

The role-play in interactive research

Academic actors

The views about the function of social research in genomics vary widely. Some feel that it should socially embed the opportunities offered by genomics. On the other hand, others expect the research to cause a debate on social issues. **Bernhard Wieser** and **Maud Radstake** examined how social scientists see their own role. They perceived a wide range of role perceptions and most researchers appear to play multiple roles.

Although a little over ten years ago the concept of genomics itself was hardly known outside the molecular biologists' circle, these days it has become routine for a whole contingent of researchers from various backgrounds. In various countries, investment in research into the 'social' implications of this new technology followed in the slipstream of large-scale public investment in genomics. This social research around the life sciences has become known under the name ELSA (*Ethical, Legal and Societal Aspects*) and covers a wide range of disciplines in the humanities and social sciences. "In many countries, ELSA genomics was initiated *top-down*, certainly also in response to the social debate about biotechnology in the late nineties. Such a controversy had to be avoided in regard to genomics," said Bernhard Wieser, senior researcher at the *Interuniversitäres Forschungszentrum für Technik, Arbeit und Kultur (IFZ)* of the University of Graz, Austria.

TIME FOR REFLECTION

"The start of the second term of the Austrian genomics programme seemed a suitable time to me for a moment of reflection and to highlight the role of the ELSA researchers and their



Koen Dortmans is a PhD student and conducts the CSG project 'DNA in dialogue' at Radboud University Nijmegen.

"My role shifts between that of a collaborator and that of a facilitator, but if I had to choose, it would clearly be the facilitator because in the other role I would not be able to do what I do now. The aim of my research is to involve scientists in the dialogue with the public and not just to study how they do this, but also to intervene where necessary to keep the dialogue open. Intervention is also the difficult part of my role. My credibility for both scientists and the public is important because I also actively raise issues to open the

conversation. My own normative perspective plays a role. Being neutral is impossible. This creates a tension,

'As a facilitator you use your knowledge effectively'

because I request openness from the participating scientists, but my interventions can create the impression of bias.

As a scholar, you run the risk that the knowledge gained remains within the academic environment. As a facilitator you are more effective in using the knowledge and insights. The elements of the collaborator are present in 'empowering' scientists. I try to show them that a public dialogue does not always put the brakes on your research, but can indeed contribute to a socially robust 'knowledge development.'





Lise Bitsch is working as a PhD student on the CSG project 'Future scenarios of innovation processes in medical genomics' at the University of Twente.

"For my project I interview researchers who work on asthma and heart diseases and I organise workshops in which I confront this group with my analysis as an outsider. The central question of my research is how we can improve the technology development process.

The researchers - both basic researchers and physicians in the clinic - work for the patient, but their plans sometimes

lead to ethical problems they do not see. By confronting them with this in the workshops I want to help them reconsider the process and take into account additional factors. We want to prevent the ethicist from being the 'stop sign'. In that capacity I work as a facilitator and I fulfil a role in raising the awareness of this group of possible problems. I have no problem with this role or the fact that I fulfil multiple roles. You must be committed to achieve good results. A good result for is me is that I have made people consider application much earlier and integrate that. Technology development does not mean develop the technology first and then move on to practical application. Obviously there is a risk that you are regarded as a 'lubricant'. You have to maintain your autonomy and be critical, it is necessary to be a bit of a scholar. I always immediately make clear what I do, that I am doing PhD research and that I use my findings and results in my work."

'Commitment is necessary to get results'



relation to genomics researchers." Wieser formulated these aspects in the two-year project *Doing ELSA: an empirical study of ELSA in practice*, which started in August 2009. "My plan was to compare the roles of researchers in various national ELSA programmes." Besides Austria, Denmark and the United Kingdom, the Netherlands was one of his case studies, so he contacted us, says Maud Radstake, Research & Dialogue Manager at CSG. "I was doing research on whether and how CSG researchers design their projects interactively with scientists and actors in society. Bernhard's project fitted in well with this and I was immediately excited about his research question and his exploratory approach."

ANALYSE OR ORGANISE?

