EUROPEAN
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THE SIXTH FRAMEWORK PROGRAMME

The Sixth Framework Programme covers Community
activities in the field of research, technological
development and demonstration (RTD)
for the period 2002 to 2006

MEDUSE

Governance, health and medicine.
Opening dialogue between social scientists and users

Specific Support Action. Priority 7: Citizens and Governance in a Knowledge Based Society

Project: CIT6-CT-2006-028350

FINAL ACTIVITY REPORT

CENTRE DE SOCIOLOGIE DE L'INNOVATION - ARMINES

March 2008

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PROJECT EXECUTION

PROJECT OBJECTIVES

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

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

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

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

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

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

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

PARTNERS INVOLVED

The research departments involved in MEDUSE were :

- Centre de Sociologie de l'Innovation (CSI), ARMINES-Ecole des Mines: coordinator of the project (contact: items-network@ensmp.fr), and co-organiser of the conference on theme 1.
- Centro de Estudos Sociais (CES), University of Coimbra, School of Economics, co-organiser of the conference on theme 1.
- Institute for Health Research (IHR) & Institute for Women's Studies at Lancaster University UK, organiser of the conference on theme 2, with the collaboration of Centre for Technology, Innovation and Culture (TIK) University of Oslo.
- Centre de Sociologie des Organisations (CSO) & Centre de Recherche Médecine, Sciences, Santé Société (CERMES), CNRS, co-organisers of the conference on theme 3.
- Centre de Recherche et d'Intervention Sociologiques (CRIS), University of Liege, co-organiser of the conference on theme 3.

WORK PERFORMED

The project, as we designed it, comprised a number of steps that have been followed for each of the three selected themes :

1. the production of a bibliographic database to inform a longer document 'the state of the art' on the issue of.
2. the production of the State of the art document.
3. the development of a Policy Paper identifying key themes and sub themes for debate at a wider forum.
4. the identification of speakers to introduce the debate in the plenary sessions and circulation of the Policy Paper to them.
5. the organization of the venue, the identification of the potential participants, the circulation of policy paper as part of invitation strategy.
6. the event itself, i.e. the particpative conference.
7. the dissemination of conference proceedings through the website of the project.
8. the writing of a detailed report by each work package co-leaders incorporating the state of the art and the policy paper with the synthesis of discussions and highlighting of participants; concerns, problems and future work identified.

METHODOLOGIES AND APPROACHES USED

PREPARATION OF THE STATE OF THE ART

The 'state of the art' preparatory work for the conference consisted of an analysis of academic and non-academic literature around the topics covering the scope of the project. A preliminary search for the available sources of litterature resulted into three bibliographical database comprising around 200 references for each theme. These database have been published on MEDUSE website : it is worth noting that as regards theme1 and theme2, we were able to manage an access to the abstracts of most documents as well as to the website where the document can be found.

In the case of WP1 on ‘patient organizations’ and WP2 on ‘technologies and home care’, a deviation from the project’s programme can be observed consisting of the organization of « focus groups » in order to improve the preparation of the conference.

In the case of WP1, this was motivated by the fact that the literature on the emergent themes we are interested in was quite limited and crucially lacks insights on actual practices and current issues as framed by the actors : seven « focus groups » with patient organisations representatives or staff were organized in March and April 2007, both in France and in Portugal. These focus groups have been recorded transcribed, synthesis have been written : it represents a significant additionnal amount of work, but it proved to be useful as a complementary source of knowledge, as well as in the task prospecting for potential participants.

In the case of WP2, the motivation was a bit different : we devoted considerable time to identifying people we could invite to this event, and making sure that they had the broadest range of participants possible. But we realised that we would not be able to recruit older people to attend the event ; so we decided to hold focus groups before the conference and to feed this information into the conference via a plenary session. We held three focus groups, one in the UK and two in Norway, with carers and older people, to talk about relevant issues. These groups allowed us to feed in the voices of these groups without the difficulties and costs of attending an international conference.

ORGANIZATION OF THE CONFERENCES

The selection of the speakers and the « recruitment » of participants were crucial, given that the objectives of the conferences was to set up a dialogue between involved parties in each of the issues we canted to tackle. In all cases, we devoted important efforts to achieve a relevant and well-balanced participation[2] :

For the first conference on ‘Patients organizations » ‘,the focus groups have helped considerably to identify potential participants to the conference, which means the speakers as well as the other participants. On the basis of the “policy paper” mentioned above, contacts were made with social scientists who hold specific academic expertise on the issue and with key actors who voice particular political concerns, including members of the European Commission Health and Consumer Protection Directorate-General (DG SANCO). The speakers were chosen according to our aim of presenting various configurations or various viewpoints on each theme. We were confronted to a difficulty we had not enough anticipated : the fact that patient’s organizations often lack funds to pay travel expenses for their members ; so we had to offer some funding in order not to be restricted to French patients organizations. Despite this difficulty, we managed to gather participants from Belgium, (France), Germany, Ireland, Netherlands, Portugal, Romania and UK.

In the case of the second conference on ‘Technologies and home care’, a list of the key fields in the area of telecare for older people was made quite early: clinicians and social care

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[2] See in annex 1 the actual structure of the panel audience for the three conferences.

providers, policy makers, technology designers, social scientists, older people themselves, architects, psychologists and consumer advocates. We wanted to invite people from all these domains and thought carefully about key organisations and research groups to target. Ultimately, we did end up with representatives of almost all of these groups. We also tried to cover a range of European states in our invitations, although our efforts in this regard were restricted by a lack of funds to pay for participants who were not plenary speakers. We were also restricted by the requirement to hold the event in English. Ultimately we attracted participants from the UK, Spain, Portugal, France, The Netherlands, Norway, Ireland and Belgium.

The organising committee of the third conference on ‘Agencies’ also identified potential speakers for each theme. The different members, on the basis of their professional networks, quickly came up with a first list of speakers, both in academia and in and around agencies. They were contacted individually, and they often suggested other speakers. Several individual meetings were organised with potential speakers (in Paris, London and Brussels), both to present the conference and obtain names of other potential speakers. Special attention was paid in each session to reach equilibrium between academics and professionals. It was also necessary to bring in academics from different countries (UK, Italy, Germany, Poland, Belgium and France), and professionals from different backgrounds (agencies, administrations, industry, NGOs). This phase proved to be longer than expected. In parallel, information on the conference was disseminated through several networks: European heads of agencies, national agencies, and academic networks in different countries and in Europe working on health, risk or regulation. The speakers were themselves asked to disseminate information in their own networks.

ORGANIZING PARTICIPATION

We wanted the conferences to be as participative as possible, so we developed a method in order to allow the discussions to be as inclusive as possible : this method was applied especially in the cases of the two first conferences which shared two main features :

- presence of a great diversity of actors, which are not all used to discuss together nor to express themselves in the context of big assemblies with heterogeneous actors.
- A number of participants too large to allow people to sit together around the same table.

