then checked with your previous genome results.



In a population-based study in Rotterdam ($N = 3500$), it was found that this scenario of changing risk profiles is not unlikely: it happened to more than 30% of the tested people, and this number increased when more updates were added to the risk model.

Carrier status

The test results not only show risks for disease but also predict carrier status for monogenic diseases. These types of result are composed mainly of a long list of diseases, and whether you have the predisposed mutations in these genes. When most people do this test, they will get a long list of diseases with a negative carrier status (because there are so many rare, obscure diseases listed). These negative results will only confirm what you already know: you are not a carrier, because if you were, you or a family member would have developed the disease earlier on. So why should you pay money to have these diseases tested?

For breast cancer, BRCA mutations are tested. Is it reassuring to get a negative result when only three associated gene mutations are tested, which were discovered earlier in a Jewish community, while over 1000 gene mutations are linked to breast cancer? Only these three genes are tested because they are not patented, but if you do not have roots in this specific Jewish community, you are not very likely to have these gene mutations.

Despite all these uncertainties and changes, companies still offer these products to society. These companies are good for doing genotyping and comparing DNA between individuals. However, what they cannot do is provide meaningful risk estimates. Science has simply not yet advanced that far, and complex diseases are too complex to predict.

Towards personal models of risk: what lessons from Deborah's dilemma?

Ralph Levinson
University of London, London, UK

Introduction

People react ambivalently to emergent technologies. These reactions can create public and personal anxieties and put pressure on the government to respond to the potential effects of the technologies. In late modernity, the idea of a 'risk society' has become prevalent. Risk has come to permeate decision-making for individuals, families, institutions and governments.

To some extent, some emergent technologies have become part of the discourse of what we call 'post-normal science'. These technologies are known by the acronym GRAIN (Ravetz and Funtowicz, 1999), and each constitutes high stakes in terms of their impact on society, their intrinsic uncertainties and hence the high associated risks:

Genomics
Robotics
Artificial **I**ntelligence
Nanotechnology

But what do we mean by risk? It is a loose and very fluid concept. Its meaning is historically contingent. There is a diversity of interpretations and definitions of risk:

- Utility theory: the rational actor paradigm (Jaeger *et al.*, 2001). We assume that individuals make choices about events based on reason and evidence and the most desirable consequences. This is the way that experts act; they make decisions based on high-volume data and then calculate risks based on the gravity of impact of the event and its associated probability.
- Psychometrics (Slovic *et al.*, 1980). This deals with the psychology of risk and risk perception: why do people respond to risk situations in particular ways?
- Cultural theory (Douglas & Wildavsky, 1982). This takes a structural view of society and cultural views on responding to risk; people respond to risk based on their experiences, culture and relationships, and can be categorized into certain types of cultural response.
- Post-structuralism/governmentality. Risk becomes part of the discourse in society, wherein certain groups are considered to be at risk (e.g. when a woman becomes pregnant, she is suddenly seen as someone at risk: a risk that is attributed to pregnant women as a whole).
- Phenomenological accounts: risk as pleasure. This is where risk is seen as an adventure, as an adrenalin kick, as occurs in extreme sports.

The need for risk education

Risk education is now embedded in many national curricula, e.g. maths and science. We are beginning to understand science as a social practice that involves uncertainties and probabilities. Frontier technoscience is thus not a determined, certain subject. Science itself, however powerful and instrumental, is always subject to change.

Judgements about science in society need to blend scientific judgements together with other forms of discourse. There are now several examples of widely used curriculum schemes on risk, although these occur in relatively few countries and are unevenly distributed.

Risk is accepted as a key aspect of learning for young people. It is multidimensional, and cross-curricular (risk is not a concept suited only to scientific subjects but also deals with how people feel about things; in the UK, statements on risk can be found in citizenship and geography curricula as well as those of science and mathematics). However, the developments in curricula have not been based on any research-based pedagogy for risk. There is very little in the literature that theorizes the justification of including these statements about risk in the curriculum.

Example: Curriculum specifications (from a Science in Society course in the UK)

'Everything we do carries a certain risk. New technologies and processes based on scientific advances often introduce new risks.'

- In this curriculum, *'risk is a measure of the probability of harm in a given situation'*. Thus, understanding the concept of probability is very important.
- *'The perceived risk of an activity is often quite different from the actual measured risk.'* This means that there is an actual, objective risk that can be quantified.
- *'Several factors can influence a person's willingness to accept a specific risk. Most people are more willing to accept a process or situation that has some risk if they get direct benefit from it and if they choose it voluntarily rather than having it imposed.'*
- *'To make an informed decision about the management of a given risk, we need to take into account both the probability of the event occurring, and the seriousness of the consequences if it did. This is particularly difficult in the case of events of very low probability, but with very serious consequences if they occur.'*

Hence, in terms of these course specifications, to get a better grip on the concept of risk, people need to understand actual risk and therefore the probability of an event occurring as well as its impact (which will differ depending on who you are, so there is always a degree of subjectivity). Probability itself is based on uncertainty, because we do not know what the outcomes may be, and science itself also holds a degree of uncertainty.

However, there is also perceived risk, which is mediated by people's heuristics. Everybody has certain rules of thumb and ways of acting that relate the perceived risk to the actual risk. These are influenced by affect (emotional response to an event) and availability (e.g. what is in the media), and people will also filter data into their own cognitive structures to reaffirm their own beliefs about how they are going to act. This is the curriculum model, as shown in Figure 1.

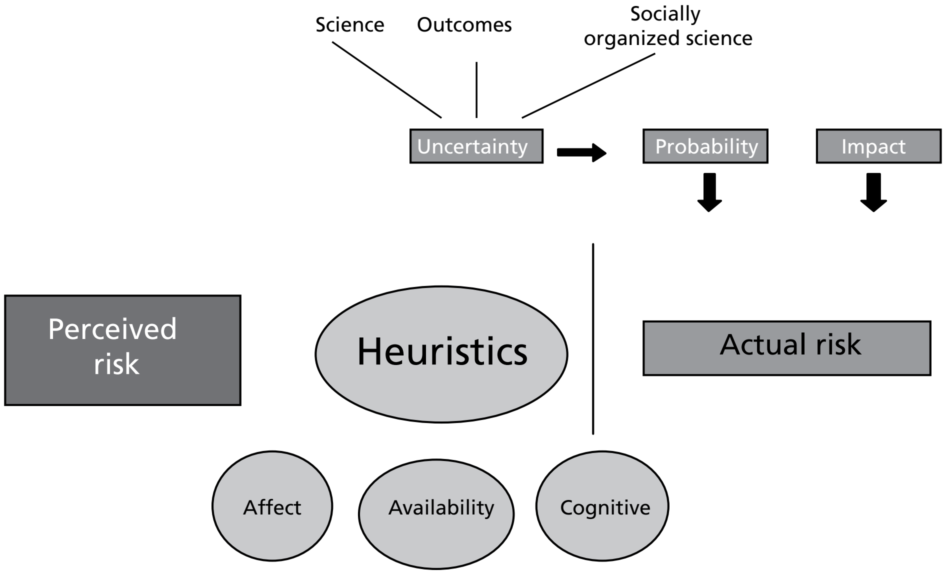


Figure 1. Curriculum model

A study promoting teachers' understanding of risk in socioscientific issues

How does the curriculum model hold up in light of the way teachers of science and maths discuss risk issues? The aim of this research was to support and enhance the teaching of the core idea of risk. This was achieved by engaging mathematics and science teachers in modelling socioscientific issues (SSIs) using new technological tools, so that they interact more deeply with interdisciplinary knowledge and become empowered to enthuse their students in meaningful activity around the use of risk.

The main research questions were summarized as follows:

- *Teachers' knowledge about risk*. What is the nature of teachers' knowledge about risk? How do teachers think about the teaching and learning of risk?
- *Pedagogy*. What are the principles that should underpin a pedagogy of risk?

Method

An iterative research design was developed, seeking successively to: (i) perturb teachers' thinking to gain an insight into their thinking-in-change about risk and its pedagogy; and (ii) embed conjectures about pedagogy into new designs of the tools.

Three pairs of teachers were used: one mathematics and one science teacher from each of three London schools.

Deborah's dilemma was a software design based on a story about a woman (Deborah) with back pain. The background story and design of this piece of software are shown in Figure 2. The software incorporated the following:

- A complex decision-making scenario, which encouraged teachers to place themselves within Deborah's dilemma.
- Different and rich perspectives and sources of information.
- Conflicting opinions from experts and evidence from personal research.
- Possibilities of trade-offs.
- Diverse representations; there were different ways in which data was communicated.
- Tracking dialogue between the pairs of maths and science teachers.

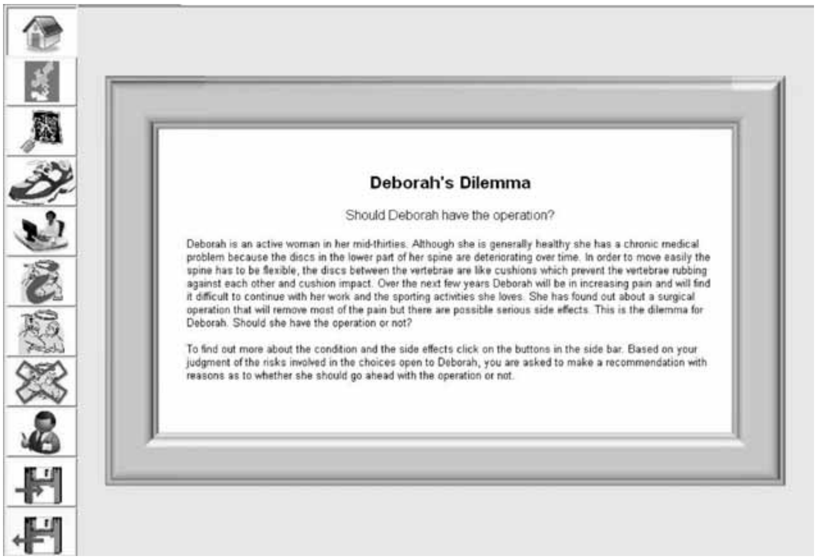


Figure 2, Deborah's dilemma. (The complete programme can be located at www.riskatioe.org.)

