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Identifying Trends in Medical European Space. Contribution of Social and Human Sciences

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Final report

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Preface

Within the Fifth Community RTD Framework Programme of the European Union (1998–2002), the Key Action 'Improving the Socio-economic Knowledge Base' had broad and ambitious objectives, namely: to improve our understanding of the structural changes taking place in European society, to identify ways of managing these changes and to promote the active involvement of European citizens in shaping their own futures. A further important aim was to mobilise the research communities in the social sciences and humanities at the European level and to provide scientific support to policies at various levels, with particular attention to EU policy fields.

This Key Action had a total budget of EUR 155 million and was implemented through three Calls for proposals. As a result, 185 projects involving more than 1 600 research teams from 38 countries have been selected for funding and have started their research between 1999 and 2002.

Most of these projects are now finalised and results are systematically published in the form of a Final Report.

The calls have addressed different but interrelated research themes which have contributed to the objectives outlined above. These themes can be grouped under a certain number of areas of policy relevance, each of which are addressed by a significant number of projects from a variety of perspectives.

These areas are the following:

- ***Societal trends and structural change***

16 projects, total investment of EUR 14.6 million, 164 teams

- ***Quality of life of European citizens***

5 projects, total investment of EUR 6.4 million, 36 teams

- ***European socio-economic models and challenges***

9 projects, total investment of EUR 9.3 million, 91 teams

- ***Social cohesion, migration and welfare***

30 projects, total investment of EUR 28 million, 249 teams

- ***Employment and changes in work***

18 projects, total investment of EUR 17.5 million, 149 teams

- ***Gender, participation and quality of life***

13 projects, total investment of EUR 12.3 million, 97 teams

- ***Dynamics of knowledge, generation and use***

8 projects, total investment of EUR 6.1 million, 77 teams

- ***Education, training and new forms of learning***

14 projects, total investment of EUR 12.9 million, 105 teams

- ***Economic development and dynamics***

22 projects, total investment of EUR 15.3 million, 134 teams

- ***Governance, democracy and citizenship***

28 projects; total investment of EUR 25.5 million, 233 teams

- ***Challenges from European enlargement***

13 projects, total investment of EUR 12.8 million, 116 teams

- ***Infrastructures to build the European research area***

9 projects, total investment of EUR 15.4 million, 74 teams

This publication contains the final report of the project 'Identifying Trends in Medical European Space. Contribution of Social and Human Sciences', whose work has primarily contributed to the area 'Education and training, quality of life'.

The report contains information about the main scientific findings of ITEMS and their policy implications. The research was carried out by twenty-three teams over a period of thirty months years, starting in January 2003.

The abstract and executive summary presented in this edition offer the reader an overview of the main scientific and policy conclusions, before the main body of the research provided in the other chapters of this report.

As the results of the projects financed under the Key Action become available to the scientific and policy communities, Priority 7 'Citizens and Governance in a knowledge based society' of the Sixth Framework Programme is building on the progress already made and aims at making a further contribution to the development of a European Research Area in the social sciences and the humanities.

I hope readers find the information in this publication both interesting and useful as well as clear evidence of the importance attached by the European Union to fostering research in the field of social sciences and the humanities.

J.-M. BAER,

Director

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Abstract

The general goals of ITEMS network, gathering 23 research centres from 10 countries, were to contribute to structure European Human and Social Science Research on health and medicine and to identify the major trends concerning four main research axes: 1) Transformations of biomedical science and their impact on the definition of disease, health and care, 2) Participation of users in the context of different political traditions, 3) Coordination in health organizations, with a specific focus on the role of information and communication technologies, 4) Articulation of health, political and social issues. The project comprises four major objectives:

1) To map European Human and Social Sciences research centres investigating health and medicine changes.

A database was set up based upon the treatment of an extensive questionnaire filled in by each of the 23 ITEMS partners. It gathers data about 160 research centres (ITEMS members and their partners), 480 researchers, 250 research projects and activities. The database has been made available through a website, including information on the ITEMS project itself and on EC programs.

2) To contribute to the scientific and methodological conception of comparative European research on the main trends of health and medicine.

A workshop, held in Granada, consisted of a cross investigation of the way each of the four research axes was represented in all research centres. It resulted into the identification of 7 themes, selected as particularly relevant in the perspective of comparative research: Methodologies, Standardisation-Formalisation, Technification, The Patient-Citizen, Health Care Organisation and Coordination, Geneticisation, Disease and the Body.

Based upon these results, a scientific symposium, held in Coimbra, allowed to deepen reflection on common interest topics and to open the network to outside participants. Extended abstracts of the papers, discussions and synthesis reports are made available in a book of proceedings, which gives an overview of current issues at stake.

As intended, these exchanges resulted in concrete projects, two of them being submitted to the European Commission before the end of 2005, others being developed in a bilateral or national-centred mode, or being in a more preliminary stage of development.

3.) To produce recommendations for common educational activities for PhD students and post-doctoral fellows

An electronic survey combined with a series of qualitative reports issued from visits of 15 PhD students in another research centre resulted into a rich overview of similarities/differences in all aspects of PhD education in ITEMS centres. It reveals a common willing for the development of joint teaching and research initiative, which will be seriously investigated in the next years.

4.)To propose forms of organization and modalities of coordination, for prolonging and transforming ITEMS investments into a European multi-disciplinary community.

The Maastricht meeting exchanges led us to the following conclusions: there exist considerable differences in the organisation and funding of research all across Europe, and thus, the incentives to engage into European collaborations are quite diverse. This pleads for a multi-centred organisation, based upon concrete projects. In this respect, it would be crucial to get a limited funding support in order to maintain exchanges and circulate information that proved to be extremely fruitful.

I. EXECUTIVE SUMMARY

Health and medicine are undergoing profound and extensive changes in various aspects. The rapid development and dissemination of biomedical knowledge throughout Europe is triggering a reconfiguration of care practices, and even a redefinition of the patient and of the states of health and disease. The pressure generated by number of "crisis" – cost inflation, greater sensitizing to health and social risks – have led many countries to take measures with a view of reorganizing the system of actors in the sphere of health. Health is increasingly placed at the centre of our values through constant reference to the notion of well-being. Health, like employment or education, has become a major issue for social cohesion in European countries, whatever the national health care system.

These upheavals have important consequences on the distribution of responsibilities among the different actors involved in the health care system. In particular, traditional forms of professional accountability are challenge since "patients", "users" of the health system, "citizens" are becoming new stakeholders and are demanding active participation in number of activities and debates in the health area.

In the long run these transformations can lead to structural changes in all Europe, with a demand for articulation between these new structures and existing or emergent national systems.

In Europe, human and social science research teams have well developed research on health and medicine so to study the multiple social, organizational, political and medical aspects of these issues. But the articulation of research between teams in the different European countries and comparative projects are two aspects of Social Sciences and Humanities research that are worth being explored and expanded. Identifying and analyzing new trends is of strategic importance for public understanding and health policies. Research can give a better comprehension of how, in different contexts, more or less specific solutions are found to address general problems. It also reveals the extend to which these approaches, beyond their possible diversity, outline a movement of convergence towards shared values.

ITEMS promotes four research axes, selected because of their key importance for the actors and for their relevance in the project of comparison and prospective work on a European scale.

- Transformations of biomedical science and their impact on the definition of disease and of health and of care.

- Participation of users in the context of different political traditions.
- Coordination in health organizations, with a specific focus on the role of information and communication technologies.
- Articulation of health, political and social issues.

The general goals of ITEMS network are to contribute to structure European Human and Social Science Research on health and medicine and to identify the major trends in this specific area. In order to reach these goals four projects were carried out:

1) To map European Human and Social Sciences research centres investigating health and medicine changes. The objective is draw a map according to the four axes chosen for the thematic network, and to make it available to a large public through a web site. The work on this communication tool consisted also in a reflection upon future modes of dissemination of research results.

2) To contribute to the scientific and methodological conception of comparative European research on the main trends of health and medicine; particular focus was put on elaborating common research tools: primary databases, bibliographic bases, etc.

3) To produce recommendations for common educational activities for PhD students and postdoctoral fellows; to propose common modules in PhD training, the modalities of joint supervision of PhD research, and the protocols of post-doc exchanges.

4) To propose forms of organization and modalities of coordination, for prolonging and transforming ITEMS investments into a European multi-disciplinary community, whose main endeavour will be comparative research.

The general methodological framework used to implement these four projects was first to build the appropriate tools to document the field, in particular as regards the communication within the thematic network. The work has been organized through five work packages which have all contributed to consolidate this European research community, but which focused on specific elements of it.

- Work Package 1 (WP1) concerned the mapping of the community.
- In WP2, current members of ITEMS have analysed the strengths and weaknesses of comparative research on the four axes selected by the network. A specific focus was put on methodological questions, and on the national context of research work.

- WP3 consisted in organizing a major scientific symposium which was intended to give European visibility to ITEMS, and to make it a locus of exchange and circulation of information on the issues raised by the network.

- In WP4 the aim was to examine doctoral and post-doctoral training in several centres of the network, and to formulate propositions for common educational activities at European level.

- Drawing upon the work done throughout WP1 to WP4, WP5 has focused on organisational aspects, including tools conceived to facilitate interactions between researchers, the management of coordinated research and the validation of research results.

1. Mapping European human and social sciences on health and medicine

In Workpackage 1, the first objective was to produce a description of the configuration of European Human and Social Sciences research on health and medicine. This description is conceived as a tool for the reflection on the structuring and the ways to carry out European collaborative research.

The database has been filled after the data collected in a questionnaire survey addressing the research centres of ITEMS network. It gathers data about 160 research centres (ITEMS members and their partners), 480 researchers, 250 research projects and activities.

Data have been submitted to a series of quantitative treatments that provide a descriptive profile of the research activity on each of the four research axes. A map of the co-occurent keywords describing the research projects has been drawn for each research centre member of ITEMS network.

The second objective was to offer an access to the database through a web site for a large audience. The visitors of the web site, members and non members of ITEMS, can find a wide range of information on the research activities in the area of health and medicine within ITEMS network: research teams, research projects and PhDs (recent and on going work), bibliographic data, etc.

The descriptive work on the configuration of European Human and Social Sciences research on health and medicine, and the data base, have been used for all the other Workpackages. The organisers, the rapporteurs, as well as the participants in the WP2 and WP3 meetings have all used both tools during their work. The mapping has also been one of the main materials used in WP4.

2. Comparing research topics and methodologies

WP2 was intended to develop a reflection through which meaning could be given to the very idea of European comparative research. The objective of WP2 was to figure out how to design future research collaborations between members of ITEMS, and/or to extend our network within the European frame. With this objective in mind, a general meeting of all ITEMS members was held in Granada in March 23rd-24th 2004. This meeting consisted of four sessions, one per axis, and the discussions were prepared, conducted and synthesized by two rapporteurs per axis. The preparation of this workshop proceeded in several steps:

In the questionnaire used to collect information, build the database and set up the website, all the members of ITEMS were asked to provide a strategic and synthetic description of the research themes covered and envisioned by their research centre and related to the ITEMS axes. Each member has been especially asked to explain and underline the theoretical interest of the themes, the methodological aspects of those themes, their practical issues for health agencies, for users and towards health policy.

On the basis of this preliminary information, the steering committee decided to organize the meeting the following way:

- The preliminary work of the rapporteurs for preparing the Granada Workshop was to make a synthesis of the axis they are in charge of. This synthesis was based on the research projects conducted by the research centres members of ITEMS network. Eventually they could draw on publications related to those projects. In order for the rapporteurs to prepare the synthesis on each axis, they were sent a document presenting all the research projects and the activities encoded into the database and classified by axis.

- The rapporteurs had to decide how to they wanted to distribute the tasks between the two of them for each axis. Apart from preparing the synthesis for the workshop, their tasks consisted in conducting the discussions during the workshop and writing the report based on those discussions. It was also the task of the rapporteurs to decide how they would like to involve the participants into the preparation of the workshop, and into the discussion during the workshop. They had to tell them what they expected: a presentation of their research projects, cross presentations...

- Participants to the workshop. The research centres members of ITEMS could have either one or two participants to the Granada workshop (depending on what the project foresees and on The budget they received). It was decided that each

participant would be asked to work on one axis, that meant to give a presentation during one sub-session.

- Finally the organisation of the workshop has been completed according to two aims:

  - participants' circulation between the four sub-sessions, each sub-session being organized around one of the four ITEMS axes;

  - in-depth and manageable discussions on ITEMS members' projects related to each axis.

The following organisation was thus adopted:

1) A general opening session for presenting the results of WP1 (ITEMS database and website).

2) A general session for presenting a synthetic overview of ITEMS members' projects in relation to the four ITEMS axes.

3) Four sub-sessions, each focusing on one of the ITEMS research axis. We have decided to have 2 x 2 parallel sub-sessions, in order to enable the participants to attend more than one sub-session.

4) A general closing session, intended to help the emergence of a set of themes that could lead to future collaborative projects between members of ITEMS network.

The results presented here are a conclusive synthesis of the common themes and issues drawn up from the exploratory work done during and after the Granada workshop. A certain number of themes have been selected as particularly relevant in the perspective of comparative research

Methodologies Implicit in all of the reports, but explicit in that from Axis 1, is the fact that almost all of the Network members use similar research approaches, methodologies and techniques. In Axis 1 these are identified as historical methods and those of the social construction of science, technology and medicine, with interests such as the negotiation and fixing of standards, the relationship between the specific sites of practice and universal knowledge claims, and the development of technoscience. Across all Axes, researchers working in health policy explored the formulation and implementation of policy in terms of a pluralist model of capitalist democracies, with professional organisations, pressure groups and the state as the main players. However, there is a desire across the Network to adopt a broad view on the number of actors, and to use

ethnographic methods where appropriate. There was also wide interest in the interplay between policy initiatives and implementation at the international, national, regional and local level. A key issue in Axes 2, 3 and 4 was how to bridge the gap in methods and topics between discipline-led research and policy-led research.

Standardisation -Formalisation Across all Axes there was a major interest in the developing trend towards the standardisation and formalisation of medicine and health care, or what might be termed the bureaucratisation of medicine, which is evident in such things as practice guidelines, practice record keeping and practice evaluation within normative frameworks. These developments are associated with the development of new information technologies, but seem mainly to be driven by economic and pressures. Firstly, there are the demand by professional's insurance agencies and the state for cost-effectiveness and efficiency in health service provision. Secondly, there are demands for greater equity in access to, and standards of, health care, for example, to minimise regional differences. Thirdly, there are pressures from the public, through individual patients and patient advocacy groups for 'best practice medicine'. In addition, the advance of the Evidence Based Medicine (EBM) movement amongst medical professionals of all types has led to greater convergence and standardisation in clinical regimes and health policies. The different pressures and outcomes for standardisation across European states and regions is a field ripe for collaborative and comparative research.

Technification The growing technification of medicine, disease and health was also discussed in all Axes. Such work included historical studies of the process of technical innovation, where most studies pointed to the complexity of innovation, the weakness of linear models and questioned the neutrality of technologies. There was also wide interest in the innovation and diffusion of pharmaceuticals, information technology, prostheses, new biomedical technologies such as stem cell research, and new social technologies of organisation. The extent to which many technologies are common, being produced by a small number of suppliers, gives an excellent base for comparative studies, exploring how the same artefact is utilized and perceived in different national and local contexts. Many Network members were investigating the uses and impact of Information Technology in medicine by institutions, by professional groups and by the public, exploring the relationships between production, communication and reception. Significantly, there was a considerable amount of work being undertaken on the de-technification of medicine or low-tech medicine; for example, the development of low-tech environments such as those in palliative care and home-based care; interestingly, in these areas voluntary organizations seem to be taking the lead.

The Patient-Citizen Research on 'patients' was common across all axes and represents a welcome shift in historical and social science work from its previous focus on medicine and medical professionals. However, there was agreement on the restrictive nature of the term 'patient', on the value of identifying types of patient (e.g. the 'political patient') and on the need to pay attention to how 'patients' have changed over time. One problem that the new work raises is how much agency patients really have, though it is clear that patient organizations (the 'collective patient') are a growing force across the EU. A related theme, that also has great comparative potential, is health citizenship and questions about a citizen's rights to care and treatment. Approaches to this topic are many, including issues around individual moral choices, through to the study of marginalization and social exclusion.

Health Care Organisation and Coordination Many researchers are investigating new forms of health organisation, including care delivery networks, monitoring organisations, screening programmes, and services for specific population groups. New modes of delivering care, understood as new organisational devices, aim to improve care by defining and applying medical standards and also redefining paths of care or patient trajectories. ITEMS members are especially interested in the new demands for administration and coordination that emerge from the different levels of care, the different providers, the range of professions involved, and the interactions between the public and patients and professionals on the one hand and health care institutions on the other. Researchers are analysing the socio-organisational conditions of the emergence of new modes of coordination, the impact of Information Technology, and the symbolic aspects of new systems. They are also exploring the role of new agencies that operate between the state and clinical medicine, the new legal issues and the changing role of experts and expertise in the new structures.

Geneticisation There was cross-Axis interest in the geneticisation of medicine and health care, more specifically, the possible impacts of new methods of diagnosis, genetic screening, gene therapies, the identification of new diseases, and the impact of genomics on the understandings of self. Geneticisation also raises profound issues about the boundary between the healthy-normal and unhealthy-abnormal, the uses of information about individuals and groups, and the changing nature of risk factors and their implications for health insurance. There is great potential for comparative research on the different national regimes of regulations, public involvement in genetic regulation, reproductive medicine and the 'new eugenics'. Also, the interface of national regimes with those at higher levels, for example, the European Court.

Disease and the Body One obvious theme for comparative work is with definition, management and control of specific diseases. Most ITEMS Network researchers work with the assumption that diseases are socially as well as biologically constructed, stressing how understandings change over time, vary across medical specialisms and sites of medical practice, and between professionals and the public. Due to the number of projects being pursued by ITEMS members, there is potential for collaborative and comparative work on two specific disease problems: cancers and mental illness. Finally, across the Network researchers are exploring the 'human body' as a heuristic device as well as a specific topic, however, it is important to stress that all members see the human body as being biologically and socially constituted.

3. Discussing potential cross-cutting issues

Granada workshop aimed at presenting the involvement of ITEMS members' (research centres) in the four axis of the network. The workshop helped to increase mutual knowledge about ITEMS members' contributions to the four axes, and to identify cross-cutting sub-themes. Coimbra Scientific Symposium had two main objectives:

i) to give European visibility to ITEMS, and to enhance ITEMS' current members' knowledge on European research related to the four axes selected by the network. The symposium was conceived of as a locus for exchange and circulation of information, and was thus opened to members and non members of the network;

ii) to deepen discussion on topics onto which common interest might develop, through presentations of individuals projects related to the four axis. The rationale was to promote interaction between researchers concerned by these four axes, and thus to feed into reflection planned in WP5 on ways of constituting a future research and training network.

The scientific symposium took place in Coimbra, on December 15th-17th 2004. Joao Nuñes, Marisa Matias, from the University of Coimbra were the main organizers of the event. Based on the map drawn in WP1 of European research centres which invested in the four axes selected by the network, and on reflection in WP2 on the scientific content and methodological aspects of these four axes, they collaborated with Ilana Löwy an the CSI for elaborating the programme.

The symposium gathered more than 90 participants, out of which 42, i.e. almost half participants, were not coming from research centres involved into ITEMS network. Thus, the opening of the network to its outside was quite successful.

Participants were asked long before the conference to provide a 5 pages long abstract of the research project on which their presentations would draw. These abstracts had been sent to discussants, who prepared in advance a comment of the whole session, highlighting complementarities, convergences, divergences, differences between the various papers of the session. These comments had been sent before the symposium to speakers, in order to give them the opportunity to reflect upon suggestions and comments and thus enrich the actual discussion.

All papers' abstracts were also made available, before the conference, to all participants on the website.

After an opening plenary session, in which Madeleine Akrich recalled ITEMS project – especially for the participants coming from the outside of the network – and the meeting's objectives, three to four parallel sessions were held during 5 time-slots (15 sessions), where 60 papers were presented; each session comprised also a presentation prepared by a discussant, which makes about 75 presentations.

The last part of the meeting was devoted to a plenary session in which rapporteurs for each axis made their comments. Three other persons were invited to comment: one Canadian academic working on medicine, Alberto Cambrosio, and two patients' representatives, Catherine Lé (from Belgium), and Bernard Bel (from France).

Finally, a general discussion was opened on the future of ITEMS.

Sessions related to Axis 1 manifested a vast range of heterogeneous projects. Besides, these Axis-1 related sessions gathered the highest number of presentations (18 out of 60 papers). Albeit their diversity, papers presented in these sessions hold a strong common feature: they were all concerned with the articulation between medicine and science. A majority of speakers shared a background in STS (Science and Technology Studies). This is an important specificity of ITEMS network. The closing discussion pointed to the fact that if collaborative projects are to emerge in the future on this axis, they are to be designed around common empirical medical objects (for instance screening technologies for prenatal diagnosis, biomedical collectives working on particular diseases, etc.). Consequently, research centres have to redefine, at least partly, their research programmes around these common empirical medical objects.

Sessions related to Axis 2 highlighted two main research interests:

i) patients' political identification, notably through the development and increasing activity of patient groups and collectives;

ii) patienthood and care technologies.

As regards future collaborations, participants' long-lasting involvement and shared interest in these topics materialized into the decision to apply for a EU SSA project under FP-6 (Call identifier: FP6-2004-CITIZENS-6). Details on this application are provided below (Section V.).

Sessions related to Axis 3 were focused on two orientations:

i) care technologies and the organization of health care systems; this issue echoes the previous Axis-2 related topic on patienthood and care technologies;

ii) information technologies and health systems.

Again, it is worth noticing the importance of technology studies for the participants of the symposium.

Sessions related to Axis 4 crystallized interests on the issue of governance and new health institutions, both at national and European levels. Certain participants manifested a strong will to increase understanding on these institutions, and decided to join the SSA application mentioned above, and whose rationale is to disseminate ITEMS results on topics of high policy relevance.

4. Reflecting on phd training and post-doctoral circulation

One of the main elements in the constitution of a future research and training network is the circulation of PhDs and post-docs between the different European research centres, and the design of coordinated training. The effectiveness of a network depends on its capacity to maintain, at all levels of activity, high quality cooperation and exchange. PhD theses and post-doctoral research also contribute in an essential way to the formulation of questions that will constitute the field under study in the medium term. It is therefore crucial to allow PhD and post-doc researchers to meet one another on a regular basis so that they can be included from the outset in the European research community.

In line with this objective, the aim of the WP4 was to draw up an inventory of the ways in which PhD and post-doc training are organized in the different countries. This was intended as a preparatory work to the reflection planned in WP5 on the meeting and circulation of PhDs and post-docs between the different European research centres, and the coordination of common educational activities.

WP4 Conclusions

There is support within the ITEMS project for developing a future network for social and humanities studies of health and medicine. Such a network does not currently appear to exist.

There is support for an **international summer school in health and medicine studies**, co-ordinated through the ITEMS network and containing a thematic structure so that topics can be explored in sufficient depth to be of use to both doctoral and postdoctoral students and other researchers.

There is support for **a co-ordinating centre for the development of joint teaching and research initiatives** and exchanges of students and staff in social studies of health and medicine.

However, students and post-docs are concerned that EU circulation should be voluntary; that language support is available, and that sufficient funds are made available to enable study visits of medium term duration; (short visits were not seen as useful).

5. Organizing collaboration and networking

The main goals of the final workpackage (WP5) were to draw conclusions and formulate recommendations on how to better collaborate at EU level.

WP5 prominent objectives were:

1) To reflect on barriers, values and methods as regards collaboration at EU level.

2) To formulate proposals for PhD and postdoctoral training on a European scale.

3) To reflect on tools which might enhance communication.

4) To issue some recommendations that would facilitate life for European researchers.

This was done through a final workshop, held in Maastricht on 17 and 18 May 2005. Three main concerns were addressed as regards collaboration at EU level: (i) organization and management with a view to facilitating collaborative work; (ii) research approaches which are most suitable for collaborative work; (iii) comparability of methods.

A questionnaire was distributed which 20 out of 29 participants filled in. The questionnaire's themes were used to structure the actual discussion about collaborative work:

a) What are the practical barriers and boundaries encountered when setting up collaborative, European-directed projects?

b) What 'European' value would collaborative, comparative work have in terms of the multiple users/citizens that are addressed and our own interests as researchers/institutions?

c) What methodological tools do we have or might we develop for carrying out such projects?

Based upon the questionnaire and the rich exchanges we had during the meeting, the following conclusions can be drawn:

There is wide variation as to the experiences and interests groups from different countries (and universities/departments/institutions) have in doing collaborative (European) research. This is due to specific national research policies and funding strategies as well as to the sources and amount of funding for national R&D programs.

On the administrative side of the matter, barriers to setting up collaborative research projects and to applying for European funding were many. First, most groups mentioned a lack of experience and routines for setting up larger, internationally oriented and staffed projects; second, there was a strongly felt deficit of both administrative and ideological support from the home institutions. Third, a majority of the groups experienced great difficulty in coming to grips with the jargon of EU-project-application-forms as well as with the different instruments of the framework programs and with some of the requirements of the procedures for application. Fourth, the low success rate of EU applications (in comparison with national funding programs) was mentioned as a key obstacle in applying for EU funding. Moreover, national programs in some countries seem to have better arrangements for the finance of overhead costs, which makes it less interesting and appealing to apply for EU funding. Fifth, some groups felt the recruitment of researchers to be an obstacle for participating in collaborative research. Some groups/members also indicated that having a stable 'home group' of 2 or 3 researchers was necessary to start participating in EU projects. In sum, due to the additional burdens it imposes on coordinators, the coordination of EU projects in particular is regarded as unattractive, especially when adequate administrative support is lacking in host/most institutions. It seems to us that here lie important incentives for improvement, on the

level of the EU as well as on the level of individual institutions. If comparative, international research is deemed important, and if external/European funding for research becomes increasingly crucial, then incentives must be made to alleviate some of the barriers that *de facto* keep researchers from engaging in applying for such project.

In terms of intellectual/substantive constraints, for many of the groups the specificities of qualitative research in the social sciences and the humanities tends to somehow discourage setting up collaborative projects. Although it is increasingly felt that our research projects would improve from being comparative and international, and even that the object of our studies is often inherently European in character, there is still a strong tradition of individual and national based research. However, according to the experience of ITEMS coordinators, the hardest part of the process was setting up a collective of researchers and writing a proposal that would meet EU criteria, whereas the actual proceeding of the network proved to be easier to manage. We also see that in practice, qualitative methodologies and comparative work are less antagonistic than we had anticipated.

The ITEMS project itself has, however, been particularly fruitful for most of the groups present. First, it showed that setting up EU funded projects within our field is indeed valued by the ITEMS members. Second it made clear to us that we may position our work as contributing to the articulation of new problems and needs within the European health-care landscape. Third, the many contacts that were made during the project show that links between the participating groups can be and should be further expanded and strengthened.

The discussion of the session on "communication in and after ITEMS" makes it clear that for the members of ITEMS the research network has been working extremely well. This was not only based on the success of the meetings, on how many of ITEMS members have been actively participating in reports, sessions' organization and on their will to make suggestions for further collaboration, precisely when the EU funding for ITEMS project comes to the end. The more remarkable outcome of ITEMS networking through its activities has been the development of an identity within the member's group. More than sharing professional interests, many ITEMS members share the view that the network developed an identity as such. The specificity of ITEMS members' research, focused on medical innovation, democracy, governance and biomedicine should be maintained. This network of researchers exists as a European expert group, joining ideas and proposal for further collaborations in the future on subjects and methodologies, sharing not only research interest but social worries about current biomedical knowledge related to concepts such as gender, innovation, reproduction, new drugs. All of these are

issues relevant in the growing impact of biomedical sciences in everyday life as well as in social sciences and humanities research programs in Europe.

To sum up, communication proved to be a selective process. After ITEMS experience, the two forms of communication – meetings that enables face to face encounter and the electronic forms of communication (e-mail, website) – show to be complementary on the scale of the network. It is because people met that (i) they are interested in to seeking information about on-going research projects, institution, publications, etc., on the website; (ii) they pay more attention to the e-mails sent by members of the network in the amount of mails received daily.

From 2003 to 2005 ITEMS has been developing its activities, its members met, both in small meetings such as those of the steering committee and in bigger gatherings like meetings in Granada, Coimbra and Maastricht. According to ITEMS members views, the quality of the contacts is related both to the exchanges across different European countries and their inter-disciplinary dimension. During the meetings and works like reports many of us had learnt a lot, historians from sociologists, sociologists from historians on medical and biomedical research practices. The network meetings allowed bilateral relations and provided some basis for prospective collaboration, for it helps to learn what people are doing and how future collaborations may be oriented. Many prospective projects are kept in mind so as to take full advantage of any possibility the EU may offer in the near future. Benefits may also be expected in a far-off future, for the network enables a better knowledge of possible European partners for projects to be set up in the years to come.

5. Dissemination and exploitation of results

First, we would like to recall that a series of dissemination tools and actions were already implemented and conducted during ITEMS life span. ITEMS website was one important dissemination tool. The website actually served two purpose:

1) It was designed as a working device for ITEMS members: based on a database comprising detailed data on ITEMS members' projects and research centres, it was used for mapping ITEMS research context and enhancing mutual knowledge between its members.

2) It was also designed to disseminate information to the outside of the network, in order to make ITEMS project and achievements visible to a larger public. Provided the number of visits (60000) on the website, we can say that this "visibility" work was fairly successful.

All ITEMS members manifested their wish for this website being maintained. It was felt that this tool should mainly serve as a communication platform, both for ITEMS actual members, and for all those who are interested on social sciences research on health and medicine in Europe. The website should thus be slightly redesigned in the near future: reflections on this are in progress.

Alongside the website, specific dissemination actions were completed during ITEMS life-span. Coimbra Scientific symposium was particularly fruitful in this respect (see section III. 3.). It attracted many academics who were not ITEMS members, and with some of whom certain members of the network decided to set up collaborative projects. This indicates that ITEMS was able to mobilize beyond the actual network. Besides, some "outsiders" manifested their wish to stay in close contact with ITEMS, as it is considered an interesting place to go for helping collaborative plans to emerge and exchanges to develop.

Hence, both from the inside and the outside of the network, a demand was expressed for prolonging ITEMS. This is why we devoted time to reflect upon the pros and cons of the future of our network, and to envisage a few concrete follow-ups. In any case, all ITEMS participants agreed on the fact that future orientations must manifest their common willingness to enhance the visibility of social sciences contribution to issues of policy relevance, at a European level, in the domain of health and medicine.

A first project has been defined and submitted to the SSA call n° FP6-2004-CITIZENS-6. The objective of the project is 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 issues of policy relevance that have been previously identified and reflected on within ITEMS. Three issues were selected:

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.

Besides, certain members of ITEMS also put some ideas for future collaboration forward. Some of these ideas are quite advanced, and should end up into concrete applications.

Maggie Mort (Lancaster) presented a proposal on smart-health care technologies in the homes of the elderly, to be submitted as a Specific Targeted Research Project (STREP) within FP6. This proposal would aim at providing for participatory approaches to the

making of policy, and for qualitative (ethnographic) approach to the making of practices. ITEMS members and some non-members should participate to this project.

Vololona Rabeharisoa presented a plan aiming at developing research on patient groups. Reflecting on patient groups' tendency to be involved in dense networks, including affiliations to a growing number of European organizations, the project should aim at studying transnational species of patients' organizations. She should collaborate with Orla O'Donovan, a non-ITEMS member who participated to the Maastricht meeting, in a potential EU project.

María Jesús Santesmases (Madrid) presented plans to set up a collaborative project on the increasing and problematic interrelationships between genetics and reproductive health care. Delphine Gardey, a non ITEMS member who participated to the Maastricht meeting, should join this project.

João Nuñes, in collaboration with Marisa Matias (Coimbra), proposed to set up two studies: one on biographies of objects in medicine, and one on the emergence of cross-cutting concern about health and environment.

Bernike Pasveer (Maastricht) proposed to set up a collaborative study called "new brains", in which conceptual re-orderings as well as the practical transformations of the brain and diseases involving the brain should be central. Madeleine Akrich (Paris) should join this project.

Anne Lovell (Paris) proposed to set up a study about the normalization of behavioral pharmaceutical drugs, in which the main question would be whether new pharmaceuticals aimed at behaviour-related disorders affect traditional modes of social and medical normalization. Such pharmaceuticals target biomedical and morally charged disorders, and in doing that they also make for new configurations of public space, users, professionals and others involved. The study should contribute to the evaluation of legitimizing processes of behavioural drugs within Europe. She is currently making contacts with people within and outside ITEMS network to explore further plans.

All those ideas, plans, proposals, were formulated on the basis of research and interests present within ITEMS network, and it is hard to conceive of that to have happened without the network's existence and lively history. Many projects, moreover, aimed at benefiting from the network's interdisciplinary potential, at experimenting with methodologies for comparative *and* qualitative work. Finally, all projects are highly sensitive to the urgency of finding and articulating the factual, political and normative edges of health care innovations in Europe.

We would like to stress that ITEMS has been instrumental in the emergence and the setting-up of proposals and plans: neither the substance of these proposals and plans, nor the collectives of researchers that gather around them, would have been possible without the network.

The Maastricht meeting exchanges also revealed that there exist considerable differences in the organization and funding of research all across Europe. This implies that what motivates individuals or institutions to engage into European collaborations is quite diverse. At the one extreme there are groups for whom participation in European projects is vital as it is their primary source of funding for research (and even national programs are targeted through the EU framework programs). At the other extreme, there are groups for whom there is no financial incentive whatsoever to participating in European projects, as their research is almost 100% financed through national programs. The only reason for these groups to participate in collaborative (European) projects would be a substantive one. The majority of the groups find themselves located somewhere in between these extremes: whereas European funding is not vital to them, it is a welcome contribution to their resources for research and is also of substantive interest.

Thus any collaborative project must be grounded on a shared intellectual interest. And this pleads for a multi-centred organisation, based upon concrete projects; in this respect, it would be crucial to get a limited funding support in order to maintain at low cost exchanges and circulate information. This proved to be extremely fruitful and the condition upon which new projects can emerge and develop between interested partners.

II. BACKGROUND AND OBJECTIVES OF THE PROJECT

Health and medicine are undergoing profound and extensive changes in various aspects. The rapid development and dissemination of biomedical knowledge throughout Europe is triggering a reconfiguration of care practices, and even a redefinition of the patient and of the states of health and disease. The pressure generated by number of "crisis" – cost inflation, greater sensitizing to health and social risks – have led many countries to take measures with a view of reorganizing the system of actors in the sphere of health. Health is increasingly placed at the centre of our values through constant reference to the notion of well-being. Health, like employment or education, has become a major issue for social cohesion in European countries, whatever the national health care system.

