

De organisatie van een virus : over de wereldgezondheidsorganisatie, wetenschap en transnationale gezondheidspolitiek

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Summary

This study analyzes the approach of the World Health Organization (WHO) by focussing on the development of a registration. The WHO is an international organization that, together with its member states, aims to improve the health of the world's population. The WHO presents itself as a technical and apolitical organization. The technical character of the WHO is apparent, for example, in the organizational structure, the staff composition and the program choice. Many critics argue that the WHO is too technical. According to these critics, the organization focuses too exclusively upon developing medical knowledge and improving technical facilities. They expect the WHO to take a more political stance, to ensure that more politically sensitive issues, such as birth-control, or the health care system's economical interests, can be addressed. Despite increased criticism, the WHO wants to continue its technical approach of healthcare problems. The WHO maintains that due to the use of medical expertise, healthcare problems can be managed more efficiently, because in this way, political commotion can be avoided.

One of the WHO's main responsibilities is to develop and maintain registries. The WHO manages several registries, the most well-known of which is the International Classification of Diseases. Above all, registration is exemplary of the WHO's technical and apolitical approach: the WHO gathers data and orders facts, in order to allow the member states to come to the correct decisions concerning policy. The aim of this research project is to gain insight into the WHO's functioning, by analyzing the development of a registry. *The central questions in this project are thus:*

- 1 What kind of work is done to set up a registry?
- 2 What are the effects of this kind of work on the object of registration, the development of policy, and the relationships between the parties involved with the registration?

To answer these questions, the development of the registration of HIV is described. Using the minutes and other working documents of the project group that

developed the registry, the work necessary simply for registration can be mapped. The project group consists of representatives of laboratories from different countries and with diverse backgrounds. The intention is for the laboratories to map the genetic and antigenic diversity of HIV together. For this purpose, the "WHO network for the isolation and characterization of HIV" (the WHO network) was setup. This network is divided into three levels:

- 1 The primary laboratories in Uganda, Rwanda, Thailand, and Brazil, each of which is responsible for compiling sixty blood-samples.
- 2 A central repository where all blood-samples are kept and processed.
- 3 The secondary laboratories that each characterize HIV in their own way.

All data is stored in the Los Alamos National Laboratory (LANL) database.

For the theoretical framework in thesis, concepts derived from figurational sociology and from Science and Technology Studies are used. Figurational sociology has contributed to the debate on globalization in an interesting way. The central issue in the debate is the effects of the ever increasing scale upon which people and organizations function. The number of transactions over vast distances has risen sharply in a short period of time. Worldwide, people are becoming increasingly dependent on one another, and international businesses and organizations are increasing in importance. How do these developments effect society? Using concepts from the debate on globalization, the standard conception about international organizations like the WHO can be abandoned. These organizations can subsequently be investigated, from a different perspective, as locations where transnational networks are built. Typical of transnational networks are the direct relationships between international organizations and individual citizens (between the international and the local), or between organizations and citizens from different countries (between different local sites). Such transnational relationships within international organizations have hardly been researched, despite their obvious importance.

In regards to the functioning of the WHO, scientific knowledge is of central importance. However, research on globalization is primarily concerned with the development of worldwide cultural and economical networks. Relatively little attention has been paid to scientific networks, which also span the earth. For this reason, Science and Technology Studies (STS), whose focus is on the daily practice of scientific research, provides a portion of the theoretical foundation in this paper. The main question is what scientists do when they conduct research. From this focus, a new perspective on the age-old philosophical problem of how to differentiate science from other practices and knowledge has developed. According to Bruno Latour, an anthropologist of science, scientists strengthen their claims by linking them to other scientific findings, to theories, to applications, and to societal issues. A scientific claim can thus become part of a wide network of alliances, which explains the solidity of scientific statements. Concepts from Latour's "Actor Network Theory" provide tools to describe the development of a network. Moreover, they allow one to trace possible alterations in the

object of registration, in the relationships between the associated laboratories, and in the WHO's policy. What has been studied in this project using these theoretical tools?

The WHO network was set up amidst a controversy about the effectiveness of HIV vaccination. At present, large-scale vaccination programs to attack the worldwide spread of AIDS, are the only option open to the WHO. When the WHO took the initiative to set up the registration of HIV in 1989, several HIV vaccines had already been developed. The effectiveness of these vaccines, however, was questioned. Given the special characteristics of HIV, doubts were raised whether an effective vaccine could be developed at all. This question was complicated by the fact that it was unclear how to measure the effectiveness of HIV vaccines. In order to develop vaccines, the WHO wanted to collect data about both the genetic and the antigenic diversity of HIV. Most existing HIV registration programs - that derive from molecular biology - only collect information about genetical diversity. However, the WHO wanted to collect data about antigenic diversity because this information in particular was necessary in the development of vaccines.

In chapter two, the question is whether and how the approach of the WHO, for handling international health problems, may change the controversy. In this chapter, the emergence of the WHO network is described, with an emphasis on the organizational work typical of the WHO - meetings, accounting, facilitating, and the like. The description of these efforts shows how perspectives on the diversity of HIV shift within the WHO network. Instead of positioning one another by opposing differences in method, theory, and views, as is common in science, in the WHO network, such differences could exist side by side.