By contrast, the third conference gathered a more limited number of participants (around 40), of more homogeneous origins and cultures – mainly academics and professionals from public administrations – it is the reason why this method was used in a more limited way.

Prior to the two first conferences, we divided participants into three randomised groups (2 per day). These groups then held discussions after the plenary presentations of papers on each theme (so after each presentation there were 3 discussion groups, run simultaneously).

The sessions were facilitated by one of a range of people[3]: either MEDUSE project team members or other researchers well known to us. As well as a facilitator we also appointed a respondent to each group. Both Facilitators and Respondents represented a diversity of backgrounds and came from a variety of countries. They were chosen as people with high

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[3] See in annex 2 the guidance given to facilitators and respondents

level communication skills and a good understanding of the subject area. Prior to the event, they were given instructions about their roles and asked to read the policy paper so that they were aware of the relevant issues. They were also asked to request permission from participants to digitally record the sessions and to use quotations from these recordings in this report, if appropriate. The Facilitators were asked to be particularly conscientious in dealing with language issues and to assist participants with translation of words and phrases if necessary. They were also instructed to try to keep discussion on topic, and to encourage participants to supply particular examples from their experience in the field. The respondent's role was to keep notes on the discussion and, close to the end of the session, to provide a verbal and/or written summary (on flip charts provided) of the content of the discussion. The facilitator would then allow a short period of time for participants to comment on the summary.

These sessions were extremely successful. Participants were keen to go into their designated groups and showed no signs of resistance to being separated from friends or colleagues in the randomised groups. Everyone participated enthusiastically, and many participants helped each other with translations and communication in a non-native language. The discussions were always lively and stimulating, and meant that participants eventually met everyone at the event, thus facilitating the best possible sharing of ideas across disciplines, nationalities and backgrounds ; they tended to produce interesting examples and counter-examples relating to the themes under discussion.

After much thought, we had decided not to include a feedback session to the main group: we felt that such sessions are often somewhat repetitive, given the fact that we already organized a synthesis work in each group of discussion. In conference 2 on 'Technologies and home care', we had a plenary discussion session, facilitated by Celia Roberts, in which all participants were asked to write down three things that surprised them about what they had learnt at the conference, and three things that they might change or bring into practice in the future. These were then fed back verbally to the main group, listed simultaneously on the public screen, and discussed. This gave participants the opportunity to reflect on what they had learned from each other in the groups and from the plenary presentations, and to think about how they might take this learning into their own work. It was helpful to us to have these thoughts collated (and they are summarised at the end of this document). Many participants claimed to have encountered new ideas at the conference and to feel inspired to take ideas back into their clinical, policy, design or research practice.

RESULTS AND OUTPUTS OF THE PROJECT

There are four direct outputs of the projects :

1) a state of the art for each of the three themes
2) the conferences themselves : programs can be consulted in Annex 3, elements on the structure of the panels of participants are presented in Annex 2
3) the conference proceedings : as indicated in the project, conference proceedings have been made available through MEDUSE website :

   http://www.csi.ensmp.fr/WebCSI/MEDUSE/. They include papers, presentations, and synthesis of discussions. In addition, we decided to prepare a published version of the three conference proceedings in order to disseminate it to the actual participants, but also to people who were not able to attend the conference and to specific categories of public as public administrations for example.
4) a series of synthesis highlighting the main conclusions of both state of the art and the discussions

All the above mentionned productions are gathered into three work package reports.

MAIN POLICY WP1 RECOMMANDATIONS : THE DYNAMICS OF PATIENT'S ORGANIZATIONS IN THE EUROPEAN AREA

SOCIAL AND POLICAL STAKES OF PATIENT ORGANIZATIONS AS REGARDS TRANSFORMATION, PRODUCTION, CIRCULATION AND GOUVERNANCE OF KNOWLEDGE

Recommendation #1: Recognize the role of patient organizations in the governance of knowledge and health policies.

Europe can be a driver in a process of harmonizing national practices. In practical terms, as far as research is concerned, this would mean systematically including representatives of patient organizations or civil society in the elaboration of research programmes, the selection of projects and even the organization of scientific events. Interesting experiments have already been undertaken in this respect (e.g. "Meeting of Minds") but unfortunately they are still exceptions. Future measures should facilitate dialogue between the various stakeholders – civil society, researchers, firms, administrations, policy-makers – and not confine the debate to separate domains, as this complicates the subsequent translation of recommendations into effective research policies. The idea is to make health and medical policies not a field apart – this approach is transposable for many issues, especially those concerning sustainable development – but perhaps rather a driving force, owing to the accumulated experience.

Recommendation #2: Give patient organizations the means to act, which implies:

- Providing them with material and financial means relative to the services they render to the community. In-depth reflection should be undertaken on the modalities of this funding and on the potential effects of the various forms of funding that can be envisaged. Discussions have shown that there are several possible modalities which generate debate, but that in any case it is not acceptable for the organizations' contribution to collective reflection to be an "expense" or for a strong asymmetry to continue exiting between professionals and POs in this respect. Here again, Europe could be the locus of such reflection.

- Guarantee them access to the broadest possible range of information, especially information from firms or government administrations. Reflection on the evolution of tools for storing or disseminating research results should integrate the constraint of accessibility to a broader public than only the scientific community.

- Promote and support the training of representatives of patient organizations on scientific aspects, including by integrating the strategic and political dimension. This dimension could, as mentioned in the discussions, transcend the strict frame of non-profit organizations and spread to other stakeholders, especially public administrations. What does it mean today to organize the drawing up of recommendations in a pluralistic framework? How can the different forms of expertise be taken into account and discussed jointly?

Recommendation #3: Make POs actors in their own right in knowledge production, which implies:

- The development of knowledge on the organizations' actual work today, which is still partially invisible. This relative invisibility has the effect of limiting POs' strategic reflection on these questions and depriving them of the benefits that they could derive from a comparative analysis of their activities.

- The development of tools for patient organizations to extract value from patients' experiences by creating interfaces between the associative world and the research world. Research programmes on these questions ought to be developed. Here again, the health field should not have the status of an exception but serve as a locus of experimentation with new approaches in which the user is put at the centre of the learning and innovation system.

PATIENT ORGANIZATIONS AND ECONOMIC ACTORS : WHAT FORMS OF RELATIONS ?

Recommendation #1: Cooperation between POs and industry should be promoted when possible and desirable, taking into account that a number of conditions may facilitate such cooperation, including: i) the need for financial resources for the very subsistence of POs; ii) the need for investment in certain areas of biomedical research or in the development of therapies, especially where there are none available; iii) the perception of an asymmetric relation of POs with other actors, such as professionals and the State; iv) the degree of professionalization or influence of POs, implying a greater ability to mobilise wider resources and at the same time controlling them; v) the focus of POs on diseases or conditions requiring immediate, continuous or new treatment, such as rare or chronic diseases (pathology-driven organizations), in contrast with other organizations focusing on more broader concepts of health and/or on the demedicalization of certain conditions or practices (handicaps, mental illness, deafness, childbirth; vi) the absence of public research in domains of interest to the POs.