These upheavals have important consequences on the distribution of responsibilities among the different actors involved in the health care system. In particular, traditional forms of professional accountability are challenge since "patients", "users" of the health system, "citizens" are becoming new stakeholders and are demanding active participation in number of activities and debates in the health area.

In the long run these transformations can lead to structural changes in all Europe, with a demand for articulation between these new structures and existing or emergent national systems.

In Europe, human and social science research teams have well developed research on health and medicine so to study the multiple social, organizational, political and medical aspects of these issues. But the articulation of research between teams in the different European countries and comparative projects are two aspects of Social Sciences and Humanities research that are worth being explored and expanded. Identifying and analyzing new trends is of strategic importance for public understanding and health policies. Research can give a better comprehension of how, in different contexts, more or less specific solutions are found to address general problems. It also reveals the extend to which these approaches, beyond their possible diversity, outline a movement of convergence towards shared values.

ITEMS promotes four research axes, selected because of their key importance for the actors and for their relevance in the project of comparison and prospective work on a European scale.

- Transformations of biomedical science and their impact on the definition of disease and of health and of care.

- Participation of users in the context of different political traditions.
- Coordination in health organizations, with a specific focus on the role of information and communication technologies.
- Articulation of health, political and social issues.

Let's briefly describe these four axes:

- **Transformations of the biomedical sciences, of disease and of health.**

The recent upsurge of the biological sciences has resulted in a number of transformations which affect not only medicine but also, more generally, social representations of disease, health and forms of appropriate care. This scientific and technical evolution is triggering a reconfiguration of care, redefining diseases themselves, adjusting the boundaries between health and medicine, welfare and disease, and transforming relations between diagnosis, prognosis and care.

Amongst the most noteworthy developments in recent years, we find: new drugs oriented more towards an improvement in the patient's well-being than towards healing; breakthroughs in the biological sciences – particularly genetic engineering – and the resulting redefinition of care and disease (new diagnostic tools, therapeutic trials, pluridisciplinary consultations); the appearance in the medical field of « syndromes » or problems on the borderline between health and the social, and the establishment of systems to care for and treat these problems.

Beyond these biomedical innovations, health systems are confronted with the reappearance of diseases thought to have been limited or eradicated, and the need to develop new therapeutic means.

While the definition of research programmes in the biomedical sciences, the creation of new molecules by the pharmaceutical industry, and the development of new technologies are all very often taking place on an international scale, their adoption and use, and the organizational mechanisms accompanying their implementation, stem from the particular dynamics of each country or even institution. One of the major questions is precisely the comparability of the diverse national practices, a striking example of which is observed differences in the consumption of drugs, whether « conventional » medication such as antibiotics, or pain-relieving or fortifying medicines.

- **Participation of users and the redefinition of systems of actors in the domain of health and medicine.**

Alongside the classical figure of the patient, many others are taking shape, from the user of health systems to the consumer or citizen. This is manifested in three broad movements: (i) a transformation of the patient's condition through the clarification of her/his rights and the diversification of sources of information available to her/him; (ii) the emergence of new forms of collective engagement, including not only the diversification and multiplication of patient organizations, but also the constitution of patient collectives through the Internet for example; (iii) the establishment of a plurality of modes of user representations, especially at an institutional level, which raises the general question of forms of legitimization.

How, in this respect, does the heterogeneity of health care systems and political traditions impinge upon participatory trends? To what extent do these general trends lead to the redefinition, in each country, of the systems of actors concerned by health problems? These are some of the issues on which the comparison of European research seems indispensable if we want to be able to analyse historical and emerging forms of expression of citizenship in concrete situations.

- **Coordination in health care systems: information and communication technologies, and organizational devices.**

For a variety of reasons (economic, medical, demographic, social, etc.), the question of coordination lies at the heart of efforts to reorganize health care systems in Europe. In this perspective, one of the most actively explored means is information and communication technologies. Two major questions seem to arise for a comparative analysis of many reorganization projects, whether or not they are centred on the establishment of technologies. The first question concerns the articulation between technology and organization: how can forms of coordination based on technologies or on organizational devices be described in compatible terms? The second question relates to the articulation between different levels of micro and macro analysis, in so far as each local situation is an entanglement of specific and general factors related to the organization of care.

The pooling of research will make it possible to compare the way in which projects underway in different countries define the aims of health care systems in practical terms and, in particular, lead to a trade-off between sometimes contradictory aims, such as improvements in the quality of care, economic efficiency, equity in access to care, and

consideration for patients and their rights and aspirations. Apart from the diversity of health care systems, which developed over time in each national historical context, it is important to know whether current trends are pointing towards a convergence on a European scale.

- **Articulation between health and policy issues.**

In recent years we have witnessed the development of two overlapping movements which, without being entirely new, have taken on new proportions. First, there is a growing tendency to translate certain social problems (e.g. drugs, intra-family violence, violence in the working environment, immigration) into health issues. Second, certain health issues have been re-opened and put to political debate. This is linked to the fact that the notion of public health is progressively expanding to include economic, political and juridical issues.

These two movements have projected into the foreground the moral, ethical, and cultural dimensions that participate fully in each society's definition of medicine and health. In other words, the analysis of these two movements and the controversies they generate, seems to be one of the most favourable areas for observing the construction of the values and norms of our societies. Illicit drugs, alcohol, and psychotropic substances are a good example: boundaries between these substances are quite controversial, and these controversies have an important moral dimension.

The pooling of the numerous studies on public policy in relation to health issues will reveal whether or not there is any convergence in the treatment of these problems. In particular, it would be relevant to analyse the way in which these policies are put forward for debate, the role given to science, the forms of expertise that are mobilized, the forms of representation of the different stakeholders, the way in which trade-offs are made, and the resulting forms of organization of public action.

The aim of the project, in proposing the creation of a thematic network called ***Identifying Trends in the European Medical Space***, was to contribute to structure European Human and Social Science Research on health and medicine.

The general goals of ITEMS network are to contribute to structure European Human and Social Science Research on health and medicine and to identify the major trends in this specific area. In order to reach these goals four projects were carried out:

1) To map European Human and Social Sciences research centres investigating health and medicine changes. The objective is draw a map according to the four axes chosen for the thematic network, and to make it available to a large public

through a web site. The work on this communication tool consisted also in a reflection upon future modes of dissemination of research results.

2) To contribute to the scientific and methodological conception of comparative European research on the main trends of health and medicine; particular focus was put on elaborating common research tools: primary databases, bibliographic bases, etc.

3) To produce recommendations for common educational activities for PhD students and post-doctoral fellows; to propose common modules in PhD training, the modalities of joint supervision of PhD research, and the protocols of post-doc exchanges.

4) To propose forms of organization and modalities of coordination, for prolonging and transforming ITEMS investments into a European multi-disciplinary community, whose main endeavour will be comparative research.

III. SCIENTIFIC DESCRIPTION OF PROJECT RESULTS AND METHODOLOGY

The general methodological framework used to implement these four projects was first to build the appropriate tools to document the field, in particular as regards the communication within the thematic network. The work has been organized through five work packages which have all contributed to consolidate this European research community, but which focused on specific elements of it.

- Work Package 1 (WP1) concerned the mapping of the community.
- In WP2, current members of ITEMS have analysed the strengths and weaknesses of comparative research on the four axes selected by the network. A specific focus was put on methodological questions, and on the national context of research work.
- WP3 consisted in organizing a major scientific symposium which was intended to give European visibility to ITEMS, and to make it a locus of exchange and circulation of information on the issues raised by the network.
- In WP4 the aim was to examine doctoral and post-doctoral training in several centres of the network, and to formulate propositions for common educational activities at European level.
- Drawing upon the work done throughout WP1 to WP4, WP5 has focused on organisational aspects, including tools conceived to facilitate interactions between researchers, the management of coordinated research and the validation of research results.

The research field has been documented by the means of a double survey: a questionnaire survey on the research activities on health and medicine (organization, research projects, publications, training…), supplemented by visits in the research centres to provide information on research training. The organization of two symposiums, structured around the four research axes, and the editing of their the proceedings, contributed to a better knowledge of European research and collaborative work opportunities.

The material collected was used for several purposes and with different tools. Both quantitative and qualitative analysis tools and communication tools (meetings, symposium, web site, mailing lists, reports….) were complementary. The purposes were to improve the knowledge on the research field at a European level (through the mapping of human and social science research on health and medicine, and of the training

activities for early stage researchers, i.e. PhD students and post-doctoral fellows, etc.), and to produce tools for the research (by setting up a data base on the research and training activities of this research area available for a large audience; by considering the question of comparative, collaborative work within the network; by improving the dissemination of research results). The web site dedicated to ITEMS was designed to serve as a current research awareness service, as well as a channel for disseminating ITEMS activities and objectives to a large public, including policy makers and research managers.

1. Result 1: Mapping European human and social sciences on health and medicine: tools developed by items project

1.1. A description of European Human and Social Sciences research on health and medicine

In Workpackage 1, the first objective was to produce a description of the configuration of European Human and Social Sciences research on health and medicine. This description is conceived as a tool for the reflection on the structuring and the ways to carry out European collaborative research.

The database has been filled after the data collected in a questionnaire survey addressing the research centres of ITEMS network. It gathers data about 160 research centres (ITEMS members and their partners), 480 researchers, 250 research projects and activities.

Data have been submitted to a series of quantitative treatments which provide a descriptive profile of the research activity on each of the four research axes. A map of the co-occurent keywords describing the research projects has been drawn for each research centre member of ITEMS network.

1.2. A data base on European Human and Social Sciences research on health and medicine

The second objective was to offer an access to the database through a web site for a large audience. The visitors of the web site, members and non-members of ITEMS, can find a wide range of information on the research activities in the area of health and medicine within ITEMS network:

- research teams;
- research projects and PhDs (recent and on going work);

- bibliographic data;
- etc.

The web site was designed as a "dynamic web site", which means that the members of ITEMS are able to update the data concerning their own work and research centre from the web site. The database is in MySQL (data base and format of the data). The website proposes a form that each member can fill up either to update her/his data, either to add new data into the database. The still remaining question is to find what could constitute a strong motivation for people regularly updating their data by themselves.

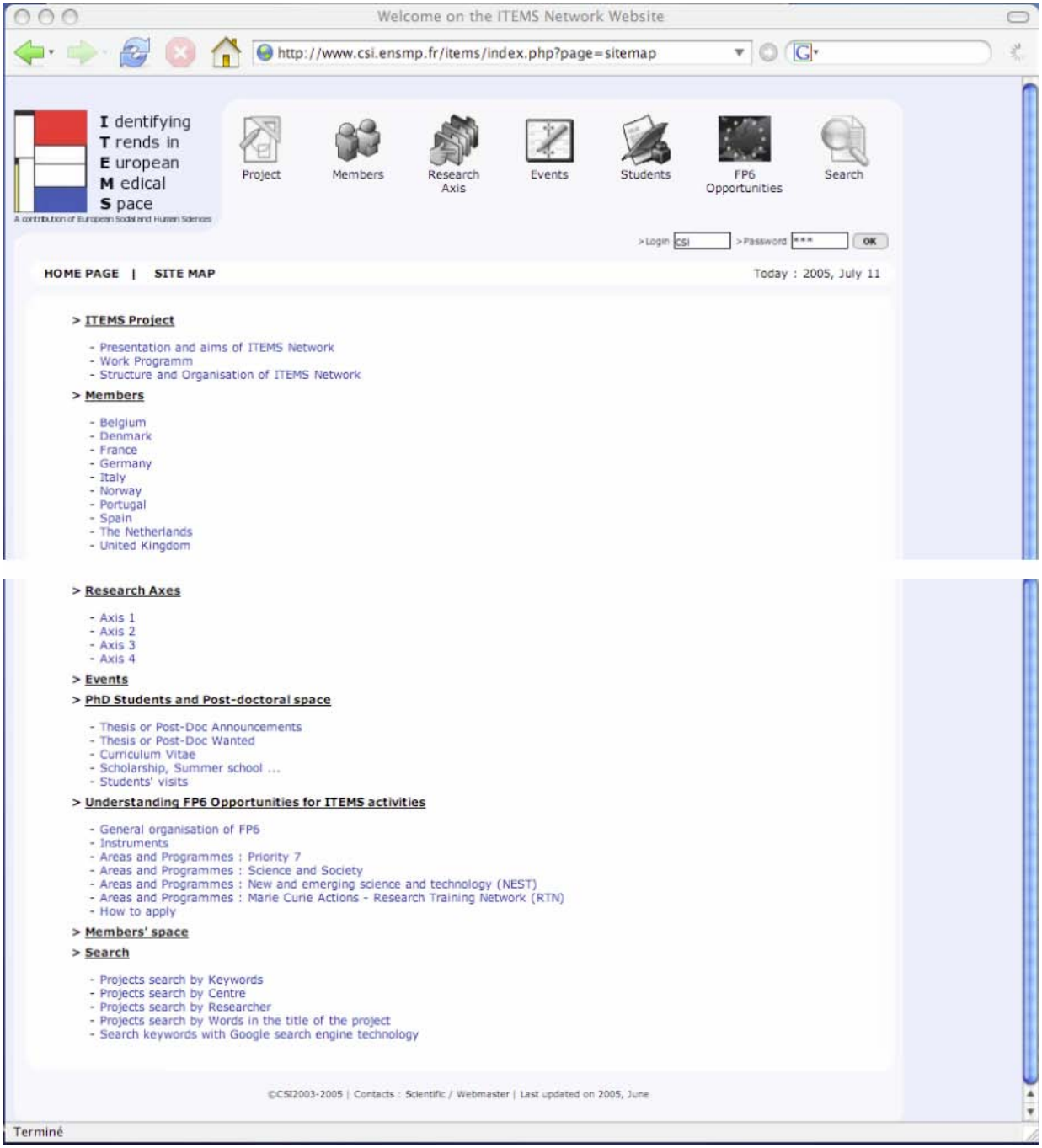
The descriptive work on the configuration of European Human and Social Sciences research on health and medicine, and the data base, have been used for all the other Workpackages. The organisers, the rapporteurs, as well as the participants in the WP2 and WP3 meetings have all used both tools during their work. The mapping has also been one of the main materials used in WP4.

The database reveals useful for future projects beyond ITEMS project: SSA and RTN.

1.3. ITEMS web site

Besides the data base, the web site contains information on the objectives and the activities of the network (events, reports on the results of the workpackages), other opportunities to carry on Social Sciences and Humanities research projects within the EC programmes, and/or included in joint research projects, and a space for the PhD students and post-doc fellows (see Annexes 2 & 3, for samples).

In fact the web site splits in two parts: the first one for public access (all visitors access) and the second one for members access only (dedicated to the updating of the data base, but also allowing access to documents intended for internal use, such as steering committee meetings reports and decisions, templates for joint research projects, etc.). The site map is the following:



1.4. Workshop and scientific symposium

After the results of WP1 (building the essential analysis and communication tools for ITEMS network), the objective of contributing to the scientific and methodological conception of comparative European research on the main trends of health and medicine was pursued with WP2 and WP3. The two work packages consisted in the organization of meetings gathering participants coming from all the research centres involved in ITEMS network.

As we already mentioned, the descriptive work on the configuration of European Human and Social Sciences research on health and medicine and the database have been used for all the other Workpackages. For the organizers of the symposiums (WP2 and WP3), both tools have formed the main background, for it informed the design of the meeting, the selection of the participants, their allocation to specific sub-sessions and the presentations of contributions. The rapporteurs of each research axis have also used these tools to inform their final reports and to include topics that were not presented in the meetings.

The first meeting consisted in a workshop, which was held in Granada University, Spain, on March 23-24 2004. The aim of the workshop was to make **an overview of the research topics and practices** on each of the four research axis selected by the network. Synthesis documents, written by the rapporteurs of the workshop, present the sub-themes relative to the four research axis, the possible added value of a European comparison and the different research contexts. (The synthesis documents are available on ITEMS web site).

The topics and recommendations resulting from the Granada Workshop constituted a work basis for the organization of a second meeting. The scientific symposium took place in Coimbra, Portugal, on December 15-17 2004. The objective was **to create a series of exchanges with a large academic audience on specific projects** including different disciplines of Human and Social Sciences and representing a whole range of European countries.

The Coimbra symposium was organized around ITEMS four research axes. Hence, the initial scheme has been slightly amended. It is extremely significant that many themes, issues and methodological concerns that have emerged so far from WP2 are evident across two or more axes. This finding suggests that there is enormous untapped scope for collaborative and comparative research on social issues in European medical space, within ITEMS network and beyond.

2. Result 2: Comparing research topics and methodologies

WP2 was intended to develop a reflection through which meaning could be given to the very idea of European comparative research. The objective of WP2 was to figure out how to design future research collaborations between members of ITEMS, and/or to extend our network within the European frame. With this objective in mind, a general meeting of all ITEMS members was held in Granada in March 23rd-24th 2004. This meeting consisted of four sessions, one per axis, and the discussions were prepared, conducted and

synthesized by two rapporteurs per axis. The preparation of this workshop proceeded in several steps (see annex 6).

In the questionnaire used to collect information, build the database and set up the website, all the members of ITEMS were asked to provide a strategic and synthetic description of the research themes covered and envisioned by their research centre and related to the ITEMS axes. Each member has been especially asked to explain and underline the theoretical interest of the themes, the methodological aspects of those themes, their practical issues for health agencies, for users and towards health policy.

On the basis of this preliminary information, the steering committee decided to organize the meeting the following way:

- The preliminary work of the rapporteurs for preparing the Granada Workshop was to make a synthesis of the axis they are in charge of. This synthesis was based on the research projects conducted by the research centres members of ITEMS network. Eventually they could draw on publications related to those projects. In order for the rapporteurs to prepare the synthesis on each axis, they were sent a document presenting all the research projects and the activities encoded into the database and classified by axis.

- The rapporteurs had to decide how to they wanted to distribute the tasks between the two of them for each axis. Apart from preparing the synthesis for the workshop, their tasks consisted in conducting the discussions during the workshop and writing the report based on those discussions. It was also the task of the rapporteurs to decide how they would like to involve the participants into the preparation of the workshop, and into the discussion during the workshop. They had to tell them what they expected: a presentation of their research projects, cross presentations...

- Participants to the workshop. The research centres members of ITEMS could have either one or two participants to the Granada workshop (depending on what the project foresees and on the budget they received). It was decided that each participant would be asked to work on one axis, which meant to give a presentation during one sub-session.

- Finally the organisation of the workshop has been completed according to two aims:

  - participants' circulation between the four sub-sessions, each sub-session being organized around one of the four ITEMS axes;

- in-depth and manageable discussions on ITEMS members' projects related to each axis.

The following organisation was thus adopted:

1) A general opening session for presenting the results of WP1 (ITEMS database and website).

2) A general session for presenting a synthetic overview of ITEMS members' projects in relation to the four ITEMS axes.

3) Four sub-sessions, each focusing on one of the ITEMS research axis. We have decided to have 2 x 2 parallel sub-sessions, in order to enable the participants to attend more than one sub-session.

4) A general closing session, intended to help the emergence of a set of themes that could lead to future collaborative projects between members of ITEMS network.

The results presented here are a conclusive synthesis of the common themes and issues drawn up from the exploratory work done during and after the Granada workshop. A certain number of themes have been selected as particularly relevant in the perspective of comparative research

Methodologies Implicit in all of the reports, but explicit in that from Axis 1, is the fact that almost all of the Network members use similar research approaches, methodologies and techniques. In Axis 1 these are identified as historical methods and those of the social construction of science, technology and medicine, with interests such as the negotiation and fixing of standards, the relationship between the specific sites of practice and universal knowledge claims, and the development of technoscience. Across all Axes, researchers working in health policy explored the formulation and implementation of policy in terms of a pluralist model of capitalist democracies, with professional organisations, pressure groups and the state as the main players. However, there is a desire across the Network to adopt a broad view on the number of actors, and to use ethnographic methods where appropriate. There was also wide interest in the interplay between policy initiatives and implementation at the international, national, regional and local level. A key issue in Axes 2, 3 and 4 was how to bridge the gap in methods and topics between discipline-led research and policy-led research.

Standardisation -Formalisation Across all Axes there was a major interest in the developing trend towards the standardisation and formalisation of medicine and health

care, or what might be termed the bureaucratisation of medicine, which is evident in such things as practice guidelines, practice record keeping and practice evaluation within normative frameworks. These developments are associated with the development of new information technologies, but seem mainly to be driven by economic and pressures. Firstly, there are the demand by professional's insurance agencies and the state for cost-effectiveness and efficiency in health service provision. Secondly, there are demands for greater equity in access to, and standards of, health care, for example, to minimise regional differences. Thirdly, there are pressures from the public, through individual patients and patient advocacy groups for 'best practice medicine'. In addition, the advance of the Evidence Based Medicine (EBM) movement amongst medical professionals of all types has led to greater convergence and standardisation in clinical regimes and health policies. The different pressures and outcomes for standardisation across European states and regions is a field ripe for collaborative and comparative research.

Technification The growing technification of medicine, disease and health was also discussed in all Axes. Such work included historical studies of the process of technical innovation, where most studies pointed to the complexity of innovation, the weakness of linear models and questioned the neutrality of technologies. There was also wide interest in the innovation and diffusion of pharmaceuticals, information technology, prostheses, new biomedical technologies such as stem cell research, and new social technologies of organisation. The extent to which many technologies are common, being produced by a small number of suppliers, gives an excellent base for comparative studies, exploring how the same artefact is utilized and perceived in different national and local contexts. Many Network members were investigating the uses and impact of Information Technology in medicine by institutions, by professional groups and by the public, exploring the relationships between production, communication and reception. Significantly, there was a considerable amount of work being undertaken on the de-technification of medicine or low-tech medicine; for example, the development of low-tech environments such as those in palliative care and home-based care; interestingly, in these areas voluntary organizations seem to be taking the lead.

The Patient-Citizen Research on 'patients' was common across all axes and represents a welcome shift in historical and social science work from its previous focus on medicine and medical professionals. However, there was agreement on the restrictive nature of the term 'patient', on the value of identifying types of patient (e.g. the 'political patient') and on the need to pay attention to how 'patients' have changed over time. One problem that the new work raises is how much agency patients really have, though it is clear that patient organizations (the 'collective patient') are a growing force across the EU. A related theme, that also has great comparative potential, is health citizenship and

questions about a citizen's rights to care and treatment. Approaches to this topic are many, including issues around individual moral choices, through to the study of marginalization and social exclusion.

Health Care Organisation and Coordination Many researchers are investigating new forms of health organisation, including care delivery networks, monitoring organisations, screening programmes, and services for specific population groups. New modes of delivering care, understood as new organisational devices, aim to improve care by defining and applying medical standards and also redefining paths of care or patient trajectories. ITEMS members are especially interested in the new demands for administration and coordination that emerge from the different levels of care, the different providers, the range of professions involved, and the interactions between the public and patients and professionals on the one hand and health care institutions on the other. Researchers are analysing the socio-organisational conditions of the emergence of new modes of coordination, the impact of Information Technology, and the symbolic aspects of new systems. They are also exploring the role of new agencies that operate between the state and clinical medicine, the new legal issues and the changing role of experts and expertise in the new structures.

Geneticisation There was cross-Axis interest in the geneticisation of medicine and health care, more specifically, the possible impacts of new methods of diagnosis, genetic screening, gene therapies, the identification of new diseases, and the impact of genomics on the understandings of self. Geneticisation also raises profound issues about the boundary between the healthy-normal and unhealthy-abnormal, the uses of information about individuals and groups, and the changing nature of risk factors and their implications for health insurance. There is great potential for comparative research on the different national regimes of regulations, public involvement in genetic regulation, reproductive medicine and the 'new eugenics'. Also, the interface of national regimes with those at higher levels, for example, the European Court.

Disease and the Body One obvious theme for comparative work is with definition, management and control of specific diseases. Most ITEMS Network researchers work with the assumption that diseases are socially as well as biologically constructed, stressing how understandings change over time, vary across medical specialisms and sites of medical practice, and between professionals and the public. Due to the number of projects being pursued by ITEMS members, there is potential for collaborative and comparative work on two specific disease problems: cancers and mental illness. Finally, across the Network researchers are exploring the 'human body' as a heuristic device as

well as a specific topic, however, it is important to stress that all members see the human body as being biologically and socially constituted.

2.1. Axis 1. Transformations of biomedical science and their impact on the definition of disease and of health and of care

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2.1.1. Introduction and overview

This review summarizes themes and sub themes, common concepts and areas of existing and potential collaboration among network members on Axis 1. It presents strengths and weaknesses of comparative work and methodological issues pertinent to such collaboration. It is based on information made available to the ITEMS Thematic Network on projects being carried out by ITEMS members[1] and on the presentations and discussions at the Grenada Axis I workshop.

Preliminary classification of studies

The majority of Axis 1 projects concern forms of knowledge related to medicine and the body, disease and health. The most commonly treated topics are *genetics and/or genomics* (13 projects), *health care* (including clinical care, new forms of palliative care, alternative care: 13 projects), *biomedical research and health technologies* (12 projects), *mental health/psychology* (12 projects). A second group of topics centers on the *body and technology* (9 projects) and on *pregnancy, birth and prenatal diagnosis* (9 projects). The other themes include *pharmaceuticals/illicit drugs* (4 projects) and 17 projects cover themes not related to one another, but mostly pertaining to *history of medicine*. The most common methodology overall is historical.

When the topics are broken down by centers, most are covered by at least six centers. The exceptions are body/technology (4 centers), pharmaceuticals/illicit drugs (3 centers) and mental health/psychology (2 centers). All topics are covered by centers in more than one country.

[1] This included reports on the content of most projects and short CVs, with research trajectories, of the researchers- network members. In addition, the review uses information from member departments and institutes, especially summaries of the major themes and orientations related to innovative trends in European medical space. We also drew on the preliminary classification made by Michael Worboys and Esteban Rodiguez-Ocaña. Thanks to Ilana Lowy for her suggestions on early versions of this report.

Over one-fifth (21) of the projects, all topics included, involve formal collaborations between research centers. Of these, 8 are cross-national collaborations (France-Switzerland (2), France-Netherlands (2), France-UK, Belgium-Luxemburg, Spain-Germany, Italy-U.S.A.), one concerns a European network of 7 countries, and some of the historical projects involve collaborations with researchers in Latin America, North America, Asia and Africa as well as Europe. The largest number of collaborations is in genetics (6 projects) and pharmaceuticals/illicit drugs (3 projects). Within given centers, researchers often collaborate across disciplines.

More generally, Axis I topics overlap. The themes of innovation in medical technologies and transformations in healthcare traverse research topics on new occupations, risk concepts and management, and the promotion of genetic/genomic bases of diseases. For example, some projects form a cluster around genetics, palliative care, diagnosis (prenatal, peri-natal and adult), the female body and new forms of care. Thus, ITEMS members share not only research subjects, but also a sort of *multi-agent* approach. These intersections broaden the possibilities for collaborations between studies with differing objects. Also, many Axis I researchers draw on similar conceptualizations of health and disease. In particular, they implicitly or explicitly reflect a comprehensive view of contemporary society, its mainstream research policies and their consequences in the construction of concepts of health and disease, and the often difficult-to-establish boundaries between the two as they are constantly reconfigured.

The projects can also be broken down more precisely, according to the objects examined: disciplines (biomedicine, alternative medicines, neurosciences…), technologies (diagnostic tools, visualization techniques, tele-medicine…), devices and techniques (prostheses, rehabilitation, psychometrics…), health practices (occupational health, home care, predictive medicine) and disease entities, signs and symptoms (autism, cancer, "psychic suffering", psychosis, diabetes…) – to mention only a few examples.

Methodological aspects

Generally, all projects are grounded in a social constructivist perspective. This said, various historical approaches comprise the most common methodology in Axis I research projects, although they differ in scale of time, concepts and type of history (social history, cultural history, etc.) used. ITEMS members have developed new ways of looking at "old" concepts ("weavers' disease", psychophysiological parallelism, colonial medicine…) technologies and material devices (hip prosthesis, drugs, radioisotopes). Some historical studies increase the understanding of current innovations, especially the connections between experimental practices and health care. Also examined are how

specific diseases, public health policies and technologies (e.g. blood screening) construct nation, ethnicity, laboring populations and citizenship. Comparisons are also made across medical disciplines and sites (measuring local, regional and transnational variations) and across time (e.g. colonial vs. post-colonial).

Many of the reviewed studies, regardless of the social science discipline, are grounded in methodologies and epistemological stances that arose from the 1970s on, in social and cultural studies of science. An example is the attention to regulation and standardization allows for an intelligibility of innovations, both recent and in-the-making. Standardization in a given area of biomedicine changes practices, affects the division of labour, redefines accountability and the boundaries between the normal and the pathological. But at the same time, standardization itself is grounded in the very practices it changes. It emerges from the crossing of multiple trajectories and earlier standards and practices. Comparison of protocols, regulation, or standards of good practices in different areas of biomedicine can reveal how standardization is constituted locally through particular configurations and situated contingencies, and how local trajectories intersect to construct universal standards, protocols, etc.[2] Standards do not exist "out there", as fixed and stable entities, but are dynamic entities that are constantly made and remade and that change through their uses. The ITEMS members' attention to new types of standardization, to the transformation of norms and rules of good practice, as well as new sites in which they are emerging, allow us to better understand these processes. The range of areas in which ITEMS researchers are applying such a perspective can enhance our understanding of the contemporary transformation of biosciences and its effects on health practices and on representations of disease and the body.

Other ITEMS projects borrow their methodology from more classical perspectives in sociology, anthropology, history or political sciences. Rather than merely 'importing' methodological approaches, however, they modify and enrich traditional methods of inquiry in social sciences as they apply them to the study of biomedicine. For example, ethnographic methods applied to new reproductive technologies or palliative care have evolved into a "clinical ethnography", a process in which transformations of the clinic modify the gaze of the researcher. Other ITEMS members use standard research tools such as the interview, but they integrate these tools within a larger theoretical framework, drawing on semiotics, feminist theory and other disciplines from the humanities. Similarly, interactionist and actor-network approaches bring into a focus an ever-larger number of actors/actants (not only doctors and scientists, patients,

[2] S. Timmerman, M. Berg. "Standardization in action. Achieving universality through medical protocols". *Social Studies of Science* 27: 2, 273-305.

pharmaceutical companies, researchers; but also devices, pharmaceuticals, visualizing techniques, etc.). There is a growing recognition that patient, family, technician, physician, nurse, researcher are all actors whose trajectories –like those of the non-human actants – will link up with, constitute, and be affected by innovations, standardization, and the redefinition of boundaries of disease. Most of the ITEMS research involving patients and their entourage is not limited, as were earlier approaches in sociology of medicine, to the role of patient's trajectories in shaping the perception of illness or in the organization of medical work, but rather on the growing importance of patients as organized, self-reflexive agents engaged in research, standardization, treatment, policy, care. "Consumers" now play a significant part in the dissemination of transforming concepts of health and disease (see below), supporting (and in some cases opposing) research endeavors, and promoting the development of new kinds of health care. (This problematic, of course, overlaps with Axis II).

2.1.2. Mediating technologies

Technology, health and society

The supposed neutrality and apparent objectivity of knowledge and technology constitute a starting point for fruitful discussion and research on technology-based society and health care systems. Decisions to promote a given technology, to use a device (diagnostic kit, instrument, pharmaceutical substance) cannot be analyzed apart from their impact on our current concepts of health, disease and body. Similarly, the definition of health and disease, and the blurring of the lines between the normal and the pathological, as well as between cure and comfort (cf. lifestyle pharmaceuticals, mental health techniques), or the medical and the social (cf. social uses of reproductive technologies), are incorporated into technologies, as are the values of a society that associates health with economic wealth and disease with poverty.

Some historical studies in the ITEMS network examine how relationships between disease and economic wealth developed over time, in a context of colonialism, domination by specific economic and political systems, and other forms of inequality. Welfare policy and science policy trends in the industrialized and post-industrialized world have always developed hand in hand. Welfare policies may currently be perceived as closely associated with the so-called "science-based society" or "knowledge society", and research seems aligned not only with new concepts of health and disease but also with health policies, social policies and R&D policies. At the same time, technology-based society, through its imbrications with economics and politics, and various stakes at hand,

produces new forms of biological citizenship: racialization, notions of the public good, subjectivities and values.

Nowadays, the decision-making processes followed by medical and research authorities is often circular: selected experts provide advice and legitimacy to policy-makers, which in turn legitimizes the role of the experts themselves. Policy increasingly relies on the opinion of external experts, that is, individuals who are not directly involved in the process of scientific or clinical decision-making.

In earlier periods, the medical profession was mainly self-regulated, and professional bodies strongly defended the clinician's right to be the only sole decider of what was best for the patient. The increasing bureaucratisation of medical decisions, and the growing role of external regulation (economic, legal, procedural) was driven in part by the massive increase in the volume of patients treated by professionals (recall that before the second World War the majority of people living in Europe seldom, if ever, saw a doctor), by the need to control the ever-escalating medical expenses, by the growing complexity of biomedicine and the importance of aligning increasingly heterogeneous elements that together constructed local or national systems of health care, and by political pressure to make doctors and scientists accountable for their actions. The bureaucratisation of medicine often went hand in hand with an increased influence of experts. Scientific and technical expertise was presented as neutral devices, able to provide the only existing rational answer to complex questions, a process that masked the fact that expert opinions are socially and culturally embedded products. Similar processes are at work in the area of scientific research, but also in those of ethics or the protection of human subjects.

Several ITEMS Axis I projects take a different approach by examining how new collectivities within a profession (e.g. oncology), between previously unconnected professionals (e.g. psychiatrists and geneticists), patients and their collectivities and other lay groups (e.g. a community) influence (or not) practices. This research raises numerous questions, such as whether such collectivities and the areas of biomedicine and scientific research they help shape create new forms of expertise, transform identities (including about race, citizenship, illness) and generate moral landscapes (emerging and changing configurations of rules, values and practices over a range of sites).

Mediating bodies

Most projects share the perspective that current concepts of health and of disease are shaped, in the main, by a complex network of intertwined actions undertaken by researchers, and by academic clinical and political authorities. Research on genetics and health risks, and the implementation of policy decisions concerning health, treatments, social implications, ethics, the role of the socially precarious and their health, includes many assumptions about the objects of experimental research. The human body, as a new object of inquiry, makes possible a more in-depth understanding of these trends towards the amplification of the concept of disease.

The human body has become an extremely useful heuristic research tool. It is considered as an experimental system, as an object of inquiry, as both an instrument and an agent of new actions in biomedical research and health care. Some of the most fruitful proposals, suggestions and methods for analyzing the transformation of biomedical sciences, disease and health care have come from women's studies. Not only women's bodies as such, but their bodies reduced to wombs, and their bodies through time: pregnancy, prenatal diagnosis, pre-natal and perinatal genetic screening carry within them notions of health and disease. These links may be displayed through the deployment of genetics in efforts to promote healthy babies, which has been called the "new eugenics" (also a topic of ITEMS researchers). A historical perspective may help us to examine the new trends toward healthy newborns and prospective mothers, but also to investigate topics such as detection of hereditary risks of gynecological cancers or the treatment of such cancers. Medical management of bodies is not limited to reproduction. It embraces all the aspects of human bodies: when to provide what care and to whom, which bodies are worthy or not, who should live and how, what is health and what is not, what is technology (drugs, psychology) and what is not—that is, decisions that are never value –free.