How exactly does organizational work have an impact on the content of the debate? This chapter shows how the different laboratory approaches to investigate the diversity of HIV are discussed separately during meetings. A report is written of every meeting, outlining the registration procedure. By writing and rewriting these reports, the laboratories develop a common registration procedure without the interference of differences of opinion. The ways in which the experiments are discussed during meetings, and are reported upon afterwards, molds the characterization of HIV in the WHO network. In the network, experiments are performed alongside one another, just like they are discussed and described in meetings and minutes. Also, the material infrastructure set up for the WHO network becomes an important link between the laboratories. The infrastructure is necessary for two reasons. First, to send the blood that has been gathered by the primary laboratories to all of the other laboratories, to be characterized in the different available ways. Secondly, the WHO has to find a solution for the problem that the laboratories all use different demands to select the material they will use to characterize HIV. Instead of developing a product that suits the minimum demands of all the laboratories, the depot constructs several different products (bloodcells, plasma, virus cultures). In this way, the laboratories need not analyze the same material while still being able to characteri-

ze the same viruses. In this (practical) way, the organization of the WHO network thus molds the relationship between genetical and antigenic diversity. Therefore, chapter two shows that while the WHO is renowned for the way in which it is able to obtain consensus, a different analysis of the WHO's organizational effort does not comply with this image. The way in which the technical working group develops a proposal for an HIV registration network shows that the group can be effective without reaching a consensus about the relationship between genetical and antigenic diversity, or about the continuation of vaccination studies.

Between 1992 and 1993, a pilot study was conducted, wherein a limited amount of blood-samples was gathered, although all steps necessary for registration were also taken. Chapter three describes, in detail, this process of registration from the very beginning until the absolute end (from collecting the blood-samples right through to the feeding of data into the database). In setting up the process of registration, the working group built on existing research-structures, classifications, and facilities. The duration of infection, which is related to the chance that the virus will be successfully isolated later in the registration process, can, for example, only be determined for those who took part in prior HIV incidence studies. The classification in genotypes made by molecular biologists serves as an important foundation for cooperation of laboratories in the genetics subgroup, as it later is for the whole working group. A molecular database, the LANL's HIV sequence database is used to store the information from the WHO network.

To the WHO, the data from the incidence studies, as well as, for example, the infrastructure necessary to register genetical data, merely facilitate the development of the registration. However, the network of classifications, facilities, and facts upon which the HIV registration leans, turns out to shape the development of the registration itself. In the beginning, its development is affected by the discipline of epidemiology. The role of epidemiology is apparent, for example, in the way in which criteria are formulated to select volunteers to participate in the project, the group that is eventually asked to participate, and the kind of data that is gathered from them. Later on, the epidemiological emphasis is diminished to the point that the epidemiological information gained from the volunteers is saved, for practical reasons, in a database separate from those data that are used to characterize HIV.

Increasingly, the role of molecular biology gains importance in the development of the registration. The differentiation in genotypes, based on the registration of HIV sequences, can not be stabilized at first. The results from the methods used to determine the HIV genotype diverge. The way in which these methods are evaluated, increases the identification between genotypes. Eventually, the classification in genotypes actually becomes the model for the identification in serotypes. The decision to use the LANL database as the location to store the information, strengthens molecular biology's position in the WHO network. In this database, the information on genetic diversity is primary. This primary position does not only refer to the order in which information is sorted, but also relates

to differences in standardization of information, which has consequences for the possibility of its exchange and analysis. Chapter three shows that the aim of registration was to map the genetic and antigenic diversity of the HIV virus. However, along the way, antigenic diversity was molded by and became subordinate to genetic diversity.

Chapter four focuses on transnational relationships. The WHO network's subsidiary aim is to improve collaboration between western and developing countries. First, the WHO aims to stimulate HIV research in developing countries. Second, it aims to use the gathered information about HIV in developing countries immediately in the planning of vaccination studies in those countries. More equal relationships are a necessary prerequisite for the intended collaboration. Therefore, the WHO intends to strengthen the position of the primary laboratories in comparison to the secondary ones, as well as the position of volunteers in relation to the WHO network. To do this, the WHO has taken a variety of initiatives. The working group has set up a training program for researchers of primary laboratories. Also, the secondary laboratories have developed simple techniques that can be used by the primary labs to characterize HIV. The practice, however, as will be shown in chapter four, is different.

During the process of registration, choices are made that seem to have little to do with the relationships between primary and secondary labs, nor with the relationships between volunteers and the WHO network. Take for example, the decision to isolate HIV centrally, or the agreements made about publication of the research results. Together, such decisions, made on separate occasions and moments, have the effect of decreasing the number of tasks assigned to primary laboratories in relation to what was intended. The further effect is that their work is not considered scientific, and that they are not included as authors of scientific publications resulting from the study. In a similar way, volunteers are linked to the WHO research for a longer period of time than planned, without having given their consent. This happens because primary laboratories select volunteers who have participated in WHO research before. These volunteers can easily be traced from the information gathered during prior research projects. Thus, the way in which the transnational relations develop in the WHO network, are the result of separate choices that seem unconnected to a preconceived plan or a general thrust. Still, it is no coincidence that the total effect of these unrelated decisions shows a specific inclination. After all, a specific infrastructure has already been developed for recruiting volunteers, and for gathering and isolating blood-samples. For this reason, some choices have become more obvious than others. If the WHO wants to divert from the more evident course of action, the effort will be greater. In conclusion, without extra effort, the already existing links of the network will become stronger, while the others will become weaker. The existing relationships are thus reinforced rather than changed.

In the concluding chapter, the description of the work done by the WHO in this thesis is contrasted to the WHO's self-image. The WHO presents itself as being

concerned with neutrality in all areas. It sees itself as refraining from taking any political stance and aims only to facilitate the development of knowledge and policy measures. As long as the WHO insists on this image of itself as an apolitical, as a merely technical organization, it will remain blind to the ways in which it effects the content of the knowledge it helps to produce, the direction of the policies it facilitates, and the relationships between the different member states, disciplines, researchers, and volunteers it tries to improve. This thesis, therefore shows that the WHO has an active and specific role in developing scientific knowledge and in the construction of transnational networks.