

Health consumer and patients' organizations in Europe: towards a comparative analysis

Rob Baggott PhD* and Rudolf Forster PhD†

*Professor and Director, Health Policy Research Unit, De Montfort University, Leicester, UK and †Professor, Institut für Soziologie, University of Vienna, Austria

Abstract

Despite the rise of health consumer and patients' organizations (HCPOs) in modern health-care systems, studies are few and far between. In particular there is a lack of comparative research across Europe and at the pan-European level. In an effort to address this gap, an expert workshop was held in Vienna in February 2006. This involved 22 delegates from 10 European Countries and was funded by the European Science Foundation (ESF). The workshop reviewed the development of HCPOs in Europe and their role in the policy process in order to establish a platform for further research in this field. It found evidence of an increase in HCPOs across European countries, increased engagement with policy makers and political institutions, and the creation of alliance organizations bringing together HCPOs across the sector. However, variations between countries were observed, relating to different political, cultural and health system contexts. There was no consensus on whether the rise of HCPOs constituted a new social movement. An increase in HCPO activity at the pan-European level was noted, reflecting the increased interest of EU institutions in health policy. At both domestic and European levels, concerns about the representativeness and legitimacy of HCPOs were raised as well as questions about their independence (notably with regard to the drugs industry). HCPOs face a number of obstacles including: lack of capacity and resources, fragmentation and the power of more established interests within the health-care system. The workshop concluded that further research is needed in this field, in the form of a comparative study of HCPOs in European countries and an analysis of their activities at the pan-European level.

Correspondence

Rob Baggott
Director
Health Policy Research Unit
De Montfort University
Bosworth House
The Gateway
Leicester
LE1 9BH
UK
E-mail: rbaggott@dmu.ac.uk

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Introduction

Collective action by patients, users and carers, and the wider public, is increasingly acknowledged as an important means of influencing health policy and service provision. Studies have examined health consumer and patients' organizations (HCPOs) in particular condition areas,

such as maternity and mental health.¹⁻³ Others have examined the activities of organizations across a range of condition areas and population groups.^{4,5} More recently, broader health movements have attracted scholarly attention.^{6,7}

Despite this recent research, comparative studies of HCPOs are few and far between (examples include: Wood's study of patients'

organizations in US and UK; Tyler's analysis of maternity organizations in Holland, Germany and the UK).^{5,8} The tendency to be country-specific is also reflected in the absence of studies of such organizations at the supra-national level. This represents a serious gap in the literature, particularly in view of the increasing role of international and European institutions in the health policy arena.

To address this, the authors secured funding from the European Science Foundation (ESF) for a workshop on this topic. Twenty-two academic researchers* from ten European countries attended along with two representatives from HCPOs (one of which was an international patients' group). The workshop took place in Vienna in February 2006. Papers were submitted on the nature, growth and activities of HCPOs in each country within the context of public policies on patient and public involvement. The knowledge base for these papers varied, reflecting the different stages of development of research projects in each country. Some were based on new research findings about HCPOs. For example, the UK paper was based on a three-year investigation of health consumer groups, funded by the Economic and Social Research Council (ESRC), the Irish contribution drew on a two-stage study of health advocacy organizations, while the Finnish researchers reported on a survey of national patient organizations. In most cases, however, there had been little or no previous research and so the contributors concentrated more on policy developments and the role of key institutions and organizations. In addition to discussions about developments in individual countries, a special session of the workshop explored the pan-European aspects of HCPO activities.⁹

This article reports on the key findings of the workshop and points the way for future research in this field. First, recent trends, similarities and differences in HCPOs within different European countries are explored. Secondly, the main

factors which appear to strengthen or weaken the contribution of HCPOs are examined. Third, developments at the pan-European level are reviewed.

