Advocating for change: The systemic advocacy role of health consumer organisations

by

Ros Bragg
Churchill Fellowship 2001
Project description: to investigate the systemic advocacy role of health consumer organisations in the United Kingdom and Belgium.

This is a report of a Churchill Fellowship study tour undertaken by Ros Bragg in 2001. It is not a statement of NC OSS policy.

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She has engaged in policy development and advocacy work in areas including community participation, earlier discharge from hospital, health-related transport, and asylum seekers.

Ros has managed a community participation program in local government and worked in State Parliament. She has degrees in Economics and Law.
Executive summary

This is the report of a Churchill Fellowship study tour undertaken by Ros Bragg in 2001. It examined the systemic advocacy role of health consumer organisations in the United Kingdom and in Belgium. The definition of a health consumer organisation was an issue for investigation in this report and is a contested issue. This project included in its scope organisations concerned with improving the health of particular communities or the community in general, and which are driven by people who use health services rather than by health service providers. Australian examples include the Motor Neurone Disease Association and the Combined Pensioners and Superannuants Association.

Systemic advocacy, sometimes referred to as lobbying, encompasses efforts to change policies, practices or legislation in a system. In this project, it covers efforts to change the health system, and the range of other human services which impact on people’s health.

Key lessons from the study tour are:

- There is a dearth of research on health consumer organisations internationally, but within the UK there are signs of growing interest in academic investigation of this area. Appropriate research would improve overall understanding and assist health consumer organisations and policy makers to improve practices.
- The UK experience highlighted the dangers of funding frameworks based on project funding or contracts for service. In the absence of funding to support core activities, community organisations were tendering for projects purely in order to obtain an income stream, facing closure (despite unquestioned public benefit as a policy/advocacy body), experiencing high levels of stress from financial uncertainty, developing competitive rather than cooperative relationships, skimming from project funding, and accepting substantial amounts of pharmaceutical industry funding.
- The UK experience also illustrates the dangers of continuing to separate funding frameworks from policies on participation, as the resource demands on organisations can be too heavy for the organisations to sustain. This is particularly a problem for small to medium organisations.
- There are enormous benefits to health consumer organisations and Government policy makers from investment in infrastructure (peak and network) bodies. There are also dangers that lack of public funding will lead to groups close to the pharmaceutical industry playing this role. There are a range of functions which infrastructure bodies can perform, including resourcing organisations to be effective advocates; improving the management capacity of organisations; and supporting the development of organisations which bring together particular groups of health consumer bodies with similar broad interests, such as chronic illness.
- Ensuring that disadvantaged people are effectively represented in decision making appears to be a challenge in the UK and Europe, as in Australia. In policy development processes it is preferable to have separate representation of disadvantaged people rather than relying on illness specific or generalist health consumer organisations to play this role.
Programme

United Kingdom
Organisations visited:

- Advocacy Online
- Age Concern London
- Arthritis Care
- Charities Commission for England and Wales
- College of Health
- International Association of Patients Organisations
- Long Term Medical Conditions Alliance
- National Association for the Relief of Pagets Disease
- National Consumer Council
- National Council of Voluntary Organisations
- Neurological Alliance
- Salford Community Health Council
- Terrence Higgins Trust Lighthouse
- The Patients Forum
- UK Breast Cancer Coalition

Other individuals:

- Judith Allsop, de Montford University
- Steve Harrison, University of Manchester
- Bruce Woods, University of Manchester
- Christine Hogg, Researcher

Belgium
Based at:

- European Public Health Alliance

Other organisations:

- Europa Donna
- European AIDS Treatment Group
- European AIDS Coalition
- European Federation of Pharmaceutical Industries and Associations
- Federation Nationale AIDES
- International Union Against Cancer/Association of European Cancer Leagues
In 1997-98, Australia spent $47,030 million on health services, which is 8.3% of gross domestic product (GDP).\textsuperscript{1} There is every indication that this figure will continue to rise. Community expectations of the health system are growing and the health industry is continuing to develop every more complex (and expensive) treatments.

It is in this context that issues of consumer/community participation are being debated.

