

Steunpunt

MILIEU
&
GEZONDHEID

ONDERZOEKSGROEP
FASENPLAN

December 2006

Het steunpunt Milieu en
Gezondheid
is een samenwerkings-
verband tussen de Vrije
Universiteit Brussel, de
Universiteit Gent, de
Universiteit Antwerpen,
de Katholieke
Universiteit Leuven,
het Limburgs
Universitair Centrum,
het Vlaams Instituut voor
Technologisch Onderzoek,
het Provinciaal Instituut voor
Hygiëne en de Universiteit
Maastricht.

Voor meer informatie
kan u terecht bij het luik
Sociaal en
Gezondheidseconomisch
onderzoek van het
steunpunt.

Hans Keune
hans.keune@ua.ac.be

Steunpunt
Milieu en Gezondheid
p/a

Universiteit Antwerpen
PSW
Sint-Jacobstraat 2
2000 Antwerpen
-
STEM
Prinsstraat 13
2000 Antwerpen

Verslag casus maatschappelijke inbedding genetisch onderzoek

Rapportage



Hans Keune, Lieve Goorden
(met dank aan Jos Kleinjans)



Inhoud

- 1. INLEIDING**
- 2. OPZET WORKSHOP**
- 3. VERLOOP WORKSHOP**
- 4. EVALUATIE**
- 5. REFERENTIES**
- 6. BIJLAGEN**

1. Inleiding

In dit rapport doen we verslag van een workshop die gehouden is in het kader van het Steunpunt Milieu & Gezondheid (<http://www.milieu-en-gezondheid.be/>). Onderwerp van de workshop betrof het onderzoek naar maatschappelijke inbedding van genetische kennis met betrekking tot de invloed van het milieu op de menselijke gezondheid. Deze workshop vond plaats op 19 december 2005 te Antwerpen. Reden voor de vertraging voor deze rapportage betreft met name het gebrek aan prioriteit voor dit aandachtspunt binnen het kader van het werk van het Steunpunt zoals die ook uit deze workshop naar voren kwam. Binnen de werkzaamheden van het sociaal wetenschappelijk luik van het Steunpunt heeft dit eveneens onvoldoende prioriteit gekregen omwille van de vele andere, meer prioritaire, activiteiten binnen dat luik. Wel is er kort na het de workshop een spoor op papier vastgelegd in de vorm van een Engelstalige paper die volgde op het wintersymposium "Genomics and Society: Chances for true love?" van het Postgraduate Forum on Genetics and Society (PFGS, <http://pfgs.org/>) in samenwerking met Cooperative Researchers on Society and Genomics (<http://www.geneyous.nl/corsage/top.htm>) dat op 16-12-2005 gehouden werd in Utrecht (Corsage and PFGS Benelux, 2005). We presenteren hier integraal de tekst van deze paper als verslag en analyse van dit project.

1.1 Een woord van dank

Deze workshop had geen gestalte gekregen zonder de bereidwillige medewerking van Jos Kleinjans, promotor van het genetisch onderzoeksluik in het Steunpunt Milieu & Gezondheid. Hij is uitgebreid bij de voorbereiding van de workshop betrokken geweest. Bij de opmaak van het verslag heb ik vruchtbaar gebruik kunnen maken van de aantekeningen tijdens de workshop door Karen Goeyens, Gudrun Koppen en Birgit Dumez, waarvoor eveneens dank. Tenslotte vanzelfsprekend een woord van dank aan de deelnemers aan de workshop.

2. Verslag project

Abstract:

Is knowledge on genetic susceptibility to environmental pollution useful for policy making? In cooperation with scientists and policy representatives, in the framework of the Centre for Health and Environment in Flanders, this was investigated. Discussions appeared to be rather unproductive in the beginning. In the search for a constructive turn, out of disagreement on policy relevance, agreement on the relevance for societal debate seemed to arise. In the end though, despite a constructive turn in discussion atmosphere, the original disagreement on policy relevance persevered. Part of the explanation is to be found in the complexity of the genetic knowledge itself: delicate but uncertain knowledge. At the same time, the complex interaction between policy and science plays a role, especially when the complex constellation of a larger scientific quest to deliver policy relevant knowledge on health and environment is considered. In the end, even good quality of deliberations could not prevent the promise of policy relevance fading away. What was gained was good understanding of the subject itself and its socially relevant aspects and, probably most importantly, insight into the process of boundary work between science and policy, as well as investment in this 'working relation'.

Key words: genetic susceptibility, health and environment, policy relevant research, boundary work, complexity, social science

1 Introduction

The Centre for Health and Environment in Flanders (Dutch speaking part of Belgium), investigates the complex relationship between Health and Environment. In this Centre, a project funded by and working directly for the Flemish government, mainly environmental health experts from all Flemish universities and the Dutch University of Maastricht are cooperating. In addition a social scientific expert unit is part of this Centre: the social scientists focus on the meaning of knowledge, scientific, societal and political, and on processes of deliberation and cooperation between different disciplines and actors.