Recommendation #2: The role of public authorities in relation to drug regulation, pharmacosurveillance, ethical issues and property rights and patents is crucial for the creation of an appropriate legal and regulatory environment for PO action.

Recommendation #3: Research centres should be called upon to mediate exchanges between patients and industries and between patients and researchers. Some specific programs exist allowing for productive interactions between representatives from POs and from scientific communities, for example in France. Participants stated clearly that this type of initiatives is crucial for enabling POs to discuss and identify general and common questions that go beyond their specific agendas, including the advancing of research orientations. Other recommendations in terms of research were made, notably the possibility and interest of a comparative approach to the relationships PO and the industry have with research institutions, or alternative ways of funding and developing research.

Recommendation #4: The questions raised by the relations between researchers, universities or public research organizations and the industry should be compared with the experiences of collaborations between POs, charities and foundations and industry, as common problems seem to emerge in both types of situations.

Recommendation #5: Initiatives developed at both the European and the national level to encourage the participation of organizations in research and the cooperation between researchers and communities (in France, the PICRI - Partnership Institutions-Citizen for Research and Innovation) should be assessed for their capacity to stimulate the involvement of POs in the design of research policies. This should be extended to a broader exploration of other types of partnerships to be developed between patient organizations and other civil society organizations

SOCIAL AND POLITICAL STAKES OF ASSOCIATIVE NETWORKS, COALITIONS, AND COLLECTIVES

Recommendation #1: Procedures for identifying and choosing stakeholders should be defined and made transparent

Although policy-makers are eager to include various stakeholders in the elaboration of health policies, they more often than not consult and partner with a limited number of coalitions, either because these coalitions are powerful players, or because they are endowed with an implicit role of representatives of the "patients' world". What we have learnt from the conference is that coalitions are very diverse, and are multiple even within a single condition area. Diversity and multiplicity are co-substantial to the development and the dynamics of coalitions of POs, and should therefore be considered as such if genuine participative democracy is to be achieved.

This comes with one element that should be put on the research agenda. Following some scholars who have warned against a homogenized view of coalitions as new social movements, in-depth empirical analysis are needed to document and characterize the species of organizations that coalitions of POs come to constitute. Why do they form? What are their membership and constituencies? What causes do they stand for? How do they position vis-à-vis one another? How do they conceive of their relations with various stakeholders? How do they gain institutional recognition? To what extent do they transform their members' modes of activism and identity? All those questions need to be addressed if social scientists are to help policy-makers to consider the variety of coalitions.

Recommendation #2: Support should be provided to coalitions in order for them to meet and to learn mutually about tools they invent to express their concerns

Involving coalitions as stakeholders makes a difference insofar as policy-making process is run differently. Top-down process is the rule rather than the exception in institutions. This is reinforced by the fact that bottom-up procedures and tools mobilized by coalitions are not always very visible, including within the patients' world. These procedures and tools are worth being publicized and discussed if policy-making process is to be changed. This should be done on a regular basis, for as the discussion during the conference has shown, some procedures and tools used by coalitions for their internal governance as well as the conduct of their political action, are very new and still on trial.

In terms of research agenda, it would be valuable to study empirically the different means that coalitions rely upon to voice their claims and express their concerns. How do they frame and materialize their arguments? To whom and how do they circulate them? To what extent tools and procedures they use might be adapted to different contexts? All these questions may be reflected together with coalitions themselves. If there is one single lesson we will draw from the conference, it is that participants have been highly interested in interacting with each another, and are very much in demand of "neutral" places to meet, to better know each other, and to exchange their experience. This is where co-operative research might add value to current initiatives for improving governance of health issues.

Recommendation #3: Opportunities should be provided for institutions to experiment new forms of governance, notably at European level

The proliferation of coalitions of POs, especially at European level, suggests that Europe, at least in the domain of health and medicine, is a formidable place for advancing new forms of citizenship. Despite many criticisms against the bureaucratic and technocratic functioning of European institutions on one hand, against the loss of identities that European people are possibly confronting, European coalitions of POs demonstrate that Europe is worth considering as an experimental space for alternative ways of doing politics. For this to be achieved, institutions should also be given room for experimenting new forms of governance.

At the very least, some research should be devoted to analyzing the Europeanisation of coalitions of POs. So far, no study has been done on what exactly is this “level” of political action that European coalitions of POs are targeting, neither on to what extent such action differs from politics as usual. Besides, very little is known on the concrete means provided to European institutions to actively accompany this dynamics. Finally, although institutions are not fluid entities, and to be fair, are not designed to be so, it is worth to provide them with some latitude to experiment different ways of doing politics.

MAIN WP2 POLICY RECOMMANDATIONS : NEW TECHNOLOGIES AND RESPONSIBILITIES FOR HEALTH CARE AT HOME

POLICY AND DESIGN ISSUES

The discussions raised a series of issues of relevance for policy in relation to the design, development and implementation of new care technologies for older people at both the level of member states and across the EU itself. These are outlined below under three sub-headings: a) policy issues; b) policy and design issues (where issues overlap both fields); and c) design issues.

At a broader level, it is also important to note that policy around new care technologies for older people developed at the European level needs to take cognizance of the following issues:

- Europe is marked by political and cultural and diversity. This has implications for who cares, where and the role of formal and informal health and social care providers in delivering that care.
- Diverse healthcare systems across Europe mean varied levels of availability of NCTs will emerge and a range of choices made by citizens about which technologies to adopt or reject
- North/south migration of older people brings with it differing normative expectations of care and the technologies to support that care.
- East/west migration of people taking employment in the caring services is creating a potential 'care gap' in their home country that will have implications for the care of older people.
- Any discourse of aging should be positive and supportive rather than emphasising how frightening and disabling aging might be.

There are potential tensions between the different goals of new care technologies. EU guidelines for the development of telecare systems would help to reduce these tensions. These should take account of the issues set out below.

POLICY ISSUES

- **Technologies don't care** – they <u>support</u> care, hence they need to be seen as one element in a wider package of care interventions.
- NCTs need to provide **'safe systems of care'**. To avoid the risk of remotely gathered data falling into the wrong hands, clear policy guidelines need to be developed about where this data is stored, who has access to it and the ethical implications.
- It should **not be assumed that NCTs are economically cheaper** or a replacement for other care interventions. To understand who benefits (in economic terms), requires a comprehensive cost/benefit analysis.
- It is important to remember that **care technologies are only part of the solution** – they always need a human environment in which to function. Any development and evaluation of NCTs must be undertaken with this in mind.