Definitional issues

One of the main problems encountered when trying to assess trends is the lack of commonly-agreed definitions. The term 'health consumer group' is contested, largely because of unease about the use of the word 'consumer' in relation to health-care, especially in state health systems such as the UK.^{4,10} Some believe that the label 'consumer' is too narrow a focus and prefer 'citizen', 'patient', or 'user'. However, these terms can also be challenged – 'patient' for example has been criticized for implying passivity and is regarded as inappropriate in many condition areas (such as pregnancy, mental health and long term chronic illnesses). As has been argued elsewhere,⁴ the term 'health consumer' should be seen as a broader political interest rather than a narrow individual or commercial entity.¹¹ Taking this approach allows one to focus on the organization of health consumers, common interests and collective actions. In the ESF workshop, the term 'health consumer' was regarded as less problematic by delegates from countries with insurance-based systems, possibly because of the greater emphasis on patient choice in these systems, while those from national health systems (such as Sweden) preferred the term 'patient'. In continuing discussions in the period following the workshop, part of a process of building a pan-European research project, participants agreed on the term HCPO because it was able to encapsulate the range of consumerist and citizen perspectives adopted by these organizations.

What constitutes a HCPO is also open to different interpretations. Much depends on specific exclusion and inclusion criteria. Discussions in the ESF workshop suggest that such criteria varied between countries, so that a group considered by one country as a HCPO might not be so regarded elsewhere. For example, in some countries, research charities were regarded as

*The scientific report from the ESF workshop can be found at: http://www.esf.org/fileadmin/be_user/ew_docs/05-281_Report.pdf. ESF Workshop Delegates are given in the appendix.

HCPOs, whereas in others they were not. More discussion is needed to clarify these criteria to embark on a systematic comparative study.

Delegates from all countries reported an increase in organizations representing patients, users and carers. In most countries this trend had become stronger in recent years, growth being described, for example, as 'exponential' since the 1990s in Finland and as 'mushrooming' in the Irish Republic. But variations were apparent. Delegates from Poland emphasized that their HCPOs were at a formative stage, in contrast to the UK and Holland, where organizations were well-established. Differences in the numbers of people involved in this sector were also reported, with membership of these organizations acknowledged as relatively small in Spain and large in Finland, for example.

Delegates from all participating countries reported the creation of alliances between HCPOs. In the UK, organizations such as the Patients Forum and the Long-term Conditions Alliance (LTCA) had helped to bring HCPOs together on common issues and represented patients, users and carers to government and Parliament.⁴ At the time of writing, there are discussions in the UK about the creation of a new national network of HCPOs.¹² Other countries also gave examples of alliances, such as the Spanish Patients' Forum, the Dutch National Patient and Consumer Federation, and the Polish Alliance for Patients. Alliances also took the form of national disability organizations such as the Swedish Disability Federation and the Czech National Council of Disabled People.

Another trend identified was the politicization of HCPOs. Across most countries, organizations had initially focused on self-help or on charitable support for sick and disabled people, but had become more politically aware and increasingly engaged in lobbying. Notably, their media profile was rising (commented on particularly by delegates from Poland, the UK, Spain and Finland). Nonetheless, the 'political maturity' of HCPOs varied. Austrian delegates commented that their organizations remained primarily

focused on self-help and support for the sick. The UK, Sweden and Finland appeared to be at the other end of the scale, with HCPOs heavily engaged with political decision makers.

In countries where these organizations were becoming politically mature, increasing incorporation by governing institutions was evident. Links between central government and HCPOs were regarded as strong in the Netherlands, while in the UK, HCPOs were increasingly incorporated by central government departments and agencies.^{4,13} The UK Parliament was also found to be extremely open to lobbying by HCPOs. A high level of access to Parliament was also reported in Finland. Most other countries reported some level of engagement by HCPOs with the political system, or at least with administrative boards that took important strategic decisions about health-care. For example, in Germany, HCPOs are represented on a body that decides what services are funded by the health insurance system (the Gemeinsamer Bundesausschuss or G-BA).

The impact of such political engagement on policy was, however, less evident. The UK study, for example, found that in most cases where HCPOs had been influential, they were supported by powerful professional or commercial interests, or by state agencies. No examples were found where HCPOs had successfully opposed powerful interests. The message from other countries was very much the same. Established interests such as the drugs industry and the medical profession remained powerful. For example, in Spain there had been a formal declaration of the principles of patient and public involvement in 2003 (the Barcelona Declaration, which included commitments to patient-centred decision-making, patient involvement in health priority setting, recognition for patients' organizations as health policy actors, and formal democratization of health-care decisions). But these had proved difficult to achieve in practice given the strength of vested interests. Meanwhile, it was reported that in Austria the health-care system remained paternalist and dominated by the medical profession. Similarly, the delegates from the Czech

Republic, reported that paternalism remained strong and that HCPOs had little independent impact on policy.