A key argument in support of consumer/community participation in health decision making is that it produces better decisions. The special expertise of the consumer leads to more informed planning.\textsuperscript{2} Active participation leads to more accessible and effective health services.\textsuperscript{3}

This position is increasingly reflected in quality improvement programs, many of which have incorporated consumer/community participation into health service standards. These programs include: CHASP, AHCSS, EQUIP, PIP.\textsuperscript{4}

Many proponents of consumer/community participation argue that citizens have a right to participation in decision making; that participation in decision making is intrinsic to active citizenship.\textsuperscript{5}

This study tour looked at one aspect of consumer/community participation in health; health consumer organisations. These are the collective voices for individual consumers and community members. The way in which these organisations operate as advocates, and the policy and financial support provided to them is a critical factor in effective consumer/community participation.

This report contains recommendations in relation to health consumer organisations in Australia. This is a requirement of the Churchill Fellowship.
1. Background

1.1 Project rationale

While there has been a great deal written about consumer participation, it is commonly written from the perspective of the policy makers and health service managers rather than the health consumer organisations themselves. While there are many common issues, there are significant differences in approach and in focus.

Health consumer organisations commonly approach consumer participation as an element of participatory democracy, rather than purely as a component of a quality improvement process. Health consumer organisations focus on relationships with other community organisation as well as with government agencies. They also work on their internal issues of effective and responsive management and governance.

Health consumer organisations, and community organisations generally, have an extremely poor record of writing up what they do, how they do it and the thinking which guided their development. This writing is particularly poorly represented in journals. There are a number of reasons for this gap, and a key reason is pressure from the community they serve and their funding agency to concentrate their very limited resources on increasing their output.

The lack of documentation does not, however, indicate the absence of sophisticated debate. It is merely that the debate tends to occur verbally, whether at committee meetings, conferences, or on a more informal basis.

1.2 The study tour

This study tour looked at health consumer organisations engaged in systemic advocacy work to improve the quality of life of their communities. It examined the factors which facilitated organisations undertaking this work more effectively and the barriers.

The term ‘health consumer organisation’ is widely used in Australia, but the formal definition is contested. One of the areas for examination in this study was the way in which community organisations in other countries approached the issue of definition. As a starting point, health consumer organisations were defined as organisations concerned with improving the health of particular communities or of the community in general, and which are driven by people who use health services rather than by health service providers.

Systemic advocacy, sometimes referred to as lobbying, encompasses efforts to change policies, practices or legislation in a system. In this project, it covers efforts to change the health system, and the range of other human services which impact on people’s health.

The study tour focussed on independently incorporated not-for-profit organisations, but it had also been intended to include UK Community Health Council, which have a statutory base. This proved difficult as the Health and Social Care Bill, then under debate in Parliament, proposed their abolition.

The study tour consisted of six weeks in the United Kingdom and five weeks in Belgium. The UK was chosen because of its universal health system and strong community sector, which bear strong similarities to Australia, and for its Community Health Councils, which have been used as a model for developments in Australia. Belgium was chosen as a base to study health consumer organisations across Europe, using the networks of the European Public Health Alliance.

In the United Kingdom, I met with eleven community organisations, three organisations with a statutory base, three academics working in this area and a director of a public relations company targeting health consumer organisations. The health consumer organisations included small, medium and large organisations; bodies based in London and in regional centres; and umbrella and network organisations.

The abolition of Community Health Councils had been announced a few months prior to my departure and, as a result, I found the resources of these organisations focussed on lobbying for their survival.
Some useful contacts were made to assist with future research in this area.

In Belgium, I was based at the European Public Health Alliance. While originally intending to review organisations across Europe, I found the issues emerging in the relationship between various health consumer organisations working at European level, and between these organisations and the European Union to be of greater interest and this was the focus of this part of the study tour. I met a number of health consumer organisations which attended EPHA meetings and held detailed discussions with four of these (including EPHA). I also held formal discussions a generic consumer organisation and a pharmaceutical industry body.

I undertook a survey of health consumer organisations operating at European level under the auspices of EPHA. It would appear that this is the first such survey undertaken at a European level.

I also wrote a draft policy on patient participation for EPHA, which was based on the findings of the study tour. This was scheduled for member consultation and endorsement in October 2001, and this debate is likely to provide further useful information.

1.3 Australian context

The Australian context for the project was the following:

Many reformers see health consumer organisations as key agents of change in the health system and the means by which the health system is to be made more focussed on the needs of consumers and less focussed on the interests of clinicians and managers. 6

Consumer participation in the health system is a stated Government priority in most Australian jurisdictions. Consumer participation initiatives are increasingly the subject of policy development and are attracting resources.

