

European Science Foundation
Standing Committee for the Social Sciences (SCSS)

ESF SCSS EXPLORATORY WORKSHOP

Health Consumer Groups And Policy Making In Europe: A Comparative And Pan-European Perspective

Scientific Report



Vienna, Austria, 16 - 18 February 2006

**Convened by:
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1. Executive summary

Aims: The workshop sought to explore the role and activities of health consumer groups/organizations within the context of health policies in various European countries and pan-European policy processes. Furthermore it aimed to establish the basis for a new research network and for the development of a comparative/collaborative project.

Participants: The workshop was attended by 22 invited researchers from 10 countries across Europe. The delegates were selected to ensure that a range of different European regions, socio-political and cultural contexts and health care systems were represented. There was a broad and balanced representation by age, gender and type of expertise/research-background among the participants. In addition, two representatives from the health consumer organization sector were invited to ensure that the users' perspective and experience were incorporated into the discussions.

Programme: In order to meet the aims of the workshop, the programme was roughly split into two parts. The first part (sessions 1-6) was dedicated to the collection and discussion of research evidence and expert knowledge about health consumer groups'/organizations' health policy activities at country and pan-European level. Participants presented papers in which they outlined relevant developments for every represented country. The second part (sessions 9-11) was primarily concerned with discussing and elaborating a framework for future research. It was informed by additional papers which addressed conceptual issues and empirical research experiences (sessions 1 and 7). User representatives were invited to put forward their points of view during all discussions as well as in a separate session (8). In total, the programme allowed ample opportunity for discussion and the final sessions involved an open discussion of future research perspectives. Common lunches and dinners throughout the workshop helped to build working relations and allowed for additional informal discussions.

Main topics of discussion: Throughout the workshop certain topics and questions frequently arose which will have to be considered and incorporated into a future research proposal:

- the object of the study, i.e. the definition of 'health consumer group', inclusion/exclusion criteria and categorization;
- the motivations and competencies of health consumer organizations;

- the variety of socio-political and cultural contexts for the emergence of health consumer organizations;
- organizational and financial resources of health consumer organizations and the potential conflicts related to them;
- questions of independence and legitimacy especially as a consequence of growing links between health consumer organizations and the pharmaceutical sector;
- questions of representativeness in membership and leadership; and
- the health policy context.

Assessment of results and future research perspectives: The state of research in this field with respect to theoretical and empirical issues is not considered to be highly developed but the topic is slowly rising on the political as well as on the academic agenda in several countries. It is likely that interest will also grow in health consumer organizations operating at a pan-European level, but this sector is even less well understood.

A comparative study will have to take into account that there are similar developments in many countries although presumably at different stages, but also that there will be very specific developments bound to particular countries' historical, cultural and political context.

One important conclusion therefore was to differentiate between a comparative country level study about health consumer organizations and alliances and a study of the role of pan-European health consumer organizations.

It was felt that a comparative study could build on more established concepts and research experience and should be pursued first. Three broad aims and corresponding research questions were outlined referring to:

1. the structure, aims, activities and resources of health consumer organizations in their specific context;
2. the facilitating and inhibiting factors experienced by health consumer organizations trying to have a stake in health care and policy making; and
3. the "construction" of the representation of patients, users, carers and citizens by national health policy and other stakeholders and the incorporation of health consumer organizations in these processes.

Different conceptual frameworks and a mix of research methods will have to be used for different research questions. Collaboration with health consumer organizations will be an essential part of the research strategy.

It was thought that the ESF framework could be a useful source of funding for a comparative study but it might be necessary to approach other kinds of funding in some countries. It may also be necessary to approach potential collaborators in other countries.

2. Scientific content

In order to meet the aims of the workshop, the programme was roughly split into two parts.. The first was dedicated to the collection and discussion of research evidence and expert knowledge about health consumer groups' activities in health policy making at country and pan-European level. The second was primarily concerned with discussing and elaborating a framework for future research activities.

2.1 Current involvement of health consumer groups in health policy decisions in Europe – evidence at a country and pan-European level.