The main research activity of the Centre for Health and Environment is biomonitoring. Part of the research concerns application of knowledge and technology for screening people's genetic susceptibility to environmental pollution for biomonitoring and policymaking. In cooperation with both genetic, medical and environmental scientists, as well as governmental experts, the societal and policy implications of this new type of knowledge were investigated. In this paper, we will describe the complexities of this search, not only with regard to content, but also to process: the dynamic interaction between policy and science.

Biomonitoring

In 2001 in Flanders a biomonitoring campaign was started. The main purpose of the biomonitoring project is to monitor some selected pollutants and certain health effects in human beings. The focus lies on three different target groups: newborn babies, adolescents and adults. Each campaign is carried out in eight areas of Flanders. These areas have different environmental characteristics, such as industrialized, rural (the countryside), urbanized, near waste incinerators, and near fruit orchards. Part of the objective of this biomonitoring is to focus on a comparison of exposure and health effects associated with these different types of environmental situations. To measure the exposure and health effects in human beings, biomarkers are used.

Genetic susceptibility to environmental pollution

The genetic research within the Centre for Health and Environment consists of two projects. One project hopes to develop a biomarker, by which genetic effects of toxic substances can be measured. The genetic activity resulting from environmental pollution can be used as an early warning signal of health effects due to exposure to toxic substances.

The other project focuses on genetic susceptibility to environmental pollution. Diseases such as cancer are a result of complex interaction between environmental and genetic factors. Genetic variation in a population may cause differences in susceptibility of subjects: people react differently to the same toxic substances. Many of these different reactions are considered to be based on genetic differences. The research focuses on the application of existing scientific knowledge and technology in relation to the biomonitoring project. In this paper we focus on the second type of genetic knowledge: knowledge of genetic susceptibility to environmental pollution.

Social scientific involvement

A direct occasion for the social scientific involvement under discussion in this paper was the rather unproductive and difficult discussion atmosphere about the genetic research between scientists of the Centre and policy representatives. Central was disagreement about the relevance of this research to policy. From the start some policymakers assessed this negatively even though it was part of the package deal the Centre was agreed upon. In 2003, the coordinator of the Centre asked the social scientists to look for opportunities for a constructive turn in this discussion.

Policy relevant research

One of the main ambitions for the Centre for Health and Environment is the production of policy relevant knowledge (Keune 2004). In 2001 in Flanders twelve Centres for policy relevant research were started. Their main task is scientific research on priority issues for government policy. This way, the Flemish government hopes to build more stability in policy

relevant research, and to broaden the information base with regard to these priority issues: e.g. Administrative Organisation, Entrepreneurship, Traffic Safety, Environmental Policy Sciences and Health and Environment. A Steering group, with representatives of governmental institutions, is attached to each Centre. In the Steering group, policy representatives discuss the knowledge production and interpretation with the researchers.

Boundary work

In general, the role of science in society seems to have changed in recent years. This change is paradoxical. On the one hand, faith in science appears to be in crisis; on the other hand, science is called upon more and more (Hoppe 2002, Bal et al. 2002). Rotmans (1999) complains that policymakers expect scientists a) to provide transparent models that are easy to use and b) to do justice to the complexity of the issues analysed in the models; a difficult exercise to combine. Since the last quarter of the twentieth century, the development of knowledge has become a subject of critical study itself. Knowledge is considered a social construction, and society itself seems to be partly the result of scientific construct. A strict division between science and society disappears. This causes problems for the standard view on science for policy: here also the strict division between science and society vanishes. This does not mean that this division disappears in daily life. Both in language and institutionally, this division is real (Bal 1998).

An interesting concept for the dynamic relationship between science and policy is 'boundary work' (Gieryn 1983, Jasanoff 1990, Hoppe 2002, Huitema 2004). Hoppe (2002) describes several models of boundary traffic between science and policy. Two dimensions are central. The first entails influence and authority between science and policy. Two extremes are the primacy of science (technocracy) and the primacy of politics. Hoppe distinguishes a third, middle ground typology: more dialogical, pragmatic. The second central dimension concerns the divergence or convergence in the way of working between science and politics. The division between the two domains has grown bigger and bigger over time: 'science and policy are social activities that have different aims and therefore are incompatible ways of life', according to Hoppe.

Dynamics of expectations

The dynamics of expectations literature deals with the different measures of success different actors may have. Brown et al (2003) point at the cyclical character of promise – disappointment sequences. Initial promises and expectations are mostly too optimistic. The reason for this is not necessarily lack of knowledge about future developments. The explanation is to be found in the strategic nature of promises, or hypes (Brown 2003), such as e.g. biotechnology and e-commerce. It is part of the game: scientists have to gain support for their ideas in order to be financed, in order to do research. Scientists have a double role: they are both entrepreneurs and researchers (Brown and Michaels 2003).