The teachers discussed how they would feel in this position. Should Deborah have the operation or not? What are the issues at stake here?

During the simulation of this dilemma, details of Deborah's love for sports and her work situation were shown, and the teachers were also presented with details of consultations by doctors with different kinds of expertise.

A probability simulator was incorporated in which teachers could estimate the probabilities of outcomes for themselves. For example, the operation itself has a 95% success rate, but there are possible complications, e.g. an infection with a chance of 1 in a 100, or a chance of dying quantified as 1 in 5000.

The teachers could run a large number of operations (e.g. 1000) to see what the possible future outcomes would be, and also a simulation of what would happen to Deborah if she did not have the operation.
The teachers were then asked to record their thoughts and what they would do and why. Their dialogues were also tracked during the process.

Results

What did teachers use to decide on their actions and decisions? These are some examples of the kind of statements that were tracked:

- Meanings of probability: *'To be honest I have no idea what one in a million means.'* (L)
- Empathy: *'That's enough, looking at how horribly wrong it could go for her.'* (L)
- Ambivalence: *'OK, I won't get any better but I don't want to walk out of here being paralysed or with spine damage or anything. And I think four out of 1000 is an acceptable risk. That's a one in 250 chance.'* (N&T)
- Trust: *'This guy knows more about it than other people, and he's seen more of these people. So I would say no to the operation, I think.'* (L)
- Sources: '*…for most people a doctor is a classic position of authority. And you never say to them, Well where does that 95% come from? Which data was that? Which nationality was that? Do they ever get asked that? I don't think so.'* (T)
- Experience: *'And also on the case of the anaesthetic side; there's a relative who's died from that about five or six years ago. . . . minor operation; like no risk, virtually zero risk. I must admit it's never affected me, in terms of thinking about operations.'* (T)
- Perception of pain: *'I'd rather die than live with intolerable pain so I'd go for the operation.' (E)*
- Social awareness: *'If it went wrong and people depended on you…You do think of other people when making these choices.'* (L)

Pieces of recorded dialogue showed tensions between the partners:

> *A: There's still pain, no matter what she's doing, always pain.*
> *L: But she's still alive.*
>
> *A: And work is difficult, so supporting herself is difficult. She has to take time off work.*
> *L: She's lived with it for a while, and she's looking.*
>
> *A: You need someone to do your shopping for you…*
> *L: Well, she can use a trolley…*

How do these results and interactions fit into a model? I hypothesize that probabilistic judgements (the way people respond to risk) are influenced by value explications (the values they hold). Probabilistic decisions are mediated through values. This is a pre-condition of risk estimation (summarized in Figure 3).

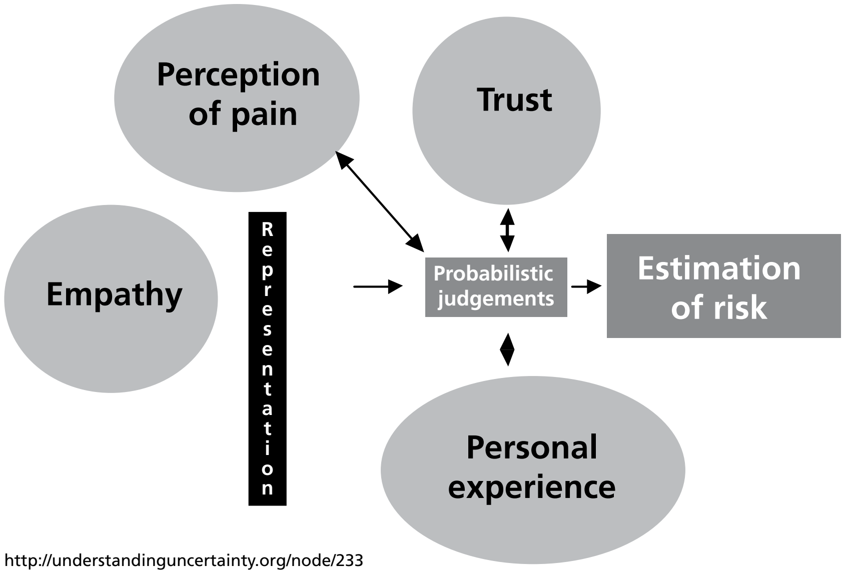


Figure 3. Risk estimation

Conclusions

What are the implications from this research for effective classroom practice?

Risk is a multi-disciplinary topic that can be addressed within conventional school structures. The explication of sociocultural values should mediate teaching and learning about probability in relation to risk in the context of biomedical issues. Thus, if you talk about probability, impact and risk, this can only be done in the context of underpinning values and experiences.

Probabilistic judgements are mediated by diverse social contexts, expert assessments and reflections by lay-people on those assessments. Hence, any task to enable students' learning of risk should be authentic and close to the interests and pre-occupations of students, and preferably in an action-oriented context.

Recognition of the dimensions of risk such as probability and outcome might be stimulated by engaging with specific contextualized socioscientific dilemmas and discussing the multifaceted nature of the dilemma.

What are the common teaching and learning challenges in risk education?

Probabilities and impacts cannot be detached from the social, cultural and personal meanings that groups and individuals bring to them. Prioritizing and opening to discussion the most important factors that derive from these meanings is therefore crucial in understanding what it means to take a risk. There is a need for a strong narrative line (a compelling story) that explicates the value position in relation to specific authentic SSIs.

Arenas in which an understanding of risk is situated in genomics education and the consequences for decision-making

These include the following:

- Forensic use of DNA profiles.
- DNA variations for behaviour traits.
- Gene associations with harm in drug-taking.
- Insurance claims: social risks.
- Genetic testing kits.
- Tools that can enable students to focus on priorities and trade-offs in relation to probabilistic data, where data is rich but uncertainty is high.

References

Douglas, M. & Wildavsky, A. (1982). *Risk and Culture.* Berkley, CA: University of California Press.

Jaeger, C.C., Renn, O., Rosa, E.A. & Webler, T. (2001). *Risk, Uncertainty and Rational Action.* London: Earthscan Publications.

Ravetz, J. & Funtowicz, S. (1999). Postnormal science: an insight now maturing. *Futures* **31,** 641–646.

Slovic, P., Fischoff, B. & Lichtenstein, S. (1980). Facts and fears: understanding perceived risk. In: Schwing, R.C. & Albers, W.A. (eds) *Societal Risk Assessment: How Safe is Safe Enough?* New York: Plenum Press, pp. 181–214.

Measuring the impact of instruction about argumentation and decision-making in high-school genetics

Vaille Dawson
Curtin University, Perth, Australia

Introduction

In Australia, there is an ongoing discussion on the teaching of science in the compulsory years of schooling in light of the proposed new Australian Curriculum in Science (Australian Curriculum Assessment and Reporting Authority, 2010). One of the aims of science education is to enable all students to develop a deeper understanding of the world and use their understanding of science to contribute to public debate and make informed and balanced decisions about socioscientific issues (SSIs) (i.e. scientific literacy).

To be able to make these evidence-based decisions, students need to understand underlying scientific concepts. They need to be able to be sceptical and questioning of the claims made by themselves and others, to weigh up evidence about opposing claims, to evaluate risk and probability, to construct and judge arguments and to use rational informal reasoning.

Until about 5 years ago, no research had been published about Australian students' argumentation skills about SSIs. Genetics, including an understanding of genetic engineering, is taught to students usually in lower secondary school (age 14–16 years). To explore the relationship between scientific literacy, informal reasoning and argumentation about gene technology, we examined argumentation skills and informal reasoning patterns of 12–17-year-old high-school students (Dawson & Venville, 2009). The study designs and results are presented here.

Reasoning and argumentation about SSIs

In the first study, semi-structured interviews were conducted where students were asked questions about biotechnology (genetically modified foods, genetic testing, forensic testing, genetic engineering and cloning of stem cells from extinct species). Students were also asked for evidence to support their views. The researchers did not probe the students or ask follow-up questions but just let them talk about the topics. Subsequently, the interviews were analysed using Toulmin's argumentation pattern (claims, data, warrants, backings, qualifiers and rebuttals) and also patterns of informal reasoning (intuitive, emotive and rational).

Findings

Bybee's (1997) hierarchy of scientific literacy (nominal, functional, conceptual and procedural and multidimensional) was used to determine the starting positions of the students. This was based on the premise that when new concepts are introduced to students, you have to know where they actually are in terms of scientific literacy. Across the whole group of students, most of them used some examples of scientific language in their interviews. Most students demonstrated at least nominal scientific literacy and one-third functional scientific literacy. However, only a quarter of the students were able to provide more than just a claim and a simple piece of data. This study served as a baseline for further studies.

Effect of explicit instructions about argumentation and decision-making

The study led to a new research project, where grade 10 students (14–15 years old) were explicitly taught about argumentation and decision-making in the context of genetics (Dawson & Venville, 2010; Dawson *et al.*, 2010; Venville & Dawson, 2010). Would that have any effect on their argumentation skills?

Students from the 10th grade were enrolled in this study, because in this grade all of the students are taught a genetics course. (After this grade, science is no longer compulsory.)

In this study, seven biology teachers from four different high-school types in Western Australia participated. Their students were divided into two groups: 193 grade 9 or 10 students from eight classes were placed in the experimental group and studied genetics with an argumentation intervention. In contrast, 186 grade 9 or 10 students from eight classes were enrolled in the control group and studied genetics with no intervention.

The intervention consisted of teacher participation in a series of professional learning sessions on argumentation, decision-making and SSIs in a genetics context. Without guidance from the researchers, the teachers taught argumentation skills using small groups and whole-class discussion and writing frames as part of a genetics topic over one to three lessons.

