

THE ITEMS NETWORK

Identifying Trends in European Medical Space – Contribution of European Social and Human Sciences (ITEMS) is a research network funded by the 5th Framework Program of the European Commission. The network includes more than 20 partners from 10 European countries. Its main aims are to synthesize current research and training in the human and social sciences focusing on medicine and health, and to structure a European multidisciplinary research and training network in this field. The ITEMS network was organized around four main axes:

1. The transformations of the biomedical sciences and their impact on the definitions of disease, health and care;
2. The participation of users in medical activities and debates in the context of different political traditions;
3. Coordination in health organizations, with a focus on the role of information and communication technologies;
4. Articulations of health, social and political issues.

On these issues, mixing up social and medical aspects, human and social sciences should add value to public understanding, through analyzing and confronting national experiences. ITEMS synthesized current research and training in human and social sciences, in order:

- To structure a European multi-disciplinary research network;
- To prepare the European research area;
- To set up the basis for comparing national contexts;
- To reflect upon the role of human and social sciences as regards policy stakes on health issues, and conceive tools for a large dissemination of research results.

The work was organized through five work packages:

Workpackage 1: Mapping European research centres and their research topics.

In order to map the community, information about research centres participating in the network, their researchers and research projects related to the four axes, a database was constituted and a website constructed. This work was used to consolidate research partnerships and to create new ones. It was also drawn upon as a resource for the other work packages.

MY TALK ABOUT GOLD!» ANALYSING THE INTERACTIONS BETWEEN GENOME-RESEARCH(ERS) AND THE PUBLIC AS A LEARNING PROCESS – FIRST RESULTS AND IMPRESSIONS

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PROBLEM DEFINITION

In recent years have witnessed an increase in public controversies concerning science and technology, in particular linked to questions of genetics, both in the domain of agriculture and of medicine. Trust in existing societal mechanisms of handling the relation of science, technology and society seems shaken. Purely expert oriented models of dealing with social and ethical issues in these domains start to be questioned. Increasingly both national governments but also actors on the EU level have had to realise that new mechanisms of science-society interactions need to be implemented in order to assure a better integration of science and technology into society. Thus it was realised – the EU Action Plan for Science and Society is an excellent example – that people do not simply need information, but have to be enabled to participate in science under radically different conditions. A more open kind of dialogue has to be established.

Through this dialogue people can express how they conceive ethical and social issues that are at stake from their point of view, they can bring in their experiences and can engage with scientists.

THEORETICAL APPROACH

In the scientific arena, the field of Social Studies of Science has devoted substantial effort to study and theorise the issue of interactions between science and lay publics for about two decades. This research focuses on the different aspects of how positions towards science are constructed in a multilayered and complex way. Engaging with science must be seen and conceptualized as a complex and situated process, in which a number of different aspects, depending on the individual's life circumstances play an active role. Besides personal affectedness, issues of gender and ethnic identity have been shown to be especially important concerning questions of biomedicine. This diversity of situated viewpoints has to be taken into account in analyzing and designing the public's engagement with biomedicine. While a number of studies have treated this subject on an individual basis, the interaction between different situated positions concerning a specific scientific issue over a longer period of time has so far not been researched extensively.

Valuable insights for our project can also be drawn from the 15 years of experience concerning citizens' engagement with scientific issues in a number of participatory settings at the interface of science and politics, of which the consensus conference is the best known. Aimed at producing an input for the political system, these settings mostly relied on small representative samples of the total population, thus arguably neglecting specific situated perspectives, e.g. that of users. Nearly all participatory processes were carried out at the back end of the knowledge production process, thus confronting the lay people with "ready made" facts. Furthermore, the relatively short time of interaction between experts and lay people enabled the latter to formulate a coherent statement, but left little room for a process of mutual learning, and the question how the lay people's opinions fed back to science was hardly considered.

This "talking back" of lay publics to science has been the focus of recent influential work by Nowotny, Scott and Gibbons. They argue that the relationship between sciences and society has shifted, and that the social contextualisation of scientific knowledge production plays an increasing role. Not only do potential users and other lay groups seek to engage with science, but also the scientists themselves, facing growing uncertainties, are increasingly called to consider the potential users and societal impacts of their research. Encounters between lay stakeholder groups and medical researchers, and the question whether science is enacted differently in these constellations have been the focus of a large number of case studies.

Contextualisation thus becomes a process of mutual learning, which leads to a new quality of scientific knowledge, that of social robustness. Socially robust knowledge is supposed to integrate the different

societal standpoints, which in turn can help to prevent controversies. While the processes of contextualisation have been quite well studied for co-operations between lay groups (e.g. patients' associations) and researchers, a detailed analysis of a contextualisation process involving a number of lay people from different contexts with research that is still in a phase far away from direct application is still lacking.

PROJECT SETTING

The project to be presented aims at initiating and analysing a more longitudinal mutual learning process between a group of lay-people and researchers engaged in basic genomic research (in the "GOLD" project of the GEN-AU programme¹). The fact that "GOLD" is an ongoing project will provide the lay people with the opportunity to see and discuss "science-in-the-making" instead of being confronted with "black-boxed" facts.