2.1.1 Evidence from participating European countries

Workshop participants were asked to write and present a paper in which they outlined the context and important developments for their country, addressing three topics:

1. Representation of patient/user/consumer interests within the general health policy context;
2. Recent national and regional policies and public debates on patient and public involvement in health care and policy;
3. Evidence of the development of a “health consumer movement”.

The following section provides a summary of these discussions (based on sessions 1-5).

Representation of patient/user/consumer interests within the general health policy context

In all countries represented at the workshop the provision of health care was based on welfare state values and arrangements, with a limited role for market mechanisms. Some of the main differences between these systems can be understood according to a simple ideal-type classification which differentiates between social health insurance systems on the one hand and tax-based national service systems on the other. While in the first type the state is responsible for basic regulations and funding, in the second the state takes over additional responsibility for organizing these services. The health care systems of Austria, Germany and the Netherlands belong to the social health insurance type systems, while health care in

Finland, Ireland, Spain, Sweden and the UK better fit the national service type systems. In practice the boundaries of both types of systems are sometimes blurred. The former socialist countries represented at the workshop - Poland and the Czech Republic - have recently moved from a socialized system to an adapted social health insurance model following the breakdown of the communist regimes. The level of health care funding is still considerably lower in these countries, for example, in Poland the public sector only provides a “basic package” of services.

Historically, in both types of systems (and even more in the former socialized systems) a rather paternalistic approach to health care provision and health policy making prevailed, with little attempt to take into account the interests of users, carers and citizens at an individual or collective level. Usually it was assumed that elected parliaments at various levels of policy making were representing the public interests and professionals (especially doctors) were taking care of the interests of individual patients. Within the “self-governing” configuration of social health insurance systems, the insurance corporations also participate in various decisions but in most of these systems the interests of patients and the insured tend to be represented indirectly rather than directly.

In some countries a move towards decentralization has occurred in recent years which may improve the chances for more direct influence for the public (e.g. Sweden, UK). In all European health care systems financial sustainability has been a major topic of discussion over the past few decades. As the level of public funding has slightly decreased in most countries and private funding has increased accordingly, concepts of individual consumerism are gaining more ground. This has also partly been fuelled by the push toward patient choice (most notably in recent government policies in the Netherlands and England). Several consequences of reduced public financing for service users were mentioned at the workshop: more reliance on private insurance and rising co-payments which challenge the claim of solidarity, problems of access to services, a decrease in consumer satisfaction and public trust. Other pressures are country specific, for example, in Poland as a consequence of low salary and unfavourable working conditions there has been a drain of young doctors.

Involving patients, users, carers and citizens in policy making therefore was a rather new phenomenon in most countries represented at the workshop. The Netherlands seem to have a

longer tradition of consumer involvement with identifiable stages of development, while the UK introduced specific policies on patient and public involvement during the 1990s.

Recent policy and public debates related to patient and public involvement

In nearly all the country reports, recent developments to strengthen the position of health consumers were mentioned. The focus lay on two issues: the codification of patient rights and their implementation; and mechanisms for the involvement of patients and the public in health care and health policy.

The establishment of patient rights has been realized in different ways. Though the term “patient charter” is used widely it takes on different meanings according to the country context. In some countries patient rights are codified and have legally binding character (e.g. Finland, the Netherlands), in others they can be considered as a proclamation of claims that have primarily a politically or morally binding character (e.g. Czech Republic, Germany). Somewhere in between is the compilation of rights into one document which are scattered across various legal frameworks (Austria). In a similar way patient rights in Sweden are the indirect result of legal obligations for service providers (“The Patient is Right”).