The study design was quasi-experimental, with pre- and post-tests on argumentation and informal reasoning about the following genetics SSI:

> *A Sydney IVF clinic has recently been offering to produce 'designer babies' for parents. For just $10,000 the clinic will check and, if necessary, change the parents' genes in order to produce the baby of their choice. Once selected, the baby develops normally inside the mother. The choice at the moment is limited to sex, intelligence, height and hair colour but a spokesperson said that several other features would soon be available. All 'designer babies' are guaranteed free from identifiable genetic diseases.*
>
> Lewis (2000)
>
> *Do you think this use of gene technology should be allowed?*

The students were asked to answer this question and write as many reasons as they could to support their answer.

Findings

Before the intervention, students were almost evenly divided between yes/no/I don't know on the SSI question. A brief argumentation intervention and genetics understanding significantly improved students' argumentation skills compared with the control group who studied genetics only. The experimental group of students who were explicitly taught about argumentation and SSIs were also better able to use claims, data, warrants, backings and qualifiers. The intervention also significantly altered students' reasoning type from intuitive and emotive to rational (although rational does not mean there is no emotive reasoning involved).

Successful teaching strategies

The researchers were encouraged by the results and subsequently sought to examine the types of teaching strategies that these teachers used in the classroom to teach argumentation (Dawson & Venville, 2010). From the former sample of seven teachers, the researchers selected the teachers who were most successful in improving students' argumentation skills.

The teachers and students were interviewed after the argumentation lessons, the lessons were audiotaped and transformed into transcripts, and field notes of professional learning sessions and classroom observations, completed writing frames and teaching programmes were evaluated in this study.

Findings

The teachers with the greatest improvement in their students' argumentation and informal reasoning demonstrated the following behaviours:

- They explicitly explained that SSIs exist in genetics (many students and teachers are not used to this notion).
- They explicitly defined what an argument is, and defined argumentation processes (e.g. stated parts of an argument and used familiar examples). Many students previously viewed arguments as conflict or as a persuasive tool only.

- They facilitated quality discussion (whole class and small group) by:
  - Encouraging ideas, positioning and valuing different positions.
  - Prompting students to provide evidence and justification.
  - Encouraging critique of arguments and the nature of evidence (versus opinion).
  - Encouraging students to reflect on the argument process they went through.

The observations of the students were collected as well, because their share in the 'success' is equally important. The researchers observed that it is necessary that students suspend their judgement, are willing to listen to opposing views and are willing to question evidence. Furthermore, students need to participate actively and listen to the views of their peers as well as those of their teacher.

Teachers' understanding, skills and beliefs

As a result of this study, a number of teacher-specific factors were identified to address the question of what understanding, skills and beliefs teachers need to develop students' decision-making abilities.

For teachers, it is important that teachers *believe* that SSIs actually exist (not every teacher does so) and that the teacher considers that using SSIs in science education is appropriate. Also, the teacher needs to believe that students are capable of developing decision-making skills about SSIs.

A teacher needs to *understand* the scientific concepts underlying SSIs and understand the concept of 'arguments', different types of reasoning and decision-making processes, and they need to understand the prior level students are at with regard to their current knowledge of science, decision-making and argumentation.

In terms of *skills,* teachers need to develop and practice pedagogical skills in facilitating whole-class and small-group discussions. They need to be able to effectively model the argumentation process and create a safe learning environment where students can freely express their views and can question the claims and evidence of their teacher and peers.

Challenges

An important question that remains unanswered is how to assess students' decision-making skills about an SSI. How can a teacher actually do this?
There are different ways to assess learning depending on the type of outcome you are looking for, such as evidence of decision-making or examining whether students are considering multiple perspectives. Depending on the students' age and experience, they

could be asked to prepare a product for assessment, e.g. an oral presentation, a poster or a website that shows their understanding of an SSI.

Assessment can be done according to:

- Type of reasoning (rational, scientific).
- Quality of argument (e.g. presence of data, warrants, backings, qualifiers, rebuttals, consistency and complexity).
- Weighing up of evidence (pros and cons).
- Consideration of multiple perspectives.
- Consideration of risk.

References

Australian Curriculum Assessment and Reporting Authority (2010). *The Australian Curriculum: Science.* Available at: http://www.acara.edu.au.

Bybee, R. (1997). *Achieving Scientific Literacy: From Purposes to Practices.* Portsmouth, NH: Heinemann Educational Books.

Dawson, V.M. & Venville, G. (2009). High school students' informal reasoning and argumentation about biotechnology: an indicator of scientific literacy? *International Journal of Science Education* **31**, 1421–1445.

Dawson, V.M. & Venville, G. (2010). Teaching strategies for developing students' argumentation skills about socioscientific issues in high school genetics. *Research in Science Education* **40,** 133–148.

Dawson, V., Carson, K. & Venville, G. (2010). Argumentation, decision-making and socioscientific issues. In: Chang, W.H., Fisher, D., Lin, C.Y. & Koul, R. (eds) *Proceedings of the Sixth International Conference on Science, Mathematics and Technology Education,* Hualien, Taiwan.

Lewis, J. (2000). Making the science relevant: classroom discussion of social issues with a science content. In: Bayrhuber, H. & Unterbruner, U. (eds) *Lehren und Lernen im Biologieunterricht.* Innsbruck/Wien/München: Studien Verlag, pp. 107–119.

Venville, G.J. & Dawson, V.M. (2010). The impact of an argumentation intervention on Grade 10 students' conceptual understanding of genetics. *Journal of Research in Science Teaching* **48,** 952–977.

Raising awareness of pre-symptomatic genetic testing

Dirk Jan Boerwinkel
Freudenthal Institute, Utrecht University, The Netherlands

Introduction

In contrast to the research by Vaille Dawson, who evaluated results at the end of an educational intervention, this research was about raising awareness at the start of education aimed at decision-making. An educational design aimed at raising awareness was tested in practice. Choices were made on the subject – pre-symptomatic genetic testing – and the context – elite sport.

Pre-symptomatic genetic testing as the subject

For several reasons, pre-symptomatic genetic testing is a suitable application of genomics to use in the classroom. This type of genetic testing is performed in healthy persons. This could be anyone, including the students themselves, which makes it meaningful for them. Furthermore, it is a field of genomic research that is expanding rapidly, but it also comes with issues of uncertainty, and conflicting values and interests. Due to its innovative nature, future scenarios can be involved in the design of a lesson that deals with this subject. An example of this is the science-fiction movie *Gattaca*, parts of which are frequently used for educational purposes.

In the specific lesson that was developed, the main goal was that students became aware of the *complexity* of decision-making. Four aspects of this complexity were distinguished based on Levinson's definition of a controversial issue (Levinson, 2006):

1 Genetic testing offers advantages and disadvantages; these have to be weighed against each others.
2 Different stakeholders have different interests; an advantage for one person could be a disadvantage for another.
3 The genetic information on which decisions are based is often uncertain.
4 Genetic testing (and the decisions to be made) often concerns conflicting values.

Elite sport as the context

In this teaching strategy, elite sport served as the context. Elite sport can be considered as a near-future scenario, because in this field developments and innovations happen earlier than in everyday life. In elite sport, extreme physical demands and extreme financial investments exist, and there are extreme emotions linked to winning and losing. These factors make elite sport very suitable as a context. In Table 1, we see how this context of elite sport relates to the four complexity factors mentioned above.

Table 1. Complexity factors in elite sport

Complexity factor	Relationship to elite sport
Genetic testing offers advantages and disadvantages	Advantage for the *athlete*: prevention of disease/death by pre-symptomatic genetic testing (Charron *et al.,* 2002; Spinney, 2004) Disadvantage for the *athlete*: exclusion from a career and/or insurance based on genetic test result (McNamee *et al.,* 2009; Rothstein & Joly, 2009) Disadvantage for the *athlete*: the effects of risk information on the quality of life
Different stakeholders have different interests	Advantage for the *sport organization*: prevention of investment in an athlete who is not fit for the top level of sport (Spriggs, 2004)
Genetic information is often uncertain	Gene variants tested in sport offer risk information, not certainty
Genetic testing often concerns conflicting values	Preventing harm versus respect for autonomy of the athlete (McNamee *et al.*, 2009)

Methods

The educational design was the last of four lessons presented through the project 'DNA labs on the Road' using mobile DNA laboratories (van Mil *et al.*, 2010). This meant a time constraint of one lesson. The lesson needed to be applicable by biology teachers without much extra preparation. Student results as possible outcomes of the strategy were predicted, and then tested.

The criteria used in this design were:

- To create empathetic involvement through narrative cases (Waarlo, 1999).
- Cases should illustrate the complexity factors and conflicting views on the topic.
- Cases should not contain explicit judgements.

Students were to be allowed first to indicate their opinion in a non-verbal way, based on intuition (Sadler & Zeidler, 2005), then to formulate arguments to justify their opinion and lastly to discuss this with the other students. Figure 1 demonstrates how students were first invited to position themselves on a scale and then to formulate arguments and questions.

Genetic testing in elite sport is:

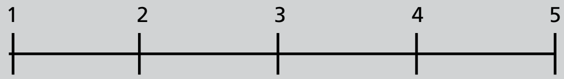
1 = a very bad idea

2 = not a good idea

3 = a doubtful idea

4 = a good idea

5 = a very good idea



Mark your position with a cross on this line between 1 and 5.

Which arguments did you consider?

What questions do you have about this?

Figure 1. Student opinion form

Cases

This procedure was repeated with a sequence of cases. Each case considered a different narrative that dealt with another complexity factor in the subject of elite sport and genetic testing.

The first case was a video of Antonio Puerta, a Spanish soccer player for the team of Sevilla. In 2009, he collapsed on the field during a match and later died of heart failure. It was discovered that Puerta had a thickened heart ventricle. Combined with extreme physical demands, this condition can be very dangerous. Several genes are connected to this disease but do not give an exact prediction of the risk of combining these genetic variants and engaging in elite sport. Hypothetically, genetic testing and refraining from elite sport based on the test results could have saved Puerta's life.

After this narrative, the students marked their position on the line (1–5) and formulated their arguments.