However, several delegates pointed out that health politics was not always a zero sum game and that alliances with other interests could be a source of strength. The UK study noted that when coalitions of HCPOs and drug companies or clinicians came together around a particular issue they could be extremely influential. The importance of partnerships and alliances on specific health conditions was mentioned by others, including the Polish, Swedish, Spanish and Czech researchers. Particular conditions, such as diabetes, multiple sclerosis and mental health provided a focus for collaboration between different interests which could advantage patients and service users with these conditions, by prioritising treatments or improving services. However, it was also noted that collaboration could have disadvantages, particularly in the context of relationships with the drugs industry, discussed later in this paper.

Looking across Europe, it appears that the numbers of HCPOs are rising, alliances are being forged across the sector, and health consumer interests are increasingly being represented at a political level. Although established interests remain powerful, they are at least being challenged by HCPOs and in other circumstances may be harnessed to influence policy and services in a particular direction consistent with patient, user or carer interests.

One of the key questions at the workshop was: does this activity constitute a new social movement? Although social movements (old or new) are somewhat imprecisely defined,¹⁴ at least some of their key characteristics are present in the context of HCPOs – the mobilization of marginalized people, identity politics, the importance of promoting particular shared values in both political and personal arenas, the encompassing of organizations and more diffuse networks of interaction and collaboration, and the challenge to dominant forms of expert knowledge and discourse. Others, however, are absent – for example, HCPOs across Europe are fairly conventional

in their political tactics and largely eschew direct action.

In the workshop clear differences in perspective emerged between the UK researchers and those from most other European countries. The UK study did find some evidence of an emerging health consumer or patient movement.¹⁵ However, researchers from Finland and Holland, while acknowledging the rise of HCPOs were uncertain that this actually constituted a new social movement. The German delegates stated that they did not believe the growth of these bodies in their country reflected a new social movement. These judgements reflected differences in researchers' perceptions of the criteria for social movements as much as variations between countries' actual experiences.

Strengths and opportunities; weaknesses and threats

Several factors appear to have strengthened HCPOs and provided opportunities to enhance their role and influence. In several European states, the political and cultural context was identified as a major factor facilitating their emergence. Support for consumerist values was identified as a key factor. Across Europe there was dissatisfaction with paternalist approaches and this created pressures for more responsiveness to patients and consumers. At the same time, a decline in deference and trust in traditional representative institutions and in professionals facilitated the development of alternative forms of public engagement.

The availability of political opportunity structures was also regarded as an important factor. It was argued by some researchers that health-care systems with multiple levels of governance (decisions made at national, regional and local level) provided greater opportunities for HCPOs to interact with decision makers and influence policy and service provision. From this perspective, the decentralization of health-care systems could be seen as a positive step. On the other hand, a highly decentralized system could weaken HCPOs by diluting their capacity and spreading their very limited resources even more thinly.

Political structures and cultures could restrain the development and activities of HCPOs. In Austria, for example, it appeared that the dominant political culture and the structures of decision-making in health-care were not conducive, and HCPOs were largely excluded from decision-making. Similarly in the Czech Republic patients' representatives on insurance committees and other boards were strongly linked to the dominant political culture and appointed either on the basis of party political allegiance or (in the case of hospital boards) chosen on the basis of their acceptability to management. Even so, former Communist bloc countries (in this case Poland and the Czech Republic) both reported that democratization had done much to encourage the formation of HCPOs.

Health-care reforms and, more specifically, reforms aimed increasing patient and public involvement, were regarded as important in creating opportunities for HCPOs. The European states represented at the workshop had introduced measures to improve public accountability of health-care – such as complaints systems and ombudsmen. Attempts to strengthen patients rights' have also been made, enshrined in the form of specific legislation (Finland, Holland), compiled into a single legal framework (Austria), taking the form of a declaration or charter with moral rather than legal force (the Czech Republic),¹⁶ or a mixture of legislation and charters (Spain/Poland). European states had also developed explicit patient and public involvement policies, which included state support for patient's advocates, the creation of fora where patients, users and carers could have their say, or the incorporation of their representatives on decision-making bodies. Examples included the representation of patients on joint bodies of doctors and sickness funds in Germany, on health service advisory committees in Spain, and on patient and public involvement forums in the NHS in England (though this has turned out to be a short-lived experiment as both the local forums and the national body, the Commission for Patient and Public Involvement in Health, now face abolition).