The degree to which these statements of rights are accompanied by institutions and mechanisms to execute them varies too. A correlate of patient rights is the introduction of rights and procedures to put forward complaints about services and staff behaviour (most prominently in the Netherlands). Ombudspersons or patient advocates have been established in several countries (e.g. Austria, Finland, Germany and Spain), they all have the task to inform patients and handle their complaints, but the mechanisms for achieving this vary. Austrian patient advocates are established at federal state level as independent institutions based in law; originally their remit was to assist hospital patients but in most federal states it has been broadened to all patients. They are also organizing themselves at national level and have thus gained access to governing bodies as “patient representatives”. In contrast in Finland, the service of patient ombudspersons has to be offered by health care institutions and each organization can decide how it provides these services. As a result there are only a few full-time ombudsmen, their number is estimated to be around 2000 and usually there is no extra budget for this activity. In Germany the patient ombudspersons mainly work in hospitals, the hospitals are not obliged to install them and their services are provided on a voluntary basis. Consequently, the number of ombudspersons is not known.

Another recent development is the establishment of patient compensation funds or patient injury acts (e.g. in Austria, Finland, Germany and Sweden) which are designed to offer compensation as an alternative to litigation, which are also realized in different countries in different ways.

Another strategy to improve the patients' position is the establishment of various mechanisms or policies relating to patient and public involvement, which potentially could involve representatives of health consumer groups or organizations. Involvement can take place in various governance arrangements (e.g. Germany) or through advisory bodies (e.g. Ireland) and at different levels of policy making. A more indirect mechanism of patient involvement is realized by institutionalizing consumer feedback and assessments in more or less standardized surveys (e.g., Germany, the Netherlands, Spain, Sweden and the UK).

Workshop discussions suggest there has not been much public debate about the health consumers' position in health care and health policy in most of the countries represented (though there are some notable exceptions e.g. the Netherlands and the UK). Rather the public debate on health care reform generally is dominated by financial and organizational issues of health care provision. Media coverage on health care matters is also centred on these topics. The perspective of patients and carers is partly reflected in the discussion of "ethical" issues and of course in cases of "medical scandals".

Evidence of the emergence of a "health consumer movement"

One of the main aims of the workshop was to collect and compare evidence of the emergence of a health consumer movement.

The pioneer UK-study by Baggott, Allsop and Jones (2005) identified various indicators for the emergence of a new social movement of health consumer groups: a continuous increase in the number of health consumer groups, a growth of alliances and networks, a shared discourse and greater professional and political and public acknowledgment of their knowledge, values and perspectives. The study also provided some evidence that health consumer groups have had more opportunities to participate and exert some influence in the policy process in recent years. In so doing, these groups have become more sophisticated in their use of the media and have built partnerships with other organized interests, especially in the medical profession and the pharmaceutical industry. The British movement is not radical in terms of strategies or tactics but rather operates through conventional channels of policy making.

Nearly all experts from the other participating countries also confirmed that there are clear indicators for an increase in self-organization of patients, users or carers. But only in about half of the represented countries (Finland, Germany, Ireland, the Netherlands) there has been notable research in this field. The evidence presented at the workshop shows that there are big differences between and within countries as follows:

- Structural characteristics: number of members, their resources/funding (high-level versus low-level, funds from local authorities versus private sponsorship, e.g. pharmaceutical industry) and the constituency they represent (condition/illness-based or population-based groups or formal alliances);
- Aims and activities: activities directed towards support and advice within the group and sharing collective experiences and/or towards political representation, lobbying and collaboration with other stakeholders in health care and health policy and the level they operate at (local, regional or national level).

The following examples illustrate these variations: In the central-European/eastern-European countries (Poland and the Czech Republic) there was a remarkable rise of groups and organizations after the political changes in the late 1980s, while in other countries there was a more continuous increase and some very old groups still survive (e.g. UK). In most of the countries nation-wide population-based groups or formal alliances are operating, although there are some exceptions (e.g. Austria). In some countries, e.g. Ireland, health consumer groups are extensively financed by private sponsors (mainly the pharmaceutical industry), while in the Netherlands the government is obliged to provide substantial support for health consumer groups; in Sweden funding from industry is not accepted and the health consumer groups are mainly funded by public authorities.