Outline of the paper

In this paper the social scientific approach to the issue of policy relevance of knowledge on genetic susceptibility to environmental pollution is sketched. This will be an intermediate view on ongoing discussions: no final conclusions are drawn yet in the context of the Centre for Health and Environment. We will focus on the complexities of genetic susceptibility to environmental pollution and on the complexities of interaction between science and policy. We will not discuss any outcomes of the genetic research itself, since no definite results were available during the social scientific project under discussion here.

In paragraph 2, we will give an overview of the methodological and procedural approach. In paragraph 3, we will describe the research outcomes. In Paragraph 4, we will draw some conclusions.

2 Method and procedure

The research procedure that emerged during the project under discussion may be qualified as a form of action research (Boog and Tromp (Eds) 2003, Boog et al. (Eds.) 1998): researcher

and research subjects work together, neither separately, nor in any hierarchical relationship and interaction and participation are central concepts. In action research, direct intervention into practice is also part of the process: the research is action-oriented. This ensures, to some extent, practice-relevance. This also means that complexities that are present in practice will have an effect on the development of the research procedure. This project was not included in the original work plans of the Centre for Health and Environment and 'space to live' between tight schedules and overloaded agendas had to be found. This entails quite a different perspective than a project carefully designed at the drawing board and carried out in a more or less 'laboratory like environment'.

Interview round

As a first step, a series of interviews with all scientific promoters as well as policy representatives connected to the Centre for Health and Environment was organized in 2003 (Keune and Goorden 2004). Main purpose was to gain insight in the different perspectives on the genetic research and the generation of policy relevant knowledge in general.

A semi-structured form of interviewing was used. Even though all interviews followed more or less the same 'agenda', there was room for free development of the conversation as far as both the interviewee and the researcher thought this to be relevant. This means that none of the conversations were totally identical due to the conditions of the conversation (time constraints, specific knowledge of the interviewee about the subjects) and to the interests of the conversation partners. An overview of interview topics:

Genetic research:

- What is the genetic research about? What is the aim?
- What is the use of this type of knowledge?
- Is a certain knowledge base about the issue considered necessary in order to take part in discussions about the research?
- What type of involvement in discussion about the research is considered relevant for different actors, possibly at different stages of the research process?
- What are views on societal debate about such technology and the use of this specific knowledge to policy?

Development of policy relevant knowledge:

- Which are the views on the development of policy relevant knowledge within the framework of the Centre for Health and Environment?
- What should be improved, and what are barriers and opportunities for improvement?
- What is the role of social scientists?

It seemed most interesting to gather a broad picture of the subject. At the same time, it seemed interesting to get different pictures from different perspectives on the genetic research. Another aim of the interviews was reflection on busy daily practice of the Centre.

As a whole, this means that the different views from the different interviewees are not entirely comparable, because of the differences in topics discussed. At the same time this was not the purpose. The aim was not to search for majorities or minorities, consensus or divergence. The aim was to sketch a diverse picture of a complex issue in a complex setting as a basis for reflection and further discussion.

Concerning the genetic research the focus was on the perception of the research from different actor perspectives. In order to start a constructive discussion about the research, it was assumed necessary to gain insight into the knowledge and interpretations different actors have about the research. This does not necessarily exclude different views on the meaning and usefulness of the research and the possible research outcomes. Even though possibly a uniform description of the research is attainable, this does not mean that the meaning and usefulness of the research should be unambiguous.

The interviews were analysed qualitatively. The categories of analysis were partly structured on the basis of the preliminary research questions, and partly emerged from the material that resulted from the interviews.

Interactive discussions

In 2004, the results of the interview round were presented to both the scientists and the policy representatives. The social scientists proposed to set up discussion in order to deal with these issues. Both the researchers and the policy representatives of the government agreed on this proposal and the need for a constructive turn.

In 2005, we organized two workshops with both scientists and policy representatives. During the preparations of these workshops, we worked closely together with the principal researcher involved in the genetic research. We chose a semi-structured approach in order to have open conversations that were flexible enough to adapt to the developments of the discussions.

In April 2005, we organized a workshop to work out a strategy for next steps. In December 2005, a workshop focussed on the type of knowledge that will come out of the genetic research. The aim was to highlight blind spots, assessment factors, and fruitful scenarios for policy learning. At a meeting of the Steering group of the Centre for Health and Environment in January 2006, the results of the workshops were presented.

3 Results

Interview results

The origin of the interview round (Keune and Goorden 2004) was to look for opportunities for a constructive turn in the difficult discussions between scientists and policymakers on genetic susceptibility to environmental pollution. The interviews were supposed to be input to a more interactive next step. During the interviews quite some disagreement about the genetic research became known. More or less this was connected to the relation a person had to the genetic research itself. The more distant, the more critical it seemed. The main critics were policymakers and researchers who were not involved directly or indirectly in the genetic research. Researchers who were more close to the genetic research seemed to be more positive.

The main disagreement concerned policy relevance. According to some interviewees, the origin of the genetic research was mainly a quest for scientific knowledge, and policy relevance was neglected by the researchers: science for science rather than science for policy. As one scientist put it: "Well, I can perfectly understand that policymakers say I don't want to know that information, just use it only to better analyze your graphs."