- In developing and commissioning NCTs for older people, it is important **to take into account the environment** within which the technology will be located, including housing, family networks, community support and so forth.
- Policies designed around 'aging in place' should recognize that **the home is not always a safe, comfortable or desirable place** for the older person to receive care. Thus, where appropriate, alternative options must be available.
- While **NCTs** can be beneficial, they **can** also **disrupt the home making it a difficult place to live**. Policies around aging in place should consider what kind of 'homeliness' we are trying to achieve.
- **NCTs should be only one element in a range of care options** – people should have the freedom to choose which care options they prefer and where that care should take place.
- Replacing face-to-face health care with remote NCTs runs the **risk of losing 'local knowledge' of individuals** and their circumstances. Hence, NCTs should only ever be seen as one element in a package of care the older person.
- **NCTs bring new sets of people into the care network** – including telephone operators, installation technologists and maintenance people. It is critical that such people have appropriate training in working with older people. Where they will be entering the homes of older people they should also be subject to Criminal Records Bureau (or equivalent) checks.
- **NCTs affect who cares** – from health professional to family care - and where that care takes place. Care should be taken that these changes do not act to reinforce traditional gendered caring roles.
- There is growing recognition that the design of NCTs has tended to focus too narrowly on medically-oriented clients' needs. This approach is too limited. When purchasing NCTs, organisations should also **address the social and affective needs** of their clients.
- Over-regulation focused on risk avoidance can stifle innovative design.
- Evaluation of technology should take as its starting point not just how effectively the NCT works, **but how care improves as a result of the technology**.

DESIGN POLICY ISSUES

- The development of NCTs needs to take as a starting point the needs and desires of older people themselves. However, it is important to recognize that there are huge variations between older people, their needs and the differing forms of frailty/ill-health they may experience. Policy-makers and NCT designers should **beware of over-generalization**.
- Rather than focusing solely on NCTs based on supervision, monitoring and risk avoidance, commissioners and designers should also focus on directly improving the life situations of older people through **flexible NCTs that can also enhance social contact and communication**.
- New care technologies cannot replace the human ability to know an individual and respond on the basis of that knowledge, hence **NCTs are an 'add-on' not a**

replacement for human care. This also raises the issue of how much of this pre-supposition goes into the design of NCT systems.

- It is important to consider **the norms that NCTs embody**, for example what it means to be old and the values attached to old age will vary across Europe.
- Care technologies tend to be developed in a gender, cultural or socio-economic vacuum. This needs to be addressed.
- **Effective design needs to bring key groups of people together** on a regular basis not just at a singular moment in the design process. This should include designers, care providers, service users, family carers and other relevant actors.
- There is often a significant difference between a comprehensive NCT trialled in a pilot and the 'pared back' version purchased by providers following such pilots. This has a significant impact on the effectiveness of an NCT. Designers should consider the economic viability of developments with a range of potential purchasers at the outset and shape NCT developments accordingly.
- It is important **to judge care technologies in action rather than in the abstract** and to make adjustments according to the needs and situations that older people encounter in their daily lives.

MAIN WP3 RESEARCH POLICY RECOMMANDATIONS : CROSS –NATIONAL AND EUROPEAN PERSPECTIVE ON HEALTH AGENCIES

The discussions raised a number of new issues concerning the role and functionning of agencies which would deserve a close attention in future research and in policy-making. It led us to reframe the initial questions concerning health security agencies in three different ways:

1) The impact and influence of agencies must be assessed in the different sectors within which they take place, **without limiting our attention to the decision-making processes**. The conference has made clear that their impact is often limited on decisions; they do not have a strong influence on regulatory processes and have mostly served to re-establish their legitimacy. Meanwhile, the influence of agencies could be more important on the private sector: in terms of production of data and knowledge, which can be used in industrial processes, innovations, standards and self-regulation…

This implies that more attention be paid: first, to the **relations agencies entertain with private actors**; second, to the **political economy of food and pharmaceuticals**. Given the shift in regulatory activities, from national governments to supranational bodies such as the EU and international organizations such as the Codex Alimentarius, given the growing importance of private standards, insurance quality, and self-regulation, agencies are called to play an important role in providing data and knowledge, providing resources in trade conflicts, but also in defending national interests.

2) Health security agencies should be compared to other agencies recently set up in the field of medicine and health in different member states (National Institute for Clinical Experience in the UK; Haute Autorité de Santé in France; Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen in Germany). Several issues justify such a comparison: the role of these organizations in the regulation of medical professions, for example through the production of best-practices and standards; their economic role, for example through decisions to reimburse health goods by public insurances; finally, the type of knowledge they produce, through the use of evidence-based medicine standards vs. health technology assessment (incorporating larger economic and social aspects).

3) If Community and member state agencies are forming together a new level of administration, between the EU and national levels, partaking in the emergence of a European bureaucratic state – rather than the regulatory state which many authors describe – this hypothesis needs to be tested more thoroughly.

But it would offer the advantage of **bringing together two strands of research traditionally separate from one another: research in political science on independent regulatory agencies or non-majoritarian institutions; research in sociology on the production and standardization of scientific knowledge**.

Furthermore, it would address **a key concern of the Commission**, i.e. that of the **coordination between national and European levels**: if this hypothesis holds true, it would imply that coordination does not just happen by vertical relations or horizontal networks, but that it develops through the emergence of an intra-level administration which presents many features of a traditional bureaucratic state.

Finally, this hypothesis would also address the issue of the **European democratic deficit**, but rather than addressing it in a usual way, i.e. by assessing transparency, stakeholder participation or accountability, it would suggest that we need to look at two other dimensions simultaneously:

- The separation of powers and the capacity for democratically accountable institutions to control and monitor the operations of health security agencies: how much are these organizations actually checked by the executive, legislative and judicial branches of government?
- The knowledge which is used in the evaluation procedures and its degree of openness to multiple actors and plural types of data: for the moment, the knowledge is mainly technocratic in nature, provided by scientific experts following standardized procedures (risk analysis, evidence based medicine); but other procedures and methods exist which can provide a more diverse type of knowledge, open to social, economic and political dimensions which have been neglected for the moment.

DISSEMINATION AND USE

DISSEMINATION OF KNOWLEDGE: WP1

Planned/ Actual Dates	Type	Type of audience	Countries addressed	Size of audience	Partner responsible/ involved
1. March 2007 onwards	Direct e-mailing	International multidisciplinary porfessional/academic/policy	EC actors, all contacts found through personal, professional.and web based searches	About 160	CSI/all partners
2. 10/11 July 2007	Participative Conference	International multidisciplinary professional/academic	Belgium, France, Germany, Netherlands, Portugal, Romania, Spain, UK	77	CSI / CES
3. July 2007	Websites : MEDUSE and CSI / CES – conference presentations and policy paper made available	International multidsciplinary professional/academic	all	unlimited	CSI / CES / /MEDUSE coordinator
4. 2008	Conference Proceedings, publisher Presses EMP	International multidsciplinary professional/academic	all	unlimited	MEDUSE coordinator
5. 2008 - 2009	Edited volume or journal issue	International multidisiplinary professional/academic	all	unlimited	CSI / CES
6. 2008 onwards	Comparative Research Project, international conference	International multidisciplinary porfessional/academic/policy	EC wide	unknown	CSI / CES

1. Emailing – see WP1 Conference Invitation Strategy in Final WP report
2. Conference – see WP1 Conference Proceedings
3. See: http://www.csi.ensmp.fr/WebCSI/MEDUSE/