The second narrative consisted of the story of Domenico Fioravanti. This Italian swimmer won an Olympics gold medal in Sydney. Italy is very caring about her athletes and therefore you cannot enter an elite sport without having passed a physical examination. Between the Sidney (2000) and Athens (2004) Olympic games, Fioravanti was tested again, and it was found that he had developed the same heart condition as Antonio Puerta. This ruled him out of defending his gold medal at the Olympics in Athens.

In this case, students again were asked whether they thought this form of testing was a good or bad idea.

The third story evolved around an advertisement for Atlasgene, a gene test available on the market. It is a test for gene variants related to muscle types and is used to test the potential sporting qualities in children. This way parents can decide what kind of sport their child could be most successful at. As will be visible in the results, the students did not think this was a good idea.

The research questions for this strategy were:

1. Does the strategy invite students to consider different views on pre-symptomatic genetic testing?
2. Does the strategy generate arguments and questions that cover the complexity factors?

Results

A striking feature of the results, shown in Table 2, was that if we had only measured the results at the start and end of the teaching strategy, the conclusion would have been that the strategy did not have an effect. However, as these (significant) results show, there is actually a change going on through the sequence of cases, and students' attitudes could be destabilized, which is a good start for awareness.

Table 2. The positions of students (N=120) before and after examination of the three cases

	Mean score on scale	Those more in favour of genetic testing (%)	Those with an unchanged view	Those less in favour of genetic testing	*P* value
At the start	3.3				
After case 1	3.8	**62**	37	1	<0.0001
After case 2	3.4	4	47	**49**	<0.0001
After case 3	3.0	15	33	**52**	<0.05
Final score	3.3				

The arguments that were used by the students are summarized in Table 3. As can be seen, the number of arguments that were used increased after the teaching strategy, especially the arguments that dealt with complexity factors regarding conflicting values and the advantages/disadvantages of genomics. Autonomy was also regarded as very important after the lesson; the arguments that the athletes have to be able to make the choice themselves, and that children should be able to choose their own future were used frequently. It is also important to mention is that, during group discussions, the teacher's role was to facilitate, and to collect and summarize arguments, rather than presenting or supplying arguments to the students. Although the complexity factors on the left were not mentioned to the students, the students automatically generated arguments that fitted these categories.

Table 3. Arguments used by students, related to the complexity factors

Complexity factor	Student arguments (*N*=138)	Before (% of students)	After (% of students)	Increase (% of students)
Genetic testing offers advantages and disadvantages *and* Different stakeholders have different interests	Prevents disease and/or death	34	89	55
	Helps in career planning	9	23	14
	Prevents waste of time and money	18	19	1
	Breaks career/dream	11	31	20
	Knowing the test results influences life too much	6	20	14
	Exclusion of top athletes	3	5	2
Genetic information is often uncertain	Risk of unnecessary rejection because test result only indicates a chance	14	24	10
	Unfair to base rejection on genes	10	13	3
Genetic testing often concerns conflicting values	Athlete has to make the choice (autonomy versus health)	3	26	23
	Children should choose their sports based on interest	0	26	26

Conclusions

The cases and the complexities that were built in enabled many shifts in opinion, which could be seen as raised awareness of different perspectives. As well as the hard impacts on decision-making, the soft impacts (e.g. questions such as 'Do I want to know this? Does it influence my life?') were also linked to this. The sequence of selected cases spontaneously generated the main arguments of the issue within the classroom discussion. Both informative and moral questions were asked; the arguments were not limited to the context of elite sport but were taken to a more general level.

Teachers can use this strategy to raise awareness in a short time with limited preparation. One can provide teachers with case sequences. The teacher's role remains important but in structuring the discussion and collecting the arguments, rather than as a supplier of values.

References

Charron, P., Heron, D. & Gargiulo, M. (2002). Genetic testing and genetic counselling in hypertrophic cardiomyopathy: the French experience. *Journal of Medical Genetics* **39**, 741–746.

Levinson, R. (2006). Towards a theoretical framework for teaching controversial socio-scientific issues. *International Journal of Science Education* **28**, 1201–1224.

McNamee, M.J., Müller, A., van Hilvoorde, I. & Holm, S. (2009). Genetic testing and sports medicine ethics. *Sports Medicine* **39,** 339–344.

Rothstein, M.A. & Joly, Y. (2009). Genetic information and insurance underwriting. Contemporary issues and approaches in the global economy. In: Atkinson, P., Glasner, P. & Lock, M. (eds) *Handbook of Genetics and Society.* London: Routledge, pp. 127–144.

Sadler, T.D. & Zeidler, D.L. (2005). Patterns of informal reasoning in the context of socioscientific decision making. *Journal of Research in Science Teaching* **42**, 112–138.

Spinney, L. (2004). Heart-stopping action. *Nature* **430**, 606–607.

Spriggs, M. (2004). Compulsory brain scans and genetic tests for boxers – or should boxing be banned? *Journal of Medical Ethics* **30**, 515–516.

van Mil, M.H.W., Boerwinkel, D.J., Buizer-Voskamp, J.E., Speksnijder, A. & Waarlo, A.J. (2010). Genomics education in practice: evaluation of a mobile lab design. *Biochemistry and Molecular Biology Education* **38**, 224–229.

Waarlo, A.J. (1999). Biology students' forming and justifying of opinions on predictive genetic testing. Towards a practicable and effective teaching strategy. In: Bandiera, M., Caravita, S., Torracca, E. & Vicentini, M. (eds) *Research in Science Education in Europe.* Dordrecht/Boston/London: Kluwer Academic Publishers, pp. 41–48.

Empowering teachers to teach socioscientific issues: the role of teacher identity in teaching

Paul van der Zande
Utrecht University, Utrecht, The Netherlands

Introduction

Anton is a biology teacher in a strict reformist protestant school, a school that 'knows' what is right and wrong for their students. Because he wanted to teach the students personal decision-making during his teaching of genetics in the controversial context of genetic testing, Anton was facing problems. The school board wanted him to explain the correct morally behaviour to his students and did not allow him to leave these moral decisions to the students.

This specific teacher serves as a case to introduce our study on teacher expertise development. During this research, Anton reported that his conscience became troubled. He started asking himself whether he was in the position to actually teach his students what is right and wrong. At first, he was convinced that it was the right attitude. However, in a concluding interview at the end of the process, Anton stated that, according to him, each person has to make his or her own decisions, and he did not have the answers for them. A major change, but how was this achieved?

Situated learning

In secondary science education, there is increasing focus on situated learning in which scientific content is taught in the context of social situations (Bennett & Lubben, 2006; Sadler, 2009; van Aalsvoort, 2004). For example, the current Dutch curriculum reform of secondary biology education encourages teaching concepts in authentic practices, referred to as contexts (Boersma *et al.*, 2007). Educational approaches based on situated learning theory aim to ensure that what is learnt is relevant (Greeno, 1998; Putnam & Borko, 2000; Sadler, 2009). An example can be found in secondary biology education, where the topic of genetics can be taught in relation to everyday situations concerning genetic testing. Genetic testing is a socioscientific issue (SSI). Because it is an SSI, it requires specific teacher expertise. The teachers have to deal with the uncertainty and complexity of these issues, but an SSI also involves themselves personally. The 'whole teacher' is involved. Thus, it is to be expected that as a result of teaching genetics in the context of genetic testing, not only will the teacher's expertise develop but there will also be personal development in terms of professional identity.

Teacher expertise and teacher identity

Although this study was initially aimed at examining the subject of teacher expertise development, there were also other, more grounded findings. There were changes in the teachers' professional identities. The study then became more focused on the relationship between teacher expertise development and changes in professional identity.

There are four areas of expertise that are particularly relevant to learning how to teach genetics, each with its own specific aspects (van der Zande *et al.* (2009a, b; 2011) (Table 1).

Table 1. Expertise required to teach genetics in the context of genetic testing

Area of expertise	Aspects of expertise area
Subject matter expertise	Curricular genetics concepts
	Extracurricular genetics concepts
	Ethical, legal and social aspects (ELSA) of genetic testing
	Characteristics of genetic test practice
	Medical information on genetic tests
	Knowledge of students' moral reasoning
Pedagogical content expertise	The use of narratives
	The use of problem-based approaches
	The use of teaching and learning activities (TLAs) (reflection) on moral reasoning
Moral expertise	Applying different roles in classroom discussions
	Applying different approaches for moral education
Interpersonal expertise	Creating a safe atmosphere
	Having good relationships with the students

Teaching controversial SSIs does not only relate to the professional identity of the teacher, but also to the teacher as, for example, a parent, or as a family member of a patient with a genetic disease. All kinds of questions can arise, for example, How do you connect with this knowledge as a religious person? What values are at stake? These questions affect the way a teacher teaches this SSI.

It has been argued that different bodies of expertise relate to different parts of a teacher's identity. Beijaard *et al.* (2000) found that teachers see their professional identity as consisting of a combination of the distinct aspects of expertise but also that their perceptions changed throughout their career and professional development. This change in teachers' perceptions of their professional identity might indicate that, if biology teachers acquire specific additional expertise, this may influence how they understand who they are as teachers. Recently, Kelchtermans (2009) described five components of teachers' self-understanding (Table 2).

Table 2. The five components of teachers' self-understanding according to Kelchtermans (2009)

Component	Description
Self-image	How teachers describe themselves (based on self-perception and what others, for example their students and colleagues, mirror back to them): the *descriptive* component
Self-esteem	The teachers' appreciation of their actual job performance: the *evaluative* component
Job motivation	What drives the teachers – their motives for becoming and staying a teacher: the *conative* component
Task perception	What the teachers think they must do in order to be a good teacher: the *normative* component
Future perspective	How the teachers see themselves in the years to come and how they feel about this: the *dynamic* component

Community of practice

For this study, a community of practice (CoP) of teachers was initiated. The teachers were able to learn in their actual lessons; they met outside of school but experimented in their classes with what they developed. A CoP is considered valuable because the members typically solve problems, discuss insights, share information, talk about their lives and ambitions, mentor and coach on each other, make plans for community activities, and develop tools and frameworks that become part of the common knowledge of the community. Over time, these mutual interactions and relationships build up a shared body of knowledge and a sense of identity (Wenger, 1999).