While promoting consumer participation, Governments are also seeking to prevent bad publicity in a high profile and controversial area of government responsibility. As the State health systems are grappling with issues of growing demand outstripping available resources, and are generally making rationing decisions behind closed doors, opening up the health system to greater consumer scrutiny is likely to result in instances of critical media coverage.

Consumer participation policies developed by government agencies commonly describe consumer participation as an element of quality improvement rather than part of a more radical reform agenda.

Government funding for non-government, community-based organisations is increasingly shifting from a grant framework to a purchaser/provider model. Under the grant framework, government funders provide a ‘contribution’ to assist the organisation with its work, and the funding and performance agreements are not binding legal contracts. The purchaser/provider model involves Government purchase of designated services under a binding contract. This model is often associated with competitive tendering arrangements. Systemic advocacy does not sit well with the purchaser/provider model.

Historically, many non-government, community-based organisations have relied on a community development model in which individual advocacy and systemic advocacy are seen as a continuum of activity in seeking outcomes for communities. The economic rationalist model has challenged this with a market-based analysis in which an individual or an organisation is either consuming goods and services or providing goods and services. The legitimacy of health consumer organisations which provide services as well as advocate for consumers is being challenged.

There is increasing focus on social capital debates in academic circles and amongst policy makers. This is refocusing attention on non-government, community-based organisations and, particularly, on their role in creating social trust and other outcomes which do not fit the purchaser/provider model of funding.

These trends are occurring in the context of limited resources.

1.4 United Kingdom – general background

In July 2000, the UK Government released The NHS Plan, a key policy document for the National Health Service.7 The document places strong emphasis on patient participation (health consumer participation).

The document commences with a statement of principles signed off by health stakeholders, including several health consumer organisations. Despite this symbolism, a key element of the document was the abolition of Community Health Councils and their replacement by a series of new structures with an emphasis on individual advocacy.
There was no consultation on the decision to abolish the Community Health Councils and the consultations about implementation were viewed as highly unsatisfactory by community organizations.

Health consumer organizations reported many invitations to take part in Government policy development processes. An area of particular activity was the development of National Service Frameworks through the National Institute for Clinical Excellence (NICE). There were mixed reports about the results of this participation.

One legacy of the Thatcher years is a National Health Service and local government sector characterised by quasi-markets. Within the NHS, purchaser and provider agencies are formally separated and competitive tendering is standard practice. The ‘Best Value’ policy document signifies a shift away from competitive tendering practices in the local government sector, however at the time of the study tour, this had yet to be widely implemented. Community organisations seeking funding for service delivery negotiate competitive tendering processes from multiple purchasing authorities.

Recent changes to tax laws, ‘Gift Aid’, encourage charitable donations by individuals. Debate is underway within the sector about the perceived excessive number of charitable bodies. A major issue of concern appears to be the impact of a profusion of bodies on public perception and charitable giving. Discussions are underway about reforming charities laws, with the National Council of Voluntary Organisations arguing for ‘an overwhelming public benefit’ test.

Other emerging issues in the relationship between government and the community sector are:

- Strong interest within Government in the development of ‘partnerships’ with community organisations, largely as a means of effectively getting services into communities
- Development and administration of the Compact and the Codes (discussed in the body of the report)
- Strong interest in social capital, but this appears to be largely expressed through support for volunteering, rather than the community sector more generally.
- A recent focus on ‘faith-based organisations’, mirroring developments in the United States.

Notes on language:
There are differences in terminology between the UK and Australia. The UK uses the term ‘patient’ in place of ‘health consumer’; refers to ‘voluntary organisations’ rather than ‘community organisation’ or ‘NGO’. More confusingly, in the UK, a community organisation is a category of voluntary organisation, and is characterised by its smaller size and more local focus. In this report, the Australian terminology has been used.

1.5 European Union – general background

The European Union (EU) has limited formal competence (jurisdiction) in relation to health as health care services remain an exclusive competence of EU member states. The EU competence on health is largely limited to public health: contributing towards ensuring the attainment of a high level of health protection; improving public health; preventing human illness and disease; and obviating sources of danger to human health. These objectives are taken up in a wide range of EU policies including internal market, environment, consumer protection, social affairs, agriculture, research, trade and development and others.