DISSEMINATION OF KNOWLEDGE: WP2

Planned/ Actual Dates	Type	Type of audience	Countries addressed	Size of audience	Partner responsible / involved
1. May 2007 onwards	Direct e-mailing	International multidisciplinary porfessional/academic/policy	EC actors, all contacts found through personal, professional.and web based searches	About 200	Lancaster/ all partners
2. 20/21 Sept 2007	Participative Conference	International multidisciplinary professional/academic	Netherlands, UK, France, Spain, Norway, Denmark, Portugal, Sweden,	61	Lancaster
3. Sept 2008	Websites : MEDUSE and Lancaster University – conf.presentations and policy paper made available	International multidsciplinary professional/academic	all	unlimited	Lancaster/ MEDUSE coordinator
4. August 20-22 2008	Paper presentations	The intedisciplinary scholarly field of Science & Technology Studies	Biennial Global/International conference	Unknown – at least 30	Lancaster
5. 2008	Conference Proceedings, publisher Ecole des Mines de Paris	International multidsciplinary professional/academic	all	unlimited	MEDUSE coordinator
6. Spring 2009	Special issue of journal	International multidisiplinary professional/academic	all	unlimited	Lancaster
7. March 2008-Feb 2011	EC FP7 Research Project, project leaflet, website, international conference	International multidisciplinary porfessional/academic/policy	EC wide	unknown	Lancaster

1. Emailing – see WP2 Conference Invitation Strategy in Final WP report
2. Conference – see WP2 Conference Proceedings
3. See : http://www.csi.ensmp.fr/WebCSI/MEDUSE/

   http://www.lancs.ac.uk/fass/ihr/events/utrechtTelecare.html

4. This conference is the joint sessions (every 4 years) of the Society for Social Studies of Science (4S) and the European Association for the Study of Science and Technology (EASST) see:

http://www.4sonline.org/meeting.htm

5. This is a new journal whose aims are to gather researchers and works in this field; to promote research on the history of various processes (social, economic, political, medical, psychological, religious, ideological) participating in the social construction of infirmity, impairment, disabilities, handicaps; to address a broad range of topics, notably the emergence of practices related to the identification, categorization and treatment of these populations in different cultures and periods of history and to sensitize and lead actions for the census, conservation and exploitation of (written, oral, iconographic, material) sources of the patrimony related to this field.

see : http://www.alter-asso.org/

DISSEMINATION OF KNOWLEDGE: WP3

Dates	Type	Type of audience	Countries addressed	Size of audience	responsible/ involved
1. May 2007 onwards	Direct e-mailing	International multidisciplinary porfessional/academic/policy	EC actors, all contacts found through personal, professional.and web based searches		CSO/ CERMES/ CRIS /all partners
2. Sept 2007	*Food and pharmaceutical agencies in Europe. Between bureaucracy and democracy. Cross-national perspectives. A commented bibliography* [4](	International multidisiplinary professional/academic	all		CSO/ CERMES/ CRIS
3. 15/16 Nov. 2007	Participative Conference	International multidisciplinary professional/academic	Belgium, Denmark, France, Germany, Italy, Portugal, Spain, UK	40	CSO/ CERMES/ CRIS
4. Nov 2008	Conference presentations and policy paper made available on MEDUSE website	International multidsciplinary professional/academic	all	Unli-mited	CSO/ CERMES/ CRIS /MEDUSE coordinator
5. 2008	Conference Proceedings, publisher Ecole des Mines de Paris	International multidsciplinary professional/academic	all	Unli-mited	MEDUSE coordinator
6. 2008 - 2009	Edited volume or journal issue	International multidisiplinary professional/academic	all	Unli-mited	CSO/ CERMES/ CRIS

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[4] Cahiers Risques Collectifs et Situations de Crise n° 7, Publications de la MSH-Alpes, Grenoble, 250 p.

7. 2008 onwards	Comparative Research Project, international conference	International multidisciplinary porfessional/academic/policy	EC wide	unknown	CSO/ CERMES/ CRIS

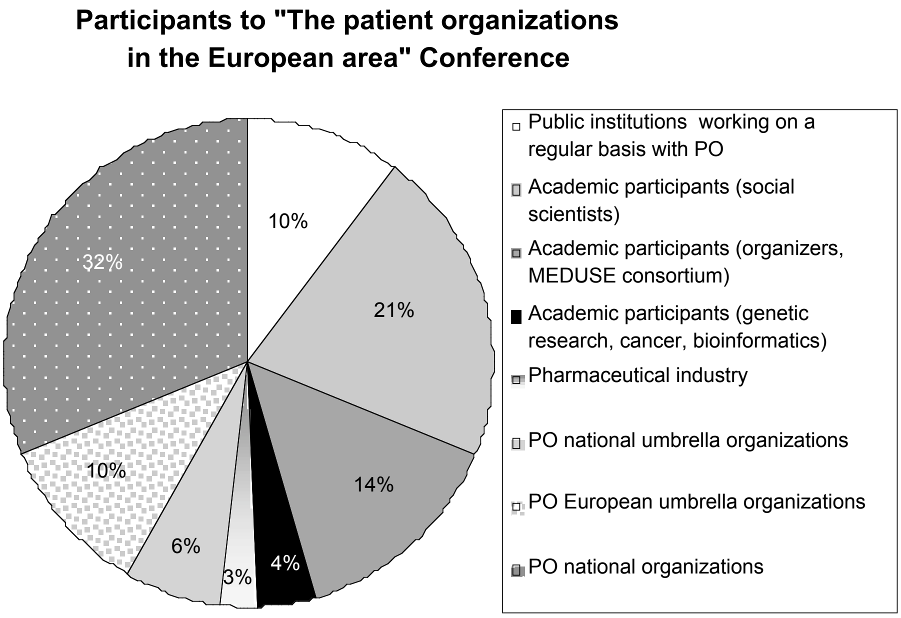
1. Emailing – see WP3 Conference Invitation Strategy in Final WP report
2. Conference – see WP3 Conference Proceedings
3. See : http://www.csi.ensmp.fr/WebCSI/MEDUSE/

ANNEX 1 : THE EFFECTIVE STRUCTURE OF THE PANELS OF PARTICIPANTS

All together, and despite some difficulties already mentionned, we think we met the objectives of the project, i.e. to gather participants for different backgournds and milieux in order to set up a dialogue including academics.

CONFERENCE ON THE DYNAMICS OF PATIENT ORGANIZATIONS IN THE EUROPEAN AREA, PARIS, ECOLE DES MINES, 2007, JULY 10-11TH

77 persons attended the conference. The aim of the participative conference was to place academic and non-academic participants on an equal footing. Therefore it was important to find a well balanced set of participants. The following graph shows how the different categories of delegates were distributed:



Patient organizations representatives were nearly half of the participants (48%). 6% of the participants represented national umbrella organizations 10% European organizations and 32% were representatives of national PO, settled in France, UK, Ireland, Portugal, Belgium and the Netherlands. The great diversity of PO was represented, either in terms of their aims, their size, their positioning on the topics discussed during the conference.