In what ways can a teacher community contribute to biology teachers' learning, both in terms of growth in expertise and in terms of changes in self-understanding, to teach an SSI such as genetic testing?

The community started with eight teachers, and myself as the researcher. Seven meetings (duration: 2 hours each) were organized over a period of 14 months. One of the main goals of the community was mutual support: to help each other by implementation of the situated learning approach in their own personal settings. Teachers from strict religious schools as well as teachers from more liberal schools had to feel safe in the community. During the meetings, many topics in different expertise areas were discussed, e.g. ELSA, personal dilemmas, how to react to students' emotions, developing and practising teaching and learning activities (TLAs) such as role-play, giving feedback on each other's materials, etc. The teachers translated the building blocks provided by myself into their own classroom and then evaluated the processes in the CoP.

To examine teachers' expertise development, digital logs and notes on their learning activities were collected. The teachers' learning development was categorized according to Bakkenes *et al.* (2010):

- Experimenting.
- Considering their own practice.
- Getting ideas from others.
- Experiencing friction.
- Struggling not to revert to old ways.
- Avoiding learning.

Due to the community approach, these learning activities were extended to include:

- Linking theory with practice.
- Practising.

These learning activities happened throughout different phases of the learning process, e.g. getting ideas from others occurred during role-play. Friction was experienced when the result of teaching SSIs did not match the teachers' expectations. One teacher, for example, experienced stress when her lessons were rescheduled, and opted instead to teach genetic testing the way she was used to.

Results

For every teacher in the community, I wrote an individual narrative of about two or three pages. This narrative was a strict constructed story, composed of the collected data concerning the teacher involved. A member check was conducted in order to determine the validity of their narratives. For the member check, the narratives were presented to the teachers with the question of whether I had captured their experiences in the teacher community correctly. All of the respondents recognized themselves in the constructed narratives and found that their most important experiences were included. Myself, as the researcher, and the teachers were not 'blank slates' for each other. I therefore considered it wise to conduct a summative audit procedure in order to check the reliability and validity of the analyses that resulted in the narratives (Akkerman *et al.*, 2008; Guba, 1981).

Strikingly, none of the teachers referred to expertise as a major learning outcome; they all reported outcomes in terms of self-understanding. For them, the growth in professional identity appeared to be more important than the growth in expertise.

Table 3 presents the overall development in expertise as reported by the biology teachers at the end of the project. The knowledge of students' moral reasoning increased, as well as the knowledge of the genetic test practice. These teacher expertise areas are the most important areas if teachers want to prepare students for being successful participants in a genetic test situation. The findings showed that the teacher community facilitated a growth in expertise in three out of the four areas for all of the teachers

Table 3. Expertise development

Areas of expertise	Start	End	MV
Subject matter expertise			1
Curricular genetics	^{S} 4	^{S} 8	
Extracurricular genetics concept	^{S} 0	^{S} 8	
ELSA	^{S} 1	^{S} 4, ^{I} 4	
Characteristics of genetic test practice	^{S} 1	^{S} 6, ^{I} 2	
Medical information genetic tests	^{S} 4	^{S} 8	
Knowledge of students' moral reasoning	^{S} 0	^{S} 5, ^{I} 2	*
Pedagogical content expertise			3
Using narratives	^{S} 3	^{S} 7, ^{I} 1	
Using a problem-based approach	^{S} 2	^{S} 6, ^{I} 2	
TLA (reflection) on moral reasoning	^{S} 0	^{S} 4, ^{I} 3	*
Moral expertise			3
Different roles in classroom discussion	^{S} 1	^{S} 4, ^{I} 4	
Approaches to moral education	^{S} 1	^{S} 4, ^{I} 4	
Interpersonal expertise			2
Creating a safe atmosphere	^{S} 5	^{S} 7, ^{I} 1	
Good relationships with students	^{S} 5	^{S} 7, ^{I} 1	

^{S} = Sufficient, ^{I} = improved, but not sufficient, MV = most valued.
* One teacher who did not execute the lessons reported no improvement of expertise in some areas

In terms of teacher identity (Table 4), the major changes included an increase in self-esteem and intrinsic motivation, although for one of the teachers a decline in self-esteem was noted because she felt the other teachers were doing better. This can be the flipside of working in a teacher community.

Table 4. Identity development

Changed part of self-understanding	No. of teachers
Self-esteem	3
Self-image	2
Task perception	4
Future perspective	1
Job motivation	4

A noteworthy finding was that changes in self-understanding were related to the valuation of specific expertise areas. This indicated that, although growth was reported in all expertise areas, some can have more impact on a teacher in the sense of how they understand themselves. Looking at the initial motives of teachers to participate, some teachers already seemed to be more interested in a particular area of expertise than in others. For example, one teacher changed mainly in self-esteem due to her struggle with the content and pedagogical content knowledge (PCK) area, while another changed more in self-image due to a struggle with the interpersonal perspective.

The learning activities reported by the teachers, and labelled by myself as the researcher, showed that no one reported 'avoiding learning' as a learning activity. Most teachers described learning from others and experimenting as valuable learning activities (Table 5).

The learning activities reported by the teachers connected mostly to the expertise area they were struggling in.

Table 5. Reported learning activities

Learning activity	Number	Percentage
Experimenting	17	36
Considering own practice	6	13
Getting ideas from others	18	38
Experiencing friction	1	2
Struggling not to revert to old ways	2	4
Avoiding learning	–	–
Linking theory to practice	1	2
Practising	2	4
Total	**47**	**100**

Two out of eight teachers did not execute the lessons. One was a teacher who was very influential in the CoP. His wife had had two miscarriages due to a genetic disorder, and he was still emotional about it. A few days before his lessons were scheduled, he reported that he was not able to teach about this issue. The other teacher was a lady who considered the students' emotions to be too complex for her to handle.

In conclusion, it can be said that a teacher community can contribute to biology teachers' learning of how to handle an SSI such as genetic testing by providing teachers with the opportunity to learn from each other while experimenting in their own classes. Teaching SSIs is demanding and relates to teacher identity; the dialogue and mutual feedback in the CoP proved to be very helpful for the teachers. Therefore, further research is needed on how expertise development connects to teacher identity, as well as further exploration of the separate effects of learning in a community and learning how to teach controversial SSIs.

References

Akkerman, S., Admiraal, W., Brekelmans, M. & Oost, H. (2008). Auditing quality of research in social science. *Quality and Quantity* **42**, 257–274.

Bakkenes, I., Vermunt, J.D. & Wubbels, T. (2010). Teacher learning in the context of educational innovation: Learning activities and learning outcomes of experienced teachers. *Learning and Instruction* **20**, 533–548.

Bennett, J. & Lubben, F. (2006). Context-based chemistry: the Salters approach. *International Journal of Science Education* **28**, 999–1015.

Beijaard, D., Verloop, N. & Vermunt, J.D. (2000). Teachers' perceptions of professional identity: an exploratory study from a personal knowledge perspective. *Teaching and Teacher Education* **16**, 749–764.

Boersma, K.T., Graft, M., van Harteveld, A. *et al.* (2007). *Leerlijn biologie van 4–18 jaar. Uitwerking van de concept -contextbenadering tot doelstellingen voor het biologieonderwijs [A learning line for biology for 4–18-year-olds based on a concept-context approach].* Utrecht: CVBO.

Greeno, J.G. (1998). The situativity of knowing, learning, and research. *American Psychologist* **53,** 5–26.

Guba, E.G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology Journal* **29**, 75–91.

Kelchtermans, G. (2009). Who I am in how I teach is the message: self-understanding, vulnerability and reflection. *Teachers and Teaching: Theory and Practice* **15**, 257–272.

Putnam, R.T. & Borko, H. (2000). What do new views of knowledge and thinking have to say about research on teacher learning? *Educational Researcher* **29**, 4–15.

Sadler, T.D. (2009). Situated learning in science education: socio-scientific issues as contexts for practice. *Studies in Science Education* **45**, 1–42.

van Aalsvoort, J. (2004). Activity theory as a tool to address the problem of chemistry's lack of relevance in secondary school chemical education. *International Journal of Science Education* **26**, 1635–1651.

van der Zande, P.A.M. (2009a). Health-related genomics in classroom practice. In: Boerwinkel, D.J. & Waarlo, A.J. (eds) *Rethinking Science Curricula in the Genomics Era.* FIsme series on Research in Science Education No. **62.** Available at: http://igitur-archive.library.uu.nl/bio/2009-1208-200117/UUindex.html. Utrecht: CD-β Press, pp. 82–89.

van der Zande, P., Brekelmans, M., Vermunt, J.D. & Waarlo, A.J. (2009b). Moral reasoning in genetics education. *Journal of Biological Education* **44**, 31–36.

van der Zande, P., Waarlo, A.J., Brekelmans, M., Akkerman, S.F. & Vermunt, J.D. (2011). A knowledge base for teaching biology situated in the context of genetic testing. *International Journal of Science Education* (in press). doi:10.1080/09500693.2010.525797.

Wenger, E. (1999) Communities of practice: Learning as a social system. *Systems Thinker* **9,** 2-3.

Discussion 3: What kind of learning activities should be developed and tested? How should teachers be prepared?

Chair: Jenny Lewis, University of Leeds, Leeds, UK

Teacher roles and identities

Francois Lombard asked what model we have of teacher development. Should the focus be on the development of professional capacities (expertise) or on development of teacher identity?

Paul van der Zande believed that everybody has an identity composed of different 'I' positions, according to the theory of Hermans. Identity defines itself in every specific context. There is I as a teacher, I as a father, I as a sportsman, etc. There is a constant dialogue in the head between the different 'I' positions, but this does not rule out interplay between positions. You can act emotionally and professionally at the same time. To go back to the question Francois raised: expertise and teacher identity are linked. We want to see, from the teacher perspective, how they both develop. However, studies on expertise development are from the perspective of outside the teacher.