Wieser: "The interaction in interactive research is strategic in nature. Scientists are aware of what they communicate and how they do it; they do not tell everything. The context in which research takes place is important for the content and performance of that research." In his analysis of the interviews, he arrives at four main storylines, which he characterises as four roles or positions: collaborator, facilitator, scholar and advocate. In brief, the *collaborator* acts as a partner in genomics research or in its translation into practical applications, the *facilitator* creates a social space for interaction between scientists and others, the *scholar* takes distance to analyse it academically, and the *advocate* emphatically takes a position and tries to attain that. Radstake: "Bernhard's presentation of his preliminary results at the CSG researchers days in September 2010 evoked many positive responses. It made people think about their own role."

DUTCH DIALOGUE

Bernhard Wieser started the project with a reflection on his own work as an ELSA genomics researcher. "I wondered: Who am I? And who decides that? What you are and do as a researcher, you do not decide yourself. You also have, for instance, an institutional identity." He started with interviewing investigators he already knew and who he could talk informally with. He emphasises that he was not looking for specific roles. "No, the experiences of the people I interview form the basis of my analysis. During the project I continuously adjusted my ideas on various roles and positions. When I went to the Netherlands, I distinguished two roles, the collaborator and the scholar. In the Netherlands, dialogue

The *collaborator* acts as a partner, the *facilitator* enables interaction, the *scholar* analyses and the *advocate* emphatically takes a position

proved to be important for many researchers, which I translated into the role of facilitator. But it appeared not to be a specifically Dutch role: I then found facilitators everywhere.” The role of advocate appeared to apply most to researchers who actively try to bring about a social change. He deliberately did not choose the label of activist. “It is a widespread prejudice that social scientists are activists and therefore against something. An advocate, on the other hand, is someone who is in favour of something, and tries to contribute to a change in a positive way.” He laughs: “I had to reformulate many things during the interviews.”

WHAT IS RELEVANT?

Radstake often sees how difficult it is for researchers to manoeuvre between the proximity to the life sciences that characterises CSG research and the distance required by critical research. “How does one conduct social research of high academic quality that is also relevant and useful?” These tensions exist everywhere, but are expressed in different ways in different countries, says Wieser. “The autonomy of ELSA researchers varies per country, as does the expected output and the criteria used to assess whether research is relevant. If, in the UK academic output is extremely important and considered ‘relevant’ this means: relevant to policymakers. In the Netherlands the focus is more on relevance to science and the life sciences in particular.” They both think that understanding their own position and the circumstances that (partly) determine certain positions can help researchers deal with such tensions. Wieser: “The description of the roles provides a common typology with which we can make tensions explicit.” It may even strengthen your research, think Radstake. “A common language is a prerequisite to be able to compare experiences and learn from each other. If you know where the sensitivities lie, you can respond to them in your work and add value.” The intention is not to use the roles to simply categorise social scientists and that would not work with this group. Imagine! Wieser, laughing: “Social scientists are particularly good at studying and characterising others, but of course those labels do not apply to us.”

TAMED ADVOCATE

And what is his own role? “When I started in the ELSA genomics field, I was mostly a collaborator. I was working with



Erich Griessler is a sociologist and senior researcher at the *Institut für Höhere Studien* at the University of Vienna. His work focuses on for instance development and regulation of (xeno) transplantation, stem cell research, application of genetic testing in reproductive medicine and public participation in these areas.

“I’ve worked on several projects in which public participation in addressing ethical questions about controversial technologies, xenotransplantation in this case, was central. In these projects we had a clear role as a facilitator. The parties had to be brought together actively, the subject had to become known to the public, we had to create websites, etc. These were all tasks that were not purely research-related and that did not suit me that well. I feel more comfortable in the role of a scholar. Currently, I am coordinating a project on how genetic tests change our *Images of Life* when it comes to pre-implantation genetic diagnosis and prenatal diagnosis. To this end, we conduct interviews with a wide range of stakeholders, including physicians, women who have undergone

this form of diagnosis or are considering it, and policymakers.

‘In heated discussions, you have to be a scholar’

In this project I primarily act as a scholar. Incidentally, we are already actively communicating our results to a larger audience, because

otherwise there would be no point in doing such research. At the same time, it is essential that you are seen as a scholar in these sensitive issues. Here in Austria, a heated debate is raging between two factions when it comes to the very beginning of human life. You can only take a neutral position as a scholar, to avoid being pushed straight into one of those factions.”