Another factor believed to have enhanced the role of HCPOs was the growing recognition of the expertise of patients, users and carers. In the UK there is an Expert Patients Programme, which seeks to bring this expertise to bear on the management of chronic and long term illness. Patients, users and carers, and their representatives, have been incorporated on to committees setting clinical and service standards, not only in the UK, but in Germany and Holland (as reported by workshop participants). Increasingly HCPOs are seen as 'holders' of this expertise and are seen as a resource by those who wish to improve services.

On the other hand, there are weaknesses and threats which undermine the role of HCPOs. Researchers from all countries participating in the workshop observed that, despite the formation of strategic alliance organizations, the HCPOs sector remained fragmented. This was commented on particularly by researchers in the UK, Germany, Finland, Spain and the Czech Republic. Although a large number of organizations may be regarded as evidence of vibrant pluralism, and therefore a source of strength, problems can arise from poor coordination. Moreover, there are tensions between organizations – arising out of personal or ideological differences – which are exacerbated by competition for media attention, membership and funding. It is not unusual for patients with a particular condition – such as breast cancer for example – to be represented by more than one HCPO. Moreover, there are generic organizations that represent broader patient and user interests, as well as population-based groups that represent a particular section of the population such as the elderly, children or ethnic minorities and which are increasingly active on health issues. These organizations may be engaged in the same issues as conditions-based groups but, given their broader focus, do not necessarily share the same perspective.

A further problem is the representativeness and legitimacy of HCPOs. Although they claim to represent patients, users and/or carers, they may not be doing this effectively. As the UK study found, little is known about their internal

structures and the extent to which they encourage participation by members. Even if such organizations are democratic, they may not represent all those with a particular condition, as some may not join. Some of those who are members may be less able to participate because of the advanced nature of their condition, communication difficulties, class or other social, economic or cultural barriers (such as ethnicity). Indeed, it is possible that HCPOs could contribute to an 'inverse care law' where health-care resources are allocated to the 'better off' people in society rather than those in most need.¹⁷ Several delegates at the ESF workshop raised concerns about representativeness, notably researchers from the Czech Republic, Spain and Germany. Even where memberships were reportedly high (in Finland, for example) concern was expressed about the ability of HCPOs to represent patients, users and carers effectively.

Another obstacle identified by participants in the workshop was capacity. The UK study found that HCPOs depended on a relatively small pool of lay activists. While these people were often highly effective, overall the organizations lacked capacity, such as specialist skills in lobbying and campaigning. Some organizations experienced deficits in leadership and management skills. Such problems of capacity were also noted by delegates from the other European states (notably Germany).

The lack of financial resources was regarded as a major challenge for health consumer organizations across Europe. A shortage of resources was identified as a key inhibiting factor by almost all of the European states represented at the workshop. Although affecting organizations in most countries, resource constraints seemed to be a particular problem in Spain and Austria. Moreover, as the UK study showed, there are great inequalities in resources between organizations, with some attracting high levels of funding, but most operating on very small budgets.^{4,5} Concerns were also expressed about the source of funds and the implications for the independence of HCPOs. Indeed, researchers from almost every country represented at the workshop identified funding

by drugs companies as a major issue. Concerns were expressed that such dependence on drug companies increased the likelihood that HCPOs would support the industry's line.

Delegates also noted that dependence on other interests, such as professionals, could compromise the independence of HCPOs. Dependence on the state could also be a problem, preventing the organization from pursuing aims that did not fit with government policy. Dependence on state funding was higher in some countries, notably, Sweden and Holland, than in others. Funding for HCPOs took a variety of forms and was not necessarily through central government grants (where the potential for state influence is high). In Finland, for example, resources were channelled through a fund based on a gambling levy, administered at arms length from the state. In Germany, the sickness funds were required to allocate resources to HCPOs and self-help groups, providing a source of earmarked funding, while in Austria, some financial support came from local authorities.