Actions that are not intensively technical, such as some forms of basic care for disabled persons, are another key aspect of health care as it is configured today. The difficulties national health care systems face in providing adequate attention to many of the elderly, new born, homeless or poor ill citizen have led to the birth of a new class of actors—non-professional health care givers. A civil society –not medicalized, not 'militarized' by the 'wars again disease' implemented after WWII – is now reacting to new needs generated by increasing life expectancy. One result is that volunteers as well as publicly funded organizations are taking the lead in home-care assistance. These new forms of social engagement of what was previously called 'new social movements' are becoming

constitutive of the health care system and the social system. At the same time, they are transforming the borders between the private and the public sphere, the at-home and the at-health-center services, and are reconfiguring the boundaries around what constitutes health, recovery, disability, citizenship. These tensions are many, between values of autonomy and fear of a return to old forms of charity, for example.

Thus, not only are new borders in biomedicine and health care being constructed from research, the health care system and the health policy and research. From within these domains new *social* borders are under construction as well. And on the edges of health and the social, such as through volunteer assistance in the home, new ideas about health and disease are spreading in turn. Although some of this home-care action is being developed as a counter to medicalization and technicalisation, it also generates new concepts of health, welfare and care that minimize such techniques. And those techniques have become the object of social action, although the role of growing technification –'cold' clinical treatment- in these actions are far from being completely understood. This socialization of health-care, which is the object of some ITEMS projects, as an 'event', makes up part of the emerging cultures of technically based society and care systems.

More ambiguous is the way mental health and various psychologies, as technologies, construct social borders, as they become more intricately tied up with notions of citizenship and new forms of individualism. Advances in biomedical and psychological disciplines, and their incorporation into everyday discourse and social representations, affect identity work. As with new reproductive technologies and genetics, they reconfigure (and are reconfigured by) the way we think about society, kinship, citizenship, responsibility. At the same time, evermore forms of social suffering, including moral harassment and work place issues, poverty, traumas are reinterpreted in the language of psychic suffering, mental health, neurology, psychology. "Mental" diseases old and new displace "somatic" diseases in the socially-created hierarchies of diseases that merit public attention. Current social uses of technologies such as psychotropic medication confuse the lines between lifestyle issues, performance, well-being, suffering, pathology.

Patient organizations, and those of their relatives and friends, are concerned with health care, but not only. (While these are discussed under Axis 2, we mention them here because of their relationship to the transformation of technologies and medicine and vice versa; they cross numerous Axis I projects). One of the most interesting recent

phenomena is the strong support of technically-based medicine by disease- or disability-oriented groups[3]. Their efforts in increasing funding for research on their respective diseases or disabilities (Muscular Dystrophy, disability from traffic accidents, illicit drug use, epidemics like foot and mouth disease or HIV) are inseparably linked to the help they offer to patients' families. Disease oriented associations that collect funds for biomedical research are not a new phenomenon. The main -and dramatic- innovation is their aspiration to the right to decide what kind of research they want to fund, and to supervise this research. Such an attitude, in contrast with that of traditional associations, is grounded in sometimes uncritical support of medical experts. Moreover, patients' associations of the new kind combine a support for cutting-edge medical research with a high level of commitment to a support to people directly affected by the disability. This commitment to the sick shapes the association's choice of research priorities, and thus in some cases indirectly influences fundamental biological investigations.

A different kind of lay collectivity is generated through medical research on populations, such as in the case of haplotype genetic research[4]. In this case, not only do popular and professional understandings of genetic variation, heritage and identity emerge, but ethics are co-constructed and revised as local populations participate actively in the research.

Technologies (devices, apparatuses, drugs and the concept of health embedded when using any of them) and (human) bodies can be conceptualized as mediating devices, that act either on living or non-living matter, and promote the transformation of biomedical research, health, disease and health care. They mediate between researchers and users, between care givers and care consumers, between researchers (again) and funding agencies; between bench and bedside, and they are, in parallel, transformed during this process. Bodies, technologies, the notions of health and disease, the administrative organization of health and health policies care change together. Hence the need for studies able to bring together the multiple strands of this dynamic process.

2.1.3. Conclusion: Shaping borders between health and disease

Towards a new "civilization of care"?

When one takes into account - as studies included in the ITEMS Axis I network do - all the factors that shape recent concepts of health and disease, social and political constraints begin to emerge less as constraints and more as part of the very process of

[3] See the works and seminars on Evidence Based Medicine 2003 and the recent EBM seminar organized by Mort and Singleton.
[4] See current work carried out by D. Gordon and M.C. Manca (CSPO, UCSF).

transformation, and of the shifting of borders between what is considered healthy and normal and what is seen as pathological and abnormal.

Many proposals and suggestions included in the projects of ITEMS members do not reflect the mainstream trend in policy making. Rather, they are calling into question traditional assumptions on dualities such as cause and effect, authorities and the public, private and public domain of action, health givers and health care consumers, 'natural' and 'cultural', mind and body, physical and moral. We believe nevertheless that these studies, especially when taken together, are well adapted to the investigation of the complex interactions at the heart of present-day medicine. While the projects of the ITEMS members may display a great variety of interests and approaches, they share a core set of assumptions, grounded in recent development in historical, sociological and anthropological studies of science and medicine, including the importance of material cultures of science, the social construction of health objectives and of concepts of health and disease that are culturally and socially embedded. Innovation is, as a rule, a risky enterprise, involving feedback loops between technologies, clinical practices, and social practices of exclusion and inclusion based on health and wealth have the potential to become a powerful tool for the understanding and shaping health policies. They may thus, we hope, contribute to the construction of a European Space for Technology and Health.

The complex interactions analyzed by ITEMS members in their projects and publications, call into question the post-Second World War assumption of a linear relationship between innovations, economic development and welfare. We expect that, together with reports of the three other axes, this one may contribute to understanding how collaborative research can bring about not only a better understanding of the concepts of health and disease, but also recommendations for policy-making and regulation. Thanks to the multiple aspects afforded in the many research projects of ITEMS members, we were able to aim not only at diagnosing the currently prevailing trends toward geneticisation and technification of disease and health, but also at outlining a new civilization of care. This recent de-technification of care, whether palliative, voluntary, home-based or in the form of 'soft' technologies - emerge from the review of those projects. Its effects studied longitudinally may allow the assessment of good practices. At the same time, the increasing number of diseases and diagnostic capabilities offered by medical research should be examined critically. They can be a form of state disinvestment in health, as has happened in the US. We have to question how to use this kind of care in a way that does not reproduce medical inequalities: high tech care for the wealthy, do-it-yourself for the poor.

Recommendations and questions raised

Of the wide range of topics originally examined, three were proposed by workshop participants as themes for future collaboration: cancer, genetics (including prenatal diagnoses) and mental health. Within these topics, emphasis was put on social reflections (the relationship between new technologies and political issues, or the emergence of social-medical problems), national particularities and cultural differences, and local-global and articulation, among other issues.

Several concepts that seemed either particularly useful or important to pursue were suggested, including: susceptibility (essentialist, non-essentialist and hybrid definitions), identity (whether individual, national, etc.), moral landscapes and medical technologies.

Workshop participants differed in the extent to which they considered collaborative work feasible or desirable. The point was made that historians (the largest discipline group in Axis I) tend to work alone. However, projects from Spain, Portugal and even some in the United Kingdom belied that observation. Another problem was the limitations of methods used in comparative work. In Axis I, collaboration often involves case studies. While some funders consider this a weak method, it was pointed out that case study methods vary (compare an individual case study to the potentially richer extended case study method of the Manchester School of anthropology). Lack of funding and bureaucratic entanglements were mentioned as hampering the long-term investment needed by most collaborative research. Finally, some participants questioned whether we really know what collaborative research is. Future workshops could include discussions of collaborative models.

At the same time, various levels of possible collaboration were then suggested: applying a common question to very different research objects, choosing a single empirical object to examine in various sites, working with a given concept in different kinds of research and sharing an overall methodology. Finally, it was pointed out that theory could be used to bridge the gaps between various studies carried out locally.

2.2. Axis 2. Participation of users and the redefinition of systems of actors in the domain of health and medicine

Nicolas Dodier and John Welshman

Before the Granada Meeting, we tried to classify the Axis 2 projects. We attach this preliminary report as Annex 1. There were 49 main projects in Axis 2; 36 Axis 2 projects in Axis 1; 11 Axis 2 projects in Axis 3; and 16 Axis 2 projects listed under Axis 4.

Therefore in total there were 49 projects that gave Axis 2 as their main Axis, and 63 other projects that gave Axis 2 as a secondary heading.

The Granada Meeting for Axis 2 had been organised around 4 themes:

1) From the Sick Patient to the Political Patient: Historical Perspectives.

2) The Shaping of the Patient Through Technical Innovation.

3) Individual Patients to Collective Patients.

4) From the Passive Patient to the Active Patient.

The papers tended to focus on quite specific individual or personal research projects, rather than providing a summary of the general work of a Centre, and opportunities for collaboration. This had the advantage of generating focused discussion.

2.2.1. From the Sick Patient to the Political Patient: Historical Perspectives

The papers in the first session all shared a historical perspective. The paper by Julie Anderson focused on 'Assessing the Patient: Hip Replacement Surgery in the Twentieth Century', and looked at the cultural representation of ageing, from 1960 to the present. It led to discussion about disability and the acceptance of pain. The argument was made that the patient and the innovation were produced at the same time. Working with people in museums (the Wrighington Hospital in the UK) seemed a fruitful area. There was exploration of the role of gender, and of perceptions of risk - the idea that all may be disabled one day.

The paper by Carsten Timmermans focused on 'Science, Technology, and Medicine: High Blood Pressure and Hypertension', exploring transformations from acute disease to risk factors, and how the hypertensive patient becomes the political patient. There was discussion about statistics and the construction of disease, but there were also questions about where the political patient really was. What is the meaning of the political patient?

John Welshman gave a paper on the 'Knights, Knaves, Pawns, and Queens: Attitudes Towards Behaviour and Motivation in Postwar Britain'. It laid out the conceptual framework for understanding attitudes to behaviour and motivation in post-war Britain provided by Le Grand (2003), and assessed the usefulness of these metaphors by looking at the literature on 'problem families'. There was interest in the Le Grand diagram, and in the knights-knaves, pawns-queens dualisms.

2.2.2. The Shaping of the Patient through technical Innovation

Maud Radstake's paper was called 'Affective Images: Mediated Bodies in Real-Time Medical Imaging'. The aspects of the thesis were anatomy and its representation; depicting skin; ultrasound endoscopy and the visualisation of the human body; medical imaging and contemporary art; and towards a theory of the mediated body. The key question was how do real-time imaging technologies and the images they produce affect patient bodies. There was discussion about the public exposure of patient and body, and the question was again posed of who are the patients.

Celia Roberts asked 'Who is the Patient in Reproductive Medicine?', stressing the interdiscplinary nature of the research she has been involved in. Key questions were who and where is the patient; what sorts of patients are there; how and when are patients linked; and who is not a potential patient. Who the patient is changes over time, and reproductive medicine troubles conventional notions of the patient. New forms of patients are formed, and the question was posed of whether the term 'patient' works at all. Discussion focused on the idea that the patient is always partial; the construction of human beings as potential patients; and the question of how much agency patients really have.

This led into a more general discussion around how collective action happens, and on the importance of the concept of stigma. Hence private issues are designated a public problem. Where should we locate ourselves as researchers?

2.2.3. Individual Patients to collective Patients

Vololona Rabeharisoa talked about 'Patient Organisations' Involvement in Research: Towards a Framework for Comparative Studies'. She explored patient organisations' involvement in research; internet groups; the participation of the general public; and the implications for care. Vololona used the history of the French Muscular Dystrophy Association to identify three models -delegation; emancipation; and partnership. There was discussion about new forms of citizenship, including scientific citizenship and genetics. There was debate about the existence or not of a linear model; and about the unit of patient organisation, whether the patient or the family.

The paper by Nicolas Dodier 'Shaping of Patients' Place into the Biomedical World' summarised work at CERMES on patient associations. Various themes were identified for the 1982-1999 period -the political mutation of the medical world; transformations from clinical tradition to state scientific authority; resistance; the sidelining of other

associations in the 1990s; criticism of pharmaceutical capitalism; and the alternative globalisation movement. Nicolas also identified new orientations of research.

2.2.4. From the Passive Patient to the Active Patient

The paper by Julien Pierart 'The Local Worlds of Public Health' was located in urban sociology, and posed questions of what the 'local' really meant, and where patients were coming from. New public health policies in Belgium demonstrated the need for locality level activity. Nevertheless the WHO Healthy Cities Movement, and the WHO definition of health seemed to miss out the inhabitants of areas, and raised questions about whether the local level was the most appropriate scale at which to tackle problems. Inhabitants described their experiences in terms of powerlessness. This led into discussion about how to conceptualise proximity; and about why attempts at capacity building seem to repeatedly fail.

Michel Naiditch explored the participation of the citizen and the patient in a paper entitled 'Citizen and/or Patient Empowerment: Lessons from Methods for Involving Lay Citizens'. Using the example of public health, he explored how recent crises in the French context - asbestosis; contaminated blood; and BSE - have led to a lack of confidence in the decision-making process. These have in turn led to debates about individual rights for patients, and collective action. A special 'Health Democracy' has been created in the Ministry, in order to rebuild confidence in the system. Fifteen citizens juries have been used as tools for enhancing collective debate. This fed into discussion about the meaning of participation for the lay person; how participation can be integrated into institutional processes; the interaction between expertise and policies; and moral assumptions about the belief in the value of participation.

2.2.5. Analysis and Conclusions

The aim of this report is to list ITEMS network projects belonging to the second Axis of research, either because researchers explicitly described the project as such in their file, or, in the case of some projects, because we considered that they fit into this Axis. We also attempted to define possible sub-headings. There are some obvious disadvantages to working with files: they are more or less specific and can be difficult to interpret. Most of the files describe ongoing projects, but some refer to past research, very old in some cases. We chose to include projects only (with some uncertainty at times as to the exact status of the file). Given the great diversity of the projects studied, we also had some difficulty fitting all of them into the few major sub-headings defined. This report should be seen as a working document whose only ambition is to provide a slightly clearer overview of the work currently being done in the ITEMS network.

We identified two major lines of research. The first concerns work which, generally speaking, examines transformations in the place of users or patients in the field of health and medicine, the terms 'user' and 'patient' themselves being obviously restrictive, since they presuppose a certain way of looking at people. The second line of research brings together work in the social sciences, which also focuses, in one way or another, on users and seeks to render an account of their condition, according to quite different configurations.

Shape and status of user/patient in health and medicine

Three shifts, more or less interconnected, are examined:

- **From the passive patient to the active patient**. Here, researchers concern themselves with the study of mechanisms intended to increase patient participation in the care relationship. The patient, who before had a largely passive role, is now considered to have specific knowledge, rights and responsibilities. Here we find studies looking at the different mechanisms of patient empowerment, which aim to give patients a more active role (informed consent, access to new sources of information, creation of observatories of specialised practices…).

- From the individual patient to the collective patient. The question raised here is that of collective mobilisation rather than participation. The patient transforms his/her individual experience into a shared and common experience. Patients come together and may formulate claims. We list all the studies on collective mobilisation and the emergence and diversity of these new forms of collective engagement in this sub-heading.

- From the sick patient to the political/citizen patient. The question examined here is that of the wider representation of groups in society. Here patients take an active part in the decision-making process, through their representatives. We bring together here all the work on the varied forms of representation of the patient/user in the social/public/political space, and on the different ways in which this representation of the user is legitimised (citizen's conferences, committees, collaboration with associations…).

In the second half of the 20th century, changes in these three areas took place with varying degrees of rapidity and simultaneity, given the potential interconnections between the three questions.

Shape and status of the user/patient from social science

In parallel to and connected with this transformation of the figure of the user in the field of health and medicine, we also note the diversity of ways in which the social sciences have attributed the patient a place in their own research. This "taking into account of the user" in the social sciences has also evolved. The question here is the way in which the social sciences speak of the user and take his/her discourse into account. Several types of approach coexist:

- Behaviour. The study of behaviour, without any particular attention being paid to the extent to which the patient is "active".
- Analysis of the experience.
- Shaping through practice/technical innovation/discourse. Analysis of the different ways of configuring users in relation to a practice, technique or discourse. This research can lead on to an examination of the place attributed to the "user" and subsequently intersect with the first line of research.
- Analysis of perceptions and opinions concerning individual questions (what people think about themselves), or more collective questions. Here, the point of view of non-specialists can be seen as a good way for the researcher to gather relevant facts. We are dealing here with a form of community-based epidemiology.
- Action research. Some research can be seen as "action-research": it focuses on the experience of individuals, with the aim of simultaneously giving them the possibility of acquiring a more active position. Once again, we are at the crossroads of the two major lines of research distinguished earlier.

2.3. Axis 3. Coordination in Health Care Systems: Organisational Reform and Information and Communication Technologies

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For different reasons the question of coordination lies at the heart of efforts to reorganise health care systems in Europe. The main drivers of this development are attempts to improve the quality of medical care, to increase the efficiency of health services, and fundamental social and demographic changes in many European societies. Coordination is a multi-faceted concept. In health care it applies to coordination between different

levels of a health care system, e.g. between policy-makers and provider organisations, between different types of providers, e.g. hospitals and ambulatory care physicians, different groups of health professionals, e.g. doctors and nurses, and between the health system or health professionals and the public, i.e. patients, the press and the related information flows. The other focus of research in this field deals with the question on how coordination between actors and institutions can be improved, in particular using innovative information and communication technology (ICT).

Within the projects belonging to ITEMS Axis 3, we identified six different approaches on how to investigate issues around coordination in health care systems. These are

- Formalisation and standardisation of care practices.
- Role and position of health care providers.
- New forms of health care organisation.
- Production of information.
- Sociological, historical, cultural and/or ethnical analysis, on the sociological construction of diseases or health problems and/or treatments.

After an outline of the methodological approach used in this paper, these approaches to investigate coordination in health systems will be explored in detail, including a categorisation of all ITEMS Axis 3 projects to the specific topics, and where appropriate a short summary of these research projects. The paper ends with a summary of main conclusions, in particular concerning gaps in current research in the ITEMS network on coordination issues identified in this analysis.

2.3.1. Method

In order to draw a picture on how to investigate issues around coordination in health care systems, we used a two-stage analysis. We first built a grid encompassing items arising from a primary (or initial) reading of around ten projects. These items cover different themes such as: topic (cancer, palliative care...) of the project, interest on either coordination between providers or information and communication technology, level and type of provider studied (groups of health professionals

e.g. doctors and nurses, organisations, such as hospitals or other health centres, health care network organisation, health care system). Attention focused either on professional practice (individual, collective including network relationships and/or in relation to the reorganisation of patient care or care pathways), organisational reform (hospital, cancer

centre, etc.). Finally, the research method employed, in particular whether a comparative research design including different countries and the main outcome of the study were extracted.

Based on this grid we were then able to describe in a synthetic manner, within a single table of ten pages, every project of the database belonging to ITEMS Axis 3 The process led us to propose main lines which span and represent the different approaches to investigate coordination in health systems as they emerge from the database. Thirty nine research projects were reviewed with a focus on ITEMS Axis 3, with some centres listing many small projects in the database, e.g. Erasmus University, whereas other centres chose to group research projects under main lines of investigation and entered them as one project, e.g. TU Berlin.

2.3.2. Identified approaches on how to investigate issues around coordination in health care system

Formalisation and standardisation of care practices

For the past ten years, the health care systems in most European countries have witnessed the development and use of practice formalisation and/or standardisation as we can see a growing interest in practice guidelines, practice recording and/or formatting, e.g. the use of a shared record between providers, writing on a record work, tasks, etc., associated with the development of new information technologies -whether paper-based or electronic. These different formal devices, based on process standardisation are supposed to facilitate and increase coordination between health care providers, both on an individual and organisation level.

Thus the first approach we identified explores, at a micro-level, the use and development of these tools and consequences on the practice, organisation and coordination of care. The research activities gathered together here attempt to analyse the work carried out by health care professionals to put these tools to use as well as the changes and reconfiguration of professional practices, and on organisation in terms of work content, task sharing, and communication between providers.

Projects focusing on evidence-based standards or on practice formatting or recording concentrate first on one type of provider, e.g. hospital doctors, GPs, nurses, etc. Following the processes of co-construction between practice formalisation and health care work/knowledge/organisation, they examine what types of configuration emerge between work content, work coordination, organisation, and the health care system. Further analysis looks at the evolution and/or construction of the concerned professions. The

latter consideration leads to the question of communication between the micro- and meso-level of analysis. This is in part tackled within the second approach.

Two other projects focus on the co-development of new information technologies (IT) and health care changes, and the interactions between the two are more specifically studied at the level of a health care organisation.

Two related projects are more theoretical. A toolbox to evaluate IT applications in health care has been developed, intending to guide organisational decision-makers when evaluating IT systems for patient care. The factors promoting or hindering the evaluation of telemedicine interventions are studied in another project.

Role and position of health care providers

The introduction of new organisational devices addressing the need for more practice formalisation and/or improved IT communication between providers has consequences on professional practice and coordination of care. It may also contribute to organisational re-design of care pathways, and around this re-design to the redefinition of tasks, roles and relations between providers. The second approach addresses this specific question, focusing on how coordination leads to the evolution of role and/or position of providers within the health care system. This question can be studied at ether a professional (e.g. GPs, Nurses) or organisational level (e.g. hospitals, cancer centres).

From the professional perspective, work at CERMES in France tries to understand the involvement of general practitioners in cancer care. More specifically, the authors examine key phases of the care process: prevention and detection, the process of diagnosis, treatment, and medical follow-up of patients. Within these phases, the authors studied the relationship between GPs and specialists of the medical team, the GPs participation during these different phases, and the distribution of tasks between general practitioners and specialists in five European countries (France, Belgium, United Kingston, Norway, Italy).

A different approach is taken by a project at IMAGE in France that focuses on new forms of care delivery and on 'coordination' promoted by this new type of care "organisations" in particular. The project, based on case studies of networks covering two areas of care (palliative care and gerontology), seeks to elaborate a framework for analysis to study the question of what is coordination (what providers, what functions, what tasks?) and to understand how emphasis on coordination mechanisms and formalisation contributes (or not) to the redefinition of the roles and tasks of professionals, and to the emergence (or not) of a new occupational function of "coordination" (or a new profession) in health care.

The introduction of ICT systems is also studied from the point of view of the contribution to emerging changes in role and position of health professionals, such as nurses, GPs, or medical specialists, in organisations. The analysis is based on the examination of how ICT affects work tasks and the position of different health professions. The shifts in tasks from ophthalmologists to other health care professionals resulting from specific IT innovations in eye care represent a detailed aspect of this field of research.

From the organisational perspective, a Project at CSO in France analyses a reform programme implemented by 20 French cancer hospitals. It is based in part on the introduction of medical standards to improve the management and the quality of medical practices. The project analyses how relations changed between these cancer centres and other institutions involved into the fight against cancer, and especially how medical standards initiated by that reform, contribute to strengthen the position of these cancer centres within the cancer care system. Indeed medical standards established by these cancer centres have become *the* medical standards for cancer in France. At the same time they allowed cooperation between physicians and other health suppliers, which in turn increased their specialization and their scientific leadership.

New forms of health care organisation

In most European countries there is a growing interest in new forms of health care organisation, as health care networks or different type of care apparatus are devised to monitor health problems

(e.g. specific programmes for cancer or palliative care) or the health care of a particular segment of the population (e.g. programmes for elderly persons). Indeed, these new modes of delivering care, understood as new organisational devices, should improve quality of care -by defining and applying medical standards and also redefining paths of care or trajectories. This should then lead to a better coordination between different health care providers. The emergence of these new forms of health care organisation represents the third approach on how to examine coordination.

In this framework, research activities aim to analyse the socio-organisational conditions of the emergence of these new modes of coordination and focus, in this perspective, on the organisational and symbolic aspects at stake. Beyond the question of socio-organisational aspects, a crucial issue is embodied in the matter of articulation between new forms of health care organisation, especially in terms of modes of coordination and patient health care trajectories. This is the subject of a project also at IMAGE which analyses, on a comparative basis, the different contrasting systems of obstetrical-paediatric care, some of which are organised in networks and situated in France and

Holland. The project investigates at the same time mechanisms of coordination/orientation that are implemented, ideal trajectories that are *a priory* defined and real trajectories that are accomplished. The latter was explored from the point of view of providers, medical records, and female patients/users. It showed that the realisation of ideal trajectories depends largely on their legibility and understanding, and on the mechanisms of cooperation/coordination that allow their realisation, by professionals and patients/users alike.

Another project evaluates the needs of terminal cancer patients for palliative care and the impact of providing palliative care on the general pattern of care for terminally ill cancer patients.

2.3.3. Production of information

Another way to treat the question of coordination is accomplished in an indirect manner by producing information on health and/or health care systems. In fact, to make information available is useful for different stakeholder as individuals, user groups, professional groups, and health policy decision makers. However, the production of information is differently considered depending on the public's target: that is on one hand, the decision makers and providers, in a general understanding, and on the other hand, the user/patient which overlaps with ITEMS Axis 2 devoted to user participation.

Projects belonging to the first perspective seek to inform health policy decision-making. Some of them aim to build observatories on health and/or health care systems focusing on the production of information at a macro-level, that is on health systems in general, and on specific health system characteristics and health priorities. They actually seek to build comprehensive and transparent databases to make information available in a useful format for individuals, user groups, and/or health policy decision makers. The prime goal of these research projects is to narrow the gap between health research and policy-making and to provide a solid evidence-base for health policy decision-making. At the same time most of these projects, which take place at a national, European, or international level include countries in transition. For these countries research seeks to provide analytical descriptions of health care systems and reform initiatives in progress or under development.

A different approach to the study of macro-level information is taken in two projects, one at CERMES in France and one at the Unit of Public Policies, Madrid. The first is about the amount and quality of health economic information available to medical professionals, complemented by an assessment of the conceptions of doctors concerning economic regulation of the health system. The second project analyses the contents of health

information conveyed by the media on the basis of expert opinion on biotechnology issues. On the receiving side it also looks at public opinion on transgenic crops and gene therapy.

The second perspective, in which information is devoted to users/patient, considers information as the opportunity to capture the quality of medical services, and therefore to optimise patient choice. In return, this should provide an incentive for health professionals to deliver services more efficiently through innovations in their organisations. Research has actually shown that the opinion of professionals, regarding the type of information for consumers does not match the expectancies of the latter. On the other side, public information is considered by regulators as a powerful device, notably through the mechanism of competition. In this perspective, one project seeks to test the ability of building a common information system for hospital performance, aiming to capture different stakeholders' positions, and thus bring more efficiency to the health care system.

2.3.4. Sociological, historical, cultural and/or ethnical analysis, on the sociological construction of diseases or health problems and or treatments

The projects clustered under this area of research focus on the evolution of beliefs, perceptions and representations of different stakeholders such as citizens, users, administrators and health professionals on health and the health care system. From this perspective they treat the question of coordination in a very indirect manner, which strongly overlaps with ITEMS Axis 4 on articulation between health and policy issues. These projects are concerned with ways in which diseases have been socially constructed; with the historical development of health care systems, including public health and hospital provision; and with how health and policy issues are articulated. They aim to produce knowledge, based on sociological, historical, cultural and/or ethnical analysis, on the sociological construction of diseases or health problems (hypertension, psychiatry, cancer pain, telemedicine, etc…) and on the associated organisation of health care systems and care, and some seek to set current policy initiatives in a historical context.

2.3.5. Conclusions: collaborative themes identified at the items Granada workshop and recommendations

The five following themes were presented in the Axis 3 session of the Granada workshop: formalisation and standardisation of care practices; new forms of health care organisation; production of information for decision makers and providers on the one hand and production of information for users and patients on the other hand; sociological, historical, cultural and/or ethnical analysis of the sociological construction of diseases, health problems and treatments.

Of the wide range of topics discussed, tree potential overarching themes emerged as potentially fruitful topics for the Coimbra symposium and eventually for future research collaboration:

- Health care transformation and formalisation of care practices, organisational practices, or the organisation of care pathways.
- Evidence-based medicine.
- Relation between policy decisions taken at the local and the national level and their relation with international health reform trends.

Behind these possible connections, we identified some gaps within the research approaches carried out under Axis 3. Firstly, few ITEMS network research projects investigate coordination from a socio-organisational or from a management perspective. This is probably due to the fact that only tree teams within the network could be identified as belonging to the socio-organisational or management background. Secondly, a scarcity of quantitative research projects in the database was noted. Few centres use epidemiological and economic methods to investigate social sciences issues in health. This reflects the under-representation of research centres from a traditional public health and/or epidemiology background in the ITEMS network. Finally, few projects included comparisons with other European countries. However, this is a field where improved networking within the ITEMS project and beyond could be of use to stimulate research centres and individual researchers to engage in future European comparative studies.

2.4. Axis 4. Articulation between health and policy issues

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2.4.1. Introduction and overview

Axis 4 has been described, in the ITEMS proposal, as: 'Articulation between health and policy issues'. Based on an analysis of the projects subsumed under Axis 4, the co-ordinators of the Granada workshop (Jean de Munck, François Delforge, and Dick Willems) identified four themes that were discussed during the Granada workshop. In the convocation for the workshop, the themes were described as follows.

Theme One: Setting up a "Safe environment"

The basic idea of this theme of Axis 4 was that public action must not only provide health care. It must also develop a general environment policy. What are the changes in these environmental policies? Changes in technologies? Changes in relevant actors? How to manage uncertainty and risk?

Many of the projects in this Axis are about health risks and policies aimed at reducing such risks, both in the sense of product control (drugs, food) and in the sense of predictive and preventive medicine. The role of genomics will be part of these concerns.

This theme encompasses questions on safety standards and practices of dealing with risks: What is the moral and political duty of the political system in a society regarding such problems? What are the new innovative practices?

Theme Two. New governance and networking

Two questions seem relevant with regard to the Axis 4 projects. The first one is the new relationship between hospital and home care. This issue is obviously one of the main trends in Europe, which has interesting links with the 'safe environment' issue. The second one is networking as a new mode of governance. What are the instruments of public action? Assessment (evaluation) devices? A priori and a posteriori controls? Information systems?

With these two questions, the boundary between public action and private arrangements is blurring. We must deal with this problem in descriptive and in normative terms, and there seem to be opportunities here for collaborative and comparative research,

Theme Three. New inequalities and health policies

Many research centres in our network work on this topic. The problem is the question of the links between new inequalities and health problems at the individual and collective levels. Questions concerning cultural inequalities and the position of the handicapped are frequently addressed in projects and seem as relevant for the ITEMS network as the question of economic inequalities. Again, the role of genomics as a new technology of both social diversification and social cohesion needs to be addressed. Besides, we must not miss the new connections between health and social policies of the so-called "Active Social State". The issue of mental health is especially relevant on this topic.

Theme Four. Politization of health issues

Some of the questions addressed by the Axis 4 projects are: How do people mobilise around health issues? Are there new actors in the field of health policies (for instance, patient organizations), beyond the classical neo-corporatist arrangements of our Social States? What is the function of the State as a "sanitary democracy" animator? Is the legal channel appropriate to increase involvement of people in public health concerns? What about the public hearing procedures and attempts at organizing public debates (for instance around genetically modified foods)? What is the involvement of European political level in these nationally (very) structured deliberation and decision processes?

2.4.2. Emerging collaborative themes on axis 4 at Granada workshop

During the discussion of these four themes in the workshop, three major collaborative themes emerged:

- Towards a new health administration culture in Europe.
- High and low technologies environments.
- Morality and health issues

These themes will be discussed in what follows.

Towards a new health administration culture in Europe

The discussions on this theme focused on the emergence of "new forms of administration and ways of organising". Formulated differently from one area to another, and facing very different situations from one country to another, the issue appears to belong clearly to the present major European trends. This trend appears to be fragmented into three

major issues: the emergence of alternative bodies (such as Agencies); the legal side of such new forms of administration; a general questioning of the notion of "expertise".

Emergence of Agencies and/or other alternative/intermediary Bodies.

"Health governance" and the trend towards a new administrative culture may stand as one of the major European issues emerging from Axis 4, particularly considering the different food security and environmental safety crises[5] that Europe faced during the last few years. There is obviously a general inclination in Europe to create organisations that are, at different degrees, independent from the central administration and from the parliamentary forms of democratic control. The agency structure seems to be a taken for granted political response to sanitary crisis, stressing the need to study alternative bodies working on bridging the gap between clinical research and politics. Links do exist in between those intermediary bodies and represent sort of an integrated system[6].

Agencies and other new intermediary bodies raise similar issues and research perspectives:

- The need to analyse the reasons of their emergence and to evaluate their impact on the regulation of risk.
- The need to study the scope of competences and prerogatives of such bodies[7].
- The necessity to examine the political aspects of the increasing role of management in health care[8].

[5] In Belgium, the emergence of institutions answering to those crises and the health hazards concerns they brought up, was mostly linked to specific crises situations (Mad cow crises, Dioxin Crises, etc…). It brought up the notion of "Agencies" into our bureaucracy and democratic system, emforcing a new way of managing crises, through flexibility and high expertise.

[6] One example is raised through the sociological divide existing in Belgium between the Health and safety administration (an old one, very bureaucratic, routinised, working with very formal standards), and on the opposite, the Environmental administration (very flexible and decentralised). Both administrations worked separately for a time, but are nowadays facing the obligation to consider each other, health and environmental issues becoming strongly interpenetrated (whether because of legal decisions, social demand, etc.).

[7] Different situations are interesting to be lightly depicted here, such as the French Food Agency which acts only as a provider of scientific expertise for the French government, while the French drug agency is responsible for delivering market authorisation. On a Spanish side of the question, the influence (co-influence?) of European Agencies on National Agencies seems to become an issue. Nevertheless, the Spanish situation seems specific since the question of agencies has not been yet very relevant and invested theoretically and practically. At present time national agencies are considered as sub-agencies; only European agencies have political recognition. Their main function is to stand as providers of information for local actors. No further involvement is considered and put into action.

[8] Roland Bal questions how can management contribute to more effective practices of care.

- The need to clarify the way these Agencies articulate their work: are they instance of a "dislocative/disintegration process"[9] or of an integrative one?

- The necessity to look at specifics uses of coordination tools/mechanisms, due to the definition of boundaries between science and policy boundary by national and European advisory bodies (studying both 'boundary configurations' and boundary work').