Scientific complexity

One of the central elements of critique with regard to policy relevance was complexity: the power of the knowledge produced by the applied technology was believed to be too weak to tackle the complexity of the matter in order to be used by policymakers. This refers to both the complexity of the interaction between different genetic factors and different toxic substances, as well as the complex and bigger story of the relation between the environment and human health of which the genetic component only forms one of the important elements. Also, according to some interviewees, the state of the art (technology) was still too much in the fundamental development stages to be suitable for policy relevant knowledge. On the other hand, others argued that, even if this were true, the fact that the technology is tried out during the ongoing biomonitoring research on inhabitants of Flanders, makes it in effect a form of applied research.

Social complexity: different expectations, policy dilemmas and discourse

Next to the scientific complexity (non-social scientific that is), several aspects of social complexity were discussed during the interviews. The application of the technology within the framework of the biomonitoring seemed to offer good scientific opportunities: greater understanding of etiological mechanisms would be made possible due to research on several hundreds of participants. Another big promise of this type of knowledge development, that was brought forward mainly by researchers closest to the genetic research, was related to public health and environmental policy making. They referred in that respect to a statement in a policy memorandum from the Flemish Parliament in 2001 (Vlaams parlement, 2001): "Norms based on health effects usually depart from a "standard" healthy adult, and do not take into account specific vulnerable groups. There is need for adjusting current and developing new health or exposure norms, taking into account the newest insights in scientific

research and attuned to the most vulnerable groups.” Apparently, during the preparation stages of the Centre, the government representatives did not agree to this interpretation of the Parliaments’ policy statement and did not appreciate the inclusion of such genetic research. The scientists insisted though during the negotiations and persevered.

Policy dilemmas

Even when scientific knowledge is unhampered by uncertainties, policy implications may be problematic. Some interviewees referred to the example of the ozone problem to illustrate the problematic relationship between knowledge on environmental issues and policymaking: some years ago, scientific knowledge was generated on health risks of ozone for certain vulnerable groups and on traffic being one of the main producers of ozone. Despite policy intentions to protect these groups, this did not result in adequate policy measures. What will be the policy implications, some interviewees asked, of knowing that in some areas with specific environmental problems a substantial part of the population is at (health) risk due to their genetic constitution? Should these people move? Alternatively, should the environmental problem, if possible, ‘move’? When is the number of people at risk substantial enough for policy measures to be taken? When is a health risk serious enough?

The potential use in society of the type of knowledge that will be generated by the screening technology opens up a lot of questions, expectations and worries. Major concerns shown are about the possible discriminating use of knowledge about genetic susceptibility to certain substances. Most interviewees agreed that a discriminating use of this type of knowledge in both the work situation and insurance should be avoided. Some though stressed the importance of the individual autonomy in using this knowledge, and put less emphasis on a solidarity perspective. Areas such as work, insurance and residence were mentioned in this respect.

Actors and discourse: experts only?

What should debate about this type of knowledge look like according to the interviewees? Who should be involved, and in what manner and at what stage of the process?

When it comes to the more technical discussions about the research itself, most interviewees consider it an expert matter. Peer review seems to be sufficient for the majority. Some also consider it wise to involve policymakers at an early stage. This could form a basis for common understanding and joint decision making about research choices. One policymaker though considered this too late for the current research, since all research choices in effect are already made, the trajectory is quite clear. Some consider it interesting to involve non-experts external to the Centre at an early stage. Main advantage being that preparatory work can be done for communication purposes: how to communicate about complex technical research. But, overall, expert knowledge is considered necessary by most interviewees in order to take part in the technical discussions.

It is striking that even though views about the desirability of this genetic research differed, none of the interviewees wished to debate the acceptability of the ongoing research itself. If there is debate needed, it should be about how to handle the type of knowledge that will come out of the research process.

Science first?

At what stage of the development process should one discuss the use and meaning of scientific knowledge in society? Two extremes resulted from the interviews. One policy representative considered discussion necessary before the science is developed: agreement about the conditions for a (careful) use of the knowledge as a prerequisite for starting the development process.

The other extreme position was that social debate is only relevant once the scientific knowledge is fully developed. Should the scientific knowledge in the end appear not to live up to expectations, no time is wasted on intensive public debate it was argued. Another argument was that matters are too complex in the early stages of the research to be understood by non-experts. Also, the absence of scientific certainty was addressed: this is

hard to explain to outsiders. Furthermore, it was stated that scientists fear the vulnerability of their position when they have to debate about uncertain science.

An intermediate position was the preference for a parallel debate starting at an early stage of the research. The main advantage is timely attention for the use of the outcomes.

Who's next?

Who should be involved in such a parallel discussion? In principle, a step-by-step discussion strategy was what most interviewees opt for. This would mean that a wide variety of social actors are welcome for discussion, but not immediately. We can think of both genetic experts as well as public health experts; social scientists as well as policymakers; citizens and unions, environmental groups and companies; patients and doctors.