The pan-European level

The workshop also considered the role of organizations at the pan-European level, focusing particularly on EU countries. Despite deliberate restrictions on its competences in health-care matters, EU influence was perceived as increasing, partly because of its expanded brief in the field of public health and partly due to involvement in other policy arenas that impinged on health policy (such as, the European single market; mobility of citizens and employees, social policy, the environment, health and safety). Moreover, it was acknowledged that the EU's involvement in health was driven by common concerns of member states and their citizens on issues such as technological innovation in health-care, rising health-care costs, access to treatment, patient safety, patients' rights and health inequalities. A further factor was the potential for increased patient mobility across Europe, seen as providing impetus towards minimum standards and common rights at the European level. An example of this was the

production of a European Charter of Patients' Rights in 2002 – produced by an EU-funded project, which formed a basis for patients' rights activities across Europe.¹⁸

Despite the growing importance of the EU in health, remarkably little research has been undertaken on the relationship between HCPOs and EU institutions. The UK study, though focused on domestic policy networks, did find some evidence of European level activity. A fifth of the organizations surveyed by this study claimed to have had regular contact with EU institutions. There was also evidence of UK HCPO involvement with pan-European organizations focused on particular conditions, such as the European League Against Rheumatism and the European Federation of Families of People with Mental Illness. It appears that there is a growing trend towards the creation of European level organizations, often as part of a campaign to raise the profile of particular conditions and their treatment. For example, a Stroke Alliance for Europe was established in 2004 within the context of a ten point plan to prioritise the prevention and treatment of this condition.

EU institutions have promoted the involvement of HCPOs in various fora and committees. DG Sanco established a Health Forum on which a number of European HCPOs are represented among the 46 permanent members (alongside other stakeholder groups of professionals, public health groups, health service providers and insurers). These include the European Older People's Platform, the European Breast Cancer Coalition, Mental Health Europe, the European Organization for Rare Disorders, the European Patient's Forum and the International Alliance of Patients' Organizations. The Health Forum is used to exchange views and information on EU-wide policy issues and is part of an effort to improve the openness, transparency and responsiveness of EU decision-making. There is also an Open Forum, which engages with delegates from a larger number of (around 400) organizations on a less frequent (annual) basis, as well as a virtual forum for the exchange of information between the European Commission and the stakeholder groups. In addition, HCPOs

are increasingly co-opted on to committees and working groups exploring particular policy issues as well as within Executive Agencies. For example, patient and user group representatives occupy two places on the European Medicines Evaluation Agency's Management Board.

A further development was the creation of a peak association, claiming to represent the broad interests of patients, not just those with particular conditions. The European Patients Forum (EPF) – which is a member of the Health Forum – was established as an umbrella group for the HCPO sector. It includes within its membership other pan-European HCPOs and public health groups (such as Alzheimer's Europe, the European Breast Cancer Coalition, and the European Men's Health Forum). The EPF was formed in 2003 with the backing of EU institutions that urged the establishment of a pan-European umbrella body for patients. Another body which has a wider brief on issues of patient and public empowerment in Europe is the International Alliance of Patients' Organizations (IAPO), whose members include the European Federation of Crohn's and Colitis Associations, the European Organization for Rare Disorders, European Cancer Patients' Coalition and the European Liver Patients' Association.

The ESF workshop discussions raised a number of issues about European HCPOs. Concerns were expressed about their relationship with commercial interests, in particular drugs companies. As the European organizations lack a direct individual membership base (being federations of national bodies) it could be argued that they are more dependent on commercial donations and risk being influenced by these interests. Notably both the EPF and IAPO receive substantial financial and other support from commercial interests, including the drugs industry, though are aiming to broaden their funding streams.¹⁹ Specific pan-European condition groups and campaigns also have close links with industry. For example, Cancer United, a campaign bringing together HCPOs, health professionals and industry to develop an EU cancer strategy and national plans was

heavily criticized for relying on funding from a manufacturer of cancer drugs.²⁰ Such cases have led to calls for greater openness and transparency in the relationship between organizations and commercial interests.¹⁸ Notably, the European Medicines Agency (EMA) has produced a set of guidelines on the representativeness and legitimacy of HCPOs, which include declarations about finances and conflicts of interest.²¹ These guidelines may become more widely used by other EU bodies when incorporating HCPOs.