Concerning the involvement of health consumer groups in the policy process there are also wide variations between countries. They relate to the level at which involvement takes place (local, regional and national level policy making; interactional, organizational or system level of health care); to the phases of the political process (e.g. consultation, agenda setting, decision making, implementation or assessment); or if involvement is on a statutory or informal basis. For example, the Swedish health consumer groups are involved in the policy process on a regular basis, they are also invited by Parliament to express their opinion in their fields of interest. In Germany health consumer groups are represented in the “Gemeinsamer Bundesausschuss”, a national governance body composed of various stakeholders and its

committees. In the Czech Republic some of the nation-wide health consumer groups are involved in various commissions and condition-based groups are involved via informal meetings, although their actual role and influence is open to question. In contrast in Austria there is no evidence of involvement of health consumer groups in the policy process at all.

2.1.2 Evidence on Pan-European level

Developments at pan-European level were discussed in an extra session (session 6). No comprehensive study had been undertaken by the workshop participants on this topic and no evidence of such research was brought forward at the workshop. Yet some of the participants had researched certain aspects of European-level involvement or had gained expert knowledge on other occasions. The following is a summary of statements given by Rob Baggott (UK), Meri Koivusalo (Finland), Orla O'Donovan (Ireland) and by the consumer representatives Rita Rosa Martin (PINK – a German consumer organization for a specific condition, with some international links) and Rod Mitchell (IAPO – an alliance operating at European and global level).

Though EU competence is rather restricted in healthcare policy (but is greater in the field of public health) the influence of European policy on national healthcare is increasing, either by developments in other political arenas (liberalisation of services; the mobility of staff and patients) or by voluntary collaboration and exchange (for example, in the field of patient rights). There is a common concern with rising costs for health care in nearly all countries, driven to a considerable degree by the innovations in technology provided by the globally operating pharmaceutical and biotechnology industries. Collaboration with, and funding by, industry are therefore not surprisingly major topics concerning health consumer groups activities at European level.

Despite the limited evidence on the health consumer movement on pan-European level some observations have been made:

A considerable proportion (e.g. UK around half the interview groups, in Ireland 66% of the groups studied) of national health consumer groups have some international affiliations. This can be through sister organizations or membership in international organizations. In the main, the links exist to share and exchange information and offer advice and support. A fifth of UK-

groups were in contact with EU-institutions and some had regular contact with members of the European Parliament.

There are some large alliance groups operating at EU-level: The European Patients' Forum, International Diabetes Federations European Region, IAPO European Region (with a strong Irish presence). The question arises, why are some countries much more involved than others? There are also some active organizations at European level, which are for example, engaged in formulating a European patient rights charter and attempting to convince the national governments of the EU to implement them. Some of these organizations are also influencing national consumer movements by establishing local branches. In general a strong influence of pharmaceutical industries on health consumer groups operating at European level is suggested.

The European Commission is beginning to collaborate with EU-level health consumer organizations and is supporting the foundation of such organizations – which could raise some doubts about their legitimacy. Yet at present there is no EU funding for health consumer organizations.

2.2 Setting up the framework for potential collaborative research

The possibility of future comparative and pan-European research was discussed throughout the workshop. Two sessions (1 and 7) were explicitly dedicated to empirical research and conceptual issues and the final sessions relied on an open discussion of perspectives.

2.2.1 Research design and methods – the UK pioneer study

The workshop was started with a presentation by the British participants about an innovative study undertaken between 1999 and 2003 which explored how health consumer groups in the UK were involved in policy making at national level (Baggott, Allsop and Jones 2005). This presentation was thought to provide a frame of reference for the discussion of potential comparative research and for questions of research design and methods. In the discussion, the inclusion/exclusion criteria gained special attention relating to the definition of health consumer group and the time focus of the study was debated. Generally it was agreed that – as in the UK study – a mix of quantitative and qualitative methods would be appropriate for a comparative study but this would need to be supplemented by case studies on specific issues in selected countries.

2.2.2 Conceptual issues

One session (session 7) of the workshop was explicitly dedicated to addressing conceptual issues. Different theoretical and conceptual approaches that might underpin research on health consumer groups' engagement in the policy process were presented.