From an interpersonal perspective of teaching, student identity is equally important. How can you expect students to be emotionally involved while at the same time they are shy about showing these emotions? A teacher has to react with the same commitment to the subject as the students to keep their trust in the long term. Francois agreed with Paul that both rationality and emotions are important for teachers' personal development and involvement. However, the point is that most of the interactions we want to develop are between some form of knowledge and the student, rather than between the teacher and the student. If we want the students to develop their own knowledge, we must encourage them to interact with some form of knowledge, rather than an interaction between the teacher and the learner. This implies that we accept emotions and let the students deal with their own emotions linked to the form of knowledge you are trying to help them develop. Unfortunately, there is often little place for emotions because teachers who allow too much emotion are considered to do a bad job. Paul answered that, in his experience, as a teacher using a problem-based approach, he creates a learning community that he himself is part of. It is not only their interaction with knowledge, but also himself interacting with knowledge in some lessons. Maria Pilar Jiménez-Aleixandre thought that this aspect was interesting but difficult to discuss from a short presentation. In detail, there is much work on teacher reflection in practice as a tool for professional development of teachers. It is an honourable idea that a teacher's identity and a teacher as a practitioner are complementary. There are so many identities in one person: as a teacher, a parent, a religious person, etc. However, the question here is which one of these is relevant for you when you are teaching a teacher. The most important identity in that situation is of you being a teacher because you are looking at the context of teaching. Other identities may interact, but this has to be the basis. Henk van Netten mentioned from his experience that identities can conflict in the classroom. In class, he is the teacher, but he also has to be an independent chairman; students want to know how you think about things. Ralph Levinson presented another side of teacher identity in socioscientific issues (SSIs). Some years ago, he talked with a pre-service teacher. This teacher was not enthusiastic about teaching SSIs, saying that they knew how complex the issue was and that there was a risk that teaching it would make them unhappy. In Ralph's opinion, this is an area that is interesting, problematic and under-researched. Dana Zeidler wanted to go back to the roles of the teacher. It has been said that a good teacher is a seducer – someone who takes distant and new material into the lives of students and attaches meaning to it. But now, the roles of the teacher include many other aspects. In SSIs, they are a facilitator, a mediator, a mentor and a source of authority. There is nothing wrong with correcting misconceptions. The trick is knowing which role you have to play and how much power you should give to the class.

Research and resources

Vaille Dawson called for an overview of good practices to teach pre-service teachers how to handle emotions in the classroom. For example, take pre-service teachers through an SSI scenario that allows them to see the range of emotions that can come out in a classroom situation. It is then important to reflect on these feelings in several types of SSI. We have to empower teachers to handle emotions in a science classroom. It is okay for them to feel strongly about something, because then they know how to act when students show strong emotions.

Dana Zeidler turned the discussion to what teacher trainers have to do. The current models are lacking. Teachers need to realize that they have to keep learning. If they are serious about their profession, they will try to improve their students' lives. Take time to think about your own favourite teachers when you were a student: how did they inspire you?

Laurence Simonneaux called for the identification of controversial issues in society and the media. One has to make some kind of enquiry about the controversy itself or, as she calls it, social epistemology. There is always an interest behind these issues, and it is sometimes hard to put your finger on the controversy. How should we build this and where should we stop? Can you describe controversy and use it as a teacher strategy? What do you choose? And are you always objective when dealing with this enquiry?

Nature of science

Maria Pilar Jiménez-Aleixandre thought that as well as teacher training, there is also the question of curriculum design. If you introduce a scenario about, for example, eye colour and talk about genetic variations to be used for identifying Roma people in Italy as part of the scenario, you are at risk that the students will perceive ethnicity as genetically determined. Vaille Dawson thought that this issue should not be addressed in terms of teaching but in terms of the power of research. Of course, a deterministic view of science is bad. But why do students have this view? By letting the students themselves explore, multiple answers can be expected to emerge in the classroom. This is in line with the characteristic of SSIs that scientific context is often contested. This introduces the nature of science, which can be very confrontational for teachers and students. To talk about this in class, you need a topic where some scientists say one thing, while others say another. It is important for students to know that we live with ambiguity and that they know that science progresses by disagreeing, as in the debates about climate and vaccination. Marc van Mil added that these kinds of SSI are used not only to stress that scientists disagree, but, equally importantly, that there is much we still do not know. It is important to show that, although it is possible for us to sequence a whole genome, scientists still do not understand other aspects of the genome (e.g. the relationship between genes and intelligence). You have to make it intelligible to students that these relationships are so complex that we can sometimes only 'understand that we do not understand'. If scientists agree on one thing, it is that we do not know everything. Ralph Levinson gave an example of a book written by a social biologist that describes how certain animals use rape techniques to attack the females. The writer said it was about the human drives in our society and justified them. About 10–12 years ago when the whole genetic debate was rising, children had questions about these issues and teachers wondered how to address them. What worries Ralph is that we can still hear teachers talking about genes for intelligence in a totally misguided way, so how teachers understand these issues is the key point here. If you want to teach SSIs, you should read what Clive Sutton and Jim Donnely have to say about this. There are really important questions from a reductionist point of view.

Summary of Discussion 3

The teacher has many roles, including being a guardian of correct knowledge, an impartial moderator and a role model from whom the students expect an honest answer on their views.

These roles can conflict, and there is a continuing debate on whether development of teacher identity is or should be part of professional development and whether the teacher should express their emotions. SSIs are challenging for every teacher and can be threatening for some.

Other conflicting roles concern knowledge. The teacher should clarify concepts and relationships and so avoid confusion in the students' minds. On the other hand, the teacher should demonstrate that there exists confusion within science and its applications, and they should teach the students how to handle ambiguity.

For example, on issues related to genetic determinism, it is important to demonstrate that there is a debate among scientists and that there still is much uncertainty about the links between the genome, the environment and the phenotype. There is a need both for good practices to handle emotions in the classrooms and for the identification and description of controversial issues to use in genomics education as material to train teachers in the nature of science. These are areas for further research.

Research-informed criteria for developing genomics education aimed at decision-making

Dirk Jan Boerwinkel and Arend Jan Waarlo
Utrecht University, The Netherlands

Introduction

Criteria for developing education generally address the questions Why?, What? and How? This was also the case in the proceedings of the 2008 workshop 'Rethinking Science Curricula in the Genomics Era'. Building on the results of the 2008 workshop, we have used the information from the presentations and discussions in this workshop to add more specific answers to the questions Why?, What? and How? At the end of this chapter, we summarize which recommendations can be given for curriculum change, teacher training and further research.

1. WHY genomics education for decision making?

Socioscientific issues have common characteristics that should be represented in education aiming at decision-making. In general, these issues include the weighing of advantages and disadvantages. This weighing cannot be decided based on factual knowledge alone, because the weighing includes values and different stakeholders with different interests. Genomics-related issues have additional characteristics that also should be represented in education. These include the following:

1 Genomics issues are consequences of a new technology.
2 Genomics issues often concern predictions based on interpretation of genetic risk information.
3 Genomics issues often include storage of and access to personal information.

We will discuss each of these in turn.

Genomics issues are consequences of a new technology

This characteristic has three aspects that are important for education.

1 Technologies can have hard and soft impacts. Hard impacts are the direct consequences or risks of the application of a technology, such as interbreeding of genetically modified organisms with wild varieties. Soft impacts are the often indirect consequences of a technology, which often have far more impact on human lives than the hard impacts. New possibilities of genetic information or genetic modification bring new choices and responsibilities, and change the way diseases are accepted or even insured against. New genomics applications in agriculture can change the dependency of farmers on agricultural companies. These soft impacts and stakeholders related to them are often not apparent

to students. Students often consider technologies as instruments that you can choose to use or neglect. They do not realize that, with or without their consent, new technologies have an impact on their lives. For example, new testing possibilities force you to think about the risk when you do not make use of it, especially as a (future) parent. On the other hand, students often do not realize that they can have an influence on technological developments.

2 The fact that many issues related to genetic testing are linked to evolving technologies means that these issues are also evolving or are not even realized yet. An example is the 'thousand dollar genome', which is not reality yet but is likely to be in the foreseeable future. Some issues will be new, whereas others will be articulations of already existing issues. This means that for some issues, future scenarios are needed when addressing them. Future scenarios for genomics applications have already been developed for policy-makers.

3 A third consequence of the fact that new technologies are involved is that many aspects are still under debate. These aspects include both the societal debate on applications of the new technologies, and the scientific debate on the nature and relevance of genetic information itself. This means that both societal and biological knowledge is relevant in informed decision-making and in understanding the debate.

Answering the WHY question (I): In order for students to estimate correctly the influence of new technologies in genetic testing, education is needed on the influence of technological innovations on human lives and morality, and on the ways technological innovations can be influenced.

Genomics issues often concern predictions based on interpretation of genetic information

Issues relating to genetic tests are not new in biology education. For diseases in which a strong correlation exists between one gene variant and the disease (high-risk genes), several educational strategies concerning informed decision-making have been developed. Issues related to these monogenetic diseases concern, for example, the advantage or disadvantage of genetic information, the question of whether to inform relatives and decisions concerning pregnancy. These issues remain relevant but are complicated by new elements in this discussion, created by new or future applications of genomics research. These include the consequences of screening of large groups, if not the whole population, with genome-wide sequencing. Commercial firms already offer different types of genome tests on the internet, and with ever quicker and cheaper sequencing methods, whole-genome testing will probably become a normal part of medical practice. Genome-wide testing produces information that can be used in the diagnosis of 'genetic' diseases such as cystic fibrosis but will also reveal more complex interactions between the genome and common diseases such as diabetes. Whole-genome testing will often produce more information than required, which generates new questions on the responsibilities of medical professionals and patients. Much larger groups will potentially be confronted with these kinds of question than in the situation where testing was limited to monogenetic diseases.

Answering the WHY question (II): In order to be prepared for the situation in which larger groups receive results from genome-wide testing, medical professionals and people who are tested have to be able to use and weigh information derived from genome-wide testing in informed decision-making.

Genomics issues often include storage of and access to personal information

Data from patients can be stored both as tissue and as digital information. The storage of personal information is in itself not a new issue and is related to questions of privacy, access and autonomy. However, in genomics data, extra questions arise such as the storage of information in forensic databanks and the responsibilities of professionals when new research could lead to new health information from personal genetic data already present in the databank.