According to some participants at the workshop, among them Daniel Benamouzig, the best way to investigate those issues to take some examples, by insisting on transversal phenomena involving both the state and the market, in a larger social environment. Maurice Cassier and Janine Barbot, from the CERMES, are working on such question, through different projects that may appear interesting for future ITEMS members' collaborations:

- One of the CERMES projects is an annotated bibliography, to be published next summer. This could be part of a larger process, involving other countries.

- A second project is to organise during the year 2005 a research seminar by inviting top executives working in different agencies. We can imagine that this kind of seminar could take place at a European level. This could be organised in a centralised way, at the level of ITEMS, or in a more decentralised way, through networking between interested laboratories in different countries.

Expertise (transformation, evolution of roles, complexity). The emergence of such "new health administration culture", within the changing relationships between science and society, puts on the table the notion and status of "experts and expertise". It brings in the question of boundaries and roles, "lay expertise" playing an important role in the field of "politics of medicine and health" in various countries. It questions the appearance of what seem to be "new forms of inequalities" linked to new forms of relationships between expert knowledge and lay knowledge[10].

[9] Disintegration is a lot worth being studied, since it is a lot more complex to understand than integration.

[10] During the workshop, Joëlle Vailly interrogated the translation of inequalities in the public sphere, through the study of discrimination in access to health care that brought to light two features. First, she showed that the health sector was characterized by tension between the strong social legitimacy of health issues -she proposed to call "biolegitimacy" the recognition granted in public debate to the health argument -, and the disqualification of certain categories of the population often expressed in everyday activity at health service centres. Second, she established that, contrary to what is commonly assumed, discrimination in health care affected not only undocumented foreigners singled out by the law, but also legally settled foreign groups, French groups of foreign origin and even French citizens from the overseas departments and territories.

Roland Bal, whose main present work is an anthropological research on the Dutch Health Council, gave one research example on the transformation of expertise[11]. He argued that the Council, caught into the "science advice paradox", diminishes credibility of science advice in technological culture on one hand; and increases the politicization of science on the other hand. His close look at the way the Dutch Health Council is taken up by the government raises the dangers and the potentials of politicization of science and expertise[12] (dependence/independence, bridging the gap between politics and "reality", between "experts" and "laymen"). Another example is the main focus made by the CERMES on the rationale of the laboratory referring to the social and historical transformations of the relationship between medicine and society. This relationship has evolved from a publicly organized delegation of power to the medical profession, in the post-war decades, to a much more intricate system, in which the "central expert position" of medicine has been challenged by new actors, new knowledge, and new forms of organization. There appears clearly the potential of new transversal relationships between different kinds of actors/experts, such as the "patients", "users", "public", objectified through the notion of "lay expertise"[13].

This "expertise" question raises new issues and research perspectives:

- The need to study the articulation between expertise and political decision. The creation of agencies has contributed to a new definition of the relation between these two functions. It allows clarifying the respective responsibilities of experts and political actors. Experts are handling, through their scientific discussion, political issues. Reciprocally, in the food sector political actors intervene directly in the process of scientific evaluation.

- The need to examine the involvement of stakeholders (firms, patients) in the regulation of risks, and the emergence of so-called "health democracies" (participatory democracies).

- The need to follow-up the mediation of medical expertise, and to evaluate the role of technologies in the distribution of expertise in health care practice and policy.

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[11] The main Dutch advisory body to the Dutch government on heallth issues.

[12] According to Jean de Munck, in the field of mental health and psychiatry, there is a revival of the old divide between organicism and psychodynamics in a new epistemological and practical situation. The politicization of scientific debates in the field of psychiatry reinforces the tension between scientization of politics and politicization of science.

[13] In the field of "lay expertise", different European research centres are questioning the rise of so-called "health democracy" through the evolution of the role of users, from a rather passive role to a more active one. Such a democracy needs some places where citizens, users or sick persons can express their point of view, formulate their preferences and make their rights acknowledged.

- The need to evaluate the impact of new accountability practices on expertise.

- The need to study the consequences of these issues on the ways science advice deals with uncertainties (understood as science-policy hybrids), in/exclusion of knowledge and approaches (and policy options), in/exclusion of actors (both certified science and not)

Legal aspects. The emergence of such "New Health administration culture" brings up the necessity to question a European legal framework. Besides this framework, new relationships between the " legal system" and the "health system"[14] were raised among participants[15].

Here appears the necessity to put forward the role of legal instruments in the definition of "new health administration culture", in "legalisation and penalisation" of medical problems16, in the clarification of frontiers between public and private property and public health17, on the analysis of "knowledge and norms in the medical practice"[18], etc.

Multiple subsequent questions are underlined, from the regulation of human genetics and medically assisted reproduction[19] to the numerous legal and political consequences of the new social/mental health complex issues[20].

High and low technology environments

Some participants underlined an important issue on "Home care". This manifests into the emergence of new networks set up through the transfer of technologies from high tech

[14] Such as the emergence of the penal obligation of care in some European countries, like Great Britain.
[15] One research digging arund this issue is brought by Claudine Perez Diaz, on alcohol addiction and violence.
[16] In France like in other countries, the acknowledgement of patient rights tend to lead victims of medical accidents to courts. This evolution is not massive, but it can be considered as a new relationship between care providers and users.
[17] Maurice Cassier (CERMES) studies the practices used in taking out patents on human genes and their effects on, first, the provision of health services and, second, biomedical research. He analyses the balance and conflicts between public, collective and private property in the area of genetics and genomics. Putting forward the role of legal instruments in the definition of frontiers between public and private property, he handles with crucial problems of governance in the field of biomedical research.
[18] It includes Joëlle Vailly's projects on reproductive health (new practices like subcutaneous hormonal implants and male and female sterilisation; the consequences of the recent modification on French abortion legislation ; reproductive health policies in Brazil, studied by one of PhD student, etc.). Her purpose is to relate changes at the political and economic macro-level, to trends that can be seen at the micro-social level of agents.
[19] Matias M. and J. A. Nunes (2004). Regulation of human genetics and medically assisted reproduction. ITEMS Network: Health care Policies and Politics, Granada, Spain.
[20] According to Jean de Munck, important changes in the legal framework during the last thirty years are based upon decisions taken at Strasbourg about patient' s rights, and, as a consequence, revision of European laws and institutions.

environments to low tech (homes). Three major reasons were given by Dick Willems as explanation for the rising importance given throughout Europe to "Home care":

- Ageing population: constant increasing age of the average European population.
- Financial reasons: home care as a potential reduction of health care costs (cheaper than hospital or health centres), underlining the danger to consider transfer of technology as a simple question, instead of understanding the consequences of "translation" from a high-tech environment to a low-tech environment (homes).
- Social reasons: growing percentage of persons wanting to stay at home while facing health problems.

This emerging issue of transfer of technology into low-tech environment raises multiple problems linked to "home care": What kind of competencies, of networks, are needed for those transfers? Transferring technologies to the home also questions the safety of the environment: Will transfer (translation) make home a safer place to live in, or a more frightful place to live in (because of high-tech changing home into an environment in which it might not be safe anymore to live in)? Emergence of new inequalities is also directly linked to the question, since the issue of "home care" is at the core of a multitude of crossing elements (social networks, solidarity, financial and culture capabilities, consequences of decentralisation, etc.). With "home care", two new actors (not present before the coming of high-tech transfer into homes) seem to appear as critical and "unavoidable":

- On one hand, families become central partners in the network around the care, and invite both professionals and researchers to question the positioning of the patient within technology transfer (emerging from the question of politics of medical technology and medical expertise).
- On the other hand, technicians of machinery (providers of machines and services) become sort of the rooting points between technology, families, and external partners.

In a way, it is the issue of "safe environment for care"[21] that is at stake here: do we deal with those transfers of competencies, technologies, knowledge, to new "actors"? According to Roland Bal, it also questions the role of information and technologies bounding and co-ordinating professional and laymen practices.

[21] Borrowing from the "environmental field", Marisa Matias calls it "a sustainable health environment".

Morality and health issues

With the shifting boundaries between health and social policies comes the question of the re-definition of "normal behaviour" and "health care". According to Jean de Munck, the question is more of "socialisation process" than classical medical care. It concerns the transformation of social policies as new "active welfare programs".

One example was underlined by Claudine Perez-Diaz, with the extension of the notion of addiction to different fields[22], amongst which the mental health area. Two issues are raised here: first, there seems to be no more consensus about what is a "good life"; second, regulation seems to reinforce "medicalisation"[23] and "environmentalisation" of health and social problems. Things also happen the other way around: the increasing politicisation of health and medical issues fosters sort of a moralisation of medicine.

One particular field of research, crossed by moralisation aims, concerns the regulation of human genetics[24] and medically assisted reproduction. Marisa Matias and Joao Arriscado-Nunes carried out the general interest and often difficult situations faced by lots of European researchers working on these issues. Even though the question of the regulation of human genetics has been addressed through major scientific investments and research since more than a decade in most of European countries[25], the regulation of such practices seems to still suffer from great lacks of serious and clear political decisions, despite evident moral questioning. One of the consequences, present in multiple EU countries, that we described through the question of "expertise", is the tension between academics and politics, between practitioners and decision makers.

[22] Pérez-Diaz, C., Ed. (Octobre -Décembre 2000). Alcool et délinquance -Etat des lieux. Documents du CESAMES. Paris, CNRS - Université René Descartes Paris V.

[23] Joëlle Vailly describes such process of translating social problems into health problems, which is also called the "sanitarisation" of social problems (i.e. reconstruction of social problems into mainly health ones). One example is the new configuration around the notion of race inspired by genetics. Another example is the development of new category and their use in the public space (like the category of "carrier").

[24] This, according to Joëlle Vailly, raises the question of the new bio-politics in biomedical context, in a foucauldien approach, an the use of the rhetoric of inequalities to justify genetic screening.

[25] Bernike Pasveer talks about the Mushrooming of practices in the field of human genetics and medically assisted reproduction, despite a serious lack of regulation in the field. Most participants agreed on the importance of studying such mushrooming, from different European perspectives.

2.4.3. Final remarks

Discussions on Axis 4 were lively and interesting, although ITEMS' s members have subsumed highly heterogeneous set of studies on this Axis. At the end of the Granada meeting, ITEMS Steering Committee was advised to restrict Axis 4 to health policy issues (our themes 1 and 2), and to subsume the other themes, especially technology transfer and genetics, to one or more other axes.

This notwithstanding, there was a feeling that issues addressed at this workshop gave wide opportunity for collaboration within ITEMS network, and should be addressed at the Coimbra conference.

3. Result 3: Discussing potential cross-cutting issues

3.1. Objectives and preparatory work

Granada workshop aimed at presenting the involvement of ITEMS members' (research centres) in the four axis of the network. The workshop helped to increase mutual knowledge about ITEMS members' contributions to the four axes, and to identify crosscutting sub-themes. Coimbra Scientific Symposium had two main objectives:

i) to give European visibility to ITEMS, and to enhance ITEMS' current members' knowledge on European research related to the four axes selected by the network. The symposium was conceived of as a locus for exchange and circulation of information, and was thus opened to members and non members of the network;

ii) to deepen discussion on topics onto which common interest might develop, through presentations of individuals projects related to the four axes. The rationale was to promote interaction between researchers concerned by these four axes, and thus to feed into reflection planned in WP5 on ways of constituting a future research and training network.

The scientific symposium took place in Coimbra, on December 15th-17th 2004. Joao Nuñes, Marisa Matias, from the University of Coimbra were the main organizers of the event. Based on the map drawn in WP1 of European research centres which invested in the four axes selected by the network, and on reflection in WP2 on the scientific content and methodological aspects of these four axes, they collaborated with Ilana Löwy an the CSI for elaborating the programme (see the programme Annex 7).

The symposium gathered more than 90 participants, out of which 42, i.e. almost half participants, were not coming from research centres involved into ITEMS network. Thus, the opening of the network to its outside was quite successful.

After an opening plenary session, in which Madeleine Akrich recalled ITEMS project – especially for the participants coming from the outside of the network – and the meeting's objectives, three to four parallel sessions were held during 5 time-slots (15 sessions), where 60 papers were presented; each session comprised also a presentation prepared by a discussant, which makes about 75 presentations.

Participants were asked long before the conference to provide a 5 pages long abstract of the research project on which their presentations would draw. These abstracts had been sent to discussants, who prepared in advance a comment of the whole session, highlighting complementarities, convergences, divergences, differences between the various papers of the session. These comments had been sent before the symposium to speakers, in order to give them the opportunity to reflect upon suggestions and comments and thus enrich the actual discussion. All papers' abstracts were also made available, before the conference, to all participants on the website.

The last part of the meeting was devoted to a plenary session in which rapporteurs for each axis made their comments. Three other persons were invited to comment: one Canadian academic working on medicine, Alberto Cambrosio, and two patients' representatives, Catherine Lé (from Belgium), and Bernard Bel (from France). Finally, a general discussion was opened on the future of ITEMS.

Results

General view

Sessions related to Axis 1 manifested a vast range of heterogeneous projects. Besides, these Axis-1 related sessions gathered the highest number of presentations (18 out of 60 papers). Albeit their diversity, papers presented in these sessions hold a strong common feature: they were all concerned with the articulation between medicine and science. A majority of speakers shared a background in STS (Science and Technology Studies). This is an important specificity of ITEMS network. The closing discussion pointed to the fact that if collaborative projects are to emerge in the future on this axis, they are to be designed around common empirical medical objects (for instance screening technologies for prenatal diagnosis, biomedical collectives working on particular diseases, etc.). Consequently, research centres have to redefine, at least partly, their research programmes around these common empirical medical objects.

Sessions related to Axis 2 highlighted two main research interests:

iii) patients' political identification, notably through the development and increasing activity of patient groups and collectives;

iv) patienthood and care technologies.

As regards future collaborations, participants' long-lasting involvement and shared interest in these topics materialized into the decision to apply for a EU SSA project under FP-6 (Call identifier: FP6-2004-CITIZENS-6). Details on this application are provided below (Section V.).

Sessions related to Axis 3 were focused on two orientations:

iii) care technologies and the organization of health care systems; this issue echoes the previous Axis-2 related topic on patienthood and care technologies;

iv) information technologies and health systems.

Again, it is worth noticing that importance of technology studies for participants to the symposium.

Sessions related to Axis 4 crystallized interests on the issue of governance and new health institutions, both at national and European levels. Certain participants manifested a strong will to increase understanding on these institutions, and decided to join the SSA application mentioned above, and whose rationale is to disseminate ITEMS results on topics of high policy relevance.

The following paragraphs display rapporteurs' reports on the four axes.

3.2. Axis 1. Transformations of biomedical science and their impact on the definition of disease and of health and of care

Emilio Muñoz

3.2.1.General view

The objective of the Coimbra Symposium, as relevant component of Work Package 3, was to situate the ITEMS Network in the European Research Area. For doing so, it aimed to seeing how the four axes and the projects presented and related to them, may match with the current lines of the 6th Framework Programme, as well as with existing traditions in social studies of science, technology, health and disease and also with lines of thought which may be guiding the future Framework Programme 7.

According to this objective, the present report attempts to delineate the assets and problems existing to attain this objective in the projects presented under the label "Transformations of the biomedical sciences, of disease and health" which shapes Axis 1.

A topic such this touches on scientific and technological dynamics and processes where the intervention of social sciences can be approached through, in my opinion, two traditional frames: the STS studies, including the social evaluation of scientific and technological issues and developments (formerly referred as "technology assessment" approach), and the ElSI/ELSA (ethical, legal, social implications or aspects) line of action that become a significant part of the programmes initiatives related to life sciences in Framework programmes 4 and 5[26].

Several lines of action covered by FP6 keep links to the interests of the ITEMS network, in particular to the topics dealt under Axis 1, such as:

Line 1: Life sciences: genomics and biotechnology for health, in particular the thematic areas: a) application of knowledge and technologies in the field of genomics and biotechnology for health; b) application – oriented genomic approaches to major diseases; c) combating cancer.

Line 5: Food quality and safety with focus on: impact of food on health and environmental health risks.

Line 7: Citizens and governance in a knowledge-based society, thematic areas: a) knowledge based society and social cohesion (all three topics) and b) Citizenship, democracy and new focus of governance essentially on the topic "new forms of governance"

There are also some horizontal lines such as that of *"Science and society"* within the heading **"Structuring the ERA"** and among the ***"Cross-Cutting Research activities***" heading, the NEST (New Emerging Science and Technology) and International cooperation activities where the matching with ITEMS interests is not only possible but should be considered as desirable.

Last, but no less relevant, is worth to mention one initiative launched by the Dutch Presidency. Under the metaphoric and integral name of "Images of Science", the goal seems to produce a strong interaction between humanities and social sciences in order to study the processes of science production, its evolution and consequences, paying special

[26] During the last Framework Programme the ethical issues are considered as horizontal ones crossing all R&D+I programmes and activities within the European Union.

attention to the development of new technologies related to the fields of life technologies and nanotechnologies. It remains to be seen what future will provide to this initiative though the active intervention in it of European Commission responsible must await some continuity to it.

In the following, each one of the sessions is discussed and analyzed against an introductory background which varies depending on the topic of the session and the details of each one of the projects presented. The contents of the sessions will be schematically outlined and a tentative assessment will be provided.

One of the first general points emerging from the overall analysis is that a high degree of heterogeneity is observed between the sessions as rightly pointed out by some of the discussants.

3.2.2. Genetics between laboratory and clinic

João Ariscado Nunes, Biographies of objects and narratives of discovery in the biomedical sciences: The case of helicobacter pylori

Pascale Bourret and Vololona Rabeharisoa, *Comparing collectives in clinical genetics. The cases of breast cancer and autism*

Ulrike Felt, Maximilian Fochler, Annina Müller, Michael Strassing, *Let's talk about GOLD! Analysing the interactions between genome-research(ers) and the public as a learning process*

The projects

As the discussant (Madeleine Akrich) has well established the three projects are quite different but there is intersection between them. In addition to supporting the three directions for future directions that M. Akrich raises, I would like to insist in some arguments and add some new ones.

Some of the projects enter clearly in illustrating the "translational" process between laboratory and the clinic.

- Nunes shows the linking of the discovery of a novel, totally surprising new biomedical entity –*Helycobacter pylori* able to exist in the so-believed inhospitable environment of the stomach- to become the causative agent of gastric diseases, including some type of cancer, but at the same time providing apparent protection against other diseases, including other type of cancer.

Under this contradictory pathological situation, it was likely that *H. pylori* emerged as a subject of interest for genetic research, both for addressing the characterization of the "diversity" of the agent and the susceptibility differences of the hosts.

The history of *H. pylori* served to identify controversies between biomedical research and clinical practices as well as their intersections and the need for multidisciplinary approaches in the study of new biomedical (pathological) entities.

- By looking to clinical practices, Bourret and Rabeharisoa are also able to demonstrate the "traslation" between research and clinical practice, in this case referring particularly to the field of diagnosis.

  Moreover, the need to use multidisciplinary approaches for developing the professional settings and for studying the two pathological problems is self-evident.

- The third project, while being in a more preliminary stage, also brings complexity to surface by selecting the problem of "Genomics of Lipid – Associated Disorders" (GOLD), which involves a variety of expertises and the implication of a very large segment of the population, the concept of plurality of information and interests, a concept to which we can refer as "pluri-specialization", related though different to that of multidisciplinary.

A second point, new and interesting one, emerging from Nunes' study is that it provides support to the model of "developmental origins and disease" through the case of *H. pylori*. This argument is also present, albeit in a less explicit manner, in the Bourret and Rabeharisoa's paper where the issue appears more as a consequence of the object of the research than a cause of it. As a matter of fact, it would be interesting to integrate this issue into the analysis of the two clinical settings studied by the social scientists.

This concept of environmental influence on health and disease could be also explored in the project by Felt *et al*. by incorporating it into the interaction process between scientists and lay people. Lastly, the Felt project seems to have interesting intersection with other two Axis, 2 and 3.

Assessment of the session

Two papers were presented (Nunes and Bourret- Rabeharisoa) while the one by Felt *et al.* was withdrawn by the justified absence of Ulrike Felt.

J. A. Nunes stressed the interest of the case study for Portugal where 80% of population are carriers of *H. Pylory* what led to emphasize the importance of the geographical dimension (country variable) for this new subject of research in biomedicine and clinical landscapes (Latin America and Asia versus Nordic European countries)

Genetics was not an important discipline at the onset of the identification of this "new biomedical entity" but has become crucial for advancing in the understanding of susceptibility of humans to the bacterial agent and for the pathogenecity of the different strains of *H. Pylori.*

P. Bourret (breast cancer) and V. Raberharisoa (autism) presented their paper by treating each one of them the topics studied particularly.

Emphasis was put in the extension of medical genetics to medical relevant areas such as oncology and psychiatry. This has led to the concept of "collectives" integrating professionals with different backgrounds and skills.

Ideas were presented about the distinction between biomedicine and classical medicine and their eventual convergence leading to the identification of problems surrounding the instability of biomedical entities, the need to combine knowledge, experiences and technical instrument and competencies.

Reference was given to the process of mutual learning between the "collectives" to shape genuine communities what drives to transformations, such as the emergence of "oncogeneticists" or "bioclinicians".

Points from the discussion:

- The concept of "newness"
- Is there shifting from individual to collective in medical decisions?
- Specificities of genetic knowledge
- Convenience of comparisons with other settings.

Relation to EU programmes and activities

The projects presented under the session *"Genetics"* could fit into a European activity associated to an STS study within the *Science and Society* line or in completing some scientific projects (Networks of Excellence or Integrated Projects) from line 1 of FP6, with reference to thematic areas such as:

- application – oriented genomic approaches to major diseases

- combating cancer

Furthermore, if the idea of *Images of Science* does progress to become integrated into the activities of European R&D programmes, this line of action on *"Genetics"* within ITEMS may be well suited for it.

3.2.3. Stem cells

Maja Horst, Public articulation of stem cell innovation in Denmark

Mette Nordahl Sveendsen and Lene Koch, Moral Landscapes in the clinical encounter of stem cell research in Denmark: the issue of donating fertilized eggs

Torben Nielsen, The political ethics of human embryonic stem cells

Assessment of the session

Unlike the former session, the session on *Stem Cells* reveals a high degree of homogeneity both thematic and geographic. Some of the presentations belong to a single project and, in any case, all of them concern the Nordic countries points of view.

The objective of the projects is to delve into the public involvement in the process of political regulation of embryonic stem cells, thus fitting into the classical line of ELSI/ELSA studies or, alternatively, corresponding to the line 7 on Governance corresponding to the thematic area b) Citizenship, democracy and governance. Nevertheless, it should be opportune to enlarge the comparative part of the project extending the analysis of the process to other countries.

3.2.4. Sociology of expectations

Carsten Timmerman, Lost Hopes: *lung cancer and what the link with smoking may have done to therapy*

Christoph Gradman, "*At War with Bacteria*." Reality, Imagination and the rise of medical bacteriology (1880-1910)

Nik Brown, Alison Kraft and Paul Martin, *From promissory pasts to promissory presents: the bloody history of stem cell expectations*

Expectation can refer either to an action or state of looking forward or to something that is expected. This second meaning seems most appropriate to the objectives of this session of the ITEMS Network Coimbra Symposium.

To look at what is expected is the goal of a critical view to unfold the evolution of science production, its applications and their social projections. The outcomes to be expected and how should be expected would be different depending on the actors involved: experts, as producers and transmitters of knowledge, the users (consumers) as beneficiaries (buyers) of the knowledge produced, the social and political actors as regulators as drivers of change or brake levers for progress.

There is a common ground underlying differences and commonalities in the dynamics of the productions, institutional organization and evolution of knowledge. The consequence of the change stems in a new context for knowledge production. This new context present new interests and new rules for scientific recognition and grant funding. It also reveals the emergence of a new way of disseminating the research results and their potential effects by making them public through mass media like conventional newspapers, magazines or even Internet.

The new conditions have led to the confrontations which have shaped distinct positions and attitudes of lay people with regard to science practice and scientific researchers. This situation has been and continues to be particularly evident in the case of life sciences. Criticisms have been raised against these new trends in the production and management of knowledge addressed from different points of views and with distinct arguments. Defenders of the rights that religions (the religious thoughts) have to be part of an extended ELSI approach use to argue that science is like religion because it is based on

beliefs[27]. Others according to moral laicism, criticize the new modes by arguing that scientists (life and biomedical scientists in the particular case) act responding to interests and marketing strategies, which in fact may result from a very competitive environment to get funds and gain professional recognition.

Comments on the projects

The three projects fit into the analysis of the problems of expectations generated by scientific advances and distil a mild positive view of the progress of biomedicine. Though, at the same time, there is marked heterogeneity among them in, at least, three aspects: the disciplines and the scientific heroes involved; the underlying strategies responsible for the expectations (or their lack of); and the time scale for each case.

- The paper by Brown *et al.* discusses the case of hematopoietic stems cells, used in hematological neoplasias therapeutical assays, converted now by the force of interests to other therapeutic objectives; there are not "heroes" but a strong conflict between scientists, politicians, ethicists, norms and laws, as well as some more or less hidden national, cultural and commercial strategies. The time scale is relatively short.

- The paper by Carsten Timmerman tries to explore the links between lung cancer lost hopes for therapy and smoking. This long suspected relationship found a scientific ground in a seminal paper published 50 years ago by the group of the eminent epidemiologist Richard Doll. He was the scientific heroe but it is clear that the public imagination on an epidemiological study is quite different from that of a paper proposing a structure for DNA, both scientific facts having occurred at the same time but with different impact in representation. However, the impact of Doll's work in the domain of health policies has been very high. But lung cancer has not received all the same attention from molecular biology than other types of cancer: surgery being the main instrument for therapy, the innovative action having been addressed essentially to improve diagnosis aiming to help physicians to take decisions for application of surgery. The question is whether this medical strategy was a consequence of the scientific discourse which has prevailed in the case of lung cancer to consider it as a disease which may be prevented or to ask whether this has been an indirect consequence of the hidden agenda of the relationships

[27] It is true that scientists are believers but they need the truthness of their beliefs, in short time scale and before and expert community (usually behaving like "wolfs"). These are some differences with respect to how religious practices evolve.

between public (state) and private (tobacco multinationals) in the assumption of the costs of tobacco addition.

The time scale in this case can be taken as medium.

- The third project by C. Grandman presents a different story but also with an historical perspective.

The history of medical bacteriology has a pace lasting from one century and a half since this discipline and its strategies to fight bacteria as pathogenic agents began at the end of the 19th century and was one of the big factors to delineate the first clues of the now called "traslational" medicine. Bacteriology started in the lab and reached a high projection on therapeutic medicine advancing through progress in diagnosis, new chemotherapeutic agents, strategies to act in preventive medicine, and the development of vaccines. Unlike Gradmann states, the promises of medical bacteriology have been largely attained: millions of lives saved, improvement of life expectancy and quality, huge contribution to economic prosperity, and extension of the scientific principles and strategies of (medical) to bacteriology (medical) virology, to cite a few.

Many scientific heroes have constructed this story of success and the time scale for this case is long, resting on centuries-old work.

However, it is true that the success of the story has driven into new problems: i. e. the resistance of pathogenic bacteria to modern therapies or the emergence or reappearance of new/old microbial agents producing disease. But this is something than would be lucidly foreseen from a philosophical analysis of the characteristics of biological entities: a war against biological organisms can hardly arrive to an end.

The three projects, in spite their heterogeneity, present a series of relevant convergences. The three use the same socio – historical approach for analysing the cases selected. The disparity in the diseases, pathogenic agents involved, scientific bases to support the arguments, is not, in my opinion, a drawback but an asset as this may help to understand the underlining of the development of biomedicine, in both the research and clinical aspects.

It not so easy though how the projects can be integrated into a line of action of the European Union programmes and activities. They represent a reasonable ensemble of a "sociology of knowledge" programme but this type of research does not easily fit into the Framework Programme 6, leaving apart the *Science and Society* line. Concerning the future, I would like to draw the attention to the possibilities that could be offered by a programme responding to the concept of "*Images of Science*" as outlined previously.

It is worth to mention, in my opinion, the possibility to blend the programme that may result from this session projects with one resulting from some of those of the session on *"Genetics between laboratory and clinic"*.

3.2.5. Brave new mothers, brave new babies 1 and 2

Ilana Lowy, FISHing for identity: Maternal-foetal traffic and the change in meaning of pregnancy

Maria Jesùs Santesmases and Esther Ortega, *Pregnancy technicalised. Prenatal testing and social expectation for healthy new-borns in Spain*

Myra vans Zweiten, Tests never decide. How new technology for prenatal testing will increase professional responsibility

Amélia Augusto, Infertility *and Medically Assisted Reproduction in Portugal: From "private problems" to "social issues"*

Joëlle Vailly, Forms of judgement in the context of evidence-based medicine. Neonatal screening for cystic fibrosis in France

Tina Miller, *Transition to first-time motherhood: shifting constructions of expert, medical knowledge*

The reproductive technologies have been gaining increasing relevance and extension with time. From *in vitro* fertilization and embryo transfer first experiments, dated to late 19th century, to the incorporation of genetic analysis -preimplantation genetics and testing for genetic disease - cystic fibrosis was one of the first controversial cases- one century has elapsed. Along it, there has been a long trajectory of basic and clinical research undertaken from a multidisciplinary approach, ethical issues, norms and laws. It is also worth signalling that this subject of human transformation is at the core of the women life and the increasing recognition of their wide rights in modern societies.

Moreover, these technologies, their strategies and outcomes are at the heart of the new developments in biomedical research and clinical potentialities; I am referring particularly to the emergence of "omics" and stem cells as tools for acting in the fields of preventive and personalized medicine, respectively.

Therefore, the topic suits to the objective of Axis1: "*Transformations of the biomedical sciences, of disease and of health".*

The six papers grouped under the title *"Brave new mothers, brave new babies"* (in two?) sessions of the ITEMS Network Coimbra Symposium, dealing with issues including themes of reproduction technologies, their disciplinary contexts and prenatal testing, constitute a reasonable good research programme in which the European dimension is well present, since the authors belong to five European countries. The excellent discussion paper prepared by Celia Roberts rounds off a brilliant ensemble on which to develop a research agenda that may be integrated into the lines of action of FP6 (see below).

Ironically, the richest and more complex set of activities developed under Axis 1 in the Coimbra meeting is the one that, in my opinion, requires the minimum reporting effort, due to homogenization and self integration. The subjects treated, the comparative dimension, the organization of the sessions, as well as their contents seem to offer an adequate representation, though obviously partial, of the research landscape.

On the other hand, it is well known that the surveys to European citizenship to test the public opinions and attitudes towards the application of new genetics knowledge and techniques show the greater support to genetic testing and diagnosis among the biotechnological developments. This is an interesting, and somewhat puzzling, fact for which there is no evident explanation, leaving aside the general social support given to health applications. It could be precisely due to the links between reproductive technologies and the possibility of health protection to new borns. But it must be clear that this support does not conceal the problems inherent to this medical practice, problems that extend beyond the ELSI/ELSA frame to go into the technoscientific realm. In this context, it is worth to recall the controversy originated when the test for one-gene disease, cystic fibrosis, was settled.

The pace of the discovery of diseases with the involvement of one gene has been kept good, but he number of these diseases, though significant, is going to be limited and in many cases corresponding to rare diseases. However, unravelling the genetics of multifactorial disorders corresponding essentially to the prevalent diseases is likely to be a long and complex process.

The European Commission, while recognizing the importance of the genetic diagnostic, is well aware of the diversity existing between the European member countries regarding that technique not only at technical level but also with regard to norms and laws. Consequently, it has launched a comparative exercise that should be looked carefully for any prospect of the ITEMS Network on the topic.

i) The discussion paper prepared by Celia Roberts constitute a base document on which the contents of the two sessions can be explored and made knowledgeable. It offers very good insights as point of departure for information, reflection and discussion.

ii) The first session discussed three papers dealing with specific topics, ranging from the descriptive analysis of the FISH technique (I. Lowy) to the professional responsibility as a result of the application of several (new)techniques to prenatal diagnosis (M. van Zwieten) by passing through the problems of prenatal diagnosis of Down syndrome in Spain (M. J. Santesmanses). The second session treated more general themes: reproductive medicine in Portugal and its consequences for concepts such as biological motherhood, and adoption (A. Augusto) the application of cystic fibrosis detection in France (J. Vally) or the evolution of medicalized childbearing in the United Kingdom (Tina Miller).

It has been left clear that the projects presented in the two sessions represent a positive, highly structured step to develop a research agenda with probabilities to have links with the research interests and programmes of the European Commission. The topics cut several lines of action both vertical and horizontal, like *"Genomics and health"* under the specific theme application of knowledge and technologies in the field of genomics and biotechnology for health, *"Science and society"* with particular emphasis to gender issues. The ethical and legal aspects and the links with hot controversial issues like right to privacy and stem cells as source for future research are tightly associated to the topics explored in these sessions, what reinforces their potential interest for future actions. (*Governance as a field for projects*).

From the inner side, the subjects explored also cut across other of the ITEM Axes.

In summary, the topics dealt under the *"Brave new mothers, brave new babies"* heading must be a thread of illusion to join stones, more or less valuable, from the ITEMS quarry.

3.2.6. Drugs 2

Isabelle Feroni, *French GP's and opioid maintenance therapy with buprenorphine: professional characteristics and new medical practices*

Noémia Lopes, *Modernity, medicines and self-modification*

Petra Jonvallen, *Producing Pills, Constructing Obesity: Intersections of Research, Industry and Care in a Clinical Trial*

This session dealt with presentations on social constructed diseases and problems: opioid treatments to correct addiction (I. Feroni), self medication as a critical issue for health systems (N. Lopes) and obesity as a cross-cutting problem between research, industry and care (P. Jonvallen), by saying that the world of drugs with the complicated and diverse mechanisms of production, approval, dissemination and commercialization represents an interesting case for the social, political and ethical analysis of each step consequences. Themes such this can fit into the horizontal lines (Structuring the ERA) such as *Science and Society* or in the *Cross-cutting Research activities* such as in the NEST activities (New and emerging science and technology) where INSIGHT projects may attempt to look to the evolution of highly debated, hot topics observed from a pluridisciplinary point of view.

3.3. Axis 2. Participation of users and the redefinition of systems of actors in the domain of health and medicine

Christine Milligan

The symposium had three main aims: firstly, to map and discuss participants' research on themes related to four Axes; secondly, to identify potential areas for collaborative research across Europe; and thirdly to identify individuals and institutions that might, productively, contribute to a widening of the network. This section of the report focuses on those papers and issues arising from discussion within Axis 2. It draws out common themes emerging from the papers and reports on questions raised in group discussion. Finally, it considers the extent to which the issues raised in discussion may offer potential areas for future research.

The call for papers within this Axis focused on 'the participation of users in medical activities and debates in the context of different political traditions'.

Papers were organised around the following four themed sessions:

1) Technology/power.

2) Patients to citizens.

3) The patient partially connected, transformed or still marginalized; and

4) Risk.