Most interviewees welcomed different perspectives, but some stated this to be dependent of the specific topic under discussion: only people with adequate expertise should be present. One interviewee though argued: "When people feel threatened, they have the expertise of feeling threatened."

Interactive discussions

Next steps

In April 2005, we organized a meeting with scientists and policy representatives to discuss the results of the interview round further and to work out a strategy for next steps. These next steps should follow the interest shown by both scientists and policy representatives to develop a trajectory parallel to the genetic research, focussing on the societal and policy implications. During a preparation meeting with the principal genetic researcher, the idea came up to broaden the subject to susceptibility to environmental pollution in general. The main argument was that the essential issue is knowledge about susceptibility and its societal implications, not so much the way by which susceptible groups are defined and detected. In a discussion document, this option was further introduced. We also introduced some methodological options for investigating future scenarios with experts and stakeholders, more specific the method of backcasting.

The discussion on broadening the focus to susceptibility to environmental pollution in general opened up new complex issues. The definition of susceptibility and susceptible groups appeared not to be that simple. In the end, it was decided that the original focus, genetic susceptibility to environmental pollution, should remain for several reasons. Firstly, it appeared to be difficult to bring different sorts of susceptible groups and different forms of knowledge about susceptibility under one denominator. Secondly, genetic aspects were considered somewhat special and relatively new. Finally, this specific case could also be illustrative for conclusions at a more general level.

As next steps, the following trajectory was proposed. First the type of knowledge that can come out of the genetic research should be discussed more concrete and more in detail. Also, relevant assessment factors should be reflected on. For this part, the principal genetic researcher was willing to prepare (in cooperation with the social scientists) a case for discussion in order to make clearer what type of knowledge may come out of the research. Based on this, possibly policy scenarios can be formulated. Secondly, wishful thinking with regard to societal embedding of that knowledge should be discussed: what are relevant social assessment criteria? Who are relevant actors to be involved in further discussion?

These two steps were planned for a workshop with more or less the same people who took part in the April discussion. A broader exploration of future scenarios could be part of a future workshop following thereafter. The social scientists proposed the backcasting methodology: considering the possible sorts of knowledge that will come out of the genetic research, considering possible policy scenarios and considering the main worries about careful use of such knowledge in the future, how can steps be taken in the present to make sure that a satisfactory societal embedding of the knowledge will be ensured in future?

Specifically, during the April workshop, it was stressed that an interactive next step, a workshop, was preferred to other options, such as interviews, questionnaires or a Delphi. At the same time though, policy representatives in particular stressed that taking part in several

meetings was not realistic due to workload and other priorities. Thus, the opportunities for in depth discussion of these issues appeared to be very limited, even though ambitions did not really show any drawback.

Several conclusions can be drawn after this workshop. Firstly, the focus on genetic susceptibility to environmental pollution remained as the most relevant issue for further discussion on societal and policy implications. Secondly, though, a need was shown for a more concrete illustration about the sort(s) of knowledge that will come out of the genetic research. Thirdly, the discussion atmosphere showed clearly to be much more constructive and less difficult with regard to interactions between the scientists and the policy representatives in comparison to the atmosphere before the interview round. Finally, the findings of the interview round (as synthesized by the social scientists) were accepted as good 'working material'.

Step back?

The workshop in December 2005 started with a presentation by the genetic researcher about the type of knowledge that will be generated. After this, a case-exercise was introduced in which the carcinogenic effects of Polycyclic Aromatic Hydrocarbons from cigarette smoke and from environmental pollution were compared. Participants were asked to assess the results of environmental pollution based on scientific research results with regard to cigarette smoke. Without going into too much detail here, we can state that the discussion of the case highlighted some relevant issues:

- Scientific knowledge is very limited
- No validated biomarkers are available in the case of environmental pollution (as opposed to cigarette smoke)
- Data are difficult to interpret

Where the case-exercise made it possible to base the interpretation of environmental effects on the known effects of cigarette smoke, in the case of biomonitoring, even less scientific certainty for interpretation, let alone decision making for policy is available. One policy representative clearly stated: "For the government this will not lead to certain measures." This brings us at some of the 'old weaknesses' of the knowledge on genetic susceptibility to environmental pollution that also were brought forward during the interview round. Furthermore it was argued, again mainly by policy representatives that the research will not bring forward new or yet unknown susceptible groups: "We perfectly know which the vulnerable groups are." Apart from that, the rather limited number of research participants in the biomonitoring with regard to genetic susceptibility to environmental pollution, will limit the possibilities to draw scientific conclusions. Furthermore, at an individual (participants') level interpretation is impossible.

The researchers did not oppose to these criticisms, and agreed that the results would not present a firm scientific basis to draw policy conclusions. Nevertheless they can help to give some directions for policy choices it was argued. The main conclusion though from this discussion was that no urgency existed to 'worry' too much about policy implications from the upcoming research results on genetic susceptibility to environmental pollution. Only with regard to the last biomonitoring campaign, adults, end of 2006, attention is needed for communication activities: the informed consent for the adult participants specifically mentions this issue. More urgency suddenly was attributed to the research on genetic effect markers: the policy and communication implications of this part of the genetic research suddenly appeared to be both more interesting and more urgent to deal with. Both policy representatives and scientists seemed to agree on this.