Judith Allsop gave an overview of political and social theories that were drawn on in the study of UK health consumer groups: social movement theories; pressure group theories; theories of representation and participatory democracy; structural interest theories and theories of policy making in a pluralistic democracy.

Roughly these frameworks can be differentiated according to their focus on either a “bottom-up”, grass-roots perspective (social movements; pressure groups), a “top-down”, stakeholder perspective (policy making; structural interests) or a perspective that links them (representation and participatory democracy; policy networks). Allsop's conclusions on the contribution of these theories to further comparative work were: (1) Social movement theory could be particularly helpful to analyse similarities and differences in group formation, interaction and identity politics across countries within a common set of theoretically-based parameters. (2) Analysing the political influence of these groups in different health care and policy contexts will be a complex task that might require extensive preliminary work prior to embarking on a research study which can not easily be based on a common theoretical understanding.

Rudolf Forster pointed to recent patient and public involvement policies as a more specific and relevant context for comparatively analysing the potential impact of health consumer groups in policy making. He suggested that a theory of functional differentiation and a typology of inclusion of lay people may be a basis for theoretically based understanding of different types and political strategies of involvement. It was argued that a conceptual framework would have to be elaborated for a comparative study addressing inclusive and exclusive policies and practices and related micro-politics and symbolic struggles.

2.2.3 Discussion threads – potential research topics and questions

Throughout the workshop a number of topics and questions frequently arose which will have to be considered and reflected in the elaboration of a future research proposal:

The object of the study: The definition of ‘health consumer group’, inclusion/exclusion criteria and categorization: What is the most appropriate term for the groups and organizations under investigation? The term “health consumer” as used in the UK pioneer study is as contested as terms like “patients” or “users”. For a comparative European study it would be necessary to identify the term that would fit best in different national contexts. It was agreed that the term “health consumer organizations” will be used at present. As already mentioned the questions of which groups and organizations to include or exclude will be crucial and depend on national contexts. Notably, in the UK study a typology of groups was developed which could be used for comparisons (condition-based; population-based; formal alliance organizations).

Motivations and competencies: These questions were raised in connection with questions of impact and effectiveness. What kinds of motivations are fuelling the political activism of health consumer organizations, what are they actually lobbying for? And how do members of these groups acquire the necessary competencies to do this efficiently and successfully? Questions of impact and effectiveness also relate to situational factors which are discussed below.

The cultural context of the emergence and ongoing activities of health consumer organizations: While the medical, psychological and social problems and needs of persons with particular illnesses might be supposed to be similar in different countries within Europe, the question of self-organization of interests is deeply embedded into the cultural context (e.g. values; religious beliefs; civil engagement). To understand differences between countries concerning the aims, the amount and the characteristics of self-organization of health consumers, it is especially important to understand the traditions and characteristics of voluntary engagement and voluntary sector formation in a historical perspective. The growing role of the media in bringing up questions of health and health care must also be observed.

Organizational and financial resources of health consumer organizations: The activities of health consumer organizations are heavily based on voluntary engagement. But in order to challenge the established stakeholders in the health policy arena, organizational effectiveness and financial resources are vital. Thus these organizations face dilemmas: One is the potential conflict between voluntary engagement of lay people and professional management of activities – which means that either lay activists become “professionalized” and potentially

estranged from their fellow members or that professionals who do not share the original concern or cause of self-organization take over. The other is the potential dependency on providers of funding. Public funding at both country and EU level is scarce.

Independence and legitimacy: Many health consumer organizations see themselves obliged to turn to other sources of funding. That not only raises conflicts of interest and the risk of becoming dependent, but also questions of legitimacy in the political arena. There is evidence of growing links between health consumer organizations and the pharmaceutical sector not only at country but also at EU-level. The implications of these connections for representing consumer interests and attempts to prevent the potential risks (e.g. by establishing a code of practice) could become a specific focus of both a comparative and a pan-European study.