3% were people having an activity in the pharmaceutical industry.

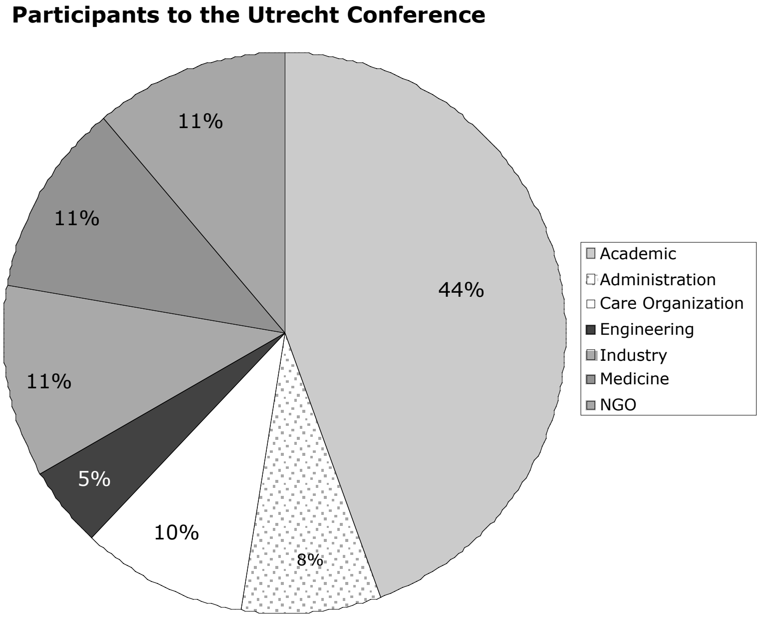
10% were people working in public institutions who work on a regular basis with PO in France, the Netherlands and UK: DGS (direction générale de la santé, HAS, HPAP, Inserm mission associations, ZonMw, Innovia). The representative of the European Commission, DG Research was included in this group of participants.

Academic participants were 39%. 4% were researchers working in close relationship with POs, in the field of genetic research, cancer or bioinformatics; 21% were social scientist whose work is related to topics debated during the conference and 14% were also in this case, but were the organisers or members of MEDUSE consortium (AO). The scientists belong to research institutions from Canada, France, Belgium, Romania, Portugal, Germany, Ireland, UK and the Netherlands.

Some participants from the pharmaceutical industry and from research teams and networks working in close relationship with patient organizations have been invited in "couples", along with a representative of their patient organization partner. The aim was to benefit from the experience of both partners from their respective points of view. For instance, Annelaure Pham, executive director of the French Association of People with Diabetes and Isabelle Aubert from Medtronic were one of these "industry-patient organization" couple invited to present a common paper during a plenary session.

CONFERENCE ON THE EMERGENCE OF NEW TECHNOLOGIES AND RESPONSIBILITIES FOR HEALTH CARE AT HOME ACROSS DIVERSE EUROPEAN SYSTEMS AND CULTURES, UTRECHT, 'THE TRIANGLE', 2007, SEPTEMBER 20-21TH

61 delegates and speakers participated in the Utrecht conference. The parts of academic participants and non-academic participants represented each roughly half of the participants (44% vs. 56%).



The graphic shows the diversity of the participants' backgrounds: academic, but also from administration, care organizations, medical field, NGO, engineering and industrial field involved in the development of telehome care devices. Invitations were made so as to obtain a balance panel of non academic participants representing each around 10% of the participants.

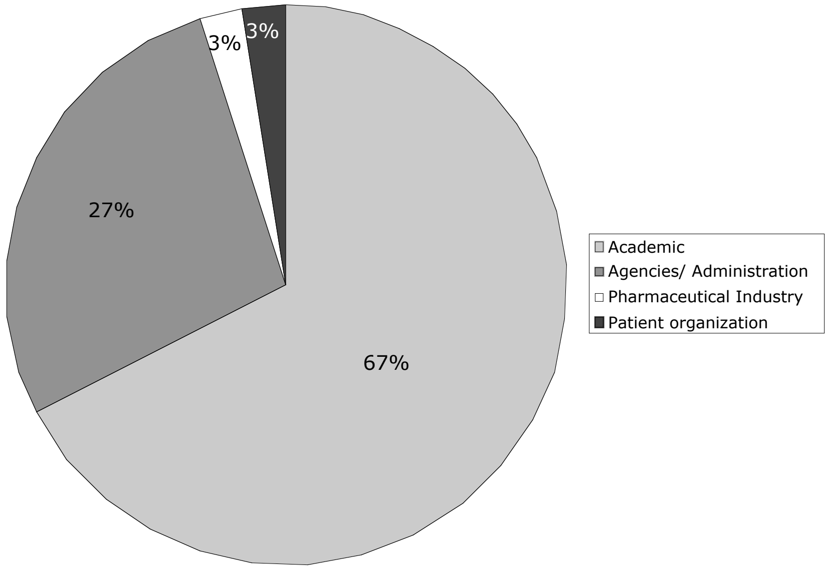
CONFERENCE ON CROSS-NATIONAL AND EUROPEAN PERSPECTIVES ON HEALTH SAFETY AGENCIES, LIEGE, UNIVERSITY, 2007, NOVEMBER 15-16TH

During the conference, the audience was made up mostly of academics, with a fair amount of professionals from public administrations. The difficulty in getting people to come to the conference was related in part to its geographical location: Liège is not as easy a city to reach as capital cities such as Brussels, London, Amsterdam or Paris. Many potential participants hesitated since coming and leaving Liège was costly and implied staying the full two days. Furthermore, many participants who had registered did not come on account of the train strikes in France and Germany that week. It is also possible that albeit efforts to frame the conference as addressing issues of general interest, it was still perceived as essentially academic.

Nonetheless, around 40 persons took part in the conference.

Although limited in number, this actually helped foster intense discussions during the two days. Last minute cancellations on the part of several speakers also had to be managed. Solutions were found and in the end, the discussions did not suffer too much from these changes.

Participants to the "Agencies" Conference



The mix of academics and professionals worked extremely well. Some already knew each other, but many participants did not know anyone beforehand. The limited number of participants, along with the extended time given to discussions (and the lunches and diner), played a key role in helping foster discussions and establish a general level of confidence. All four of the themes identified for the conference gave way to sometimes heated debates, between academics, but also between academics and professionals. All of the professionals present greatly appreciated the discussions, and after hesitating during the first part of the conference, progressively joined in the discussions which they saw as not being strictly academic but on the contrary addressing key issues such as openness or independence.

ANNEX 2 : GUIDANCE GIVEN TO FACILITATORS AND RESPONDENTS

What is the aim of the workgroups?