With regard to discussion of future scenarios and societal implications as far as genetic susceptibility to environmental pollution is concerned, no further continuity was preferred: instant policy relevance suddenly appeared to be vaporised. This also concerned any involvement of stakeholders external to the Centre for Health and Environment and application of the backcasting methodology. Only some progress was made on assessment factors. The list of factors that resulted from the interview round was supplemented:

| <i>Assessment factors Interview Round</i> | <i>Added assessment factors Workshop</i> |
|---|--|
| Seriousness of the health effect | Accessibility of the exposed groups |
| Characteristics of the target group | Are people voluntarily or involuntarily exposed? |
| Possibilities for intervention | Cure policies are easier to implement than prevention policies |
| Standard of scientific knowledge | |
| Cost – benefit analyses | |
| Societal aspects such as the balance between economical and public health interests | |

This workshop was evaluated as very interesting on the one hand, especially as preparation for the upcoming 'real' results from the genetic research. On the other hand, some participants wondered whether actually any progress was made. Partly this was probably caused by the fact that time between discussions was rather long, which resulted to some extend in discussing part of the issues all over again.

Presentation workshop results

In the Steering group meeting of the Centre for Health and Environment in January 2006 the outcomes of this workshop were (briefly) presented. The Steering group was asked whether they accorded the workshop conclusion not to pay special further attention at this stage to policy implications of the research on genetic susceptibility to environmental pollution. The policy representatives present at this meeting (none of them took part in the workshops discussed) reacted more or less flabbergasted... For most of them, the issue of genetic research appeared to be rather unknown territory. The complex constellation of the Centre for Health and Environment and the Steering group in combination with such a complex issue clearly caused this to happen. The subject receives only minor attention on the policy agenda: only the policy representatives directly involved in the workshops really know the details. Their colleagues representing them in the Steering group due to busy other responsibilities appeared not to be well informed. A change in government halfway the working period of the Centre for Health and Environment moreover caused a personnel change at the side of the government representatives in the Steering group, resulting more or less in a blanked political memory. Moreover, some of the scientists present at this meeting reacted with mixed feelings to the rather black and white presentation and defended the research and its use.

The discussion that followed was mainly characterized by (clearing) misunderstandings: most of the policy and governmental representatives present said they had insufficient knowledge about the research in order to decide on it. The conclusion was that more information clearly was needed and that the interview and workshop results should be sent to them. The intermediate result of this project, thus, is difficult to assess definitely: no distinct conclusions are drawn by the Steering group.

4. Discussion and conclusion

The fate of the knowledge on genetic susceptibility to environmental pollution remains somewhat unclear. Insight was gained with respect to the type of knowledge that will possibly be generated. Insight was gained about its complexity in several regards. Insight was also gained in different opinions mainly with regard to policy relevance. Furthermore, insight was gained in the interaction between science and policy on this issue. Clearly when we look at the process of interaction, progress was made from a rather difficult discussion atmosphere to a more constructive atmosphere. What remains undefined is what policymakers will do with this knowledge when it will actually be presented, probably in the second half of 2006. Little it seems, when we look at the discussions in the last workshop: the policy representatives show little interest. On the other hand, nothing has formally been decided yet.

How can we interpret these results? How can we interpret the results from the perspective of theoretical notions presented in the introduction of this paper: boundary work and the

dynamics of expectations? What seems to be the added value of involvement of the social scientists?

Boundary works

Clearly, during the process, the discussion atmosphere improved: the constructive turn was accomplished. In Hoppe's (2002) words, a dialogical model interaction seems to be established. On the other hand, though, this does not explain why, in the end, the joint investment in discussion about the knowledge suddenly vanished. Following the clouded discussion atmosphere prior to this project, the air gradually cleared. The substance, however, seemed to vanish: the knowledge disappears from the discussion agenda; science and policy go their own way. The difference in aims between science and policy is highlighted by this disagreement. At the same time, science and policy representatives, in the end, agreed that the assessment of the scientific knowledge was a meagre basis for policymaking (at this stage of development). Why the substance disappeared, we can explain further in terms of the dynamics of expectations vocabulary.

Expectations from start to finish

The promise raised by the researchers supporting the genetic research to a large extent was related to policy relevance. This seems to have changed in the end. When a more concrete picture of the type of knowledge that will actually come out of the research was presented, this promise lost ambition. A cynic might point out that the critical view of scientists as entrepreneurs was affirmed: in the final stages of the project, the scientific quest is satisfied, leaving the 'other ambition' behind.