Each session was structured around three short submitted papers followed by a facilitated discussion that focused on: a) topic-specific issues related to individual papers; b) emergent common themes; and c) wider research questions raised by the papers. A discussant was assigned to each of the themed sessions to facilitate this process. Each discussant firstly, produced a summary of the issues raised in the submitted abstracts prior to the symposium, and secondly, drew out issues from the papers for wider discussion. Submitted abstracts and discussants' comments are attached in Annex 1.

Key themes arising from each of the sessions are outlined below. This is followed by brief discussion of some of the overarching issues that emerged from the Axis as a whole.

3.3.1. TECHNOLOGY/POWER

(Discussant: Ingunn Moser)

> Beatrice Xavier, *Beneficence and Medical Technology: a study of doctor-patient relationship in intensive care units (Portugal*)
>
> Helena Serra, *The social construction of medical technocracies: the sociological gaze in the world of liver transplantation (Portugal*)
>
> Dawn Goodwin, *Access boundaries and their effects: participating in anaesthesia (UK)*

Xavier's paper focused on how new medical technologies and the interactions between humans and these new technologies are [re]shaping medical space and the strategies and skills required of health professionals to manage these new spaces are creating changes in the medical culture. Similar issues were raised in the papers given by both Serra and Goodwin. Serra, in particular, was concerned to examine how the power strategies inherent within these new medical technocracies are acting to [re]define the frontiers of medical knowledge. Pointing to the emergence of 'new communities of practice' that inhabit the space of the operating theatre, Goodwin maintained that these developments are manifest through the emergence of a stratification of legitimate participation within these spaces based on professional identity and expertise. For both,

the impact of new medical technology on illness and illness trajectories is creating a reorganisation and renegotiation of work tasks in clinical practice.

The general theme linking all three papers in this session was that of authority and power linked to competence or knowledge. More specifically, how authority, power, and boundaries in health care collectives are connected with, built and maintained through knowledge/competence. The papers centred on the ways in which new medical technologies are creating different medical specialisms and while each of these forms part of a 'community of practice', it raises questions about the extent to which these new technologies, and the discourse surrounding them, are also being used as a 'tool of power' giving rise to the emergence of 'technocracies' in which the division of power and labour is heavily contested. One consequence, it was suggested, is that we may be seeing the emergence of stratified and/or legitimate peripheral participation and expertise. In the main, the papers addressed how medical technologies are creating a reformulation of relationships between medical practitioners and clinicians. Xavier's paper, however, also sought to consider the relevance of new technologies in medical practice and the impact on doctor-patient relationships.

These papers also raised questions about how work is made meaningful for those involved; the gendered nature of these developments; the extent to which medical technology might replace the human face of medicine and how this experienced and understood by patients and relatives.

Methodologically, all three papers drew on research undertaken within the qualitative tradition - most significantly observation and interviews. While these are clearly the most effective tools or the kinds of research undertaken here, one issue raised was the extent to which it may be worth considering how different and complementary knowledge surrounding these issues might be uncovered using differing methodological techniques.

During the discussion, it was noted that researchers should focus not just on issues of power and hegemony, but also on disputes and breaches in and across these newly emerging technocracies as a means of examining how it might be possible to avoid colluding with the reinforcement of medical power and its distributions. It was also suggested that while most of the papers focused on bounded and time-specific aspects of practice and technology, it may also be beneficial to focus on *temporal* processes as a means of providing new insights into how these technocracies emerge and become stabilised/destabilised over time.

One final point of discussion focused on issues of risk and medical responsibility raising questions about how changing risk, associated with new medical technologies and the

rising litigation culture, may be effecting changes in medical practice from reactive to preventative procedures in some areas of medicine.

3.3.2.Patients to citizens

(Discussant: Pascale Bourret)

> Madeleine Akrich and Cécile Méadel, *Internet discussion groups and new collectives around health problems. (France)*
>
> Janine Barbot and Nicholas Dodier, *Patient Organisations, Medicine and Capitalism (France)*
>
> Susanne de Kort, *To choose or not to choose: about the chemotherapeutic treatment options in non-curable cancer. (Netherlands)*

The core theme linking this group of papers focused on patients and citizenship and questioned the status of different forms of knowledge and the interrelationship between power and knowledge.

The first paper by Akrich and Méadel raised questions about the *status and construction of health knowledge* through the medium of the Internet. Specifically they were concerned: firstly, to examine how the Internet can act as a medium for creation of new and original collectives that might act in similar ways to traditional patient's organisations. In doing so, they noted the emergence of differing 'roles' within the collective that are similar to those evident within face-to-face organisations. Secondly, they noted that as both consumers and producers of knowledge, participants in closed internet discussion groups contribute to a collective production of [lay] knowledge around health and illness that not only challenges the notion of the passive patient, but which can also challenge official medical knowledge (though this was seen to be dependent on the pathology of a specific illness and its medico-political organisation).

Focusing on more traditional forms of medico-political organisation, i.e. patients' organisations, Barbot and Dodier drew on the example of AIDs organisations in France to illustrate the tensions that can exist between traditional bio-medicine that seeks to reinforce the status quo, and the pressures of external organisations, such as patient groups, that attempt to disrupt what they refer to as 'bio-medical capitalism'. Barbot and Dodier illustrated how, over time, AIDS organisations have sought to challenge what they refer to the 'evidence-based capitalism' of the clinician in order to create a legitimate role for themselves as new actors in the production of evidence based medicine.

Finally, De Kort's paper focused on the paradox of *choice* and what constitutes real choice in potentially life or death decision-making around treatment. While knowledge equates to power – and the power to make informed choices - de Kort illustrated that in palliative treatment settings the time factor is weighted against patients' ability to gain that knowledge, inhibiting their ability to find possible alternative options. In palliative settings, then, not only may choice be filtered through the clinician but, she maintains, a critical understanding of factors affecting patients' choices needs to take account of wider contextual factors, such as the degree of choice available, quality of life and family issues.

One set of issues arising from discussion in this session focused on expertise and the transformation of the passive to active patient in medical and social space. In part this focused on patient empowerment but also raised questions about what constitutes a patient collective and what are its distinctive features. In turn, this lead to discussion about how, one the one hand membership of the collective might affect individual action; and on the other, whether [or to what extent] lay knowledge 'seeps in' to and affects medical expertise contributing to a co-production of medical knowledge.

A second set of issues running through the papers focused on choice, suggesting that choice may only exist a) where there is no real choice; or b) where it is defined by the medical profession. Questions were thus raised firstly, about the extent to which real choice is predicated on the handling of a shared body of knowledge; and secondly, about the links between choice and compliance. A final point of discussion focused on the extent to which all these issues might be translated within a broader European or institutional framework.

3.3.3. The patient – partially connected, transformed or still marginalized?

(Discussant: João Ariscado Nunes)

Celia Roberts, *New kinds of patient? Examples from contemporary hormonal discourses. (UK)*

Maggie Mort, *The future patient: appearing in telemedicine, telehealthcare and e-health. (UK)*

Christine Milligan, *Towards inclusive spaces of care: care transitions and informal care-giving in the 21st century. (UK)*

This session explored how the contemporary 'patient' and care-giver is being formed and reformed through new health technologies, health controversies and the spatial politics of healthcare. Assumptions about "agency, compliance, resistance or empowerment" were called upon to engage with this 'ongoing shaping'. The main questions asked as triggers for this engagement included:

What **socio-technical forms of patient** are currently emerging?

What kinds of **social and power relations** underpin the contemporary patient and care-giver?

How are understandings of **risk and responsibility** played out in these new versions of the patient and carer?

How are **old relationalities replayed or mutated** within these new conceptualisations?

To what extent are technical and socio-political developments **reforming the complex landscapes and organisational spatialities** of health and care?

Robert's paper was concerned to bring recent feminist debates around sex, gender and the body together with critical approaches to techno-science and biomedicine as a means of thinking through questions concerning: a) biological science from a social science perspective; and b) the emergence of 'new kinds of patients'. Using examples linked to controversies surrounding hormone replacement therapy (HRT) and environmental estrogens, Roberts' project illuminated how scientific discourse and media debate around risk and benefit impacts on the everyday lives of women – seen as gendered patients - who are the target of controversial therapeutic interventions. Such interventions not only 'pathologise' women, but also raise questions around risk and responsibility as women's' biological development (through the sexed body) and reproductive health is affected.

In a paper that had close synergies with that of Akrich and Méadel, Mort raised questions around: a) the construction and practice of telemedicine; how it is constituted as a field where risk is experienced and resolved; and c) what this means in terms of the patient/practitioner relationship. Focusing on the changing (and future?) configuration of the patient she critiqued the ways in which ICTs are seen to act as means of empowering patients by, firstly reducing their dependency on health professionals; and secondly, shifting responsibility and agency to the patient. Rather it is suggested that these developments may be acting conservatively, extending and recreating asymmetrical power relations in the clinical encounter. This also raises the question of the extent to which ICTs may be shifting the responsibility for care from the health professional to the family.

Finally, Milligan's paper drew on spatial perspectives of care and care-giving to set out a political topology of healthcare linked to the socio-spatial attachments and redistributions, which shape and enrol new actors in the field of care-giving. A central question raised by the Milligan concerned the changing attachments to place over time in situations of long-term care, where the initial experience of displacement, of moving from "home" to a "non-place" (Marc Augé's term) may "take on some of those characteristics more commonly associated with home", depending on conditions for integration.

Underlying these papers was a concern with how new technologies and differing patterns of healthcare delivery may on the one hand, be acting to reconstruct the patient as a disembodied actor – or in Mort's terms as 'the absent patient', and on the other, redefining those traditional medical spaces in which healthcare takes place. In doing so, the papers in this session generated debate around a range of issues that can be broadly summarised within three key themes:

Firstly, discussion was raised around the reconfiguration of the patient defined as the patient/user and patient/carer. More specifically questions were raised about responsibilisation and the extent to which new technologies and the changing place of care may be placing increased responsibility on the patient to become an 'expert' in the self-monitoring of his or her care. This in turn raised discussion about the status of knowledge, what constitutes 'expert knowledge' and the role of indigenous innovation in the practice of healthcare. Finally, within this theme, discussion centred on what happens (or has happened) to the 'irresponsible patient' within these newly [re]emerging care settings.

The reconfiguration of the patient also led to discussion around to the political topology of care, the redefinition of attachment to place over time, and the rise of the absent/distant patient. Not only was it noted that the home was [re]emerging as a critical site of care, but linking back to the previous session, it was suggested that this development left ambiguous room for the formation of patient collectives. The second theme, thus, focused on the healthcare implications arising from the reconfiguration of medical space as both geographically and virtually conceptualised.

Both of the themes above gave rise to discussion around the development of new forms of dependency on medical proficiency, the redistribution of skills in healthcare and the changing configuration of risk.

Thirdly, discussion centred disparities in health and healthcare. In part this was linked to the need to examine the impact of new medical technologies from both a gendered and

class perspective. It was also suggested, however, that there was a need to examine how these developments were reflected in the asymmetries in health and medicine across Europe, that is, the extent to which the 'imagination of the core' (advanced countries) may be impacting on 'catch up' (peripheral) countries.

3.3.4. Risk

(Discussant: Pascale Bourret)

> Boel Berner, *The Blood of Others. Technology and the Construction of Risk and Safety in Blood Transfusion (Sweden)*
>
> Lindsay Prior, *Repositioning the patient: the implications of being 'at risk' (UK)*
>
> G. G. Palmboom, *Life at risk -living at risk? Predicting in medicine: disclosing low risk information in patient-physician (Netherlands)*

The three papers in this session took as their starting point the increasing presence of risk in contemporary medical practice. The proliferation of risk was analysed as a consequence of the introduction of technologies (in particular, genetic tests) associated with the development of epidemiological tools and data allowing for the calculation of new categories of risk and lower risk thresholds. The papers brought to the fore the multiple forms and natures of "risk" in the biomedical field, as well as the multiple issues raised by this notion from a social sciences perspective.

Within the session, risk was addressed in two ways: firstly, Berner and Palmbloom discussed risk in relation to the performance of medical interventions. For Berner this was examined in relation to the construction of risk and safety in blood transfusion technologies. Underpinned by an actor network approach, he sought to explore the linkages between technology, politics and public health. Palmbloom considered medical risk in relation to colonoscopy procedures and foetal testing and sought to ask questions about the nature of risk and expertise in relation to risk disclosure and decision-making around risk-taking.

Secondly, Prior focused on questions of genetic risk in the context of hereditary predispositions to cancer. In doing so, he sought to examine how people integrate genetic risk information into their life-worlds and suggested that those 'at risk' see themselves as occupying a liminal position between healthy and sick. His overall project aimed to make sense of how genetic knowledge acts to redefine 'the patient' to include those 'at risk' of disease as well as those who are already ill.

All the papers in this session were concerned with how risk is constructed and performed and drew attention to the issue of *low risk* and how patients and practitioners deal with risk (particularly low risk) knowledge. This in turn raised questions about avoidance of risk knowledge versus the desire to know. In pointing to patients' lack of interest in low risk knowledge on the one hand, their desire to be prepared in case of materialised risk on the other, and how this paradox is managed within the healthcare profession, we are drawn to consider what counts as knowledge/information. Prior further noted the differing ways in which lay people and practitioners evaluate risk, arguing that for some, the monitoring attached to high risk status is seen as more comforting than a low risk status in that it defines where the individual belongs in the healthcare system. This all raised questions around the ownership of risk knowledge, what we mean by risk, who determines it and whether risk assessment should be individually or population based.

Discussion within this session focused on the proliferation of risk in contemporary medical practices and explanations to account for it. These included: the adoption of new tools and techniques to address medical issues (particularly genetic ones); the increase in predictive and calculative capabilities; and social transformations in the perception and evaluation of risk in contemporary society. Secondly, attention focused on the extent to which differing policies, practices and professional ethical standards occurring within differing communities of practice across Europe impact on how problems of risk are constructed. Thirdly, questions were raised about how risk is articulated through medical interventions, how it is related to communities of practice and the relationship to technology and patients. This in turn raised the issue of uncertainty and whether there is a place for uncertainty in the construction of risk.

Finally, discussion within this session focused on the shift from the care of disease to the management of risk and whom the actors involved might be.

3.3.5. Common themes across all four sessions?

Some common themes were identified within this Axis that ran across the four sessions. These may hold potential for future potential European research collaborations and are outlined below.

1) Many of the papers in this Axis shared a common preoccupation with the re-configuration of patient identities, roles and activities within medical/social space. This did not mean that each project had a similar understanding of what constitutes a patient, to the contrary, "the patient" was constructed and understood in very different ways – examples focused on the 'patient collective'; the 'absent patient'; and the 'liminal patient', pointing to the potential for the

development of further work that explored the implications of the reconfigured patient for policy and practice within a wider European framework.

2) Secondly, there was a broad concern with the changing political topology of health care, linked both to socio-technical assemblages and spatial redistributions, that shape new actors and reshape the "patient", whose attachments move from the doctor-patient relationship to a broader web of social, technical and spatial connections.

3) Thirdly, cross-cutting many of the papers in this Axis was a concern with the status and construction of information and knowledge/power through, or surrounding, new medical technologies and the discourses surrounding them. Here, there was a concern was to further examine the paradox of how new medical technologies are contributing to a [re]construction of medical 'expert knowledge' on the one hand; and on the other, a reconstitution (or elevation) of the status of lay knowledge in ways that affect patient/users' decision-making and choices.

4) Fourthly, there was a common concern with risk and the proliferation of risk in contemporary medical practices arising: a) from the introduction of new technologies (in particular, genetic tests); and b) the development of epidemiological tools and data allowing for the calculation of new categories of risk and lower risk thresholds. The papers brought to the fore the multiple forms and natures of "risk" in the biomedical field, as well as the multiple issues raised by risk from a social sciences perspective.

5) Fifthly, many of the papers referred to time and space and how medical technology etc. requires us to rethink or reorder our understandings of how those medical spaces in which patients/clinicians are active are reconstructed over time. It was suggested that while space and time are frequently used in a metaphorical sense, there is room for a greater engagement with spatial and historical concepts as a means of drawing out the interrelationships between time and space in the provision/practice/experience of health treatment or medicine.

6) Finally, nearly all the papers presented drew on qualitative methods – particularly ethnographic approaches -to examine the topic of interest. This raised questions about the differing sorts of knowledge that might be uncovered by engaging with differing methodological approaches. This suggests the need

for collaborative research that focuses on the development of innovative methodologies.

3.4. Axis 3. Coordination in Health Care Systems: Organisational Reform and Information and Communication Technologies

Antoinette de Bont

Axis 3 focused on the developing trend towards standardisation and formalisation of medicine and health care. The Coimbra meeting for axis 3 had been organized around three themes:

1) Standardization and evidence based medicine; Evidence based medicine amongst medical professionals might have lead to greater convergence and standardization in clinical regimes and health policies.

2) Health and information; Efficient and qualitatively better services are said to hinge upon electronic information flow through care processes.

3) Technologies and health care; ICTs are conceived as the tools for improving the coordination and continuity in service delivery, strengthening the quality in such trajectories, securing information availability and more efficient planning and resource utilization.

We discussed this trend by analysing the different pressures and outcomes for standardization. Most papers focused upon:

1) The local, material and emergent conditions for information and communication technologies.

2) The interference of standards and information– and communication technologies with care processes.

3.4.1. Standardization and evidence based medicine

Chair: Christian A Gericke, Discussant: Jean de Munck

Christian A Gericke, *Ethical issues in applying economic tools for priority setting to health research funding*

Eeva Sointu, *In search of wellbeing*

Joachim Gerich and Roland Lehner, *CASI-Methods in Heath-Related Research*

Schreyögg J, Busse, R, *Effects of drug budgets on physicians' prescription behaviour - experiences from Germany*

The papers presented by Jonas Schreyögg, and Christian Gericke focussed on the pressure of the state for cost-effectiveness in health care provision and equity in access to health care. According to Schreyögg, the introduction of drug budgets in Germany in 1993 improved the quality of the physicians prescribing behaviour as physicians have described less pharmaceuticals with disputed effectiveness and more undisputed ones since then. According to Gericke, priority setting tools can guide health policy decisions more adequately if ethical criteria like moral obligations of non-abandonment and a professional obligation to advance medical science are included.

Eeva Sointu's paper showed another, totally different outcome of standardization in health care by giving an explanation for the rise of alternative and complementary health practices. She showed how patients discovered and followed one's own and individually specific path in these health practices. The patients she studied wanted their personal experiences and understandings of illness to be recognized. Their goal highly contrasted with the goal of many states that patients and users shall experience their meeting with the health services as one integrated and informed trajectory.

3.4.2. Health and information

C. Raghavendra Ranjini, *Coordination between Norway and India in developing a health information system for primary health care*

Margunn Aanestad and Ingunn Moser, *Making information flow across boundaries. Visions meet work practice in health care*

Perdiguero, E., Ballester, R., Castejón, R., *Mass-Media and health information campaigns in Spain (1920-1936)*

Samantha Adams, *«The reliability claims of tools (hyper-linked seals, portals) that have been designed to help users assess medical information on the internet"*

The papers in the second session focussed upon the local, material and emergent conditions for information sharing. Raghavendra Ranjini showed why computer-based health information systems could contribute to better resource allocation, planning and

health care delivery in Norway, but could not do the same in India. According to Ingunn Moser electronic production and exchange of patient related information will always remain partial. Hybrid solutions (paper records plus digital records) as well as a portfolio of specialised IT systems will always be needed as the patient information does not follow simple and linear trajectories. All information is made in a particular time and space and for specific purposes. Sam Adam's paper focused upon the different reliability claims of tools (hyper-linked seals, portals) that have been designed to help users assess medical information on the internet.

Information, we concluded at the end of this session, is a problematic analytical concept. Assumptions about how information is shared and made mobile that the concept of information carries, should carefully be studied. Therefore we will need other concepts, like situated knowledge.

3.4.3 Technologies and health care

Antoinette de Bont and Roland Bal, *Face to face in a database. A reflexive study about monitoring quality of care*

Dick Willems, *Care at distance. Tele-care as the promised land of the care of chronic diseases*

Ericka Johnson, *Situating medical simulators in clinical training: reconstituting medical patients and practices*

Roland Bal and Femke Mastboom, *Optimizing GP -Specialist interaction through ICT: A qualitative analysis*

All papers in the last session focused on how ICTs interfere with work or care processes. According to Dick Willems, tele-care will change the relationships between physicians, nurses, and patients. Patients will for example relate in new ways to their body as bodily functions will be measured from the home that is filled with machines. Femke Mastboom's paper showed how tasks and roles between GP's and specialists changed subtly as new ICTs were introduced. She showed us the problems caused by the new distribution of responsibilities, duties and risks. Ericka Johnson studied how teaching physicians are *reconstituting practices* to incorporate electronic simulators into situated learning. Professional practices, according to Johnson, are not replaced by ICT, they are recreated. Antoinette de Bont's paper was about how the use of ICT reconfigured the way 'being a professional' was interpreted and organized. She explained why professionals want to abandon a project that has proved to be an example more efficient and effective

care and in which these professionals have participated for more than three years. Issues of trust and changing communication patterns were central in this regard.

Overarching themes

At the end of Granada workshop three overarching themes were selected for the Coimbra workshop:

Evidence based medicine;

Health care transformation and formalisation of care practices (like care pathways);

Relation between local and national decisions in relation to international health reform trends.

We discussed these themes from two different perspectives, a public health perspective and a constructivist perspective. Researchers with a public health or epidemiological background presented evidence based medicine and the formalisation of care practices as opportunities to modernize health care. Researchers with a sociological or philosophical background presented evidence base medicine as a strong ideal which assumptions need to be discussed (see table 1)

Rationalization	**Bureaucratization**
Modernization of health care	Effectivity is only one notion about health and health care. Other notions are as important
Data should be well defined for managers, physicians and patients	Local adjustments to local goals and systems are needed
Integrated systems are needed	Much work is needed to make ICT work
Every should have access to electronic information	ICT can only work together with other (paper) systems

The discussants and the participants started to link both perspectives by asking the following questions:

What is evidence at a particular moment for a particular actor?

What is information at a particular moment for a particular actor?

Hoe does ICT work at a particular moment for a particular actor?

As was suggested in the report about axis 3 in the Granada workshop we also started to discuss ways to mix qualitative and quantitative methods. We, for example, discussed the possibilities to study drug use or prescription patterns by taking into account specific cultures of medical consumption. Or we explored the options to grasp non-standard dimensions of health care by the formal, standardized by rich electronic survey that Joachim Gerich developed. What became clear were the different takes there are in approaching these issues (of which table 1 is a summary). The Maastricht workshop should discuss the possibilities of integrating these different perspectives.

3.5. Axis 4: Articulation between health and policy issues

Patrick Castel, Centre de Sociologie des Organisations (CNRS/Sciences Po), France

This report aims at exposing a synthetic overview of the themes, subthemes and concepts that had been tackled by the communications and discussions related to health and policy issues during the Coimbra Symposium. However, relying on these exchanges and taking into account the report on Granada workshop, its main aim is to assess possibilities, perspectives and challenges for further collaboration between ITEMS members.

3.5.1. Overview

AXIS 4 was composed of 5 sessions which grouped between two and four communications:

Session 1: Health Medicine and National Borders.

Session 2: Governance.

Session 3: Disability.

Session 4: Drugs.

Session 5: Concepts.

Given the diversity of the researches that were presented during these two days (regarding their field of research, their theoretical backgrounds as well as their state of progress), it would not have much sense to try to summarize exhaustively the different sessions. It is thus also impossible to identify some common trends regarding the evolutions of European health care systems or, on the contrary, some major differences between European countries regarding health policies yet.

However, we will present in this report i) some themes which may be considered as key-words that were very often shared and used by participants across sessions and ii) three more general cross-cutting issues that were discussed and debated.

3.5.2. Key-words

Obviously, the topic *"public policy"* was often at the core of the communications. *Disability*, *mental health*, *health promotion*, *health and environment*, *development and regulation of drugs* were the major fields of research regarding health and policy issues.

Biomedicine – and in particular *genomics*, *genetics*, *biotechnology* – appeared to be also a frequent field of investigation.

Concerning analytical and theoretical questionings, some common concepts were also very often used by the participants. We must add that these concepts were rarely strongly defined, so that it is difficult to assume that all participants agreed on their meaning.

The classical questioning around *"medicalisation and/or politicisation of health problems"* appeared to structure more or less explicitly many communications and discussions. *Norms* and *deviance* as structuring patterns concerning the articulation between health and policy issues and *normalisation* as a new orientation of public policies were also tackled by many communications.

To finish, two broad themes underlined communications: *(in)equity* and *quality* in the health care system. These are of course major issues in this field. They may be considered as political in three ways: i) actors (and mainly regulators) assume that improvements in equity and quality are two main goals of health care systems and, thus, two major areas of public policies; ii) equity and quality represent issues that are at the core of power relations between actors in health care systems; ii) they imply very often a (more or less conscious) political positioning of the researchers or, to put it in other terms, one may observe frequent ambiguities in the statements made by the researchers on these issues, those being situated between moral judgements and scientific, positive assessments.

3.5.3. Cross-cutting issues

Three cost-cutting issues may be identified.

Impact of biomedicine and new types of medical knowledge on health care systems

First, the transformations that biomedicine and, more broadly, the new types of medical knowledge imply for European health care systems have been a major issue tackled by the participants. In particular, the possible impact of these transformations on public values and on the definitions and shaping of disease, health, citizenship, integrity of human body and even identity was underlined.

More precisely, the way these transformations spread among populations and impact the relationships between the different categories of actors was under scrutiny. How do the various actors position themselves regarding these new types of knowledge and issues that are related to them? Can we observe the apparition of new individual or collective actors who play a role – or try to play a role – in the formulation of the problems and solutions and in the control of some issues related to biomedicine? Obviously and not surprisingly enough, the question of the differences and possible conflicts between medical knowledge and other kinds of knowledge – such as lay knowledge and patients' knowledge – was pregnant.

Many communications tried also to answer the following question: can we observe some new integration processes – which would then have to be characterised and theorised – around (new) health issues that have emerged from biomedicine and medical discoveries or is the medical approach still dominant and someway exclusive in the formulation and handling of these issues?

How do health care systems take care of poor and/or disadvantaged people?

This issue was tackled mainly through the question of the definition and implementation of the public policies that aim at taking care of this category of users. Some communications underlined more or less explicitly the dangers of purely medical approaches or purely technocratic choices to define and implement such policies. Can we observe some controversies or conflicts in this domain?

The question of the involvement of poor and disadvantaged people in the definition of the policies that concern them was also at the core of the exchanges between participants. Two types of communications were presented: some were positive, aiming at assessing

how these users are involved in research and policy development, and some were more normatively-oriented trying to propose solutions for a better involvement of these users.

Let's notice that it seems all the more interesting to investigate this issue since health care systems have been more and more oriented towards public health spending restraint. In a context characterised by public spending restrictions on the one hand and by more and more expensive medical techniques on the other hand, how is the question of the poor and disadvantaged people tackled by decision makers and by health professionals? Is there a risk that they become the forgotten and forsaken users of our health care systems, health policies being focused on the regulation and funding of innovative medical techniques and neglecting social orientations to the prejudice of these disadvantaged people?

Government and/or governance?

A last cross-cutting issue is related to government and governance. This issue was especially tackled during the session on "governance" and on "drugs", but may well be suited for other topics.

It was raised during discussions that it may be surprising that the concept "governance", which has been mainly used in the field of public policies – and especially local ones –, is used in the field of biomedicine. One has to be careful that this concept does not impede close attention to, and acute characterisation of the nature of the relations between actors in this domain.

Communications and discussions were interested in clarifying the role played by the States in the definition and implementation of health policies concerning issues which are more and more complex. Are the States nowadays more involved in keeping things running than in shaping or changing them? The way other actors or institutions interfere with public policies was a major questioning. In particular, it was underlined that the pharmaceutical industry, the associations of patients and the researchers were more and more influent actors, whom it is important to study while classical studies in history and sociology of medicine have tended to neglect them.

Another major topic concerning this issue dealt with the participation of users. Do public decision makers try to involve them, how do they try to improve this participation, and what are the consequences of their choices? On the other hand, can we observe some social movements (i.e. some bottom-up collective action), which have a strong impact on policies?

We must notice that, quite surprisingly, the role of supranational institutions such as European regulation bodies and World Health Organization was tackled by only few communications.

3.5.4. Perspectives of further collaboration among ITEMS members

Methodological aspects

Main studies adopted qualitative methods, based on interviews, focus-groups, ethnographic methods and/or archives. Only one communication was based on a quantitative study. This may be astonishing since there is a strong tradition of quantitative studies in medical sociology. Just to mention the early works of the Chicago school or even, more recently, the much-praised book of

W. Richard Scott on institutional change in the American health care system. Should we consider this qualitative orientation as a European trend – a kind of European peculiarity on this topic – or is it just a contingent result due to the submission and selection process of the symposium?

Nevertheless, on the one hand it may represent a facilitator for further collaborations and debates between several research teams and even for the conduct of future multi-centre studies.

On the other hand, more quantitative studies and data would be welcome in order to possibly assess some global or European trends regarding the evolutions of our health care systems and to allow other kinds of comparisons between European countries (regarding health policies, for instance).

Few comparative researches

The second point deals also partly with methodology: few researches had a European dimension. Few adopted a comparative approach between European countries and few tried to assess a Europeanization process or a European integration regarding health policy issues (3/16). Most studies were exclusively nationally based (10/16). On the opposite, some others were internationally oriented, beyond Europe (3/16). Not surprisingly, these were communications dealing with the World Health Organization, Biotechnology, (new) diseases and (new) medical knowledge…

What kind of comments can we draw from this? One may adopt two points of view: the first one is pessimistic and the other one is optimistic.

First, the pessimistic view: Europe is not a taken-for-granted reality for European social scientists in the field of health policies… yet. No doubt, this reflects the fact that policies remain on many health topics largely States-centered. But, even on such topics, which we should explicitly identify, to investigate why there is not a European reality could be very interesting.

And this leads up to the optimistic point of view: thanks to the richness and the quality of the empirical researches which were presented during the symposium, comparative studies could be a very promising opportunity. To compare national policies against addiction, inequity, or for health promotion, waste management, etc. could be very interesting and heuristic. The comparison of the ways users are involved in the different countries concerning some health issues represents also a promising object (e.g. involvement through State-driven deliberation processes vs. bottom-up mobilisation). Can we identify a European model or not? If, for some topics, the answer is no, understanding the reasons why is worthwhile. If, for other topics, the answer is yes, what kinds of social mechanisms can be identified?

Such a comparative approach could be fruitful in two main ways.

First, ITEMS members could contribute to more general debates in social science, beyond the sole field of health. Just to mention two examples, comparative studies led in the field of health could contribute to debates about the European integration and about institutions – institutions being defined either as organisations or as values or taken-for-granted scripts. For instance, what can be said about regulation bodies such as agencies in the different European countries and at the European level? How do they emerge, how do they function and what do they produce? Another possible topic would be the "institution of quality (of care)" in Europe, since most communications dealt more or less explicitly with it. What kinds of organisations are responsible for quality in the different European countries? Can we identify some national differences in the conceptions of "quality of care"? And is the national level the relevant one to investigate such a topic? The same investigations could be pursued for "equity".

Second, adopting a comparative approach for the topics tackled during the symposium could improve our understanding of the transformations that have occurred regarding classical questions in the sociology and history of health, illness and medicine: the professional work, the factors affecting the integration or disintegration of the medical profession, the roles of the users in the health care systems, the relations between regulators and professionals… In particular, it is a heuristic way to show evidence of some convergences and divergences on these matters and to assess the relevant factors

that explain these converging or diverging evolutions. For instance, it should allow a better understanding of the way some macro variables such as the emergence of biomedicine and new types of medical knowledge structure the evolutions of European health care systems.

Challenges at hand: towards new shared theoretical backgrounds?

To conclude, it appears that participants lack some (shared) theoretical concepts or devices to enrich their discussions. For instance, the concept of "medical profession" had been a core concept able to integrate the field of history and sociology of medicine in the 1970s and the 1980s, every researcher trying to contribute more or less to this debate in refining the concept or in criticising it. It may be doubtful if one may find such a successful, integrative concept nowadays. However, developing new concepts seems to be a worthwhile purpose for ITEMS members to continue scientific dialogues as well as a challenge in order to enrich future collaboration.

Indeed, our last two points are intertwined. On the one hand, more comparative researches are necessary to refine our knowledge about the divergent and convergent transformations affecting European health care systems, and thus to succeed in developing relevant theoretical concepts which allow a comprehensive understanding of the social mechanisms at stakes. On the other hand, theoretical reflections are needed in order to aggregate more fruitfully the results of the different empirical researches.

Given the very constructive nature of the debates between participants during the sessions and, more generally, given the conviviality of the informal exchanges during these two days, one may be optimistic on the willingness of ITEMS members to pursue and to improve collaboration, so that they may be well able to take up the challenges that have been proposed.

4. Result 4: Reflecting On Phd Training And Post-Doctoral Circulation

One of the main elements in the constitution of a future research and training network is the circulation of PhDs and post-docs between the different European research centres, and the design of coordinated training. The effectiveness of a network depends on its capacity to maintain, at all levels of activity, high quality cooperation and exchange. PhD theses and post-doctoral research also contribute in an essential way to the formulation of questions that will constitute the field under study in the medium term. It is therefore crucial to allow PhD and post-doc researchers to meet one another on a regular basis so that they can be included from the outset in the European research community.

In line with this objective, the aim of the WP4 was to draw up an inventory of the ways in which PhD and post-doc training are organized in the different countries. This was intended as a preparatory work to the reflection planned in WP5 on the meeting and circulation of PhDs and post-docs between the different European research centres, and the coordination of common educational activities.

The method consisted in an electronic survey of PhD and postdoctoral training across network members: key persons in 22 centres across the network answered 17 questions relating to PhD and post-doctoral training and circulation, i.e. current policy and practice, if relevant collaborative European initiatives members may already be pursuing, or ideas about what would enhance such circulation for the future. (see annex 4.)

The second part of the survey consisted in arranging for PhD students to visit member centres to follow up on information provided in the surveys. The purpose of the visits was to follow up in more detail on responses in the survey questionnaire, and to obtain the views of PhD students and postdoctoral fellows themselves about the value of increased circulation and collaborative training across the network. 15 students visited 13 centres across the network between January and May 2004. (see annex 5.)

The extent of the WP4 'community' is large – on the responses received by early 2004 the centres included **150 PhD students and 33 post-doctoral fellows**.

Each visitor wrote a detailed narrative report. On the basis of these reports and on the basis of the survey, a final report was issued that provide detailed description of each research centre, PhD programme and opportunities. Besides being confronted with another academic context, the visitors developed reflection on PhD training and circulation, which led to the following conclusions:

4.1. WP4 Conclusions

There is support within the ITEMS project for developing a future network for social and humanities studies of health and medicine. Such a network does not currently appear to exist.