The EU internal market provisions affect health service delivery in the following areas: the free movement of good and services (health care), the free movement of professionals and other workers, and the free movement of citizens (potential health consumers).

The EU is currently engaged in a debate about governance, which is described as “improving democracy in Europe.” This incorporates issues of participation.8

The EU faces significant challenges to effective coordination. There are 15 member countries and 13 countries working towards membership (candidate countries), and some decisions require agreement of all member countries. There are 11 official EU languages, creating formidable challenges for effective communication between the representatives of the member states, and significant burdens on interpreting and translation services. The European Parliament meets in two sites and these are in different countries, and directorates of the European Commission (similar to government departments) are also located in more than one country. These factors also affect the capacity of community organisations to lobby for change.

Each EU directorate has separate arrangements for funding NGOs.

Notes on language:
As in the UK, the EU institutions and the European NGO network use the term ‘patient’ where Australians would use ‘health consumer’. Europeans use the term ‘consumer’, but apply a narrower meaning, which is discussed below. In this report, the Australian terminology has been used.
2. Patients, citizens and consumers

In Australia, the term ‘health consumers’ is widely used within the community sector and government. While distinctions are sometimes drawn between ‘health consumers’ and the ‘community’ more broadly, the term ‘health consumer’ is widely used to cover a variety of categories of individuals with a relationship to the health system. These categories include people who use a particular service; potential as well as actual users of a service; and ‘the population as a whole’. This last usage is generally employed as a means of distinguishing ‘the community’ from health professionals, industry, government and other stakeholders.

In the UK and Europe, different terminology was used and there was an emphasis on articulating distinct differences between groups which are commonly encapsulated in the catch-all Australian term.

In the UK, the term ‘patient’ was widely used. Another common term was ‘user’, or ‘service user’. UK community sector informants were adamant that ‘health consumer’ was not interchangeable with ‘patient’. The term ‘health consumer’ was seen to be associated with Thatcherite market models. Informants considered ‘consumer’ to relate to the act of purchasing a service, and to imply limited scope for participation in decision making. While not clearly articulated, the concept of ‘patient’ was more closely associated with ideas of participatory democracy and social capital.

At European level, formal distinctions were drawn by NGOs between ‘consumers’, ‘citizens’, and ‘patients’. ‘Consumers’ were purchasers of goods or services or, on occasions, users of good and services. ‘Patients’ were users of the health system. ‘Citizens’ were the population as a whole.

NGOs appeared to describe themselves as ‘consumer’ or ‘citizen’ or ‘patient’ organisations, but not any combination of these terms.

These distinctions and their policy consequences are discussed in more detail in the draft EPHA policy on patient participation which I wrote during my visit (Attachment). An issue driving this policy was concern that policy makers were being persuaded to the view that patients organisations were the sole or primary community representatives in health decision making, and that citizens organisations were peripheral. This view was associated with pharmaceutical companies and patients organisations closely connected with them.

3. Research into health consumer organisations

In the UK, there was evidence of academic interest in documenting and analysing patients’ organisations, and in particular, in investigating their participation in the policy process. Research in the political science discipline offered very useful insights on the systemic advocacy activity of patients’ organisations.

At the time of the study tour, Judith Alsopp (de Montford University) and others were undertaking a research project funded by the Economic and Social Research Council. Based in the sociology and political science disciplines, the study aimed to investigate the ways in which health consumer organisations involved their membership in decision making, and to identify the ways in which they participated in the policy process with government, Parliament and other professional interests.

The project grant was due to cease in August 2001, but the work was anticipated to continue as the group had obtained a book contract and planned to submit the draft manuscript twelve months later.

This study defined health consumer groups as “a [community] sector organisation that is concerned with promoting or representing the interests of users and/or carers in the health arena at national level.” (Henderson (ed.), forthcoming, see below) They commented that organisations were not fixed in character as health consumer groups or not, but instead moved in and out of this definition over time as their practices changed.

The different types of groups identified were:

- single issue/condition groups;
- cross-issue groups that had a brief including health (such as older people’s organisations);
- generic patients’ groups and groups based on alliances.