As Brown (2003) puts it, this is not explained by lack of knowledge about future developments. One might also argue though that unforeseen complexities show along the way: the proof of the pudding is in the eating. Useful concepts do not automatically or instantly lead to useful practical results. The main research effort of the Centre for Health and Environment (biomonitoring) is a good example of this: along the way unforeseen complexities show, that would not have occurred probably when limited to some conceptual discussion. Such complexities appear to be underestimated.

The social scientific promise of providing methods for constructive interdisciplinary and transdisciplinary discussions more or less paid off: the discussion atmosphere became more constructive. A social scientific focus on technology assessment as a process of social construction that will benefit from early attention for social meanings of knowledge and technology and involvement of relevant actors did not survive in the end. The potential benefits of such an approach (knowledge about different perspectives and perceptions in society, policy support; see e.g. Fisher 2000) thus remain in the blind. Possibly the interest will revive once the actual genetic research results are presented. Partly though, this will remain dependent on the power of the scientific knowledge produced with regard to policy relevance; clearly, science has its limits.

Lessons from a 'stubborn practice'

As De Vries and Horstman (2004) put it in the preface of their book: there is need for documentation on practical learning processes on the societal meaning of genetic knowledge. Clearly the complexities with regard to genetic knowledge that came forward are comparable to issues discussed elsewhere (see e.g. Glassner 2004, Tutton and Corrigan 2004), and in that sense no surprise. This does not mean that the 'exercise' is redundant. An approach of merely academically 'thinking through' societal issues, without involving actors from relevant practices, runs the risk of not being accepted by those actors: they will feel excluded. Moreover, they will not easily comprehend the complexities of an issue as complex as the one discussed in this paper. As we saw, getting a grip on the type of knowledge was not very easy for actors not directly involved in the research. Also, a blind spot will be included in the approach: actors' perceptions will remain unclear. Conclusions drawn from such an exercise run the risk of collision with unknowns in social practice.

Thus, an interactive approach may be fruitful. But, that does not mean that it is easy. Daily practice of the Centre for Health and Environment clearly differs from a laboratory situation. In laboratory research conditions are controlled to a large extent (or controllable) and

complexities are limited to a certain degree. The research practice of a social scientist in a setting such as the Centre is something completely different. In the laboratory, atoms and molecules more or less do what they are expected to do. In social practice, research subjects will go into discussion with the researcher, they talk back (Bal et al. 2002). We can therefore speak of a 'stubborn' practice.

The effort under discussion here turned out to be an effort hampered by unforeseen complexities, tight schedules and lack of time. The work of the Centre for Health and Environment is primarily attuned to collecting and processing data, not to reflection on data interpretation, especially with regard to policy relevance. Most of the actors involved in the process have overloaded agendas. Discussing complex issues takes time and energy, and often goes hand in hand with a lot of 'paperwork'.

Boundary cooperation looks perhaps somewhat obvious on the drawing board. In practice, it demands extra effort. In the case of the Centre for Health and Environment scientists suddenly have to discuss work with (sometimes totally) different disciplines. They also have to talk (to) politics. Policy representatives suddenly have to discuss science and different fields of policy expertise also have to come to terms. Also, to some extent, common vocabularies need to be developed. In the case of the research on genetic susceptibility to environmental pollution, it is difficult to judge what the effect of the rather difficult discussion atmosphere was. Probably the general atmosphere benefited most from the constructive turn in this case.

Social science

When does a social scientist do his or her work properly one may ask? When all textbook methods and principles of communication, cooperation and co-production of knowledge are fluently put to work? Is the work of a social scientist comparable to the work of a physicist doing laboratory research? Social scientists have to negotiate with other actors and are bound to practical limitations. How then can we evaluate this case study?

The interviews were appreciated by some of the interviewees for the opportunity to step back from busy daily practice and to reflect on it. Little room seems to be available for such reflection in busy work programs such as the Centre for Health and Environment. Another advantage of the individual interviews seems to be the opportunity to 'let off steam': all interviewees could release otherwise hidden frustrations about both the subject of discussion and the discussion atmosphere. At the same time though, the interviews clearly resulted in a more nuanced view in some cases: after letting off steam, sometimes more understanding for the perspective and arguments of other actors was shown. Finally, the interviews resulted in a rich picture of the complex issues and provided all participants with insight in 'other' views. Good working material for next steps was thus produced.

A main advantage of direct interaction during workshops is the opportunity for social learning: a group discussion might work as a catalyst and create an opportunity for people to learn from each other. At the same time, it is a necessary step in preparing practical cooperation between different actors. The fact that in the end the discussion seemed to return to some of the 'original positions' with regard to policy relevance, does not contradict this. During the discussions, the picture of the issue was further enriched and nuanced. Insight in the type of knowledge gradually grew, and appeared itself not to be taken for granted: a lot of interaction and some creativity (the case-exercise) were needed to clarify what remained to some extent a blind spot for most participants.

Conclusion

Mission completed: the social scientists were involved to clear the air in the discussion atmosphere, and succeeded. What about the substance though? In the last workshop, the lessons learned were put on a shelf. During discussion in the Steering group, it seemed that lessons were only learned by participants involved in the process: policy representatives are also individuals, and (internal) communication has its limitations due to priority settings, personnel change and workload. When other policy representatives get involved, discussions more or less restart. The substance clearly is very complex and the process of discussion needs time and involvement. Lack of agenda-priority for the genetic research hampered reflection.