There is support for an **international summer school in health and medicine studies**, co-ordinated through the ITEMS network and containing a thematic structure so that topics can be explored in sufficient depth to be of use to both doctoral and postdoctoral students and other researchers.

There is support for **a co-ordinating centre for the development of joint teaching and research initiatives** and exchanges of students and staff in social studies of health and medicine.

However, students and post-docs are concerned that EU circulation should be voluntary; that language support is available, and that sufficient funds are made available to enable study visits of medium term duration; (short visits were not seen as useful).

Erasmus and Marie Curie schemes were mentioned by only one respondent to our survey, indicating they were playing little part in the development of health and medicine studies in the social sciences or humanities. Erasmus and Marie Curie schemes are not specifically targeted at health and medicine studies and so perhaps are not considered by researchers working in this area.

4.2. What would enhance phd support and training within the context of EU collaboration?

Increasing communication – interactive websites to encourage PhDs to contact each other, to publicise courses and workshops, to publicise opportunities for joint supervision, to post working papers and receive comments, to pose questions (about studies in other countries, bibliography etc.). Provision of annually updated European PhD research interest register. Increased communication between research centres about availability of institutional resources.

Establishing funding opportunities – dedicated travel fund for postgraduates as part of broader funding for EU networks; set up funding opportunities to enable students to attend international conferences and workshops, 3 month bursaries for PhD students to visit another EU centre relevant to their work.

Building on existing schemes and developing new avenues for collaboration – Many useful examples were cited here and we list them below:

- Student exchange visits (one term e.g. 10 weeks approx, between collaborating depts.).
- Workshops/intensive courses/summer schools on specific research methods or topics that encourage exchanges of approaches and ideas (e.g. comparative studies in the history of cancer in 20th century; uses of sex hormones as drugs; Actor-Network Theory and health).
- Developing opportunities for co-supervision of students.

- Formation of virtual interest groups – these should be student-led e.g. around migrant health or new health technologies.

- Organisation of conferences/symposia perhaps following the model of the Joint Atlantic seminars in USA.

- Developing a flexible distance-learning teaching programme that can draw on lectures from different countries in the scope of a common modules.

- More reporting (through brief notes on the website) of activities, visits plans, employment opportunities.

- Exchange opportunities for lecturers/researchers (long and short exchanges).

- Shared teaching in European Masters degrees.

- Language teaching at Masters and PhD level.

4.3. Prospects

Maggie Mort presented the findings of Workpackage 4, gathering data on the existing provision for post grads across the members of the network and their views on the merits of research exchanges, etc. WP4 stressed that there is considerable support for some kind of international summer school on social science applied to health and medicine and that this currently does not exist. A possible RTN could respond to this requirement.

Provided these conclusions, various options for a future RTN were considered at the last steering committee meeting in Paris in January 2005. These options were presented and discussed at ITEMS final meeting in Maastricht. There, four groups were set up to deepen refection on three related questions.

GROUP WORK

The discussion in groups was oriented around three related questions:

1) Research question – themes: to what extent are these likely to give rise to coherent focused research projects?

2) What's the deficit? On other words, to what present deficit in knowledge would the RTN respond? This could for instance be concerned with the present weaknesses of mainstream Health Technology Assessment (HTA), etc.

3) What kinds of activities should be organized to feature in an RTN?

Feedback from the small groups:

- The core focus of the RTN should stress the role of new and emerging technological innovation and questions that arise from the novel challenges presented by innovation – building on this we could, for instance, use various boundaries (classifications, taxonomies of disease and therapeutics) as a basis for understanding innovation and assessing the implications of novelty. In a sense, this would play to the strengths of the network in Science and Technology Studies.

- To what extent would Europeanisation or the 'cosmopolitanisation' of medicine figure in the definition of the problem? The ITEMS network already has a track record in focusing on the comparative position of health technologies in different national contexts and this should be given a high profile in any subsequent application.

Questions that arise here might, for instance, focus on the movement of patients across European national borders and the phenomenon of treatment tourism, or the 'out-sourcing' of treatment by some nation states to others. What is the role of regulation and standardization across and between these national systems and to what extent might this imply some form of 'de-Europeanisation' as patients increasingly look beyond Europe for treatment?

The question to be developed here is how these border-crossing map onto technological innovation, in say the consumption of reproductive medicine, the regulation of tissue engineering, the formation of international patient organizations lobbying for particular avenues of research and treatment? A core consideration here is the different ways in which innovative health technologies figure in either the stabilization or destabilization of European medical space.

There was some lengthy consideration in the discussion given to the role that might be played by questions of 'standards' and standardization in assessing these processes of convergence and difference across European medical sectors. This gives rise to questions of who defines standards, patterns of agency and authorship, resistances to standards from various communities, their different levels of obligation and enforcement, ranging from strong legislative measures (on say cloning) to professional and voluntary guidelines (on say, 'best practice', etc).

Another point to develop is the relationships between micro research considerations in highly specific case studies and how young researchers might, or might not, be differently skilled in making these cases speak to 'bigger' questions – the relationships

between the empirical and the theoretical, case based specificities and network-wide comparative questions.

4.4. Further discussion

It was seen to be essential that we stress strongly the limitations of existing approaches to medical innovation, especially the tendencies in HTA and bioethics to start from highly normative positions that do not necessarily lend themselves to reflexive consideration or 'stock taking'.

Again, any future initiatives should very strongly stress the internationally comparative interdisciplinarity of the network, but without compromising coherence.

In terms of coordination, this remains a serious problem yet to be resolved. Coordination is likely to require an existing administrative and scientific capacity that can focus concertedly during both the outline stage (Sept 2005) and subsequently if the application is developed into a full proposal. There are problems for most institutions in terms of not having sufficient 'slack' to free time up to concentrate on coordination. There are the additional problems of the Commission having received a very disproportionate number of applications from UK institutions. Country representation may well prove to be a highly significant political hurdle when the decision is put to the research committee.

IV. CONCLUSIONS AND POLICY RECOMMENDATIONS

During its history, ITEMS has succeeded in creating an inventory of relevant research and research teams in the European realm (WP1), as well as assembling spokespersons of these research teams and others interested during two meetings: a workshop in Granada (WP 2) and a scientific symposium in Coimbra (WP 3). In this part, we report on the final workpackage (WP5), whose main goals were to draw conclusions and formulate recommendations on how to better collaborate at EU level.

WP5 prominent objectives were:

1) To reflect on barriers, values and methods as regards collaboration at EU level.

2) To formulate proposals for PhD and postdoctoral training on a European scale.

3) To reflect on tools which might enhance communication.

4) To issue some recommendations that would facilitate life for European researchers.

This was done through a final workshop, held in Maastricht on 17 and 18 May, 2005, where we counted the blessings of the ITEMS network (which, we felt, were many) and discussed the options and barriers for actually applying on the European level for research projects we think are important and doable. (see Annex 8)

In the *first section*, Collaborating and Comparing, we discuss what has been achieved so far with regard to setting up collaborative and comparative, inter/multidisciplinary research projects within the European context.

In the *second section*, Teaching and Training, we dwell on the options for setting up PhD and postdoctoral training programs.

In the *third section*, Futures Featured, we discuss the possible futures for ITEMS.

In the *last section*, Recommendations, we discuss relevant items for further consideration both on the level of the EU and on the level of national and local institutions.

1. Collaborating and comparing:barriers, values and methods

At the workshop, three main concerns were addressed as regards collaboration at EU level: (i) organization and management with a view to facilitating collaborative work; (ii) research approaches which are most suitable for collaborative work; (iii) comparability of methods.

A questionnaire was distributed (see Annex 9) which 20 out of 29 participants filled in (Annex 9). The questionnaire's themes were used to structure the actual discussion about collaborative work:

a) What are the practical barriers and boundaries encountered when setting up collaborative, European-directed projects?

b) What 'European' value would collaborative, comparative work have in terms of the multiple users/citizens that are addressed and our own interests as researchers/institutions?

c) What methodological tools do we have or might we develop for carrying out such projects?

Questions of organization and management with a view to facilitating collaborative work

In the two years of having collaborated within the context of the emerging ITEMS network, the Granada meeting has shown us that most participating laboratories all directed at least part of their research effort to themes that allow for or actually involve international comparison. The Coimbra scientific symposium, moreover, made clear that on a considerably number of topics, participants to the network and others interested were very productive in opening up and setting up plans for collaborative and comparative (European minded) research projects. In Coimbra it also became clear that the emerging collective shared a number of important characteristics: first, an attentive feel for topics that take place in but also shape a European space of/for health care and medical technologies related transformations; second, a strong incentive to follow and reflect on these transformations on more than only the national, local level; third, a sense that health care and body politics could profit considerably from the interdisciplinary, qualitatively oriented studies the ITEMS network-members tend to focus on.

What also occurred to us was this: despite this continuous and promising array of fruitful and important ideas, research plans and perspectives, something seemed to inhibit most of us from actually engaging in applying for European funding. And so we decided to ask ITEMS members and others present at the Maastricht meeting what they felt as inhibitions to such practical engagements. To this aim, we designed a small questionnaire which was filled in during the actual meeting by 20 out of 29 relevant participants. We refer to Annex 9 for the questionnaire, and for an overview of the answers it generated. We used the questionnaire as a heuristic for the discussion about this problem during the workshop itself. Here is what came out.

There is wide variation as to the experiences and interests groups from different countries (and universities/departments/institutions) have in doing collaborative (European) research. This is due to specific national research policies and funding strategies as well as to the sources and amount of funding for national R&D programs. This variation may be seen as a continuum. At the one extreme there are groups for whom participation in European projects is vital as it is their primary source of funding for research (and even national programs are targeted through the EU framework programs). At the other extreme, there are groups for whom there is no financial incentive whatsoever to participating in European projects, as their research is almost 100% financed through national programs. The only reason for these groups to participate in collaborative (European) projects would be a substantive one. The majority of the groups find themselves located somewhere in between these extremes: whereas European funding is not vital to them, it is a welcome contribution to their resources for research and is also of substantive interest.

This diversity of interests is to some extent reflected in the experience that groups have in participating or setting-up European projects: while all had experience in one or two collaborative projects, only a few groups had extensive experience in actively participating in and coordinating projects at the European level. Not surprisingly, these latter groups included those who were most dependent on European projects/external money as a source of funding.

On the administrative side of the matter, barriers to setting up collaborative research projects and to applying for European funding were many. It seems to us that here lie important incentives for improvement, on the level of the EU as well as on the level of individual institutions. If comparative, international research is deemed important, and if external/European funding for research becomes increasingly crucial, then incentives must be made to alleviate some of the barriers that *de facto* keep researchers from engaging in applying for such projects (see section 5. below).

First, most groups mentioned a lack of experience and routines for setting up larger, internationally oriented and staffed projects. Obviously, experience results out of practice, but the other barriers quite effectively seem to prevent researchers and their centers from building up useful and efficient practices such as protocols, active administrative support, etc.

Second, there was a strongly felt deficit of both administrative and ideological support from the home institutions. This can be inferred from the combination of answers to questions 4 and 7, as well as from the explanations provided under question 7: most institutions put no barriers or encourage international projects but provide no routine administrative support. Hence most respondents were more than hesitant to actually lead collaborative work, precisely for that reason. The difficulties we currently encounter to find an institution to lead a RTN (see section "Teaching and Training"), one of the most promising follow-up to ITEMS, is telling in this respect.

Third, a majority of the groups experienced great difficulty in coming to grips with the jargon of EU-project-application-forms as well as with the different instruments of the framework programs and with some of the requirements of the procedures for application.

Fourth, the low success rate of EU applications (in comparison with national funding programs) was mentioned as a key obstacle in applying for EU funding. Moreover, national programs in some countries seem to have better arrangements for the finance of overhead costs, which makes it less interesting and appealing to apply for EU funding.

Fifth, some groups felt the recruitment of researchers to be an obstacle for participating in collaborative research. Some groups/members also indicated that having a stable 'home group' of 2 or 3 researchers was necessary to start participating in EU projects.

In sum, due to the additional burdens it imposes on coordinators, the coordination of EU projects in particular is regarded as unattractive, especially when adequate administrative support is lacking in host/most institutions. At least, it is regarded as an obstacle to achieve what is considered as central in the research carrier, especially publication of papers in ggod academic journals

In terms of intellectual/substantive constraints, for many of the groups the specificities of qualitative research in the social sciences and the humanities tends to somehow discourage setting up collaborative projects. Although it is increasingly felt that our research projects would improve from being comparative and international, and even that the object of our studies is often inherently European in character, there is still a

strong tradition of individual and national based research. When collaboration is sought, this is often carried out in small groups. Moreover, as EU funded research somehow presupposes the collaboration of a larger groups of researchers, this is also found to be an obstacle to setting up such projects, both because of the extra administrative/bureaucratic workload large projects bring with them, as well as because of the difficulty of matching large scale comparative studies with the qualitative and ethnographic methodological orientations of our field. However, according to the experience of ITEMS coordinators, the hardest part of the process was setting up a collective of researchers and writing a proposal that would meet EU criteria, whereas the actual proceeding of the network proved to be easier to manage. We also see that in practice, qualitative methodologies and comparative work are less antagonistic than we had anticipated.

The ITEMS project itself has, however, been particularly fruitful for most of the groups present. First, it showed that setting up EU funded projects within our field is indeed valued by the ITEMS members. Second it made clear to us that we may position our work as contributing to the articulation of new problems and needs within the European health-care landscape. Third, the many contacts that were made during the project show that links between the participating groups can be and should be further expanded and strengthened. In the final part of this report we will elaborate further on plans for collaborative projects that emerged within the network so far.

Research approaches most suitable for collaborative work

Notwithstanding the practical and sometimes ideological problems that participants encountered in setting up or participating in EU funded projects, there was a strong and widely shared sense that international collaboration on health care matters is important if not crucial both intellectually and politically.

First, it was noted that the *object of study/knowledge* as it was defined in the ITEMS proposal – transformations in European medical space – in and of itself transgresses national boundaries, while of course not rendering local articulations of such transformations obsolete. Donor organs travel the whole of Europe while at the same time being subject to national regulation and control. Genetic knowledge enters patients'/citizens' lives in manners that may be mediated by national health care arrangements and cultures as well as by local routines, but it is also part of a transformation from diagnostic to preventive medicine that is of enormous impact already and that transgresses the local and the national in many ways. The politically induced movement in which health care becomes conceptualized and organized in terms

of a liberal market is "European" in and of itself; it makes for interesting redefinitions of patients in terms of citizens, but also of numerous and hard to trace (but important to study! re-orderings of responsibility and (in)equality. New information and communication technologies – quite generally hailed as neutral facilitators of knowledge – work in many different ways. They transform, enhance as well as internationalize the work of patient/citizens' organizations, but they also reorder home care for the disabled and the elderly in ways that largely transgress local and national boundaries. Including and comparing different (national/local) perspectives and practices in research could produce rich and important results on such and other matters.

In all these developments and many others, we feel it is of great importance to study not only their eventual effects, but also these processes as they occur, for they require important re-orderings of the landscapes and practices of health-care and medical technology in order to proceed at all. It is these re-orderings, and the "normativities" involved, that need to be studied as well as the effects they bring about.

ITEMS network-members bring a number of qualities essential for such work. The network is *interdisciplinary*, both in terms of the kinds of questions its members tend to find relevant, and in terms of the members' disciplinary backgrounds. It was felt that this interdisciplinarity is a strong asset for and in collaborative, international research. Moreover, its members' focus on *qualitative* methodology and on the "situatedness" of knowledge and practices, would render comparative and process/practice-oriented research particularly interesting. Such studies would not only strengthen analyses in one's "home country", they might also have consequences for the ways in which specific issues can be studied. In terms of the socio-political importance of the work to be set up through and as a result of the ITEMS network, we think that comparative projects lend themselves more easily to the formulation of policy recommendations that would be sensitive to local specificities while at the same time being directed towards translocal/transnational/European fora of health care users.

Although we all found these reasons to be important arguments in favor of international collaboration, there was also a clear understanding that not all issues can be taken up in EU projects. Although we think that our interdisciplinarity and our intellectual interests will protect our studies from being carried out and understood as collections of national case studies, we also think we should select issues that either are European in nature, or that work so as to constitute Europe. Moreover, not all internationally oriented studies are necessarily directed to or focused on or relevant for Europe. In many ways, the US form a reference point in developments in medical science, technology and governance. However, despite the existence of lots of comparative research projects in the social

studies of science, technology and medicine, most of these comparisons are between a European country and the US, and comparisons are rarely made between EU-countries. Questions concerning the Europeanization of such issues are thus rarely addressed. Defining issues at a European level is an important step the network has begun to take, and that needs to be picked up in future projects. This concerns at once the identification of a European twitch to health-care transformations, as well as the possibility of constituting Europe ourselves through new and transnational perspectives on these transformations.

The issues that could be taken up for research are many, and many of them have clear policy implications, which should enhance their value for the EU. They include research on the very dynamics of transformation of "Europe"; the issues of North-South relations and questions concerning technology transfer; the building of a European civil society around e.g. patient perspectives in heath policy and research; the development and spread of practices of evidence-based medicine; the development of new accountability structures in healthcare; questions concerning the ways in which pharmaceuticals are taken up in different EU countries, how they relate to the global dynamics of the sector and the consequences this might engender for issues related to the governance of drugs. This is just a small sample of the issues that collaborative research from ITEMS members could contribute to. We think that in all cases, it would be important to stress both the needs (on the part of users/patients, on the part of health-care workers and institutions, and on the part of European policy making) our studies articulate or answer; and the special features our work brings with regard to such articulations and answers.

Comparability of methods

An interesting obstacle to participating in collaborative (European) research projects is caused by a combination of tradition and methodology. Tradition has it that work in the social sciences and humanities is often carried out by individual researchers – on their own. In terms of methodology, most ITEMS members tend to stress the (epistemological) importance of knowledge as situated, contextualized and therefore on uneasy grounds with generalization and comparability. This combination of individuality of researchers and the uniqueness of their research topics, demands for special methodological attention when setting up collaborative and comparative work. Which is why the Maastricht meeting spent time to address these issues.

First of all, many members stressed the importance of studying the transformations of local health-care arrangements as they become the object of translocal (European or even global) developments. Here again, such developments do not only eventually have

effects on the local level, the processes themselves also require new local orientations and practices. It is important to study these as it is here too – on the road – that needs and "normativities" of patients, health care workers, or others may be in trouble or need reformulation. Many ITEMS members feel competent to study the local in the global: our expertise in studying micro-politics makes many of us fit for studying these matters.

Second, we discussed the ways in which comparative studies could be made to match with qualitative methods, and more in particular with the ethnographic orientation of many of ITEMS members. It was proposed we might develop further the methodology of "multi-site ethnographies". This may mean two things: either co-workers develop comparable research agenda's and checklists for fieldwork in their own home-setting, or they actually do (parts) of the fieldwork together. In particular this latter option was held to be attractive, both in terms of the results it would yield and in terms of the need felt by some to "see with different eyes", to work alongside or in "indigenous" teams, and to create inter-national research teams. Still another way of proceeding might be to integrate not only the "strange eyes" of researchers from other countries, but also the users' eyes: to turn the object of a study into a participant in the research itself (this might be viewed as the mirror image of "action research"). Citizen panels and other innovations could be particularly interesting ways of advancing along these lines.

Third, methodological innovations might include the development of methods that "travel" well across research settings and that may be easily shared by different national and local research teams. One may think here of approaches that take "Europe" to be more than a juxtaposition of national situations and contexts.

Finally, we need conceptual innovations articulated in common with methodological innovations that will allow questions asked in different countries to be related to common conceptual frameworks. For instance, the topic of a given study may be defined from the outset as European (e.g. EU patient organizations), but within that common understanding it might focus on European policies and search for the convergences, divergences, national framings and implementations of these policies. The very notion of Europe as a process, rather than something "closed" or finished, requires that these commonalities and diversities be identified and analyzed. Even juxtaposing a series of monographs, in spite of its limitations, can lead to asking new questions if innovative frameworks are developed and drawn upon. New ways of looking at the "local" are as likely to lead to new insights on European issues as are "macro" approaches, provided we keep in mind that all research is situated and that "local" studies are comparative by constitution. The experience of research in Science & Technology Studies (STS) may be particularly valuable here. STS has been very successful in researching how knowledge

and technologies "travel" across places and scales, from the "local" to the "global" and vise versa— i.e. whereas the global can be studied as the result of a multitude of local developments, so much can (the constitution of) the local be studied as an effect of globalizing tendencies.

The need for exchanges and for more sharing and reflection on research requires tools beyond collaborative research projects is clear. Research Training Networks seem to provide a proper tool for this purpose (see part I). Nevertheless, we think that collaborative projects would need to show sensitivity to these and other methodological matters. They require investments too -material, personal, institutional - in collaborative projects and there is a need to make for them as part of the "normal" flow of research activities.

2. PHD training and post-doctoral circulation

Based on the most prominent results of Workpackage 4, the possibilities for setting up some sort of Research and Training Network for PhD students and post-docs within the field were discussed. WP4's most important recommentations were:

1) to set up an international summer school in health and medicine studies, coordinated through ITEMS network and containing a thematic structure so that topics can be explored in sufficient depth to be of use to both doctoral and postdoctoral students and other researchers;

2) to appoint a coordinating center for the development of joint teaching and research initiatives and exchange of students and staff in social studies of health and medicine.

Discussion focused on the feasibility of setting up an RTN, as that was considered to be the most concrete opportunity within the EU scheme. Within that, two issues were at stake: matters of content and matters of organization. Two experts (Florence Paterson of the CSI/Paris and Christine Neuhold of the UM/Maastricht) were consulted. The whole discussion was reported on by Nik Brown.

As to the content of an RTN, and its potential curriculum, it was held important to focus on one or two themes that would be broad and systematic enough to encompass the network's intellectual and methodological competencies, and specific enough to afford a focused and socio-politically relevant curriculum during a summer school and eventual other meetings. Although no real decisions were made on these issues during the ITEMS workshop, participants agreed broadly that it would be crucial to focus on the roles of new and emerging health care technologies, on the Europeanization of health care as

comprised within processes of innovation, and to do all this with our experience in the field of medical STS (science and technology studies focused on medicine) as a starting point. Under that broad umbrella, issues of health care design and regulation, technologies as boundary objects, de- and re-localization, the work of health-care professionals, patients/citizens, inclusion and exclusion, and methodological matters could easily find a place.

It was also held important that researchers within the network would be able to function as resource persons for the students involved. Moreover, it was held important that not only students would meet, but also that researchers would have opportunities to meet and catch up on matters of R&D in the field.

As to the organization of a RTN, the major concern was to find one research center that is willing to coordinate such a network and has the administrative support to do so. Indeed, it was felt by most that once this role would be taken up by one or another institution, they would be ready to lead a workpackage, to engage into concrete work such as organizing summer schools, to collectively run an actual RTN. For the time being, this question of coordination has not been answered. Most prominent amongst these factors is the issue of time: coordination would require an existing administrative and scientific capacity that can focus concertedly during both the outline stage (September 2005) and subsequently if the application is developed into a full proposal. Most members/institutions noted that they were lacking a sufficient amount of "extra" time to concentrate on setting up and coordinating a RTN. A suggestion was made that coordination tasks and responsibilities be shared by several research centers, but it seems that actual European contract forms would not allow for such a solution. So up to now, discussions are still pending, but it might be that the September 2005 deadline would not be reached.

3. Tools for communication

There was agreement by everyone that perhaps the greatest benefit of ITEMS network had been how it had facilitated new contacts from the meetings, conferences, exchanges, and from collaborative working and planning. Maintaining effective communication between its members is an important challenge for the future of the network that emerged from ITEMS. The last session of the Maastricht meeting was devoted to a discussion over the most suitable means to sustain the momentum created in face-to-face interactions in Granada and Coimbra. Electronic communication tools offer opportunities, but also come with specific problems. Thus, part of the discussion was devoted to these tools.

This session was chaired by Marias Jesus Santasmeses and Florence Paterson, and reported on by Carsten Timmermans and Michael Worboys.

3.1. Electronic communication tools: the Website and E-mails

With 60 000 visits since its inception, ITEMS website may be considered quite successful in terms of visibility and dissemination of information to the outside of the network (45% of the visits originated from search engines such as Google). What did not really work about the website is the updating of information from ITEMS members. Among the 22 research centers of the network,very few made announcements by using the website. Having a website makes sense only if it is updated and if it contains information about on-going work. It is necessary to organize this updating work and in particular to have persons who will take the responsibility to collect information.

Communication between members was good during the meetings, but worked less better after and in-between meetings. As the coordinators mentioned, it occasionally proved difficult to sustain exchanges after the meetings and to motivate members to respond to calls for proposals or queries distributed through the ITEMS mailing list. The main reason for the occasional lack of responsiveness given by participants in the discussion was information overload, caused by email communication associated with other every-day administrative tasks. In the use of electronic communication tools, we thus must be aware of their limits and not to have too much expectations on the benefits that can be drawn from them. On one hand, the dense flow of information makes it disappear. On the other hand, because e-mail exchange puts a lot a stress to answer immediately (in contrast a letter), it leads to select the most urgent messages and to drop the rest. This means that: (i) using the e-mail does not necessarily mean a loss of interest in the matter discussed; (ii) there is an interest in using tools like mailing lists, but it leads to reach only a part of the audience.

The central aim of the session, thus, was to identify channels of communication for the future of the network that might help to assure that members notice announcements, queries and calls. Electronic means of communication are preferred, as they are easy to use, quick and cheap. Unfortunately, though, they are also much more easily ignored, and electronic mailing lists need frequent traffic to be sustainable. One of the session organizers is familiar with the specific problems associated with electronic mailing lists as online editor of a high-traffic list for history of science, technology and medicine. One possible solution, it seemed to us, was to use established channels of communication (rather than attempt to establish new ones) that are used by a majority of network members. Besides, for a broader use of the website it would be necessary to connect to a

mailing list which would draw the attention on the site. For example, to associate ITEMS mailing lists to those of existing associations or institutions (like the EASST or the EAHMH).

In order to find out what these established channels are, we decided to circulate a questionnaire, in hard copy during the session and in the week following the Maastricht meeting as an email, in which we asked what websites, mailing lists, or other channels of communication network members use, and what journals they read or publish in. The following list is a compilation of the responses. The return was rather sketchy (a point in case!), so quantitative evaluation would have been meaningless. However, we decided to list those websites, mailing lists and journals separately that are mentioned most frequently. As far as other forms of communication are concerned, members emphasized the importance of face-to-face interaction during meetings and workshop, thereby supporting the observations made in Granada, Coimbra and Maastricht.

How do we communicate? Responses to the questionnaire (see annex 10)

1) Websites (Most frequently mentioned).

2) Electronic Mailing lists (Most frequently mentioned).

3. Journals (Most frequently mentioned).

4) Other means of communication.

5) Directed emails and phone calls to personal contacts at various departments

6) Events & conferences

To sum up, we would say communication proved to be a selective process. After ITEMS experience, the two forms of communication – meetings that enables face to face encounter and the electronic forms of communication (e-mail, website) – show to be complementary on the scale of the network. It is because people met that (i) they are interested in to seeking information about on-going research projects, institution, publications, etc., on the website; (ii) they pay more attention to the e-mails sent by members of the network in the amount of mails received daily.

3.2. Publication channels

The publishing of the research materiel is another important communication question: where do the researchers publish in their respective countries? Is there a European audience? In the Netherlands as well as in France or in Portugal, there are both the media and the audience for the publication in local languages:

- Journal (journal for social sciences and medicine).
- Brazil offers a large audience for publications in Portuguese.
- Collective book (but editors are reluctant to this kind of publication).
- "Grey literature" is sometimes published on the web.

Language is a problematic communication means, and even more when there is not a national community in which to share approaches, reports, etc. English as a *lingua franca* is often a real difficulty when trying to get essays and works published by internationally distributed and scholarly relevant journals and publications. For the researchers there is an incentive to publish in English language, but it raises a double problem for non-native English speakers: on one hand, writing in English changes the way of thinking, but on the other hand, when written in the local language the texts need to be translated (and obviously the translation to be funded).

Reflection on this issue should be continued in the future.

4. Futures featured

4.1. Developing identities

The discussion of the session on "communication in and after ITEMS" makes it clear that for the members of ITEMS the research network has been working extremely well. This was not only based on the success of the meetings, on how many of ITEMS members have been actively participating in reports, sessions' organization and on their will to make suggestions for further collaboration, precisely when the EU funding for ITEMS project comes to the end. The more remarkable outcome of ITEMS networking through its activities has been the development of an identity within the member's group. More than sharing professional interests, many ITEMS members share the view that the network developed an identity as such. The specificity of ITEMS members' research, focused on medical innovation, democracy, governance and biomedicine should be maintained. This network of researchers exists as a European expert group, joining ideas

and proposal for further collaborations in the future on subjects and methodologies, sharing not only research interest but social worries about current biomedical knowledge related to concepts such as gender, innovation, reproduction, new drugs. All of these are issues relevant in the growing impact of biomedical sciences in everyday life as well as in social sciences and humanities research programs in Europe[28].

As regards this identity issue, a suggestion was made to change the name of the network in order to increase its visibility. The actual name is: *Identifying Trends in European Medical Space. Contribution of social and human sciences* (ITEMS). In order to better indicate the network purpose, the following names were put on the table:

- Health & Innovation Studies (HIS)
- Social Studies of Medical Innovation (SSMI)
- Medical Trends in the European Space

The idea of launching a journal on science, technology and medicine was also mentioned, if briefly. All participants were of course well aware of the difficulty of entering the market of scientific publications. But this idea asserted for the collective will to maintain ITEMS identity.

4.2. Prospective collaboration and networking

From 2003 to 2005 ITEMS has been developing its activities, its members met, both in small meetings such as those of the steering committee and in bigger gatherings like meetings in Granada, Coimbra and Maastricht. According to ITEMS members views, the quality of the contacts is related both to the exchanges across different European countries and their inter-disciplinary dimension. During the meetings and works like reports many of us had learnt a lot, historians from sociologists, sociologists from historians on medical and biomedical research practices. The network meetings allowed bilateral relations and provided some basis for prospective collaboration, for it helps to learn what people are doing and how future collaborations may be oriented. Many prospective projects are kept in mind so as to take full advantage of any possibility the EU may offer in the near future. Benefits may also be expected in a far-off future, for the network enables a better knowledge of possible European partners for projects to be set up in the years to come.

[28] One positive "network effect", due to the specificity of ITEMS' identity (as compared to classical professional associations) is that some researchers who were not at the beginning members of the network joined in (for and after the Coimbra symposium) and took part in future projects.

4.3. Meetings of a future network

As network projects do not provide funds for research there is always the problem of keeping contacts between the members of the network. The RTN proposal was envisaged as a possibility to keep many of us in touch with real works-in-progress.

Michael Worboys and Carsten Timmermans proposed to examine the possibility to associate "ITEMS" events to those of existing associations or institutions. In other words, if we want to carry on meeting, shouldn't we use other peoples associations? Although it is possible to join periodical meetings like those of EASST and 4S, some members of ITEMS would rather participate in specific thematic workshops/meetings, summer schools insofar as ITEMS has it own identity as a network focused on medical innovation, democracy, governance and biomedicine. Organizing the networks own events would certainly be more fruitful for collaborative work and projects in this research area. The main interest of ITEMS members is to keep their identity as a European expert group. That is why a prospective RTN was seriously considered (see section above), and a SSA proposal was applied for (see next part).

5. Recommendations

- Make Europe less hard to assess, the administrative process of getting access to resources and of monitoring funded projects "light" and easy to use.

- Provide researchers with the necessary administrative support when they apply for money: it is obvious that such support is tremendously inequally distributed over institutions, faculties and departments, due to national and even local regulation and preferences. The EC should be active in trying to reduce such inequalities when relevant.

- Notice the importance of interdisciplinarity as well as of a focus on processes rather than/besides outcomes/effects only. The network members' background makes us value the importance of studying both outcomes and their histories, and makes us want to focus on what would not otherwise be open for study: relations of localization and globalization; Europe as both an object and a subject of study.

- Develop attention for new methodological experiments as methodologies are quite performative in what they potentially make visible or not.

- Encourage qualitative research as it often results in important findings and sensitive suggestions for improving situations and processes. The now dominant language of

the "neo-liberal free market" tends to favor the language of quantification, indicators, needs, stakeholders/users/participants over qualification.

- Be(come) sensitive to researchers' vocabularies: there may be policy matters that would not appear in other ways because of our backgrounds in which perhaps the most central notion is that of opening black boxes of things normally taken for granted.

- Encourage reflexivity with regard to Europe. Europe is not the fixed background against which medical innovations take place, nor is it the unquestionable entity from which we study such innovations. Rather, Europe should be considered as in constant formation and open to constant amendments through such processes of innovation and its studies.

- Be particularly keen on financing mixed modes of communication rather than relying on electronic/virtual technologies only or mainly. Networks live or die in the presence/absence of "live" contacts.

- Develop limited sources of fundings in order to allow exchanges and the circulation of information. ITEMS network has shown that various projects can emerge and develop through these interactions.

V. DISSEMINATION AND EXPLOITATION OF RESULTS

Drawing upon previous conclusions and recommendations, this section displays future actions that ITEMS members agreed to undertake in order to disseminate and exploit results obtained by the network.

First, we would like to recall that a series of dissemination tools and actions were already implemented and conducted during ITEMS life-span. ITEMS website was one important dissemination tool. The website actually served two purposes (see section III. 1.):

- It was designed as a working device for ITEMS members: based on a database comprising detailed data on ITEMS members' projects and research centers, it was used for mapping ITEMS research context and enhancing mutual knowledge between its members.

- It was also designed to disseminate information to the outside of the network, in order to make ITEMS project and achievements visible to a larger public. Provided the number of visits on the website, we can say that this "visibility" work was fairly successful.

All ITEMS members manifested their wish for this website being maintained. It was felt that this tool should mainly serve as a communication platform, both for ITEMS actual members, and for all those who are interested on social sciences research on health and medicine in Europe. The website should thus be slightly redesigned in the near future: reflections on this are in progress.

Alongside the website, specific dissemination actions were completed during ITEMS life-span. Coimbra Scientific symposium was particularly fruitful in this respect (see section III. 3.). It attracted many academics who were not ITEMS members, and with some of whom certain members of the network decided to set up collaborative projects. This indicates that ITEMS was able to mobilize beyond the actual network. Besides, some "outsiders" manifested their wish to stay in close contact with ITEMS, as it is considered an interesting place to go for helping collaborative plans to emerge and exchanges to develop.

Hence, both from the inside and the outside of the network, a demand was expressed for prolonging ITEMS. This is why we devoted time to reflect upon the pros and cons of the future of our network, and to envisage a few concrete follow-ups. In any case, all ITEMS participants agreed on the fact that future orientations must manifest their common willingness to enhance the visibility of social sciences contribution to issues of policy

relevance, at a European level, in the domain of health and medicine. This is why we decide to apply for the SSA call n° FP6-2004-CITIZENS-6. A brief outline of this project is provided below. Besides, some ideas for future collaboration were also put forward by certain ITEMS members. Some of these ideas are quite advanced, and should be end up into concrete applications. A list of those ideas and potential projects is also given below.