Very preliminary results are to be published in Consuming health: the commodification of health care, Saras Henderson and Alan Petersen.
This research project builds on a study undertaken by Bruce Wood (University of Manchester), which was published as Patient Power?10 Bruce Wood’s research, undertaken as a lone scholar, sought to document and analyse the sector as a whole and to draw comparisons with the United States experience.

Commentary:
The lack of research into health consumer organisations in Australia has left a considerable gap in our knowledge.

In addition to its value in better understanding the processes of policy development in contemporary health systems, research into health consumer organisations has many potential benefits both for health consumer organisations and for Government. Of particular benefit would be the documentation of different types of organisations with the health consumer sector. The advantages of this research would include:

- It provides an opportunity to acknowledge the different strengths and contributions of different organisations. This has the potential to reduce conflict between organisations.
- It provides a framework to guide better practice in participation processes for community organisations, including peak and network bodies.
- It provides a framework to guide better practice in a range of consultation and participation processes employed by Government policy makers and health service managers.
- It provides a framework to assist in the development of appropriate funding programs for health consumer organisations.

Recommendation: That health consumer organisations and Government policy makers advocate for and support research into health consumer organisations.

4. Funding arrangements

Neither the United Kingdom nor the European Commission funding arrangements offered examples of better practice. They did, however, illustrate the dangers of pursuing programs based exclusively on project funding or contracts-for-services, or of taking a hands-off approach to the funding of NGOs engaged in advocacy work

4.1 United Kingdom

The major source of funding for health consumer organisations in England were:

- public: “section 64” Ministry of Health; Community Fund (formerly the National Lottery Charities Board); contracts for service delivery from local health authorities, local authorities (local government) and other government agencies
- charitable trusts: a significant network of well-resourced philanthropic organisations which funded projects ranging from publication of a report to multi-year research projects
- industry: project funding from pharmaceutical companies, corporate sponsorship from other sectors
- private giving: donations and legacies; ‘tax efficient giving’

4.1.2 The absence of core funding

All informants from community organisations reported that funding from public sources and charitable trusts was project based or contract for services. They reported that no core funding was available.

The lack of core funding was consistently identified by informants as a key difficulty for their organisation. One informant commented, “It is pointless funding a project when the organisation is struggling to pay its rent.”

Informants felt that the lack of core funding impacted on their capacity to undertake a wide range of activities, including systemic advocacy work, which was seldom specifically funded.

The impacts of the lack of core funding include:

- Organisations whose core objectives are patient advocacy invest significant resources in developing projects and services and in running projects and services in order to generate income to ensure survival. This is diverting organisations from their main purpose.
- Policy/advocacy organisations of unquestioned public benefit are at risk of closure because they have, through no error, lost a service contract.
- There is a high level of organisational stress flowing from uncertain funding arrangements. This is a particular problem amongst middle-sized organisations which do not have the public profile to enable them to generate substantial funds through public donations and legacies.
- The practice of skimming funds from projects and contracts to pay for systemic advocacy work is endemic. It is the only way that many organisations can support their systemic advocacy work. This is an undesirable arrangement from the perspective of the funder and there are many reports of funders querying this practice. There is also evidence of a high level of sophistication amongst community organisation in accounting and performance reporting in order to continue skimming while meeting accountability requirements.
- There are arguments that skimming should not be an issue of concern to funders as tendering arrangements are commercial contracts not contributions to organisational expenses. Despite this, the old habits of scrutiny of community organisations die hard.
• There was evidence of a high level of competition between agencies. There was consistent report of conflict about which organisations managed to obtain funding.
• Pharmaceutical company funding for community organisations was widespread. In an environment of insecure public funding, it would appear that this option is more attractive and its disadvantages less palpable.

The issue of core funding was re-entering the policy debate at the time of the study tour. For example, the newly appointed head of the Community Fund was a former chief executive of a national patients charity and was indicating an interest in looking at the issue.

Commentary:
Funding programs which are about projects and service delivery rather than organisational development place community organisations in a difficult position. The process of maintaining and developing an effective organisation must be paid for, so there are pressures to skim funding from projects, to undertake non-core work in order to obtain some income, and to actively and aggressively compete for contracts rather than develop cooperative relationships between organisations. It also encourages reliance on pharmaceutical industry funding and this poses significant dangers for individual organisations and for the health consumer sector as a whole.