In the future, more, if not all, citizens will have genomic information stored in different kinds of databank.

Answering the WHY question (III): In order to be prepared for the situation in which more genomic information from more people is stored in databanks, citizens should be informed about the nature of the information that is stored, possible consequences of storage and access to this information.

Of course, genomics research influences issues other than genetic testing, such as access to new crop varieties and the development of new microbiological production processes. Compared with genetic testing, however, these issues offer fewer situations in which personal decision-making is relevant. Therefore, a focus on the use of human genomic information seems appropriate in genomics education for decision-making.

2. WHAT should be taught in genomics education for decision-making?

Informed decision-making in issues related to genetic testing implies more than knowledge. Students need several skills, for example to use this knowledge in interpreting media information, in visits to medical professionals, in discussions with peers or in reflection on the moral aspects of their decisions. These skills have been discussed earlier, among others in the proceedings of the 2008 workshop ‘Rethinking Science Education in the Genomics Era’ and therefore will not be repeated here. In this paragraph, we focus on the conclusions of the workshop concerning the knowledge that is needed. In developing genomics education, both the skills and the knowledge should be integrated.

Knowledge to understand the influence of technological innovations on human lives and morality, and on the ways technological innovations can be influenced

The impacts of technological innovations are seldom discussed in science education, and when discussed they mostly address hard impacts. In genetic testing, there are almost no hard impacts, but there are very important soft impacts.

Answering the WHAT question (I): Genomics education could provide examples of the influences of new genetic technologies on what is considered morally acceptable and what is considered acceptable in relation to health and quality of life. This includes influences in the past and predictions of possible influences in the future. Another important element is the societal/political forces influencing implementation and regulation of a technological innovation.

Knowledge needed to understand the genetic testing practices

A range of testing possibilities has been developed and is still under development, covering the life cycle from pre-conception to adulthood. These testing possibilities include both genetic diagnosis of a known gene variant and screening of healthy people in order to determine risks of a disease at an early point. Genetic diagnosis and screening differ in many aspects in the role of individuals, medical professionals and the government. Testing at different moments in the life cycle also generates different consequences and moral aspects. It is therefore useful to construct a framework in which several genetic testing procedures can be placed (Table 1).

Table 1. Diagnostic testing and screening at different stages in the life cycle

Life cycle stage	Diagnostic testing	Screening
	Individual visits to medical professional; tests on genetic defects in the DNA	*Mostly government activities for large groups; tests mostly not on DNA but on the consequences of the genetic defect*
Pre-conception	Future parents with disease or potential carriers of a gene variant are tested with the aim of informed reproductive decision-making and decisions concerning testing of the future child.	Healthy parents (normal in the USA, almost absent in the Netherlands) are tested with the aim of informed reproductive decision-making and decisions concerning testing of the future child.
Pre-implantation	Embryos at risk of carrying a specific gene variant are tested before implantation with the aim of selecting an embryo without the gene variant.	All IVF embryos are superficially screened before implantation, but genetic screening is not yet a part of this procedure.
Pre-natal	Fetuses with an elevated risk of a genetic disease are tested with the aim of informed decision-making about whether to (dis)continue a pregnancy.	Fetuses with an elevated risk of Down syndrome are tested with the aim of informed decision-making about whether to (dis) continue a pregnancy.
Perinatal	Newborn infants with an elevated risk on a genetic disease are tested to start early treatment.	All newborn infants are tested by the heelprick for metabolic diseases and cystic fibrosis in order to start treatment early and prevent disease.
Adult	Family members of the patient and other people with a higher risk of genetic disease are tested with the aim of early treatment or decisions on reproduction. Tumour tissue of cancer patients is tested to inform decisions on therapy/medication.	Adult women over 50 are screened for breast cancer and cervical cancer with the aim of early treatment. Screening for colon cancer will start soon. Personal genome screening is offered to the general public on the internet with the aim of a checking up on possible risks.

Both personal and societal decision-making are related to these different forms of testing. Personal decisions occur in the practice of genetic diagnosis, where decisions have to be made on whether or not to have a test, to continue a pregnancy, to inform relatives, etc. The personal decisions have to be made by patients, relatives and medical professionals. Other decisions concern the participation in screening programmes, with a special issue concerning the use of personal genome tests.

In decisions on screening programmes, societal decision-making is important. Almost all screening programmes have drawbacks. People may receive false-positive results (false alarm) or false-negative results, which may lead to false reassurance. Sometimes, the numbers of false-positive results are relatively high. Decisions to start screening programmes are government decisions and must meet several screening criteria. Key criteria are that the disease must present a significant health problem (in terms of prevalence and/or severity), that a valid and reliable screening test is available and that people have practical courses of action after screening. Debate is now going on as to whether neonatal screening should be expanded to untreatable childhood-onset disorders, such as Duchenne muscular dystrophy, and whether adults should be screened for carrier status for autosomal recessive disorders such as cystic fibrosis.

Answering the WHAT question (II): In order to understand current and future genetic test practices and the choices they may be confronted with, students should be aware of different forms, aims, target groups and consequences of testing, and the personal and societal choices involved.

Knowledge needed to understand information from genome-wide test results

Genetic testing generates many elements of genetics that so far have received little attention in education. Genomics education for decision-making may thus include other emphases in teaching genetics. These emphases concern the two key concepts, indicated in the proceedings of the 2008 workshop, of complexity and uncertainty. The elements below explain that relationships between the genome and a certain trait are far more complex than is normally addressed in biology education, and that, although gene variants can be sequenced with great accuracy, predictions from these results are often of limited value.

Answering the WHAT question (III): In order to correctly interpret genomic information, an understanding the following factors is relevant.

Genome and environment

- All physical and psychological features are – to very different degrees – influenced by different elements in the genome and the environment. There is no sharp border between 'genetic diseases' and 'non-genetic diseases', only a gradient.
- The genetic influence of a feature does not imply that this characteristic is unchangeable (determinism). On the other hand, the environmental influence of a feature does not imply that this characteristic is easily changed.

Monogenetic traits

- Even 'monogenetic' diseases are influenced by more genes than the gene that is the main cause of the disease. Other genes can influence expression of the gene, the severity of the disease or the effects of medication.
- When speaking of 'the gene for cystic fibrosis' or 'the BRCA gene' for breast cancer, we are in fact referring to a range of variants of the same gene, causing more or less the same symptom (over 1700 different mutations can lead to cystic

fibrosis). Two unrelated persons with 'the gene for cystic fibrosis' will probably have different variants of the same gene.

Ethnicity

- Frequencies of gene variants differ among ethnic groups. Therefore, it can be relevant to ask for ethnicity in genetic testing and the consequences of testing can be different for different ethnic groups.

Polygenetic traits

- When speaking of 'the autism gene' or 'the aggression gene', we are referring to a genetic factor that has been proved to have a correlation with the disease. This does not indicate a causal relationship. The relationship cannot be turned around by predicting the risks for the phenomenon from the presence of the gene.
- Some gene variants have been found to be related to a higher chance of occurrence for common diseases such as diabetes. However, research has also found gene variants related to lower chances, and many more relationships are likely to be found in the future. Currently, research is not that reliable and useful predictions can be made only for common diseases.

Screening and genetic diagnosis

- The practices of genetic diagnostic testing and genetic screening are different, even when the same gene is studied. Diagnostic testing starts with a patient, and normally the gene variant that is looked for is known. In genetic screening, large groups of healthy people are tested for a range of gene variants for the same disease, or by analysing metabolic changes due to defective genes.
- The quality of a screening test is determined by the specificity (which part of the positive results will prove to be caused by changes in the gene) and the sensitivity (which group of people with the gene variant will be detected by the screening). Perfect tests will score 100% on both, but normally the specificity is lower, leading to false-positive results, and lower sensitivity will lead to false-negative results. As many students probably think that test methods are 100% reliable, this is important information. False-positive results will lead to further unnecessary, costly and potentially damaging medical examinations.

Personal genome tests

- A test result from a personal genome test indicating that you do not have the gene variants for *BRCA-1* simply means that you do not have the variants included in the test. However, you might have other variants of the same gene. The test results therefore might produce a false assurance.
- A test result from a personal genome test often includes the use of concepts such as relative risk or life-time risk. This requires special knowledge to interpret correctly. For instance, when you are already older, your chances of getting a

disease that has not yet appeared are lower, even when the test indicates a high life-time risk. A high relative risk may still be very low if the general risk is low.

- Health advice for common diseases will not be very different from general health advice on food, exercise and smoking.
- The main purpose of commercial websites offering testing is to make a profit, and therefore the information on these websites will be influenced by this.

3. HOW should genomics education for decision-making be taught and learnt?

The workshop produced various data on the use of educational strategies:

- Students have difficulties in interpreting data to evaluate the role of genes versus the environment, in particular, to see what is not there (for example in the case of the Olympic 100 m, winners from African countries). This is a competence that researchers have acquired but that has to be learnt by students through studying exemplary cases.
- Students' argumentation skills can be improved significantly by a brief argumentation intervention and genetics understanding. Student behaviour influencing argumentation included suspending judgement, having a willingness to listen to opposing views and having a willingness to question evidence.
- Educational strategies aimed at decision-making often include debate and opposite opinions. Although role play encourages students' participation and invites students to formulate arguments that are not necessarily their own, the competitive context of role play/debate invokes strategies to 'win'. Exploration of the controversy is impaired, as arguments in role play are less justified and elaborated. This means that contexts in which students take opposite opinions are not always the most effective means of learning. Cooperative contexts have been shown to stimulate dialogic argumentation just as well, and include many aspects of argumentation including types of evidence, the existence of justifications, coherence among reasoning lines and persuasion strategies.
- Another aspect to be aware of in choosing contexts is that strong personal values and emotions can also hinder critical reasoning and build resistance. The question is how we can achieve the correct distance to foster motivation and the emergence of a need for scientific and 'social' knowledge.
- Games and simulations designed to expose individuals to conflicting evidence taken from different scientific studies can improve critical analysis. The main problem with this type of serious game is that students discuss the pertinence of the model itself: they consider it to be unrealistic or too complex.
- The use of a sequence of short narrative videos in which different sides and different aspects of the issue are represented, combined with frequent probing of students' position, arguments and questions, has proved effective in raising awareness of the problem of predictive genetic testing.