We would like to stress that ITEMS has been instrumental in the emergence and the setting-up of proposals and plans: neither the substance of these proposals and plans, nor the collectives of researchers that gather around them, would have been possible without the network.

1. Meduse Governance, health, and medecine. opening dialogue between social scientists and users

MEDUSE is the major follow-up of ITEMS. The CSI-ARMINES-Ecole des mines is the main coordinator (Madeleine Akrich and Vololona Rabeharisoa). MEDUSE consists of five partners, all members of ITEMS, who will collaborate with other participants.

The objective of the project is 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 issues of policy relevance that have been previously identified and reflected on within ITEMS. Three issues were selected:

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, on exchanges that will be scheduled with a wide range of actors concerned with these three issues, as well as on a range of design, implementation and evaluation experiences across Europe, the project will propose three large conferences (60 to 100 participants), each devoted to one of these three issues. Each conference will gather half social scientists and half actors directly concerned with the issue (health care professionals, patients' representatives, clinicians, agency staffs, decision and policy-makers).

The workpackage on "The dynamics of patient organizations in the European Area" will be co-led by CSI-ARMINES Ecole des mines (Vololona Rabeharisoa) and Centro de Estudos Sociais, University of Coimbra (Joao Arriscado Nuñes). Here the increasing

involvement of patient organizations into health care matters is the core issue. The project aims at discussing the various ways in which patients organizations proto-professionalize, form coalitions with professionals, can be conceived of as mediators between different actors in the "war on diseases", and at making visible the dynamics of the European space for patients organizations.

The workpackage on "The emergence of new technologies and responsibilities for health care at home across diverse European systems and cultures" will be led by the Institute for Health Research at Lancaster University (Maggie Mort and Christine Milligan), in collaboration with the University of Oslo (Ingunn Moser). Here the focus is the increasing use of "smart-technologies" that tend to turn the homes of the elderly into sites of healthcare. The project wants to collate what is known about these shifts, about how they are experienced by their "users" (patients, care providers), and to share this knowledge with the policy, practice and user communities. Issues of agency and passivity, the ownership of knowledge, gender-roles in health care, and cultural notions concerning what is home and what is healthcare will be central. The project aims to contribute to inclusive, culturally sensitive and politically relevant ways to produce evidence about the safety, legitimacy and effectiveness of health care technologies, and to find forms of patient and carer representation and of participatory design of these modes of technologically mediated health care at home.

The workpackage on "Cross-national and European perspectives on health safety agencies" will be co-led by CSO and CERMES (CNRS Paris) and the University of Louvain (Olivier Borraz, Daniel Benamouzig, and Jean De Munck). Over the last two decades, risk regulation has become a priority on the political agenda of a number of states and the European Commission. Authorities have been prompted to adapt their regulatory regimes to new uncertainties related to health and the environment. This had led to the creation of health safety agencies related to foodstuffs, health products, workplace, and the environment. These agencies represent a pragmatic response to the public health crisis of the 1980s and 1990s. Here the issue is to discussing to what extent these agencies renew traditional policy-making on issues related to health. Furthermore, the creation of European agencies (EMEA and EFSA) and their regulatory role will also reflected on.

All three issues point to the increasing role of new actors into the definition and the regulation of health policies at European level. They are also concerned with the emergence of a new balance of powers between these new actors and traditional ones in the domain of health and medicine. Lastly, they raise important questions on governance, citizenship and democracy within contemporary European health area. The

project is expected to produce substantial impact in terms of articulation between social sciences research and policy-making in the domain of health and medicine.

2. Other future plans and potential projects

Apart from the projects entailed in MEDUSE, a series of other, more or less worked out projects for collaborative and comparative work were presented, most of them in order to see whether those present would be interested in getting engaged, and/or would know of others who might be interested in setting up a project. We will describe each of them in short here.

Maggie Mort (Lancaster) presented a proposal aimed for applying as a Specific Targeted Research Project (STREP) within FP6. It is based on her MEDUSE workpackage on smart-health care technologies in the homes of the elderly. This proposal would aim at providing for participatory approaches to the making of policy, and for qualitative (ethnographic) approach to the making of practices. A few ITEMS members and non members should participate to this project.

Vololona Rabeharisoa presented a plan that would draw on her MEDUSE workpackage on patient groups. Reflecting on patient groups' tendency to be involved in dense networks, including affiliations to a growing number of European organizations, the project should aim at studying transnational species of patients' organizations. She should collaborate with Orla O'Donovan, a non ITEMS member who participated to the Maastricht meeting, in a potential EU project.

María Jesús Santesmases (Madrid) presented plans to set up a collaborative project on the increasing and problematic interrelationships between genetics and reproductive health care. Delphine Gardey, a non ITEMS member who participated to the Maastricht meeting, should join this project.

João Nuñes, in collaboration with Marisa Matias (Coimbra), proposed to set up two studies: one on biographies of objects in medicine, and one on the emergence of cross-cutting concern about health and environment.

Bernike Pasveer (Maastricht) proposed to set up a collaborative study called "new brains", in which conceptual re-orderings as well as the practical transformations of the brain and diseases involving the brain should be central. Madeleine Akrich (Paris) should join this project.

Anne Lovell (Paris) proposed to set up a study about the normalization of behavioral pharmaceutical drugs, in which the main question would be whether new

pharmaceuticals aimed at behaviour-related disorders affect traditional modes of social and medical normalization. Such pharmaceuticals target biomedical and morally charged disorders, and in doing that they also make for new configurations of public space, users, professionals and others involved. The study should contribute to the evaluation of legitimizing processes of behavioural drugs within Europe. She is currently making contacts with people within and outside ITEMS network to explore further plans.

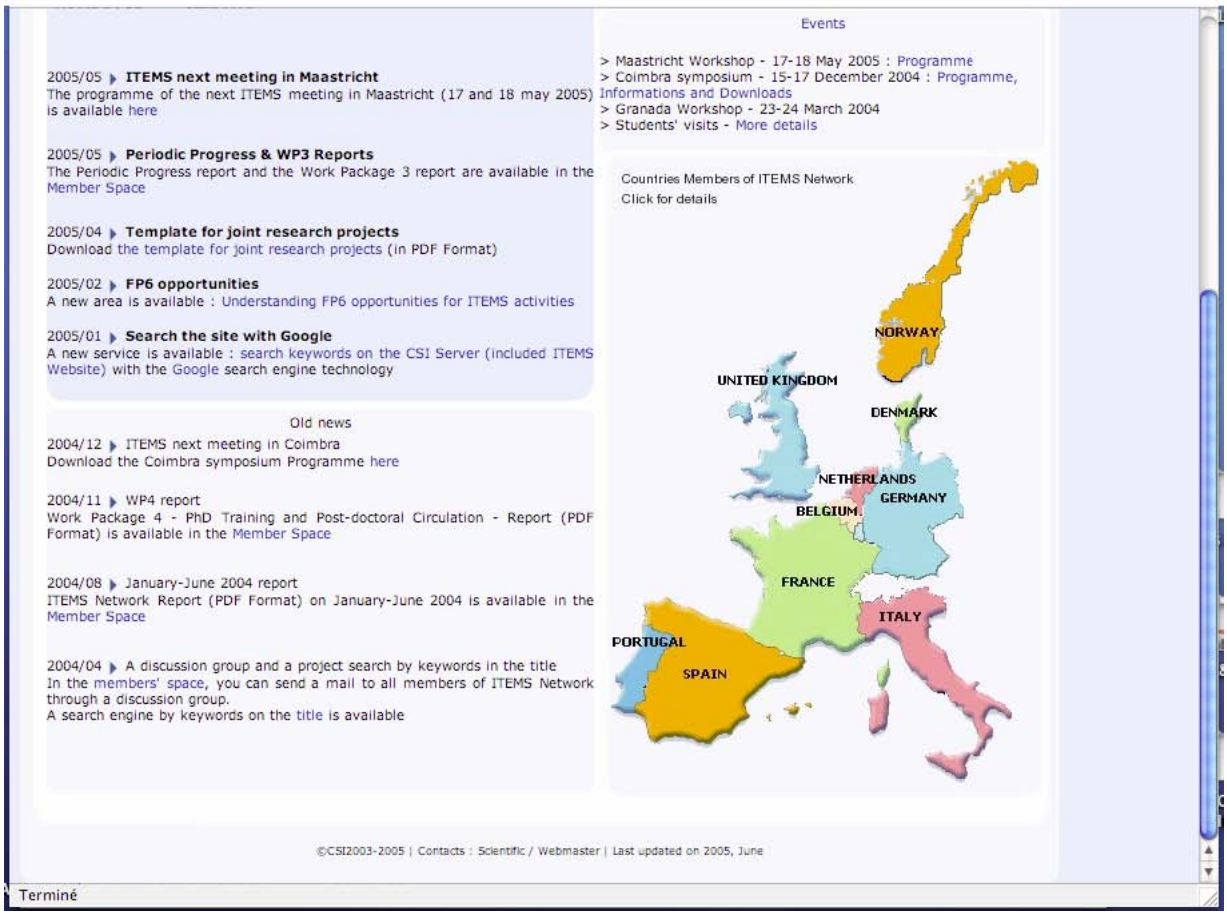
All those ideas, plans, proposals, were formulated on the basis of research and interests present within ITEMS network, and it is hard to conceive of that to have happened without the network's existence and lively history. Many projects, moreover, aimed at benefiting from the network's interdisciplinary potential, at experimenting with methodologies for comparative *and* qualitative work. Finally, all projects are highly sensitive to the urgency of finding and articulating the factual, political and normative edges of health care innovations in Europe.

VI. ANNEXES

1. Deliverables list

DL Deliverables list				
Deliverable n°	Deliverable title	Scheduled delivery date	Effective delivery date	Dissemination Level
1	ITEMS database	Month 9	October 2003	RE
2	Workshop 1 Granada, Spain	Month 15	March 2004	CO
3-6	Discussion paper 1 to 4: Granada Workshop The comparative treatment of issues (42 pages)	Month 17	June 2004	CO
7	ITEMS web site	Month 18	June 2004	PU
8	Discussion paper 5: *PhD Training and Post-doctoral circulation (76 pages)*	Month 20	November 2004	CO
9	ITEMS Scientific Symposium Coimbra, Portugal	Month 24	December 2004	PU
10	Discussion Paper 6 ITEMS Scientific Symposium Proceedings	Month 26	December 2004	PU
11-14	Discussion Paper 7 to 10: ITEMS Scientific Symposium Thematic Report (119 pages)	Month 26	April 2005	CO
15	Workshop 2 Final Conference, Maastricht, The Netherlands	Month 28	May 2005	RE
16	Discussion paper 11: Final Report and Policy Recommendations	c. month 30	July 2005	PU
17	Final presentation to the EC authorities	c. month 30		RE

2. Banner page of the web site

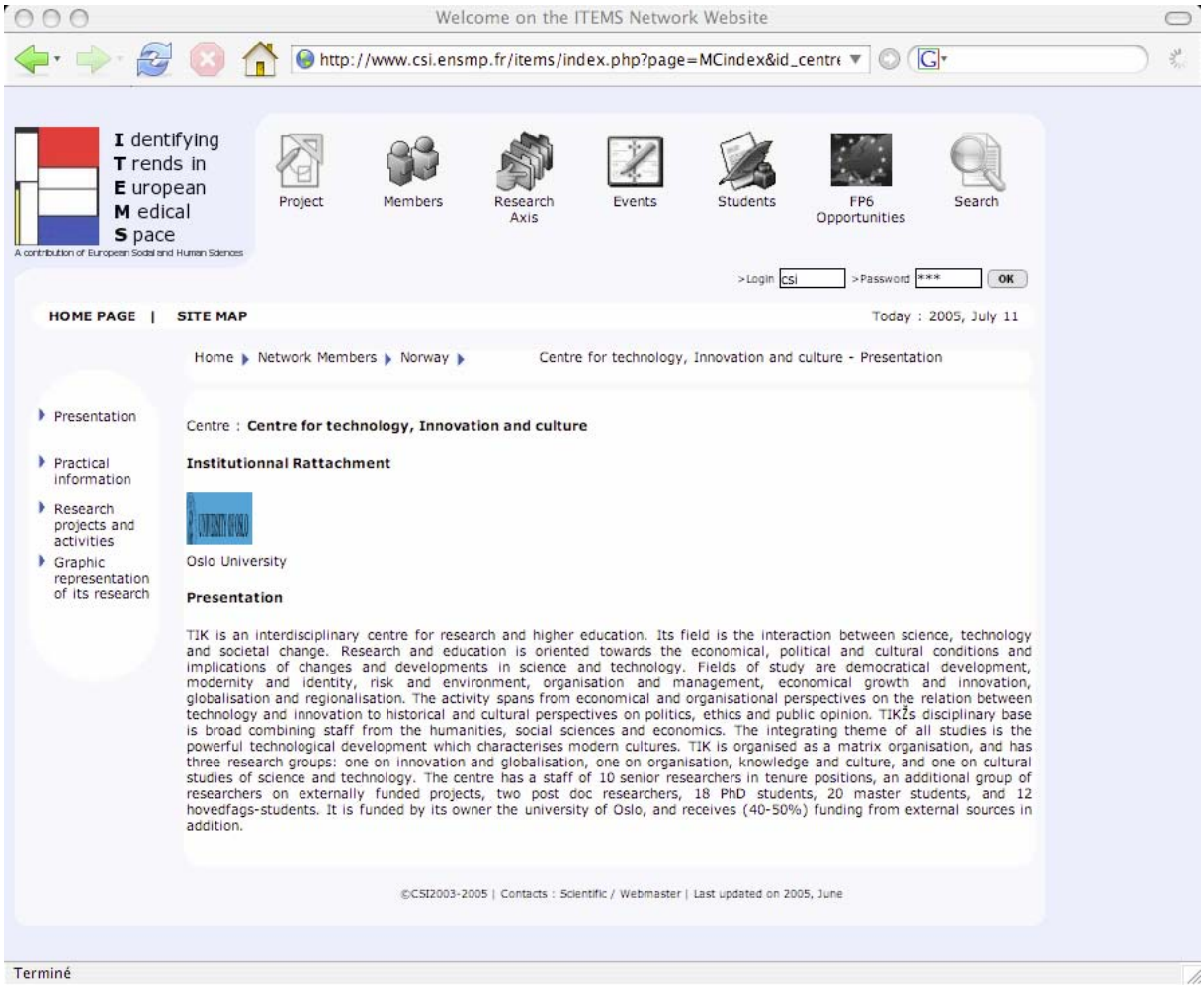


3. Information on each research centre member of items network

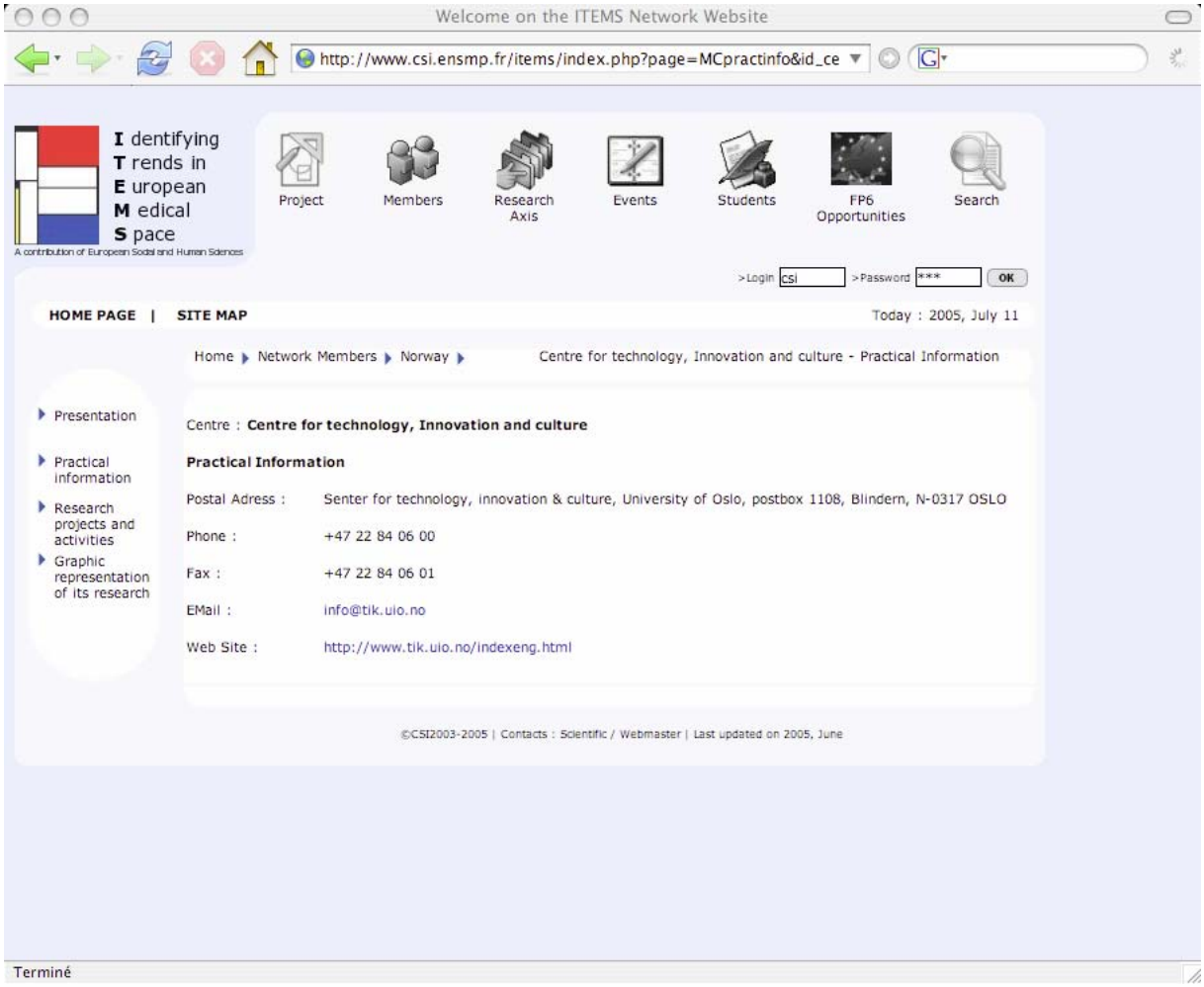
The example of The Centre for Technology, Innovation and Culture, Olso, Norway.

For each research centre member of ITEMS, the web site provides:

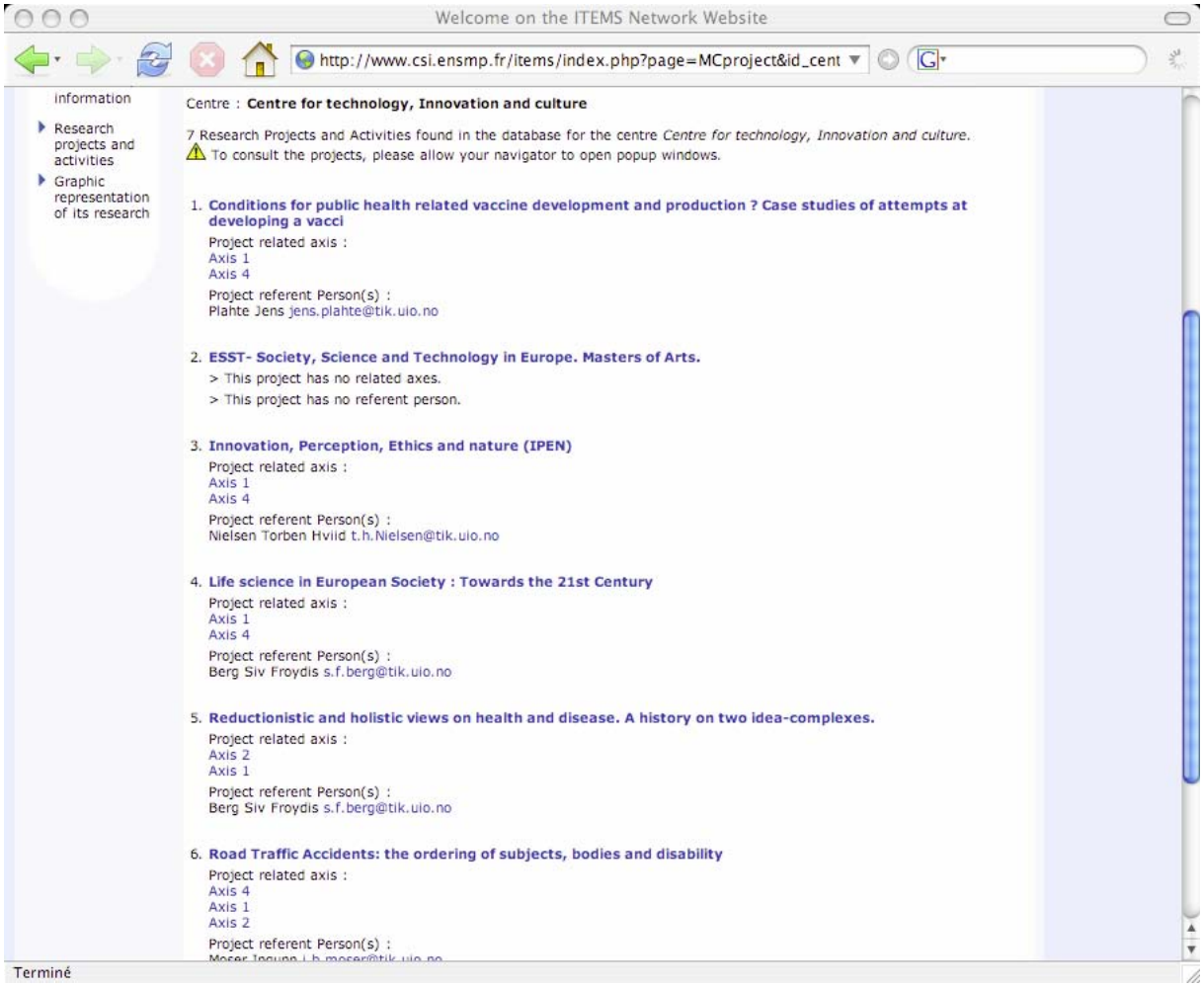
1. Presentation



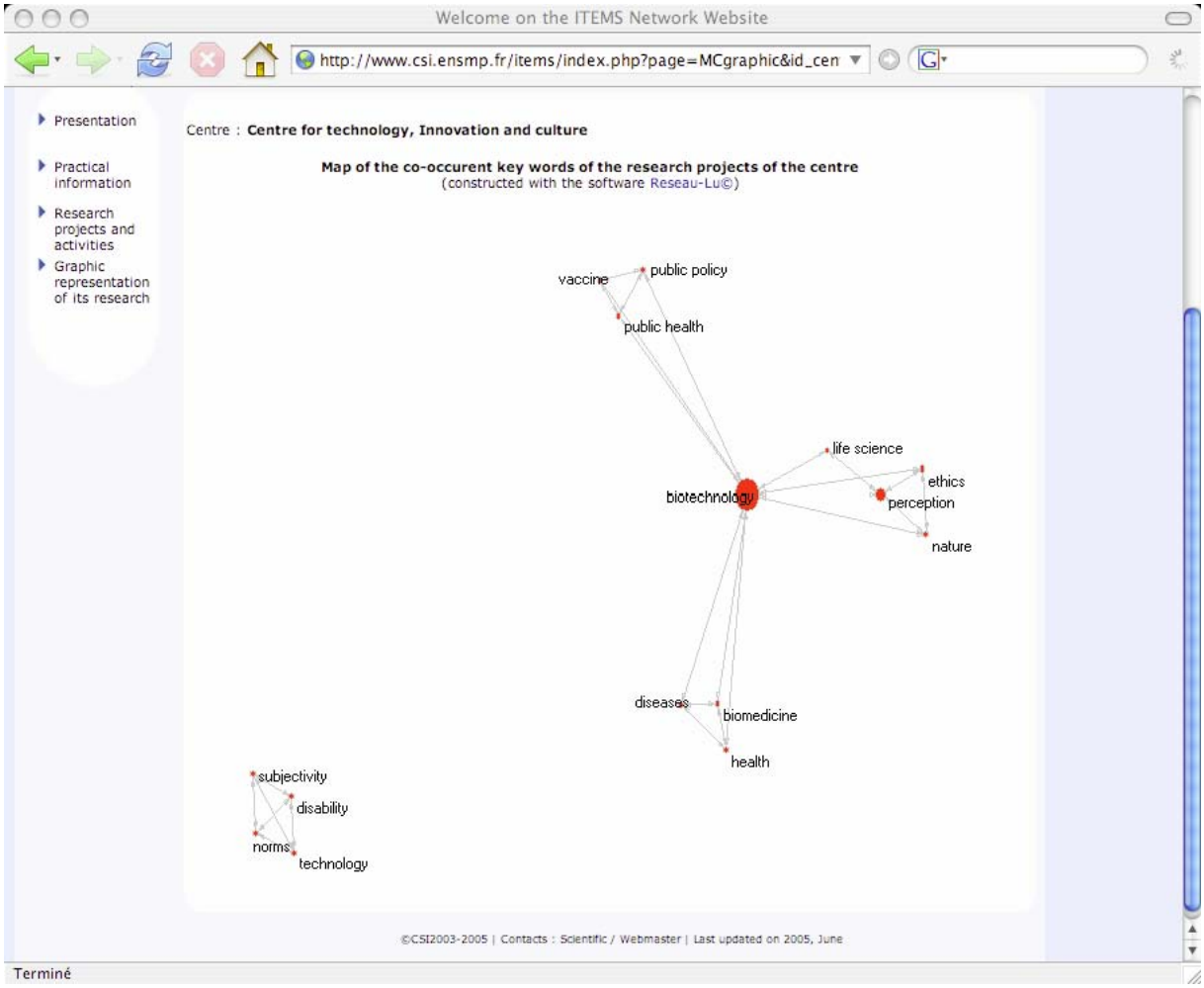
2. Practical information



3. Research projects and activities



4. Graphic representation of the research carried on by the centre



4. WP4: Questionnaire

ITEMS QUESTIONNAIRE – WP4

Inquiring about PhD and post-doc circulation within EU

The ITEMS network aims to draw together a sample of research in health and medicine being undertaken in social science and humanities across the EU. The focus of our enquiry will be research work that relates to the four ITEMS axes. These are i) transformations of the biomedical sciences, of disease and of health; ii) participation of users and the redefinition of systems of actors in the domain of health and medicine; iii) coordination in health care systems - information and communication technologies, and organizational devices; and iv) articulation between health and policy issues.

We are interested in finding out as much as possible about the different ways in which PhD and post-doc training is organised in different EU Centres and countries. Based on what you tell us, our aim is to draw up a set of proposals aimed at structuring and improving interactions between Network members, particularly around common educational activities. As well as hearing about current work practices, we want to hear your ideas for what you would want to see happen if the opportunities existed; we want to be guided by your ideas and your visions. Please be as inspirational or aspirational as you wish to be.

EXPLANATORY NOTES ABOUT FILLING IN THE QUESTIONNAIRE

In completing this form please include information about:

- all current PhD students and post-doctoral fellows; and

- all PhDs submitted and research fellowships undertaken since 1998.

Name of network member:

Survey questionnaire filled in by (Name of Centre/Department):

Q1 Please state the number of PhDs and post-doctoral fellows currently registered with your Centre/Department:

Full-time PhDs Part-time PhDs Sandwich PhDs

Full-time post-doc Part-time post-docs

Q2 How long has your Centre/Department been offering doctoral and post-doctoral training and supervision?

PhDs years

Post-docs years

Q3 Please can you provide an overview of the content of health research being carried out by PhDs and post-docs within your Centre/Department.

PhDs years

Post-docs years

Q4 Are there specific areas of health-related research that your Centre would wish to encourage or develop? If yes, please state what these areas may be.

Q5 Please can you briefly describe the content and duration of graduate training courses and/or post-doctoral training systems?

PhD training (include relevant graduate courses):

Post-doctoral training:

Q6 Do PhDs have access to other training? If yes, please state what these may be.

Q7 Please describe the expected duration of PhD and postdoctoral studies?

PhDs: Part-time years Full-time years Sandwich years

Post-docs: Part-time years Full-time years

Q8 What facilities are available to your part-time and full-time PhD students (e.g. room/desk space, access to computers/internet, resources)?

Q9 Please can you describe any existing arrangements for postdoctoral academic (or other relevant) support within your Centre/Department?

Q10 Please list all the ways in which PhDs and post-doctoral fellows are funded within your Centre/Department (e.g. through government/statutory agencies, research Councils, partnerships with NGOs)

PhDs:

Post-docs:

Q11 How are postdoctoral fellows hosted and integrated into the work of your centre? (e.g. are they involved in seminar programmes, teaching, supervision, have access to funds for such things as bursaries, travel, or conferences)

Q12 If you run postgraduate summer schools, please describe how are these organised? (e.g. in partnership with other research centres/institutions)

Q13 What policies or arrangements do you have regarding movement of PhDs and postdoctoral students within the EU (for example, co-supervision of students between countries)

Q14 What do you think would enhance PhD support and training within the context of EU collaboration?

Q15 Give examples of developments, innovations or aspirations which might utilise the ITEMS network of partners to promote exchanges and common educational activities more broadly (include virtual and face-to-face working)

Q16 Have you any plans or proposals for promoting these ideas?

Q17 Do you have any other comments in relation to PhD training, post-doctoral circulation, or any other issue at all?

Thank you very much for taking the time to fill in the questionnaire. The Institute for Health Research at Lancaster University, England will be collating all the information gathered through this consultation in order to produce the findings in a report due in August 2004. This report will be disseminated throughout the network and will serve as a basis for final discussions scheduled in WP5.

Please e-mail your completed questionnaires to e.kashefi@lancaster.ac.uk by 13 th of June 2003.

5. WP4: Exchange visits

Table 1. Details of Exchange visits

NO.	FROM (NAME OF CENTRE)	COUNTRY	TO (CENTRE VISITED)	COUNTRY	HOSTS' NAME	STUDENTS' NAME
2	IHR	UK	Maastricht University	Netherlands	Bernike Pasveer	Dawn Goodwin
	IHR	UK	TU Berlin University	Germany	Reinhart Busse	Steve Robertson
2	CSO, Paris	France	Erasmus University	Netherlands	Roland Bal	Elsa Gisquet
	CSO, Paris	France	Manchester	UK	Mick Worboys	Emmanuelle Bonetti
1	CSI, Paris	France	Louvain University / Liège University	Belgium	Jean Demunk Olgierd Kuty	Caroline Huyard
1	TIK, Oslo	Norway	Granada	Spain	Esteban Rodriguez-Ocana	Siv Frøydis Berg
1	Manchester	UK	University of Oslo	Norway	Ingunn Moser	Duncan Wilson
1	Maastricht	Netherlands	Manchester	UK	Mick Worboys	Mieneke te Henneppe
1	Erasmus University	Netherlands	IHR	UK	Maggie Mort	Samantha Adams
1	CNRS/ CERMES	France	York	UK	Andrew Webster	Laurent Rébillard
1	Univerity of Granada	Spain	CERMES	France	Ilana Lowy	Francisco Martinez-Antonio
1	University of Coimbra	Portugal	CSO	France	Patrick Castel	Gonçalo Lopes Praça
1	Louvain University / Liège University	Belgium	CSI	France	Myriam Winance	Julien Piérart
1	TU Berlin	Germany	University of Coimbra	Portugal	Joao Arriscado Nunes	Marcial Velasco-Garrido
1	CSIC Madrid	Spain	CESAMES	France		Esther Ortéga

6. List of Participants to Granada Workshop

Name	Research centre
Madeleine Akrich Vololona Rabeharisoa	CSI Centre for Sociology of Innovation, Ecole Nationale des Mines de Paris
Esteban Rodríguez-Ocaña, Teresa Ortiz, Alfredo Menéndez Rosa Medina	Department of History of Science, University of Granada
Michael Worboys Carsten, Timmermann Julie Anderson	CHSTM Centre for the History of Science, Technology and Medicine & Wellcome Unit for the History of Medicine, Manchester University
Joao Arriscado-Nuñes, Marisa Matias	Centre for Social Studies, University of Coimbra
John Welshman (RAPP. AXIS 2), Maggie Mort Celia Roberts	The Institute for Health Research, Department of Sociology, Institute for Women's Studies Lancaster University
Bernike Pasveer, Maud Radstake	Faculty of Arts and Culture, Maastricht University
Nicolas Dodier (RAPP. AXIS 2) Daniel Benamouzig	CERMES Centre de Recherche Medecine, Sciences, Santé et Societé, CNRS Paris
Maria Jesús Santesmases (RAPP. AXIS 1), Emilio Muñoz	Unit for Public Policies, Centro Superior de Investigaciones Científicas, Madrid
Jean de Munck (RAPP. AXIS 4)	ANSO Unit of Anthropology and Sociology,
Julien Pierart	Louvain University
Teun Zuiderent	Institute of Health Policy and Management,
Roland Bal	Erasmus University Rotterdam
Anne Lovell (RAPP. AXIS 1)	CESAMES Centre de Recherche
Claudine Perez-Diaz	Psychotropes, Santé Mentale, Société, Université René Descartes Paris V
Patrick Castel, Boris Hauray	CSO Centre for the Sociology of Organizations, Paris
Christian Gericke (RAPP. AXIS 3)	Berlin Centre for Public Health. Technische Universität Berlin
Dick Willems (RAPP. AXIS 4)	Department of General Practice, University of Amsterdam
Aude Develay (RAPP. AXIS 3)	Groupe IMAGE, Ecole Nationale de Santé Publique Paris

Ingunn Moser	Centre for technology, Innovation and culture, University of Oslo
Deborah R. Gordon, Maria Cristina Manca	U.O. Epidemiologia Clinico Descrittiva Centro per lo Studio e la Prevenzione Oncologica, Instituto Scientifico della Regione Toscana Firenze.
Joëlle Vailly	CRESP Centre de Recherche sur les Enjeux Contemporains en Santé Publique, Université Paris XIII
Olgierd Kuty	CRIS Centre de Recherche et d'Intervention Sociologique, Liège University
Michel Naiditch	Development, Innovation, Health Evaluation, Fondation de l'Avenir
Pascale Bourret	Epidemiology & Social Sciences Applied to Medical Innovation, INSERM, Marseille
Lene Koch	Department of Health Services Research, University of Copenhagen
Nik Brown	SATSU Science and Technology Studies Unit, York University
INVITED GUEST Laura Fernández	Spanish Patients Association (Foro Español de Pacientes), Fundació Biblioteca Josep Laporte,
INVITED GUEST Luis Gavira Sánchez	Board of Directors, Regional Health Services, (SAS Servicio Andaluz de Salud), Sevilla

Programme of the Granada Workshop

AXIS 1: Transformations of the biomedical sciences, of disease and of health

RAPPORTEURS: Anne M. Lovell, INSERM 379 and CESAMES (France) Maria Jesús Santesmases, UPC-Madrid (Spain)

Tuesday, March 23, 11:00 - 13:00

11:00 - 11:20 Presentation of Preliminary Report (Anne M. Lovell and Maria Jesus Santesmases)

11:20 - 11:35 Discussion

11:35 - 12:25 Presentations on Biotechnological innovation in genetics and genomics Pascale Bourret, U 379, France Lene Koch, Ucop, Denmark Deborah Gordon, Maria Cristina Manca, CSPO, Italy Madeleine Akrich, CSI, France

12:25 - 13:00 General discussion

Wednesday, March 24, 11:00 - 13:00

11:00 - 11:25 Presentations on Biomedical research and health technologies Maria Jesus Santesmases, UPC, Spain Michael Worboys, CHSTM, Manchester

11:25 - 11:40 Discussion

11:40 - 12:15 Presentations on Histories of health concepts, technologies and society Alfredo Menendez, UGR, Spain Joao Arriscado Nunes, CSS, Portugal Anne M. Lovell, for CESAMES, France

12:15 - 12:30 Discussion

12:30 - 13:00 General discussion and recommendations

AXIS 2: Participation of users and the redefinition of systems of actors in the domain of health and medicine

RAPPORTEURS: John Welshman (IHR/CSS-UK) Nicolas Dodier (CERMES-FR)

Tuesday 23 March, 3 - 5 pm

3.00 - 3.10 Presentation of Preliminary Report (John Welshman and Nicolas Dodier)

3.10- 3.45 From the Sick Patient to the Political Patient: Historical Perspectives Julie Anderson, 'Assessing the Patient: Hip Replacement Surgery in the Twentieth Century' Carsten Timmermans, 'Science, Technology, and Medicine: High Blood Pressure and Hypertension' John Welshman, 'Knights, Knaves, Pawns, and Queens: Attitudes Towards Behaviour and Motivation in Postwar Britain'

Discussion of Papers and Collaboration

4.05 - 5.00 The Shaping of the Patient Through Technical Innovation Maud Radstake, 'Affective Images: Mediated Bodies in Real-Time Medical Imaging' Celia Roberts, 'Who is the Patient in Reproductive Medicine?'