4.1.3 Policy gap between funding and participation policies
Informants from community organisations commented that they were facing a substantial increases in requests for their participation in a variety of processes initiated by Government agencies. The development of National Service Frameworks through the National Institute for Clinical Excellence (NICE) was a major area for involvement.

The growth in requests for participation were seen as Blair Government initiatives.

Informants consistently commented that they were facing challenges in finding resources to take part in these exercises while still maintaining the activities of their organisation. While all informants were keen to participate and welcomed the strong interest in involving their organisations, the lack of resources was an issue of concern.

There are a number of options for funding programs which support the participation of health consumer organisations in government policy development programs. These include payment of some form of ‘sitting fees’, project funding for staff time to provide input into specific government initiatives. Core funding of organisations, where participation in government policy is identified as a core activity, is another option. These were not in evidence.

One option which was in discussion in relation to the development of the National Service Framework on long-term health conditions, was the secondment of a Department of Health staff person to the relevant peak/network organisation to facilitate development of the framework. At the time of writing, this had not been confirmed.

Commentary:
Attempting to develop policies on participation in isolation from NGO funding programs ignores the resource constraints facing NGOs. Separating these areas of policy development is particularly problematic for smaller agencies which do not have sufficient resources to employ staff to act as advocates in policy development processes or to “cover” for existing staff to take part.

4.1.4 New funding models: partnerships
Cross-sectoral partnerships were emerging as a new funding model in the UK. A prime example was ‘Local Strategic Partnerships’, which are described as “a single body that brings together at local level the different parts of the public sector as well as private, voluntary and community sectors so that different initiatives and services support rather than contradict each other.”

The National Council for Voluntary Organisations, the umbrella body for the voluntary (community) sector in England, employs a project officer to work partnerships, amongst other issues. This informant emphasised the limited information available at present on the success or otherwise of the partnership models being promoted in the UK.

In relation to systemic advocacy work, this informant and others identified the following dangers in the partnership model:
• While participation in partnership creates opportunities to influence decision making and decision makers, the consensus and joint ownership models can implicate community organisations in bad decisions. This would limit their capacity to public challenge these decisions.
Public perceptions of community organisations as independent of Government are blurred by the partnership model. Community organisations with a history of active advocacy work may find themselves excluded from the partnership process. This problem is not unique to partnerships.

4.1.5 The Compact

The Compact on relations between Government and the voluntary and community sector in England is a key policy document which outlines a framework for relations between the community sector and Government.\(^\text{12}\)

It includes provisions which address the tension between systemic advocacy work and seeking Government funding:

9.1 To recognise and support the independence of the sector, including its right within the law, to campaign, to comment on Government policy, and to challenge that policy, irrespective of any funding relationship that might exist, and to determine and manage its own affairs.

The Compact document was completed in November 1998 and it has since been supplemented by a series of codes covering such issues as funding, consultation and policy appraisal, and Black and minority ethnic voluntary and community organisations.

The Compact is supported by a series of processes to enable local compacts to be developed and for ongoing monitoring of the implementation of the Compact provisions.

The National Council of Voluntary Organisations hosts the Compact Working Group Secretariat for the community sector. An informant from this unit commented that while the structures are sound, further work is required to engage public bodies in the Compact development processes. The informant also emphasised the importance of encouraging community organisations to use Compact provisions in their negotiations with Government agencies, and to participate in forums and other feedback structures.

Commentary:

The Compact fills a gap in government policy on the relationship between agencies which advocate with government as well as receiving or seeking funding from government. The processes which are attached to it appear to provide an effective strategy for monitoring its implementation. Supporting the document and the processes appears to require a substantial investment of resources within both Government and community sectors.

4.1.6 Information about funding options

In the UK, there were a profusion of agencies from which community organisations could seek funding. A particularly useful response to this was the National Council for Voluntary Organisation’s Sustainable Funding Project.

A component of this project was a website which contained a list of funding options with brief description of the programs and a hotlinks to the various funder’s sites. The project also provided resources to assist organisations in the broad task of planning the organisation’s future, as well as in developing proposals for funding, albeit with a social entrepreneurial framework.

The project was undertaken with sponsorship from a corporation, British Gas.

Commentary:

Access to funding is a critical issue for health consumer organisations and a website which provided a central reference point would be of enormous value to health consumer organisations in Australia. Resources to assist in planning would also be of assistance to smaller organisations.