Representativeness and legitimacy: Are health consumer organizations actually representing those who they claim to represent? This raises questions about how different representative claims are played out and who confers legitimacy onto these organizations. A critical question is whether the neediest, most vulnerable and socially disadvantaged patients are represented in the policy process at all. And another level of representativeness is related to the in-group level: who is representing a specific group in health policy matters, how are these persons selected and to whom are they accountable?

Health policy context: There could be systematic differences between the two main types of health care systems in Europe. As was mentioned earlier, state-organized and tax-based systems view health care consumers in quite a different way to insurance-based systems. The implications for the emergence and participation of health consumer organizations are not yet understood. Another factor is the different state of decentralization of health care systems. It has to be decided which level of health policy and health care should be addressed in research. Furthermore most health care systems in Europe are in a phase of dynamic change. Patient and public involvement policies are becoming a regular part of these changes. This leads to questions such as what role does health policy play in constituting and mobilizing groups, reshaping existing organizations and reframing traditional arguments? One specific issue is the legal framework regulating the terms of involvement and participation of patients, carers, user groups and citizens.

3. Assessment of results and future research perspectives

At the end of the workshop and after intense discussions all participants shared the view that progress in an under-researched field had been made; they also expressed their willingness to participate in further efforts to strengthen this emerging network and to contribute to the development of common research activities in the future.

This determination has to take into account the context in which these activities could take place:

Firstly, the state of research in this field with respect to theoretical and empirical issues can not be considered to be highly developed. But recent special issues of two prominent journals in the field show that the topic is not only slowly rising on the political but also on the academic agenda. One of the participants also pointed to the existence of a second emerging research network on European level with diverging as well as overlapping interests.

Secondly, a comparative study has to take into account that there will be similar developments in many countries although presumably at different stages, but also that there will be very specific developments bound to particular countries' historical, cultural and political context.

Thirdly, it was thought that health consumer organizations at a pan-European level will gain more importance in the future but their role has not been researched.

One important conclusion therefore was to differentiate two potential projects:

- a comparative national study about health consumer organizations and alliances on national level (and/or federal level in some countries) which also addresses collaboration and engagement of health consumer organizations at European level;
- a study of the role of pan-European health consumer organizations operating at EU-level.

Since it was felt that a comparative study could build on more established concepts and research experience it was decided to prioritize this and to dedicate the final debates of the workshop relating to future research perspectives mainly around this topic. Furthermore

consensus emerged that this could not be produced within a short-time schedule (with the consequence that applying for ESF funding in spring 2006 was excluded as an option).

Three broad issues emerged during these debates: (1) the potential aims, research questions and methods of a comparative study; (2) organization and funding; and (3) planning the next steps.

3.1 Aims, research questions and methods of a comparative European study

Three broad aims and corresponding research questions were outlined:

- (1) To identify the structure, aims, activities and resources of health consumer organizations and their development in a specific historical, cultural, political and health care system context.
- (2) To explore systematically the facilitating and inhibiting factors experienced by health consumer organizations claiming a stake in health care and policy making.
- (3) To find out how national health policy and other stakeholders in health care “construct” representation of patients, users, carers and citizens in general and how health consumer organizations are addressed in these processes and what the implications and consequences are.

Different conceptual frameworks will have to be used for different research questions, especially social movement theory, culture-related concepts and health policy frameworks. Consensus about an appropriate research design and methods depends on a more elaborated outline. However it was understood that a mix of methods should be considered, that a core of the data-set has to be strictly comparable (potentially this can be done with a questionnaire study), that qualitative methods will be used for explorative and interpretative stages of research, as well as for case studies restricted to single countries or a subset of countries.

Collaboration with health consumer organizations in designing, conducting and publicizing the study was considered to be an essential part of the research strategy.

3.2 Organization and funding options

Building on the advice of the attending ESF representative it was thought that the ESF framework could be a useful source for funding the comparative study while EU Seventh Framework and other EU sources should be explored for conducting a pan-European study. Eligibility of research institutions has to be checked and it might be necessary to approach different funding sources in some countries.

It was felt that it would not make sense to formally constitute the network at this stage of discussion. Drawing up a research bid in mutual discussions will lead to the selection of researchers/institutions able and willing to participate and potential collaborators in other countries might have to be approached.