From the perspective of the genetic research, the scientific interest clearly was supported by this process. The ambitions on policy relevance faded: from an item on the policy agenda the

subject was degraded to 'an issue for communication'. From a policy perspective, what was gained most was insight into the issue under discussion and reflection on the question of policy relevant research. What was gained by all participants was experience of and insight into the complex interaction between policy and science. From the perspective of social science, also part of the expectations was fulfilled: the constructive turn in discussion atmosphere. What remains on the social science agenda is the question whether it is wise to leave societal discussion about policy relevance of knowledge on susceptibility (genetic or otherwise) to environmental pollution on the shelf. Probably a different setting for such discussion is needed.

Acknowledgment

We want to thank all people who contributed to this research, especially Prof. J. Kleinjans (University of Maastricht), Prof. L. Goorden (University of Antwerp), Dirk Wildemeersch (Flemish Department of Public Health), Ludwine Casteleyn (Flemish Department of Environment), Prof. N. van Larebeke (University of Ghent), Prof. W. Baeyens (Free University of Brussels), dr. G. Koppen (the Flemish Institute of Technological Research) and Birgit Dumez (University of Leuven).

References

- Bal R. (1998), *Bounding Risk, Bounding Science - On the Organisation of Standard Setting for Occupational Chemicals*, Enschede (in Dutch).
- Bal R., Bijker W. E. en Hendriks R. (2002), *Paradox of Scientific Authority - About the societal influence of advice of the Health Council*, Health Council, Den Haag, (in Dutch).
- Boog B., Coenen H., Keune L. and Lammerts R. (Eds.) (1998), *The Complexity of relationships in action research*. Tilburg, Tilburg University Press
- Boog B. and Tromp C. (Eds) (2003), *Action Research and Emancipation*. Special issue of: Journal of Community & Applied Social Psychology. (Wiley Interscience, Chichester, West Sussex-UK), Volume 13, number 6, November-December 2003
- Brown N. (2003), *Hope against Hype – Accountability in Biopasts, Presents and Futures*, in: Science Studies, Vol 16 (2003), No. 2, pp 3-21.
- Brown N. and Michael M. (2003), *A Sociology of Expectations: Retrospecting Prospects and prospecting Retrospects*, in: Technology Analysis and Strategic Management: 15 (1), pg 3-18.
- Brown N., Van Lente H. and Rip A. (2003), *Expectations In and About Science and Technology*, Background Paper for the Expectations in S&T Workshop, 13-14 June, Utrecht, The Netherlands.
- Centre for Health and Environment, <http://www.milieu-en-gezondheid.be/>, [May, 2006]
- Fisher F. (2000), *Citizens, Experts, and the Environment, The politics of local knowledge*, Duke University Press, Durham/London.
- Gieryn T. (1983), *Boundary-work and the demarcation of science from non-science: strains and interests in the professional ideologies and cultures*, in American Sociological Review, vol 48: 781 - 795.
- Glassner P. (eds) (2004), *Reconfiguring Nature, Issues and Debates in the New Genetics*, 2004, Hampshire (UK), Burlington (USA)
- Hoppe R. (2002), *Rethinking the puzzles of the science-policy nexus: Boundary traffic, boundary work and the mutual transgression between STS and Policy Studies*, Paper prepared for the EASST 2002 Conference, 'Responsibility under Uncertainty', York, 31 July–3August.
- Huitema D. (2004), *Calculating the political. Election manifestos as the meeting point for experts and politicians in the Netherlands: the case of the RIVM*, Paper for the 4S/EASST conference, Paris 25-28 August 2004
- Jasanoff S. (1990), *The fifth branch: science advisors as policymakers*, Harvard University Press, Cambridge, Massachusetts, London England.
- Keune H., Goorden L. (2004), *Accidental complexity, Societal embedding of Science on Health & Environment*, case study Genetic Research, Centre for Health and Environment (In Dutch)
- Keune H. (2004), *The production of policy relevant knowledge on environment and health in Flanders*, in: Trans, Internet journal for cultural sciences, Nr 15, http://www.inst.at/trans/15Nr/03_2/keune15.htm, [May 2006]
- Rotmans J. (1999), *Integrated Assessment Models, Uncertainty, Quality and Use*, ICIS working paper, Maastricht.

Tutton R. and Corrigan O. (eds) (2004), *Genetic Databases: Socio-ethical Issues in the Collection and Use of DNA*, Routledge

Vlaams Parlement (2001), *Societal policy paper Environment and Health*, Stuk 740 (2000-2001) – Nr 1, 6 June 2001, Brussels, (in Dutch).

Vries De G. and Horstman K. (eds) (2004), *Genetics from laboratory to society, the unknown practice of predictive genetic tests*, Amsterdam, (in Dutch).