Another area of concern was that some patients, users or carers may be under-represented at the European level. The formation of HCPOs does not necessarily reflect levels and severity of underlying illness and it may well be that some conditions have no organization to represent them. Moreover, even where there is an HCPO, it may fail to take into account the interests and preferences of particular patients, users and carers who are less able or willing to participate in its activities (such as younger people, ethnic minorities or people with communication difficulties and with advanced stages of disease).²² In addition, anecdotal evidence presented at the workshop indicated that pan-European HCPOs do not necessarily represent all countries equally. One delegate noted that individuals from some countries (notably the Republic of Ireland) are particularly active and well-represented within European-level HCPOs, while other countries may be under-represented. If this is the case, it is possible that European HCPOs may inaccurately reflect the preferences and interests of patients, users and carers across the EU.

Conclusion

The workshop provided useful baseline and descriptive data on the development of HCPOs in EU countries and at the pan-European level. Delegates agreed that this area was under-researched and that a more systematic research programme was needed. In order to inform future research, the following conclusions were drawn.

First, it is important that any comparative study is clear about the concepts it employs. Further work must be based on agreement about what constitutes a HCPO, which implies clear exclusion and inclusion criteria to ensure that one is comparing like with like. It is also important that relevant social science conceptual frameworks are drawn upon. The workshop did discuss a range of possible frameworks, informed by the UK study (which drew on several, including policy networks, theories of structural interests, pressure group politics, theories of representation, social capital and social movement theory).

Second, it is important that the key research questions are clarified before embarking on such a study. These should focus on several issues: the structure, aims, activities and resources of HCPOs in their specific context; their representativeness and legitimacy, and their independence from other stakeholder interests; facilitating and inhibiting factors experienced by them in seeking a stake in health policy making and service development; and their engagement in these processes.

Third, it is important that the design of any comparative study captures the different political, cultural and health system context of European countries. It is also important that methods do not simply focus on 'best practice' within each country, but reflect the experiences of a broad cross-section of patients, users and carers – and the wider public. This means careful selection of case studies to ensure that they are representative of the broader picture.

Finally, it was agreed that a comparative study should be supplemented by a further study of HCPOs at the pan-European level. This should explore the emergence of such organizations, their relationship with national organizations, interaction with EU institutions and with other stakeholders such as the drugs industry and professional bodies, and their influence over policy and service development.

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Appendix

ESF Workshop Delegates.

Austria

Gudrun Braunegger-Kallinger, Institut für Soziologie, Universität Wien.
 Professor Rudolf Forster, Institut für Soziologie, Universität Wien.
 Dr Karl Krajic, Institut für Soziologie, Universität Wien.
 Peter Nowak, Institut für Soziologie, Universität Wien.
 Christa Peinhaupt, University of Applied Science, Bad Gleichenberg.

Czech Republic

Dr Hana Janeckova, School of Public Health, Institute of Postgraduate Medical Education, Prague.
 Dr Eva Krizova, Institute of Medical Ethics and Nursing, 3rd Medical Facility, Charles University, Prague.

Germany

Christoph Kranich, Director of Health-Department, Consumer-Centre, Hamburg.

Professor Alf Trojan, Department of Medical Sociology, University Medical Centre Hamburg-Eppendorf.

Finland

Dr Meri Koivusalo, National Research and Development Centre for Welfare and Health, Helsinki.

Hanna Toiviainen, National Research and Development Centre for Welfare and Health, Helsinki.

Ireland

Dr Orla O'Donovan, Department of Applied Social Studies, University of Cork.

The Netherlands

Dr Roland D. Friele, NIVEL, Utrecht.

Dr Mattanja Triemstra, NIVEL, Utrecht.

Poland

Aleksandra Banaszewska, National Centre of Quality Assessment in Health Care, Krakow.

Elzbieta Bobiatynska, National Centre for Health Information Systems, Warsaw.

Spain

Joana Gabriele Muniz, Spanish Patient Forum, Barcelona.

Sweden

Lars Fallberg, Institute for Quality Indicators, Gothenburg.

Dr Per Rosén, Health Strategist Region Skane, Lund.

United Kingdom

Professor Judith Allsop, School of Health and Health Care, University of Lincoln.

Professor Rob Baggott, Health Policy Research Unit, De Montfort University, Leicester.

Dr Kathryn Jones, Health Policy Research Unit, De Montfort University, Leicester.

Health Consumer Group Representatives

Dr Rita Rosa Martin (Germany), Breast Health, Hamburg.

Rod Mitchell (UK), International Alliance of Patients' Organisations.