- Strategies should aim towards 'destabilizing opinions', by which is meant that education aiming at decision-making should challenge existing beliefs, for example the belief that more health information is always better. This can be done by demonstrating that people can be forced to stop activities that are important to them because of genetic risk information. A recent example is the screening of American athletes for carriers of a gene variant for sickle cell anaemia, which has consequences for training and selection.

Answering the HOW question: In developing genomics education for decision-making, it is advisable to be aware of the risks of contexts in which students are asked to defend strong opposite opinions or discuss issues that are linked to strong values. Students might be easier 'destabilized' by confrontation with narratives that give opposite perspectives on an issue. Furthermore, it would be interesting to develop simulations in genetic decision-making, using among others the risk tools developed in the TUSK project.

4. Consequences for curriculum change, teacher training and further research

Recommendations for curriculum change

In order to illustrate the recommendations, they are specified for the topic of genetic testing.

In education on genetic testing, attention should be given to the following:

1. Soft impacts of new genetic technologies, such as the influence of new test methods on reproductive decisions, on testing for certain professions and on health insurance. Influences of earlier innovations on reproductive decisions can provide examples to demonstrate the interplay between innovation and societal change.
2. Current and future scenarios in genetic testing. Scenarios to discuss within the issue should avoid the extremes of 'hype–horror' stories.
3. The ways in which developments of/in genetic testing can be influenced, and in which the students themselves can play a role.
4. The difference between screening and genetic diagnosis.
5. The use of genome-wide test results.
6. The storage of genetic information.
7. A learning environment where students are required to justify their claims.

Consequences for teacher training

In practicing argumentation, the teacher has many roles, which can sometimes be in conflict:

- On the one hand, the teacher should be a guardian of correct knowledge and an impartial moderator of discussions. On the other hand, teachers are also role models from whom the students expect an honest answer as to his or her views, and developing teacher identity has proved an important element. Teachers should have experience themselves with reflection on the questions they confront their students with.

- The teacher should clarify concepts and relationships and so avoid confusion in the students' minds. However, the teacher should also demonstrate existing confusion within science and its applications, and teach the students to handle ambiguity.
- The teacher should stimulate the quality of argumentation and using evidence. However, the teacher should also apply strategies to invite students to reflect on their decision-making, including the emotional and intuitive aspects as they determine a large part of the process of decision-making.

Teacher training in the life sciences should address these conflicts, not necessarily with genomics issues but sufficient to make the translation.

Teacher expertise has been further distinguished into several components by van der Zande. During the workshop, several additional elements were added. These are given in Table 2.

Table 2. Teacher expertise for teaching genetics in the context of genetic testing, based on the overview of van der Zande. Elements added during the workshop are given in italics

Area of expertise	Aspects of expertise area
Subject matter expertise	Curricular genetics concepts
	Extracurricular genetics concept
	Ethical, legal, and social aspects (ELSA) of genetic testing, especially the societal and moral impact of technologies based on genomics research and ways in which technological developments can be influenced
	Characteristics of genetic test practice *(e.g. genetic diagnosis versus screening)*
	Medical information genetic tests
	Knowledge of students' moral reasoning
	Knowledge of argumentation patterns
	The implications of genome-wide screening
	Interpretation of media information
	Risk assessment (including life-time risk and relative risk)
Pedagogical content expertise	The use of narratives
	The use of problem-based approaches
	The use of teaching–learning–activity (reflection on) moral reasoning
	Distinguishing levels in argumentation in students
	Focusing not only on correct answers but also on relevant questions
	Stimulating students to become active knowledge producers, engaged in inquiry
	Discussing media reports with students
Moral expertise	Focusing not only on correct answers but also on relevant questions
	Stimulating students to become active knowledge producers, engaged in inquiry
Interpersonal expertise	Creating a safe atmosphere
	Good relationships with students
	Creating a classroom environment where scientific evidence is debatable

1. Research on student attitudes and educational strategies concerning genetic testing as a technological innovation

Science and technology studies (STS) on societal impacts of technological innovations show that incorrect assumptions about the influence of technological innovations on personal decisions and vice versa hinder an effective attitude towards technology, including genomics technology. Until now, these results of STS have not been translated into learning goals and educational strategies within science education aimed at decision-making. Research is needed to analyse student attitudes towards innovations in genomics technology, especially their opinion on how innovations in genetic testing can influence their lives, and on how they could influence these innovations. Based on this, specific strategies have to be developed to be included in genomics education for decision-making.

2. Research on concepts and issues necessary for empowering students in personal and societal decision-making concerning the use of genetic information

In order to empower students in personal and societal decision-making in issues concerning the use of genomic information, perspectives are needed from both ELSA researchers and clinical geneticists. Expert views are needed to determine which concepts and issues are essential for empowerment, both for the advanced science curriculum (future professionals in life sciences) and for the general curriculum (citizens). Information from earlier workshops and literature studies provided us with a framework of both types of knowledge related to genetic information (see answers to questions 1 and 2). This framework will be tested by asking ELSA researchers and clinical geneticists to react to a series of cases that cover a broad range of the use of genomics information with which the student could be confronted in his or her future professional life or as a citizen. This will result in a list of concepts and issues to be addressed in education. This list will be discussed with experts in biology education to determine which elements are new in biology education, and would require an adaptation of the curricula for future professionals, for citizens and for teacher preparation.

3. Research on effective strategies to empower students in personal and societal decision-making

Earlier research on stimulating reasoning, including moral reflection, provides a framework to develop a strategy to empower students for decision-making in issues related to genetic testing. Other elements necessary for this strategy are the results of earlier research on raising of awareness on predictive genetic testing and the results of the research question mentioned above.

List of participants

Index of speakers

Dirk Jan Boerwinkel
Researcher in Science Education
Freudenthal Institute for Science and Mathematics Education
Utrecht University
Utrecht
The Netherlands
D.J.Boerwinkel@uu.nl

Vaille Dawson
Associate Professor of Science Education
Science and Mathematics Education Centre
Curtin University
Perth
Australia
v.dawson@curtin.edu.au

Lidewij Henneman
Senior Researcher and Health Scientist
Department of Clinical Genetics & Department of Public and Occupational Health, MGO Institute for Health and Care Research
VU University Medical Center
Amsterdam
The Netherlands
L.Henneman@vumc.nl

Cecile J.W. Janssens
Associate Professor
Department of Epidemiology
Erasmus MC
University Medical Centre
Rotterdam
The Netherlands
a.janssens@erasmusmc.nl

Maria Pilar Jiménez-Aleixandre
Professor of Biology Education
Departamento Didactica das Ciencias Experimentais
University of Santiago de Compostela
Santiago de Compostela Spain
Marilarj.aleixandere@usc.es

Ralph Levinson
Senior Lecturer in Science Education
Institute of Education
University of London
London
UK
r.levinson@ioe.ac.uk

Jenny Lewis
Senior Lecturer in Science Education
School of Education
University of Leeds
Leeds
UK
j.m.lewis@education.leeds.ac.uk

Ellen Moors
Associate Professor of Innovation Studies
Copernicus Institute of Sustainable Development
Utrecht University
Utrecht
The Netherlands
e.moors@geo.uu.nl

Laurence Simonneaux
Professor of Science Education
Ecole Nationale de Formation Agronomique
Université de Toulouse
Toulouse
France
Laurence.simonneaux@educagri.fr

Tsjalling Swierstra
Professor of Philosophy
Faculty of Arts and Social Sciences
Maastricht University
Maastricht
The Netherlands
t.swierstra@maastrichtuniversity.nl

Paul van der Zande
Researcher and Teacher Trainer
Centre for Teaching and Learning
Utrecht University
Utrecht
The Netherlands
p.a.m.vanderzande@uu.nl

Dana L. Zeidler
President, National Association for Research in Science Teaching
College of Education
University of South Florida,
Tampa
Florida
USA
zeidler@usf.edu

Organizing committee

Dirk Jan Boerwinkel
Freudenthal Institute for Science and Mathematics Education
Utrecht University
Utrecht
The Netherlands
d.j.boerwinkel@uu.nl

Annelies Speksnijder
Managing Director Cancer Genomics Centre
Utrecht University
Utrecht
The Netherlands
a.speksnijder@umcutrecht.nl

Arend Jan Waarlo
Professor of Genetics & Health Communication
Freudenthal Institute for Science and Mathematics Education
Utrecht University
Utrecht
The Netherlands
a.j.waarlo@uu.nl

Other participants

Carin Cruijssen
Cancer Genomics Centre
c.cruijsen@umcutrecht.nl

Frans van Dam
Centre for Society and Genomics
dam@society-genomics.nl

Mieke Kapteyn
Teacher Trainer
VU University
miekemiekek@yahoo.co.uk

Marie Christine Knippels
Assistent Professor of Biology Education
Freudenthal Institute for Science and Mathematics Education
Utrecht University
m.c.p.j.knippels@uu

Marc van Mil
PhD student
Cancer Genomics Centre/
Freudenthal Institute for Science and Mathematics Education
Utrecht University
m.h.w.vanMil@umcutrecht.nl

Henk van Netten
Biology teacher SG Dingstede
hvnetten@hetnet.nl

Frans Olofsen
Biology teacher
fransolofsen@planet.nl

Miriam Ossevoort
Associate Professor of Science Education
Groningen University
m.a.ossevoort@rug.nl

Hienke Sminia
Netherlands Bioinformatics Centre
hienke.sminia@nbic.nl

Gerrianne van der Velde
Forensic Genomics Consortium Netherlands/Its Academy
forensisch@dnalabs.nl

Hendrika van Waveren
Leibniz Institute of Education of Science
University of Hannover
vanwaveren@biodidaktik.uni-hannover.de