The workgroups provide a space for participants to have an open discussion of the ideas and themes raised in the immediately preceding presentations. Each session has a theme (for more on these, see the 'policy paper' circulated to all conference participants). The workgroups should discuss these themes and raise issues and concerns based on the participants' experiences and points of view. The aim is to develop dialogue across disciplines and modes of practice.

What is the role of the Facilitators?

The Facilitators' role is to help the discussion flow smoothly, to make space for everyone to participate, and to keep the discussion on track in terms of topic. They should encourage people to use their name signs, to introduce themselves before they speak, and to give concrete examples from their own experience. Particular attention should be paid to language difficulties – Facilitators should ask for help with translation if anyone needs such help. Facilitators should ask people to write their occupation on their name sign.

Facilitators should explain that the sessions will be tape-recorded. Participants should feel free to request that their contributions not be cited in the future (Facilitators should keep a record of any such requests).

About three quarters of the way into the session, the Facilitator should ask the Respondent to summarise and respond to the main points of the discussion after which there will be a short time for further discussion. It would be extremely helpful if Respondents could transcribe their notes and email them to Maggie Mort (m.mort@lancaster.ac.uk) after the conference.

What is the role of the Respondents?

Respondents should keep notes on the discussion as they proceed. About _ of the way into the session, they will be asked to provide a 5-minute (approx) response/summary of the discussion. This is a kind of recapping of key ideas or themes, but also an opportunity to raise ideas or themes they feel have been missing. This response then provides an opportunity for all participants to reflect on the discussion and then to make any additional comments or raise new themes.

ANNEX 3 : CONFERENCES PROGRAMMES

Governance, health, and medicine.
Opening dialogue between social scientists and users
MEDUSE

PRACTICAL DETAILS

The conference will take place at
the École des Mines,
60 bd Saint Michel, 75006 Paris.

RER: Luxembourg

Bus : 21, 27, 84, 85, 89, 38

Plenary sessions :
Amphithéâtre Schlumberger V107

Parallel workshops :
Rooms V115, V116, V119

Participative Conference

The Dynamics of Patient and Health Organizations in Europe

July 10th

8 :45 am	Registration
9 :15 am	**Introduction to the conference,** Madeleine Akrich (CSI-École des Mines)
9:30 am	**How Challenging is Lay Knowledge to Expert Knowledge: Conflict, Competition or Complementarity?** Plenary session: with Bram van der Ende (Dutch Coalition on Disability and Development), Carole Robert (Fibromyalgie France), Dominique Dufournet (France-Acouphènes), Nicole Champavier (Association de l'Ostéogénèse Imparfaite), Madeleine Akrich (CSI-École des Mines)
10:30 am	Coffee Break
11:00 am	Parallel workshops
1:00 pm	Lunch
2:30 pm	**Patients Organizations and Economic Actors: Opposition, "Instrumentalization" or Cooperation?** Plenary session: with Orla O'Donovan (Cork University), Christel Nourissier (EURORDIS), Annelaure Pham (Association Française des diabétiques), Florence Paterson (CSI-École des Mines)
3:45 pm	Parallel workshops
5:45 pm	Reception

July 11th

9:00 am	**Patient Organizations' Alliances: Is Activism Sustainable into Large Coalitions?** Plenary session: with Stephanie Wooley (France Dépression), Rod Mitchell (EFCA), Patrice Van Anerongen (Medicines in Europe Forum), Bernard Bel (CIANE), Vololona Rabeharisoa (CSI-École des Mines)
10:00 am	Coffee-Break
10:30 am	Parallel workshops
12:30 am	Lunch
2:00 pm	**Working with Patient Organizations: A Few Institutional Experiences** with Stuart Blume (INNOVIA), Dominique Donnet-Kamel (INSERM), Etienne Caniard (HAS), Roger Steel (INVOLVE), João Nunes (University of Coimbra) General discussion
4:30 pm	End of the meeting

Governance, health, and medicine.
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MEDUSE project

This conference is part of MEDUSE project, funded by the European Commission. MEDUSE aims at setting up a dialogue between social scientists and non-academic actors. In addition to this conference, two other events tookor will take place in 2007 on issues which are considered as highly relevant for health policies:

contact : **Cross-National and European Perspectives on Health Safety Agencies**
2007, November 15th-16th
Liege University, Belgium
contact: o.borraz@cso.cnrs.fr

Past event
The Dynamics of Patient ad Health Organizations in Europe
2007, July 10th-11th
Paris, Ecole des Mines, France
contact: items-network@ensmp.fr