3.3 Next steps

The convenors and their teams (Austria, UK) are prepared to take the lead in further outlining the aims and questions for a comparative European study which thereafter can be discussed within the network.

Following this delegates will check how the potential project fits within their institutional agenda and their eligibility for various funding options (especially the ESF). Alternative options for funding – either at a national or European level will also be explored.

Potential collaboration with other European researchers in the field will be sought by members of the network.

Since the state of research in this field varies across countries, delegates from countries with currently limited research should explore opportunities for conducting national pilot-studies.

Reference:

Baggott, R., Allsop, J. and Jones, K. (2005) *Speaking for Patients and Carers: Health Consumer Groups and the Policy Process*, Basingstoke: Palgrave Macmillan.

4. Programme

ESF Exploratory Workshop Health Consumer Groups and Policy Making in Europe: A Comparative and pan-European Perspective Institute of Sociology, Vienna University, Austria, 16-18 February 2006	
Final Programme	
16 February	
5.00-5.30	registration
5.30-6.30	welcome and introductions
7.00	dinner (nearby restaurant)
17 February	
8.45-9.00	arrival and coffee
9.00-9.30	chairs welcome presentation of ESF by an official ESF representative
Reports from Participants on Country Level Activity	
9.30-10.15	session 1 chairing: Rudolf Forster <i>UK pioneering study: Context, methods, results, conclusions</i>
10.15-10.30	Coffee
10.30-11.15	session 2 chairing: Elzbieta Bobiatynska <i>short reports</i> 10.30 – 10.45 Ireland 10.45 – 11.00 Finland 11.00 – 11.15 Sweden 15 min. break before next session
11.30-12.15	session 3 chairing: Joana Gabriele Muniz <i>short reports</i> 11.30 – 11.45 Austria 11.45 – 12.00 Germany 12.00 – 12.15 Netherlands
12.15-1.45	lunch (in nearby restaurant)
1.45 -2.30	session 4 chairing: Per Rosén <i>short reports</i> 1.45 – 2.00 Poland 2.00 – 2.15 Czech Republic 2.15 – 2.30 Spain 15 min. break before next session
2.45-3.45	session 5 chairing: Meri Koivusalo <i>discussion of country level activities</i>
3.45-4.00	Coffee
Engagement of Health Consumer Groups at Pan-European Level	
4.00-4.50	session 6 chairing: Roland Friele <i>What evidence exists for health consumer group involvement at a Pan-European level?</i> 10 min. break before next session

5.00-6.00	session 7 chairing: Karl Krajic <i>European health care reforms and the participation of consumers and the public – conceptual and theoretical frameworks</i>
7.30	workshop dinner (Viennese “Heuriger”)
18 February	
9.00-9.15	arrival and coffee
	Setting a Future Research Agenda
9.15-10.00	session 8 chairing: Alf Trojan <i>Health consumer group research: The user’s perspective</i>
10.00-11.00	session 9 chairing: Rob Baggott <i>Comparative and Pan-European research perspectives: The need for further research - discussion of preliminary proposal</i>
11.00-11.15	Coffee
11.15-12.15	session 10 chairing: Judith Allsop <i>Discussion of preliminary proposal (cont.)</i>
12.15-1.15	in house lunch
1.15-2.15	Session 11 chairing: Peter Nowak <i>Final discussion and decisions</i> <i>Project structure, timetable and further arrangements</i>
2.15-2.30	Closing

5. List of participants

Academics	Full title	Institutional Affiliation	Address
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6. Statistical Information on participants

Age structure and sex:

Year of birth	Female	Male	Sum
1930 – 1939	1		1
1940 – 1949	1	3	4
1950 – 1959	3	5	8
1960 – 1969	4	2	6
1970 – 1979	5		5
Sum	14	10	24

Nationality:

Austria	5
Czech Republic	2
Germany	3
Finland	2
Ireland	1
Netherlands	2
Poland	2
Spain	1
Sweden	2
United Kingdom	4
sum	24