The project GOLD (Genomics of Lipid-Associated Disorders) fulfils all requirements for a co-operation in an optimal way. As the project description states, "In the western world obese, non-insulin-dependent diabetes mellitus and cardiovascular diseases are epidemic. [...] more than 50% of the population is overweight, and throughout the world about twice as many people die from cardiovascular diseases such as heart attack and stroke as die from cancer. Among other factors, one underlying cause of all the above-mentioned diseases is dyslipidosis (disruption of fat metabolism). The goal of this project is to discover and explain the function of each gene and protein involved in the process of uptake, storage and mobilization of lipids (fats) by cells."

The project thus deals with a topic that touches (at least potentially) a very large segment of the population and thus participants can build rather easily very concrete connections to their every-day situation. A large number of differently situated lay perspectives towards the project are imaginable.

While defining the ethical issues "at stake" in the GOLD project beforehand does not seem feasible for such an approach, this specific project was still chosen because it can be described as embodying possible ethical tensions. For example, the different imagined contexts of application range from treating a quite clearly defined disease, diabetes, to the general public health problem of obesity, and might possibly even be extended to developing "life style drugs". Thus the project may touch discussions of "shaping" bodies and possibly transforming a social issue, that of the link between individual life style, weight problems and

¹ <http://gold.uni-graz.ac.at; www.gen-au.at>

cardiovascular diseases, to a medical problem defined in terms of genetic defects. The project thus touches upon basic normative concepts of health, illness and the body and therefore upon important moral issues, of which a reflection must be seen as central.

CORE QUESTIONS OF RESEARCH

Our research will be organised around the following central research questions:

- How do the **lay-members** of this panel formulate their **ethical and social standpoints towards biomedical/genome research** and what are the cultural or personal resources they draw upon in doing so? How do the **scientists** construct the **ethical and social dimension of their research**?
- Does the **interaction process** over a longer period in time **change their respective opinions** and if so, triggered by what experiences and in what way?
- How does the **interaction process** between scientists and lay people **develop over time**? Which **roles** are taken and mutually ascribed by the various actors?
- Are there **differences in the positions lay people** develop towards genome research if they, or persons close to them, are **affected by a disease of probable genetic origin**. If yes, on what levels and articulated in what ways do they become visible?
- In what way does **gender** matter in these processes of positioning and developing social and ethical standpoints and how could this be made explicit and better understood?
- How do **scientists** themselves **perceive the way people pose their questions** and how can they make sense of their views on a given problem?
- What **general conclusions**, which could be a valuable input into **policy considerations**, can be drawn from **this experiment for developing models of interaction between science and society** (in particular with regard to bioethical issues)?

METHODOLOGICAL APPROACH

As mentioned above the **first and central data source** is a setting with which was already experimented in the Swiss context namely the "**round table**". The basic principle of the "round table" is to let a group

of lay people (in our case about 12 participants) accompany a bigger research project/topic over a longer period of time.

In sum a series of 7 meetings will be held between the members of the lay panel and researchers over a period of about one year. Various aspects of such a project are debated and analysed particularly from the lay perspective. The aspects to be covered range from the context of production of scientific knowledge to the various contexts of its application. For example it is planned to do a lab visit and to invite medical doctors who actually deal with patients affected by such illnesses as well as professional ethicists.

The lay members of the round table will be selected considering the **gender balance** as well as the **balance between those who are more or less directly involved with topics** that are linked to the research carried out in the GOLD project and those who have no such connection. The idea is not to get a representative sample of the population but to include a broad variety of situated "user" perspectives.

The **second set of data** is two series of **qualitative interviews** with both scientists as well as members of the lay panel. The goal of these interviews is to grasp the learning effects the participants (both lay members and scientists) have undergone during the period of collective debate and reflection.

The **third set of data** will be delivered by the last round-table meeting, as it is meant to be the lay people's explicit reflection of the learning process and of what happened during this year. We will also ask the scientists to recollect their experiences and organise a group discussion for this purpose with all scientists involved in our project.

PROJECT GOALS

The aim of the project is to:

1. develop a setting in which lay people interested in biomedical research can engage with scientists from this research field over a longer period in time (approx. 1 year) and develop a more refined picture of this field through different forms of interaction;
2. allow for scientists to better understand what kinds of questions lay people ask themselves about their type of research;
3. analyse the ways in which lay people develop and express their positions towards a broad variety of issues linked to this research in particular social and ethical issues;
4. provide a framework in which gender related perceptions can get their place in the debate and can be better understood in their different facets;

5. create a space where potential "users", which means those who are affected by the targeted disease, can feed back their experiences and expectations into the research process;
6. experiment with a method which could foster a better societal integration of science and technology and a more refined public debate in this domain;
7. contribute to an enlarged vision of social and ethical issues linked to the field of genome research.

COMMENTS ON THE SESSION «GENETICS BETWEEN LABORATORY AND CLINIC»

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The three projects presented in this panel are quite different, consequently it is not possible to construct a general argument in which they would all take place, as specific sub-parts, or to build out of them a general framework that would give guidelines for the elaboration of a common project. But different does not mean that there is not any intersection between them: so what I am going to do in this comment is to start from their differences and to use these differences as means of questioning each project's closure and limits.

The differences between the three projects concern their stage of development, their methods, and the object around which they are organised.

1) STAGE OF DEVELOPMENT

The project on *Helicobacter Pylori* (João Nunes) and the project on clinical genetics (Pascale Bourret and Vololona Rabeharisoa) are quite advanced, whether the GOLD project (Ulrike Felt and ali) has not yet begun.