

# MEDUSE

Governance, Health and Medicine.  
Opening Dialog between  
Social Scientists and Users



## Scientific leader

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## ABSTRACT

The objective of the MEDUSE project was to organize a dialogue between social scientists and main actors in the domain of health and medicine (professionals, patient organizations, decision and policy-makers), on three issues of policy relevance that have been previously identified and reflected on within ITEMS network<sup>1</sup>:

- ▶ 1. The dynamics of patient organizations in the European Area.
- ▶ 2. The emergence of new technologies and responsibilities for health care at home across diverse European systems and cultures.
- ▶ 3. Cross-national and European perspectives on health safety agencies.

Drawing upon ITEMS results and reflections and on exchanges with a wide range of actors concerned with these three issues, as well as on a range of design, implementation and evaluation of experiences across Europe, these three topics appeared as highly relevant issues for health policies: they put to the front matters of governance and citizenship, raised by the new framings of knowledge production and use in the domain of health and medicine. All three also relate to the increasing role played by non traditional actors (e.g. patient organizations, health agencies, networks for care at home).

The form of dialogue chosen to achieve the objective of the MEDUSE project was to organize three conferences, one on each of the three issues, gathering a medium sized group of participants (between 60 and 80 participants) in order to benefit from a variety of backgrounds, points of view and experiences and to allow the exchanges between the delegates.

The specificity of the project was that it was framed with the intention of placing academic and non-academic participants on an equal footing. The delegates – be they speakers or not – were expected to have an active participation to the conferences. The speakers and the active audience of each conference were both social scientists and actors directly concerned with the issue (health care professionals, patients' representatives, clinicians, agency staffs, decision and policy-makers).

The conferences were designed so as to facilitate the dissemination of social science findings and to permit the cross-examination of the issues at stake. Exchanges concerned: the questions likely to be put on the scientific and political agenda; the knowledge that would be needed to address these questions; the modalities of partnership between social scientists and non-academic actors which will suit the best to produce this knowledge.

A method has been developed in order to allow the discussions to be as inclusive and participative as possible : the participants were divided into three randomised groups (2 per day). These groups then held discussions after the plenary presentations of papers on each theme. The sessions were facilitated by one of a range of people either MEDUSE project team members or other researchers well known to the project team. As well as a facilitator we also appointed a respondent to each group. Both Facilitators and Respondents represented a diversity of backgrounds and came from a variety of countries. They were chosen as people with high level communication skills and a good understanding of the subject area. The Facilitators were instructed to try to keep discussion on topic, and to



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encourage participants to supply particular examples from their experience in the field. The respondent's role was to keep notes on the discussion and, close to the end of the session, to provide a verbal summary of the content of the discussion. The facilitator would then allow a short period of time for participants to comment on the summary.

These sessions were extremely successful. Participants were keen to go into their designated groups and participated enthusiastically. The discussions were always lively and stimulating, and meant that participants eventually met everyone at the event, thus facilitating the best possible sharing of ideas across disciplines, nationalities and backgrounds ; they tended to produce interesting examples and counter-examples relating to the themes under discussion. All discussions have been recorded and transcribed ; synthesis has been elaborated and will be published in Conference Proceedings.

*1. ITEMS (Identifying Trends in European Medical Space. Contribution of Social and Human Sciences), is a European thematic network funded under the 5th Framework Program of the European Commission. It gathers more than twenty European research centres working on medicine and health issues.*

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Meeting organised in Utrecht (The Netherlands)

*Telecare : Dialogue and Debate - The emergence of new technologies and responsibilities for Healthcare at home in Europe.*

### Feedback to the conference : "The dynamics of patient organizations in the European area"

Personally, I sincerely think that these two days were rich as much as concerns the organization that the contents of the conference. It should be noted that it is the first time that I take part in this particular type of conference, which had the merit of not being «wearisome». I am accustomed to be in «passive listening» position in conferences on subjects related to health (...) This is a new experiment between «professionals» and «patients» which, in any case, it was very interesting and constructive (Representative of a French patient organization).

It was very interesting to find out which are the problems of patient organizations from other European countries and which is their mode to interact with the health care system, the medical forums, the research institutes. Making the connection between these actors permitted a concrete dialog and the opening for possible solutions to the problems of the patient organizations. (Representation of a Romanian patient organization).