Discussion of Papers and Collaboration

Wednesday 24 March, 8.30 - 10.30 am

8.30 - 9.20From Individual Patients to Collective Patients

Vololona Rabeharisoa, 'Patient Organisations' Involvement in Research:

Towards a Framework for Comparative Studies'

Nicolas Dodier, 'Shaping of Patients' Place into the Biomedical World' Discussion of Papers and Collaboration

9.20 - 10.10 From the Passive Patient to the Active Patient Julien Pierart, 'The Local Worlds of Public Health' Discussion of Papers and Collaboration

10.10 - 10.30 General Discussion on Axis 2 Collaborations

AXIS 3: Coordination in Health Care Systems: Information and Communication Technologies and Organisational Tools

RAPPORTEURS: Aude Develay Groupe Image-ENSP, France Christian Gericke, TU Berlin, Germany

Tuesday 23 March: 11 - 13

11:00 - 11.10 Presentation of Preliminary Report (Aude Develay and Christian Gericke)

11:10 – 11:45 Formalisation and standardisation of care practices Ingunn Moser, University Oslo, NO

12:00 – 12:15 Role and position of health care providers within the health system Teum Zuiderent, Erasmus university, Nl

12:15 - 12.50 New forms of health care organisation Aude Develay Groupe Image-ENSP, FR

12:50 – 13:00 General discussion

Wednesday, 24 March: 11 – 13

11:00 – 11:40 Production of information at the macro-level Christian Gericke, TU Berlin, DE

11:40 – 12:00 Patient and user information and rights Michel Naiditch, Dies, FR

12:00 – 12:40 Sociological, historical, cultural and/or ethnical analysis Nik Brown, York University UK

12:40 – 13:00 Discussion on future comparative and coordinate research at a European level

AXIS 4: Articulation between health and policy issues

RAPPORTEURS: Jean de Munck, François Delforge, ANSO, Louvain University, Belgium Dick Willems, University of Amsterdam, The Netherlands

Tuesday 23 March: 3 - 5 pm

Setting up a safe environment

> Marisa Matias (Center for Social Studies, University of Coimbra), 'Relation between health and environment'
>
> Patrick Castel and Boris Hauray (Center for the sociology of organisations, Paris), 'Agencies as new instruments for regulating health and food products'
>
> Claudine Perez-Diaz (Research Center on Mental Health and Psychotropics – CESAMES – Paris), 'Intentional and non-intentional violence's, sexual aggressions and alcohol'

New governance and networking

> Dick Willems (Department of General Practice, University of Amsterdam), 'New networks of care'

Roland Bal (Institute of Health Policy and Managment – Erasmus University Rotterdam), 'Scientific advises on governance'

Daniel Benamouzig (Research Center Medicine, Sciences, health and Society – CERMES – Paris), 'CERMES researches'

Wednesday 24 March, 8.30am - 10.30am

New inequalities and health policies

Joëlle Vailly (Centre de recherche sur les enjeux contemporains en santé publique – CRESP – Paris), 'The production of inequalities and treatment of them in the public sphere' Jean De Munck (Health and Democracy Network – Unit of anthropology and Sociology, Louvain University – Centre de recherche et d'intervention sociologique, Liège University), 'Mental Health and Social Policies'

Politization of health issues

Marisa Matias (Center for Social Studies, University of Coimbra),' Regulation of human genetics and medically assisted reproduction'

7. List of participants

Coimbra Symposium

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COIMBRA SYMPOSIUM PROGRAMME

MEDICINE, HEALTH AND SOCIETY IN EUROPE: TRENDS AND PROSPECTS

15 DECEMBER 2004

16:30 18:00 Reception of participants - Faculty of Economics

16 DECEMBER 2004

9:30 10:30	**Opening Plenary Session** Madeleine Akrich and João Arriscado Nunes Representatives of the University of Coimbra			
10:30 - 11:00 COFFEE BREAK				
11:00 12:30	Technology/power AXIS 2	Health Medicine and National Borders AXIS 4	Genetics between laboratory and clinic AXIS 1	Standardization/evidence based medicine AXIS 3
	CHAIR: Helena Serra Disc: Ingunn Moser RAP: Christine Milligan	CHAIR: Rosa Medina Disc: Jorge Varandas RAP: Patrick Castel	CHAIR: Joao A Nunes Disc: Madeleine Akrich RAP: Emíliomuñoz	CHAIR: c. Gericke disc: jean de munck RAP:Antoinette De Bont
	Beatriz Xavier,Beneficence and Medical Technology:The study of doctor/patient relationship in intensive care units Dawn Goodwin, Access,boundaries and their effects: participating in anaesthesia Helena Serra, The social construction of medical technocraties: The sociological gaze in the world of liver transplantation	Graça Carapinheiro,Health Policies and Inequity in Portugal Joana Ribeiro, How toprotect the health care quality without limiting the foreign health professionals mobility? Rosa Maria Medina,Technosciences and national identities. The case of Spain and the African colony of Equatorial Guinea	João Arriscado Nunes,«Biographies of objects and narratives of discovery in the biomedical sciences: The case of helicobacter pylori» Pascale Bourret and Vololona Rabeharisoa,«Comparing collectivesin clinical genetics. The cases of breast cancer and autism» Ulrike Felt, Maximilian Fochler, Annina Müller,Michael Strassnig, Let'stalk about GOLD! Analysing the interactions between genome-research(ers)and the public as a learning process	Christian A Gericke, Ethical issues in applying economic tools for priority setting to health research funding Eeva Sointu, In search of wellbeing Joachim Gerich and Roland Lehner, CASI-Methods in Heath-Related Research Schreyögg J, Busse,R, Effects of drug budgets on physicians'prescription behaviour experiences from Germany
12:30 - 14:30 LUNCH				

	Patients to citizens AXIS 2	Governance AXIS 4	Stem cells AXIS 1
	CHAIR: Bernike Pasveer Disc: Pascale Bourret RAP: Christine Milligan	CHAIR: Daniel Benamouzig Disc: Joelle Vailly RAP:Patrick Castel	CHAIR: Lene Koch Disc: Nik Brown RAP: Emílio Muñoz
14:30 16:00	Madeleine Akrich and Cécile Méadel, Internet discussion groups and new collectives around health problems Janine Barbot and Nicolas Dodier, Patients organizations, medicine and capitalism Susanne de Kort, To choose or not to choose. About the chemotherapeutic treatment options in non-curable cancer	Daniel Benamouzig, Julien Besançon, Health agencies in France Herbert Gottweis, Transforming Health Policy: Biobanks, Pharmacogenetics/ Pharmacogenomics, and the Governance of Bio-medical Research Marisa Matias, Health,environment and sustainability:Waste management and public policies Silke Schicktanz, Challenges of Biomedicine - Socio-Cultural Contexts, European Governance and Bioethics	Maja Horst, Public articulation of stem cell innovation in Denmark Mette Nordahl Svendsen and Lene Koch, Moral landscapes in the clinical encounter of stem cell research in Denmark: The issue of donating fertilized eggs Torben Nielsen, The political ethics of human embryonic stem cells
16:00 – 16:30 COFFEE BREAK			
	The patient – Partially connected, transformed or still marginalized? AXIS 2	Disability AXIS 4	The sociology of expectations- Colonising the future AXIS 1
	CHAIR: Maggie Mort DISC: João A. Nunes RAP:Christine Milligan	CHAIR: Myriam Winance DISC: Ingunn Moser RAP:Patrick Castel	CHAIR: Carsten Timmermann DISC: Maja Horst RAP: Emílio Muñoz
16:30 18:00	Celia Roberts, New kinds of patient? Examples from contemporary hormonal discourses Christine Milligan, Towards inclusive spaces of care:Care transitions and informal care giving in the21st century Maggie Mort, The future patient: appearing in telemedicine, telehealthcare and e-care	Bruno Sena Martins, «The colonization of disability by a 'salvational belief in the powers of science'». Jeannette Pols, Good care: Enactments and interferences. Myriam Winance, «Redefining health in relation to the notion of disability. The international debate around the WHO classifications» Thomas Fink and Jasna Russo, «Taking position. Psychiatry and homelessness from users perspectives»	Carsten Timmermann, «Lost hopes: Lung cancer and what the link with smoking may have done to therapy» Christoph Gradmann, «'At war with bacteria'. Reality,Imagination and the rise of medical bacteriology (1880 - 1910)». Nik Brown, Alison Kraft and Paul Martin, «From promissory pasts to promissory presents: The bloody history of stem cell expectations»

17 DECEMBER 2004

	Drugs 1 AXIS 4	Brave new mothers,brave new babies 1 AXIS 1	Risk AXIS 2	Health and information AXIS 3
	CHAIR: Henri Bergeron DISC: Isabelle Feroni RAP: Patrick Castel	CHAIR: Ilana Lowy DISC: Celia Roberts RAP: Emílio Muñoz	CHAIR: Lindsay Prior DISC: Pascale Bourret RAP:christine Milligan	CHAIR: Ingunn Moser DISC: Michka Naiditch RAP: A. Debont
9:00 10:30	Anne Lovell, Addiction pharmaceuticals: reconfiguring disease and citizenship Emmanuelle Bonetti, The influence of the organizational conditions of the conception of drugs on the definition of disease and its incidence Henri Bergeron, Europeanisation of drug policies: from common principles to mutual agreement Toine Pieters and Stephen Snelders,Medical carreers of psychotropic drugs:Therapeutic drugs and the articulation of health, social and political issues in Europe since c. 1870	Ilana Lowy, «Fishingfor identity: Maternal foetal traffic and the change in meaning of pregnancy» Maria Jesus Santesmases and Esther Ortega, «Pregnancy technicalized. Prenatal testing and social expectation for healthy new borns in Spain» Myra van Zwieten,«Tests never decide. How new technology for prenatal testing will increase professional responsibility»	Boel Berner, The Bloodof Others. Technology and the Construction of Risk and Safety in Blood Transfusion G. G. Palmboom, Life at risk - living at risk? Predicting in medicine:disclosing low risk information in patient-physician Hélder Raposo, To dominate the random? Risk and uncertainty in modern thought: The case of biomedicine in the age of genetics Lindsay Prior,Repositioning the patient: the implications of being 'at risk'	C. Raghavendra Ranjini, Coordination between Norway and India in developing a health information system for primary health care Margunn Aanestadand Ingunn Moser, Making information flow across boundaries. Visions meet work practice in health care Perdiguero, E.,Ballester, R.,Castejón, R., Mass-Media and health information campaigns in Spain(1920-1936) Samantha Adams,«The reliability claims of tools (hyper-linked seals, portals)that have been designed to help users assess medical information on the internet
10:30 – 11:00 COFFEE BREAK				

	Concepts AXIS 4	Brave new mothers,brave new babies 2 AXIS 1	Drugs 2 AXIS 1	Technologies and health care AXIS 3
	CHAIR: John Welshman DISC: Jean De Munck RAP: Patrick Castel	CHAIR: M. Jesus Santesmases DISC: Celia Roberts RAP: Emílio Muñoz	CHAIR: Isabelle Feroni DISC: Anne Lovell RAP: Vololona Rabeharisoa	CHAIR: Dick Willems DISC: M. Naiditch RAP: A. De Bont
11:00 12:30	John Welshman, A Trojan Horse: The Concept of the Unemployable Luísa Ferreira da Silva et al., Health and wellbeing related to 'healthy behaviour? Vincent Lorant, Social Capital, Health and Health Promotion Vladimir Jankovic,Exposure and the Invention of Modern Environmental Medicine	Amélia Augusto,Infertility and Medically Assisted Reproduction in Portugal: From"private problems" to"social issues" Joëlle Vailly, Forms o f judgment in the context of evidence-based medicine. Neonatal screening for cysticfibrosis in France Tina Miller, Transition to first-time motherhood: shifting constructions of expert,medical knowledge	Isabelle Feroni, French GP's and opioid maintenance therapy with buprenorphine:professional characteristics and new medical practices Noémia Lopes,Modernity, medicines and self-medication Petra Jonvallen,Producing Pills,Constructing Obesity:Intersections of Research, Industry and Care in a Clinical Trial	Antoinette de Bont and Roland Bal, «Faceto face in a database. A reflexive study about monitoring quality of care» Dick Willems, «Care at distance. Tele-care as the promised land of the care of chronic diseases» Ericka Johnson,Situating medical simulators in clinical training:reconstituting medical patients and practices Roland Bal and Femke Mastboom,«Optimizing GP -Specialist interaction through ICT: A qualitative analysis»
12:30 - 14:00 LUNCH				
14:00 16:00	Plenary Discussion RAPPORTEURS AND INVITEES			
16:00 – 16:30 COFFEE BREAK				
16:30 17:30	Closing Session Where do we go from here? MEMBERS OF STEERING COMMITTEE AND INVITEES			

8. List of participants

	Maastricht Conference
Bernike Pasveer	Dept. of Technology and Society Studies, Universiteit Maastricht,
Babette Müller-Rockstroh	Dept. of Technology and Society Studies, Universiteit Maastricht,
Maud Radstake	Dept. of Technology and Society Studies, Universiteit Maastricht,
Mieneke te Hennepe	Dept. of History, Universiteit Maastricht Maastricht
Christine Neuhold	Dept. of Philosophy, Universiteit Maastricht, Maastricht
Jeanette Pols	Trimbos-instituut, Utrecht
Dick Willems	Afdeling Huisartsengeneeskunde, Divisie Public Health, AMC, Amsterdam
Roland Bal	Dept. of Health Policy and Management, Erasmus University,
	Medical Centre, Rotterdam
Antoinette de Bont	Dept. of Health Policy and Management, Erasmus University, Medical Centre, Rotterdam
Jean de Munck	Université de Louvain, Louvain La Neuve
Elie Faroult	DG Research, European Commission, Brussels
Sébastien Leroy	ARMINES, Paris
Madeleine Akrich	Centre de Sociologie de l'Innovation, Ecole Nationale Supérieure des Mines de Paris, Paris
Vololona Rabeharisoa	Centre de Sociologie de l'Innovation, Ecole Nationale Supérieure des Mines de Paris, Paris
Florence Paterson	Centre de Sociologie de l'Innovation, Ecole Nationale Supérieure des Mines de Paris, Paris
Delphine Gardey	Centre de recherche en histoire des sciences et des techniques, Cité des sciences et de l'industrie, Paris
Patrick Castel	CNRS, Centre de sociologie des organisations, Paris
Boris Hauray	CNRS, Centre de sociologie des organisations, Paris
Michka Naiditch	Dies, Paris
Ilana Löwy	CERMES(INSERM/CNRS/EHESS), site CNRS, Villejuif
Joëlle Vailly	CRESP, Université Paris, Bobigny

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Maggie Mort	Institute for Health Research, Lancaster University, Lancaster
Orla O'Donovan	Department of Social sciences, Cork University
Ericka Johnson	Dept of Technology and Social Change, University of Linköping

Maastricht Conference programme

ITEMS Final Conference, Maastricht

Tuesday 17 May

09:00 09.30 Coffee	
09:30 09.45	**Welcome**
09.45-10.00 *10.00-10.45*	**ITEMS up to the present: SSA, RTN, FP7** **Chair: Bernike Pasveer** **A brief summary of ITEMS work and achievements, and a presentation of the workshop** (Madeleine Akrich) *Presentation of the SSA projects (Vololona Rabeharisoa, Joao Nunes, Olivier Borraz, Maggie Mort, Ingunn Moser). Discussion.*
10.45 – 11.15 **Coffee break**	
11.15 *12.00* *12.00* *12.30*	**A presentation of FP7 orientations and discussion** Elie Faroult, DG Research, European Commission **Possible Futures** Short presentations on other potential collaborative projects Chair*: Bernike Pasveer*
12.30 14.30 **LUNCH**	
14.30 17.00	**PHd and Post-doc Training** Chairs: Maggie Mort & Madeleine Akrich Rapporteur: Nik Brown

18:00 Excursion, drinks, dinner 18:00 Bicycle tour (i.c.o. sunny weather) & diner for those who stay

Wednesday 18 May *09.00 10.15*	**ITEMS: costs, gains, constraints of/for collaborative work** **Chair: Bernike Pasveer** *Rapporteurs: Joao Nunes & Roland Bal*
10.15 – 10.45 **Coffee break**	
11.45 - 12.00	**ITEMS continued**
12.00 -14.30 LUNCH	
14.30 - 15.45 *15.45-16.00*	**Communications in & after ITEMS** *Chairs: Michael Worboys & Carsten Timmermann* *Rapporteurs: Maria Jesus Santesmases & Florence Paterson* **End of the workshop**

18:00 Bicycle tour (i.c.o. sunny weather) & diner for those who stay

9. WP5: ITEMS questionnaire on the pros and cons of collaborative research & responses to the questionnaire

We would appreciate you to fill in this questionaire. We will use its results plus this afternoon's discussion for ITEMS final report. Thanks a lot!

1).Does your laboratory/department/faculty have externally funded research activities?

Yes No

2) If yes, please, indicate approx. percentage of resources coming from:

externally funded research/institutional budget _____

national _____ Europe _____ Others _____

public sector funding _____ foundation or private sector funding _____

3) Does your laboratory/department/faculty encourage E.U./externally funded collaborative research?

Yes No

4) If so, how?

it poses no barriers, but is of no particular help

it actively stimulates initiatives for collaborative work

it provides for actual administrative support

5) What would further encourage you to apply for external funds for collaborative work?

6.)Would you be prepared to participate in a collaborative project?

Yes No

If no, why not?

7) Would you be prepared to lead a collaborative project?

Yes No

If no, why not?

8) In either case, what would (further) encourage you to participate in a collaborative project?

9) In either case, what would (further) encourage you to lead a collaborative project?

10) What modes of collaboration would you privilege?

independent acitvities with e-communication

mixed (e & live collaboration)

live collaboration only

other: _____

11) What forms of collaborative activities would you prefer?

research projects workshops/symposia

other: _____

12) Can you think of projects that would gain extra value from their expansion to a collaborative European project?

13)If yes, what kinds of projects do you think of?

14) If yes, what would this value be?

15) If no, why not?

16) Do you think qualitative methodology is commensurable with comparative research?

Yes No

Yes No

Why, or why not?

question	Granada	CSIC	CSIC2
1 external money?	yes	yes	yes
2. external/internal	70/30	50/50	
a. nat b. eur c. public d. private e. other	a. 100	a. 80 b. 20 c. 80 d. 20	
3. encourage?	yes	yes	yes
4 a. passive b. active c. actual	c	a	b not c
5. what would encourage further	1. good research goals; 2. time	1. Less administration; 2. More exchange of human capital; 3. More intellectual cooperation; 4. More interdisciplinarity	comparative work
6. willing to partipate in project?	yes	no	yes
why not?		almost retired	
7. prepared to lead?	no	no	no
why not?	workload + no local support	almost retired	administrative reasons
8. what would encourage participation further?	local support	real strategy of collaboration	regular meetings
9. What would encourage leadership?	same		administrative help
10. collaboration: a. @, b. @ + live c. live d. other	b	b	b
11. Forms: a. research b. workshops c. other	b	a & b	b
12. Extra European value?	yes	yes	yes

13. What kinds?	ITEMS	interdisciplinary, agenda-setting, politics, diversity	reproduction & risk in Europe
14. What value?	intellectual & political	Europe in sc. World, new agendas	build standard for comp. Studies
16. qualitative & comparative?	Yes, international team and/or comparative object	Yes, fundamental: diversity, cultural exchange	yes
question	**FdCW/UM**	**Trimbos**	**BMG/EUR**
1 external money?	yes	yes	yes
2. external/internal		99/1	
a. nat b. eur c. public d. private e. other		a. 95 b. 1, c. 90, d. 10	b. 5 c. 45 d. 50
3. encourage?	yes	yes	no
4 a. passive b. active c. actual	a	a	a
5. what would encourage further	administrative support	administrative support	administrative support
6. willing to partipate in project?	yes	yes	yes
why not?			
7. prepared to lead?	yes	?	?
why not?		bureaucracy	bureaucracy & time
8. what would encourage participation further?	administrative assistance, live meetings, more local recognition	information, good coworkers	someone else leads
9. What would encourage leadership?	idem	don't know	more knowledge about funding, administrative support
10. collaboration: a. @, b. @ + live c. live d. other	b	b	b

11. Forms: a. research b. workshops c. other	a & b	a & b	a & b & training
12. Extra European value?	yes	yes	yes
13. What kinds?	transnational, identity & difference	differences	comparative; multisite ethno telecare, etc., europeanisation of healthcare politics & governance; HTA
14. What value?	making Europe, gains & losses	good practice	immanent; methodological
16. qualitative & comparative?	yes	yes	yes
	methodological experiment	comparison belongs to qual. Studies	
question	**Lancaster**	**Manchester**	**Manchester2**
1 external money?	yes	yes	yes
2. external/internal	60/40		
a. nat b. eur c. public d. private e. other	c 85, d 15	c. 45 d. 45 e. 10	a. 50, d. 50
3. encourage?	yes	yes	yes
4 a. passive b. active c. actual	a & c	b	c
5. what would encourage further	time	specific calls; more flexible rules	lack of other funds; concrete incentives
6. willing to partipate in project?	yes	yes	yes
why not?			
7. prepared to lead?	yes	y & n	no
why not?		benefit but low chance of success and high administrative load	no time

8. what would encourage participation further?	good team, do research elsewhere	identification of partners/more suitable projects	synergies with existing project(s)
9. What would encourage leadership?	international publications	research objective	one at a time; incentives for coordinating center needed
10. collaboration: a. @, b. @ + live c. live d. other	c and ethnographies with indegenous teams	b	b
11. Forms: a. research b. workshops c. other	a, b, c	a & b	a & b
12. Extra European value?	yes	yes	no
13. What kinds?	knowledge production about new health technologies	clinical practice, RTD,	tools for internat. & interdisc. Collaboration
14. What value?	governance & citizenship	control of variables, localities in international context	
16. qualitative & comparative?	Y qualitative ethnography is always comparative	yes	y develop this
question	**Coimbra**	**Linkoping**	**INSERM 79**
1 external money?	yes	yes	yes
2. external/internal		70/30	25/75
a. nat b. eur c. public d. private e. other	a. 65 b. 25 c. 80 d. 20 e. 10	a. 90 b. 5 e. 5	a. 95 b. 5 c. 65 d. 5
3. encourage?	yes	yes	yes
4 a. passive b. active c. actual	b & c	a	a
5. what would	administrative support	administrative support	intellectual interest; administrative support

6. willing to partipate in project?	yes	yes	yes
why not?			
7. prepared to lead?	yes	no	no
why not?		lack of adm. support	lack of know-how
8. what would encourage participation further?	administrative support	support would help	better identification of collaborators; training for know-how; intellectual
9. What would encourage leadership?	fulltime project manager	help with bureaucracy	idem
10. collaboration: a. @, b. @ + live c. live d. other	b	b	b
11. Forms: a. research b. workshops c. other	a & b	a	a & b
12. Extra European value?	yes	yes	yes
13. What kinds?	any topic that would benefit from european approach	collaborative research	pharmaceuticals, new actors
14. What value?	understanding	forums, dissemination	comparing & following phenomena
16. qualitative & comparative?	yes	yes	yes
	qual meth = comparative, allows for flexible, context sentitive research		multi-site studies.

question	CERMES	ARMINES	CSI
1 external money?	yes	yes	yes
2. external/internal	50/50	95/5	70/30
a. nat b. eur c. public d. private e. other	a. 90 b.10, c. 100	a. 80 b. 20 c. 50 d. 50	a. 70 b. 30 c. 80 d. 20
3. encourage?	yes	yes	yes
4 a. passive b. active c. actual	a	b & c	c
5. what would encourage further	simplification of European procedures, more attention to content		intellectual, collegial exchange
6. willing to partipate in project?	yes	yes	yes
why not?			
7. prepared to lead?	no	yes	yes
why not?	too much administration		
8. what would encourage participation further?		strategic research topics; quality of the consortium	
9. What would encourage leadership?	simplification, help; circulation of staff	simplification of rules	project manager
10. collaboration: a. @, b. @ + live c. live d. other	b	b	b
11. Forms: a. research b. workshops c. other	a & b	a	a & b
12. Extra European value?	yes	yes	yes

13. What kinds?	innovation, regulation, internationalization, unification of health care	research R&D	political impact
14. What value?	local in global	visibility, quality & quantity of personel exchange	local in global
16. qualitative & comparative?	yes	yes	yes
	comparative work needs qualitative methodology		
question	**DIES**	**CRESP**	**CNRS CSO**
1 external money?	yes	yes	yes
2. external/internal	100	40/60	
a. nat b. eur c. public d. private e. other	c 50 d 50	a. 90 b. 5 c. 90 d. 10 e. 5	
3. encourage?	yes	yes	yes
4 a. passive b. active c. actual	c	b	a
5. what would encourage further	intellectual; support for own lab	know-how	common object
6. willing to participate in project?	yes	yes	no
why not?			not established
7. prepared to lead?	no	no	no
why not?	time; resources; know how		not established
8. what would encourage participation further?	common research topic	information	
9. What would	a miracle	know-how	

encourage leadership?			
10. collaboration: a. @, b. @ + live c. live d. other	b	b	b
11. Forms: a. research b. workshops c. other	a & b	a & b	b
12. Extra European value?	yes	yes	yes
13. What kinds?	HTA; elderly; genetics; risk; prof/patient	life & death; quality of life	political issues
14. What value?	local in global	intellectual	comparison; europeanization
16. qualitative & comparative?	yes	yes	yes
question	**CNRS CSO2**	**BERLIN**	**CSI2**
1 external money?	yes	yes	yes
2. external/internal		90/10	see CSI1
a. nat b. eur c. public d. private e. other		a. 20 b. 60. C. 90 d. 10 e. 20	idem
3. encourage?	yes	yes	idem
4 a. passive b. active c. actual	a	c	idem
5. what would encourage further	good collective; job position		idem
6. willing to partipate in project?	no	yes	yes
why not?	job position		
7. prepared to lead?	no	no	yes
why not?	same	lack of capacity, administrative burden	

8. what would encourage participation further?	good leadership; intellectual value		knowing some partners personally
9. What would encourage leadership?	experience		fits research, sharing tasks with collegue at center
10. collaboration: a. @, b. @ + live c. live d. other	b	b	d. depends on project
11. Forms: a. research b. workshops c. other	b	a & b	c. idem
12. Extra European value?	yes	no	yes
13. What kinds?	governance; risk; local/global		issues that are international of themselves, patient organizations, biobank networks
14. What value?	normalization & diversity	already involved	understand Europe, making Europe more less artificial
16. qualitative & comparative?	yes	yes	yes
			questions and sites matter, do research together

10. WP5: How do we communicate? responses to the questionnaire

1. Websites

Most frequently mentioned:

European Association for the Study of Science and Technology (EASST)

http://www.easst.net/

Society for Social History of Medicine:

http://www.sshm.org/

Society for Social Studies of Science (4S)

http://www.4sonline.org/

Others:

Asociation de Demografia Historica:

http://www.adeh.org/

Centre for Economic and Social Aspects of Genomics (CESAGen)

http://www.cesagen.lancs.ac.uk/

Community Research & Development Information Service (CORDIS)

http://www.cordis.lu/

European Association for the History of Medicine and Health (EAHM)

http://www.eahmh.net/

Economic and Social Research Council, UK (ESRC)

http://www.esrc.ac.uk/

European Commission

http://europa.eu.int/comm/

Institut national de la santé et de la recherche médicale (INSERM)

http://www.inserm.fr

Institut national du cancer

http://www.institutnationalducancer.fr

International Network for the History of Public Health

http://www.liu.se/tema/inhph/

Wellcome Trust

http://www.wellcome.ac.uk/

2. Electronic Mailing lists

Most frequently mentioned: Eurograd (EASST)

http://www.easst.net/joineurograd

H Net list for the History of Science, Technology and Medicine (H-SCI-MED-TECH):

http://www.h-net.org/~smt/

STS Grad listserv (4S)

http://www.4sonline.org/6s/listserv.htm

Others:

Conecta – Boletin de Noticias sobre Historia de la Ciencia, la Medicina y la Tecnologia

http://dsp.umh.es/conecta/

Interwar Health Network

interwar-health@uni-rostock.de

Red de Historia de la Salud Publica en America Latina y el Caribe (HISPALC-L):

mcueto@upch.edu.pe

H-Net list for Medical Anthropology (H-MEDANTHRO)

http://www.h-net.org/~medanthro/

Mersenne (UK list for history of science, technology and medicine)

mersenne@jiscmail.ac.uk

3. Journals

Most frequently mentioned:

Science, Technology & Human Values

http://sth.sagepub.com/

Sciences Sociales et Santé

http://www.john-libbey-eurotext.fr/fr/revues/sante_pub/sss/sommaire.md

Social History of Medicine

http://shm.oxfordjournals.org/

Social Science & Medicine

www.sciencedirect.com/science/journal/02779536

Social Studies of Science

http://sss.sagepub.com/

Sociologie du Travail

http://www.elsevier.fr/html/detrevue.cfm?code=STR

Sociology of Health and Illness

http://www.blackwellpublishing.com/journal.asp?ref=0141-9889

Others:

American Anthropologist (American Anthropological Association)

http://www.aaanet.org/aa/

Annales de Demographie Historique (Société de démographie historique, Paris) [1]

http://www.adh.msh-paris.fr/

Asclepio (Departamento de Historia de la Ciencia, Instituto de Historia, Consejo Superior de Investigaciones Cientificas, Madrid) [1]

http://www.ih.csic.es/publicaciones/webasclepio/

Body and Society

http://tcs.ntu.ac.uk/body/

British Medical Journal (BMJ, British Medical Association)

http://bmj.bmjjournals.com/

Bulletin of the History of Medicine (American Association for the History of Medicine)

http://www.press.jhu.edu/journals/bulletin_of_the_history_of_medicine/

Culture, Medicine and Psychiatry

http://web.mit.edu/dumit/www/cmp.html

Dynamis (Granada)

http://www.ugr.es/~dynamis/

Economy and Society

http://www.tandf.co.uk/journals/titles/03085147.asp

Ethics of Information Technology

http://www.springeronline.com/

European Journals of Women's Studies

http://ejw.sagepub.com/

Feminist Theory

http://fty.sagepub.com/

Health Care Analysis

http://www.springeronline.com/

Historia, Ciencias, Saude-Manguinhos (Rio de Janeiro)

http://www.scielo.br/scielo.php?script=sci_serial&pid=0104-5970&lng=pt&nrm=iso

History & Philosophy of the Life Sciences

http://www.tandf.co.uk/journals/titles/03919714.asp

History of Psychiatry

http://hpy.sagepub.com/

L'Homme – Revue française d'anthropologie

http://lhomme.revues.org/index.html

International Journal of Medical Informatics

http://www.intl.elsevierhealth.com/journals/ijmi/

International Journal for Quality in Health Care

http://intqhc.oxfordjournals.org/

International Journal of Technology Assessment in Healthcare

http://www.cambridge.org/uk/journals/journal_editors.asp?mnemonic=THC

Journal of the History of Biology

http://www.springeronline.com/

Journal for the History of Medicine and Allied Sciences

http://jhmas.oxfordjournals.org/

Medical Anthropology

http://www.tandf.co.uk/journals/titles/01459740.asp

Medical History (Wellcome Trust Centre for the History of Medicine, London)

http://www.ucl.ac.uk/histmed/medhist.html

Medicina & Storia (Florence)

http://www.polistampa.com/asp/sr.asp?id=3167

Methods of Information in Medicine

http://www.schattauer.de/z/10_de_navi_top.asp?menu=journals&submenu=inhaltmeth

New Genetics and Society

http://www.tandf.co.uk/journals/titles/14636778.asp

Patient Education and Counseling (Official journal of EACH, the European Association for Communication in Healthcare and AAPP, the American Academy on Physician and Patient)

http://www.elsevier.com/wps/find/journaldescription.cws_home/505955/description#descripti on

Qualitative Health Report Revista de Demografia Historica (Zaragoza)

http://www.adeh.org/revista/index.html

Revue Française de Sociology Science as Culture

http://human-nature.com/science-as-culture/

Social Epistemology

http://www.tandf.co.uk/journals/titles/02691728.asp

Sociologie et Societes

http://www.erudit.org/revue/socsoc/

Theoretical Medicine and Bioethics

www.kluweronline.com/issn/1386-7415/contents

Vest (a Nordic journal)

European Commission

EUR 23145 — EU RESEARCH ON SOCIAL SCIENCES AND HUMANITIES — Identifying Trends in Medical European Space. Contribution of Social and Human Sciences - ITEMS

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