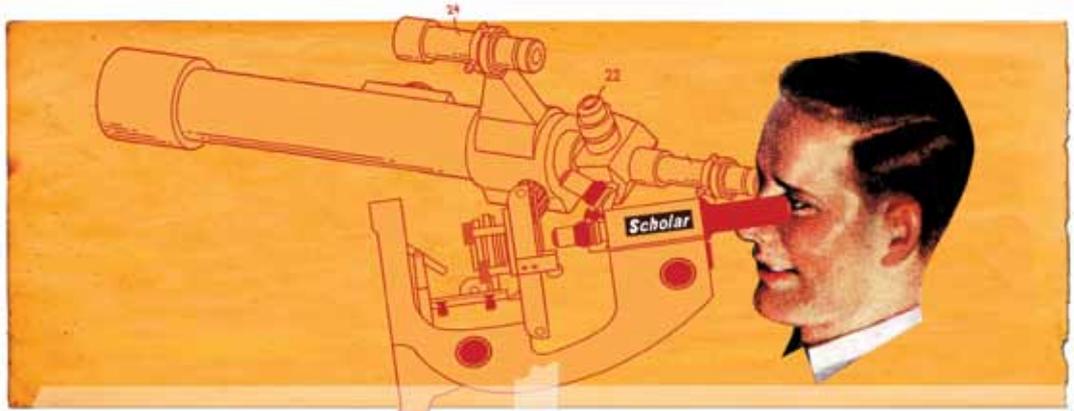




Ingrid Metzler is a political scientist and researcher at the University of Vienna. Her PhD research focuses on the embryo politics in Italy and specifically on the interface between the life sciences and the 'traditional' political field

"In general I see myself as a scholar and in that role I feel most comfortable. It gives me the freedom to study what I want and I can establish links with existing concepts and theories. What I notice in the interaction with scientists in labs and clinics is that it is sometimes difficult to explain what I do. They are open to being studied because they recognise the importance of social implications for their work, but they do not always understand why you want to study the technology development process. As an ELSA researcher you do not always control your role. There is always something new involved and it is such a dynamic field, where, on top of this, controversial technologies are often concerned, so I constantly wonder what it is I really do. Am I a facilitator now? But do I really want to be? And if not, why not? As ELSA researchers we need to consider the implications of our work for the life sciences and not just focus on the implications of the life sciences themselves."

'As an ELSA researcher you do not always control your role'



medical geneticists and I really wanted to collaborate. In addition, I was a little bit of an advocate, I had an agenda and I wanted to convince them of the need for reflection. But these roles gave me no satisfaction, it felt like I was reaching out to them and they did not respond. Partly because of that experience I moved more towards the role of the scholar and now my first target group consists of my peers." He points out that for many academics the role of advocate is difficult. Academics are expected to refrain from normative judgments. "At best you can be a tamed advocate." Radstake does not entirely agree. "How the advocate is perceived strongly depends on the field," she says. "When it comes to issues in the medical field, for example in public health or *community genetics*, it is no problem to be an advocate. But in plant genomics this is often different. There, advocates are quickly perceived as opponents of genomics research, for instance where intellectual property and developing countries are concerned. That can be difficult."

LEARNING LESSONS

In June they will jointly organise an international symposium in Graz. The symposium is entitled *Engaging with genomics: Comparing modes of social and philosophical research in the life sciences* and dozens of ELSA genomics researchers from different countries will scrutinise their own positions and roles and those of the field. Why this symposium? Wieser: "We can think up and imagine anything, but what we do is intended as a framework for a further exchange of ideas and experiences. But it goes further than this. We want to raise the debate to the level of science policy. How can we organise such research in the future?" It is time to start thinking about this since the ELSA genomics programmes will expire everywhere in a few years. Therefore it is more than just self reflection, says Radstake. "Thinking and talking about yourself is always fun, but it should not stop at navel-gazing. However, to come up with a sensible message, we must reflect on ourselves. Before rushing into the uncertain future, we should reflect on what we are doing now and what we can learn from that."