http://www.csi.ensmp.fr/

WebCSI/MEDUSE/

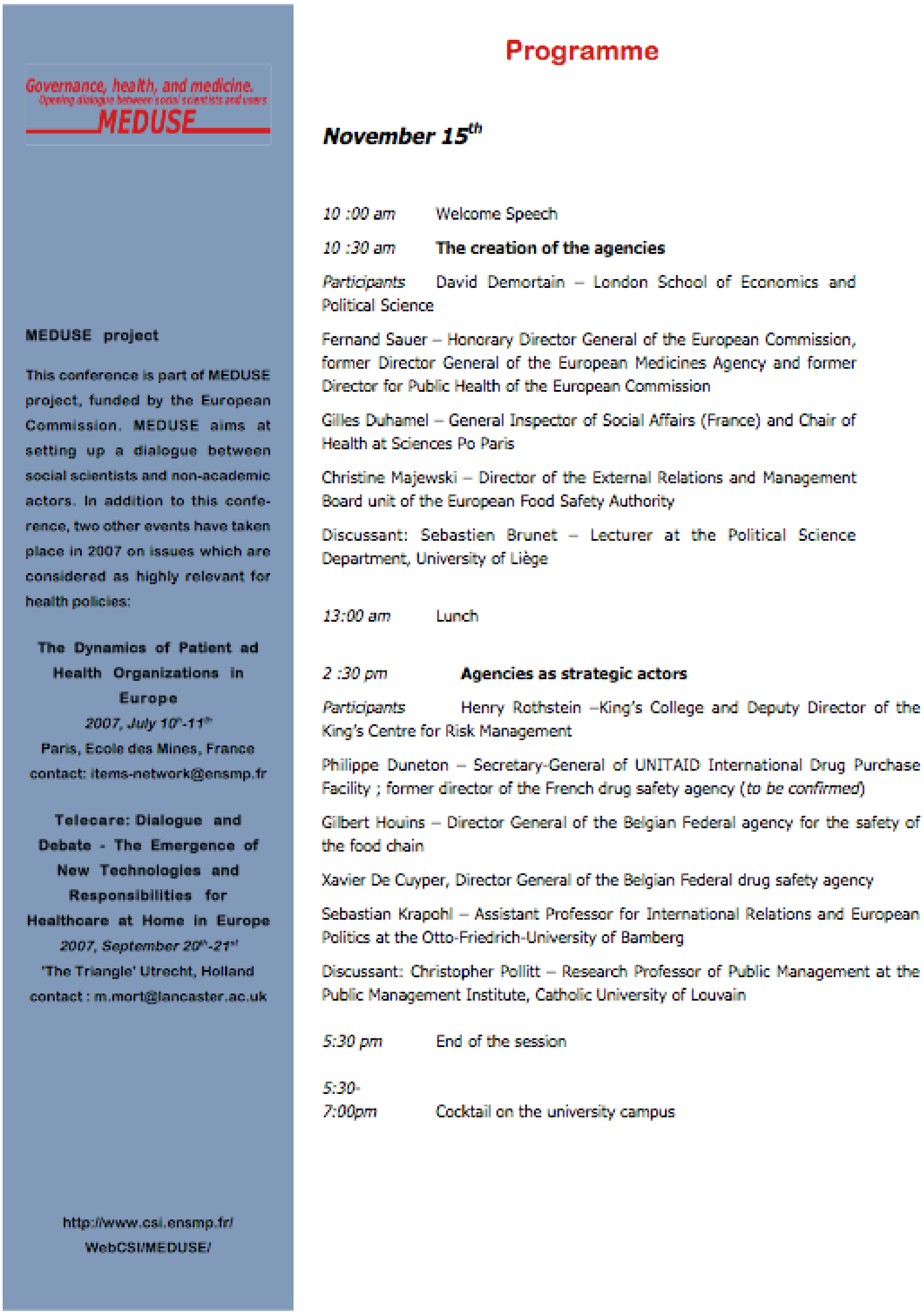
Programme

September 21st

10 :00 am	Welcome and Introduction – Maggie Mort (Lancaster University UK) –
10 :15 am	**THEME 1: WHO BENEFITS FROM THE DEVELOPMENT OF NEW CARE TECHNOLOGIES?** Andrew Sixsmith, (Social Gerontologist, Univ of Liverpool UK) Nigel Barnes (British Telecom) and Barbara Frost (Occupational Therapist, Merseycare NHS Trust, UK)
11 :30 am	coffee break
11 :30 am	Workgroup Discussion
1:00 pm	Lunch
2:00 pm	**THEME 2: HOW ARE NEW CARE TECHNOLOGIES SHAPING HOME AND WORK?** Dick Willems (Academic Medical Centre, Univ of Amsterdam) Jan Thie (Vilans Knowledge Centre for Social Care & Focus Cura Care Technology Centre, Utrecht)
3:15 pm	Break
3:45 pm	Workgroup discussion
5:00 pm	Summary of the Day – Christine Milligan (Lancaster University UK)

September 22nd

9:00 am	**THEME 3: MATERIAL, SOCIAL AND AFFECTIVE DESIGN ISSUES** Ingunn Moser (Centre for technology, Culture & Innovation, Oslo University) & Jeannette Pols (AMC Univ of Amsterdam) Judith Torrington (Architect, INDEPENDENT Project, UK)
10:15 am	Break
10: 35 am	Workgroup Discussion
11:45 am	**THEME 4: HOW NEW CARE TECHNOLOGIES MODIFY CARE INTERACTIONS?** Miguel Domenech & Daniel Lopez (Dept of Social Psychology, Autonomous University of Barcelona) Catalan Red Cross/Age Concern (Barcelona; UK)
1:00 pm	Lunch
2.00 pm	Workgroup discussions on Theme 4
3:00 pm	Break
3:15 pm	Plenary Discussion Chair: Celia Roberts (Lancaster University UK) Summary by rapporteurs
4:00 pm	Tea and depart



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The Dynamics of Patient ad Health Organizations in Europe
2007, July 10th-11th
Paris, Ecole des Mines, France
contact: items-network@ensmp.fr

Telecare: Dialogue and Debate - The Emergence of New Technologies and Responsibilities for Healthcare at Home in Europe
2007, September 20th-21st
'The Triangle' Utrecht, Holland
contact : m.mort@lancaster.ac.uk

http://www.csi.ensmp.fr/WebCSI/MEDUSE/

Programme

November 15th

10 :00 am Welcome Speech

10 :30 am **The creation of the agencies**

Participants David Demortain – London School of Economics and Political Science

Fernand Sauer – Honorary Director General of the European Commission, former Director General of the European Medicines Agency and former Director for Public Health of the European Commission

Gilles Duhamel – General Inspector of Social Affairs (France) and Chair of Health at Sciences Po Paris

Christine Majewski – Director of the External Relations and Management Board unit of the European Food Safety Authority

Discussant: Sebastien Brunet – Lecturer at the Political Science Department, University of Liège

13:00 am Lunch

2 :30 pm **Agencies as strategic actors**

Participants Henry Rothstein –King's College and Deputy Director of the King's Centre for Risk Management

Philippe Duneton – Secretary-General of UNITAID International Drug Purchase Facility ; former director of the French drug safety agency (*to be confirmed*)

Gilbert Houins – Director General of the Belgian Federal agency for the safety of the food chain

Xavier De Cuyper, Director General of the Belgian Federal drug safety agency

Sebastian Krapohl – Assistant Professor for International Relations and European Politics at the Otto-Friedrich-University of Bamberg

Discussant: Christopher Pollitt – Research Professor of Public Management at the Public Management Institute, Catholic University of Louvain

5:30 pm End of the session

5:30-7:00pm Cocktail on the university campus

Governance, health, and medicine.
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MEDUSE

November 16th

9 :00 am **The Europeanization of agencies**

Boris Hauray – INSERM Research fellow at the Institut de recherche interdisciplinaire sur les enjeux sociaux (IRIS) – CNRS-INSERM-EHESS-Paris XIII

Jytte Lyngvig – Chief Executive Officer of the Danish Medicines Agency

Susan Forda – Executive Director of European Regulatory Affairs, Eli Lilly & Co, UK, and Chair of the Scientific, Technical and Regulatory Policy Committee, EFPIA

Claudio Jommi – Lecturer in Public Management and in Management, Economy and International Healthcare Policy at the business school Bocconi University, Milan, and responsible for the OSFAR, Observatory on Medicines

Karolina Zurek (Researcher, Department of Law, European University Institute, Florence) and Partycia Dabrowska (PhD, Centre for Europe, Warsaw University)

Discussant: Renaud Dehousse – Professor of public law and political science and Director of the Centre for European Studies, Sciences Po Paris

Lunch

1:30 pm **Agencies and democratisation**

Giandomenico Majone – External Professor at the European University Institute, Florence; Visiting Distinguished Professor EU Centre and Graduate School of Public and International Affairs, Pittsburgh

François Houyez – Health Policy Officer, EURORDIS (European Organisation for Rare Diseases)

John Abraham – Professor of Sociology at Sussex University, Co-director of the Centre for Research on Health and Medicine

Jose Luis Valverde – Professor of Pharmaceutical Law, University of Granada

Discussant: João Arriscado Nunes – Associate Professor, School of Economics, University of Coimbra

4:30 pm Concluding remarks – Daniel Benamouzig – CNRS research fellow at the CERMES (CNRS-INSERM-EHESS) and Olivier Borraz – CNRS senior research fellow at the Centre de Sociologie des Organisations (CNRS-Sciences Po Paris)

5:00 pm End of the meeting