4.2 Funding arrangements – European Union

The EU had a small funding program for public health and was in the process of implementing a new program for the period 2001-2006. This was a positive step as informants reported ad hoc processes and poor understanding of the NGO sector. These included:

- the original arrangements for the shift from present arrangements to the new program involved a three month gap in funding. This would have forced NGOs to shut down or lay-off staff.
- funding under the new program was original proposed as no more than 50% of the costs. This is despite the difficulty of obtaining private funding and the controversial issues surrounding private sector involvement in health consumer advocacy organisations.
- comments by some European Commission staff about the need for NGOs to move to become self-funding just as other (ie private industry) advocacy groups were. This was not a formalised policy position.
- the apparent lack of concern about the very close relationship between some patients’ organisations and the pharmaceutical industry.
**Recommendation:** That Government agencies develop funding policies which
- resource core activities, including systemic advocacy, and
- address the policy gap between funding and participation frameworks.

**Recommendation:** That each jurisdiction develop formal agreements on key issues in the NGO-Government relationship and develop effective structures to monitor its implementation and further develop it over time.

**Recommendation:** That Government agencies fund the establishment of a web-based listing of funding options and associated resources.

### 5. Infrastructure

The term infrastructure is used here to refer to peak and network organisations.

In the United Kingdom, there was evidence of an impressive range of infrastructure organisations providing support and networking to health consumer organisations. These offered some positive models for investigation.

At European level, there was limited infrastructure and the gaps in publicly funded infrastructure were being actively filled by groups with extremely close links to pharmaceutical industry.

#### 5.1 Infrastructure – United Kingdom

**5.1.2 Generic patients’ organisations**

In the UK, the key infrastructure body working with all health consumer organisations is The Patients’ Forum. The primary function of The Patients’ Forum is information exchange. It does undertake lobbying work on rare occasions, but describes this as a residual function. There is a strong focus on information dissemination as a means of assisting organisations to undertake their own advocacy work.

When asked why the Patients Forum did not play an advocacy role, informants from the organisation emphasised the impossibility of developing positions on which all members could agree. One informant, a former Chair of the organisation, emphasised that perceptions that patients are a homogenous group are incorrect. Instead, she argued that patients are a heterogenous group with a small number of common interests, such as access to information and to be treated with respect.

Following release of The NHS Plan in 2000, the Minister agreed to fund a study into a national patients body. The NHS provided funding to a group of health consumer organisations to undertake this process and the process was managed entirely by these organisations.

The study recommended the establishment of a statutory body (with membership structures) which included the following functions:
- Provide a strong voice for patients, carers and the public on matters impacting on health, facilitating voices to be heard at a national level;
- Promote effective patient/public involvement, in particular amongst people who are often excluded at national and local levels;
- Advise on recruitment, support and training for patients and public representatives on NHS bodies;
- Set standards for Patients Councils and related bodies.

The study specifically rejected the option of an independent community organisation in favour of a statutory body. The Australian Consumers Health Forum was considered as a model, but was not adopted. According to informants, the key reason for selecting the statutory model was consciousness that a community organisation is easily marginalized because of its Government funding arrangements, and that, as a result, its independence was a function of political goodwill.

#### 5.1.2 Infrastructure to develop management capacity

Several informants in the UK discussed the impact of the demands of managing an organisation on their capacity to undertake advocacy work. This was consistently raised by smaller and medium sized organisations. There were a number of strongly phrased comments about diversion from an organisation’s stated objectives as a result of work such as developing internal policy documents, managing staff, and negotiating relationships between their management committee and paid staff.

There were a number of extremely well-developed infrastructure organisations working to improve the management capacity of the community sector in general, or particular groups of health consumer organisations.

“... a website which provided a central reference point [for funding information] would be of enormous value to health consumer organisations in Australia.”
Two groups were:

- **The National Council of Voluntary Organisations (NCVO)**
  This organisation provides information and advice to community organisations through its Helpdesk, publications, magazine, events and information networks.

- **Long Term Medical Conditions Alliance (LMCA)**
  LMCA provides a range of supports for member organisations, including a network for smaller organisations, training programs, and advice. (See the case studies for a more detailed discussion of the work of LMCA.)

A group which was received strong commendation from community sector informants was the Association of Chief Executives of Voluntary Organisations (ACEVO). This organisation describes its mission as “to contribute to the effectiveness of the voluntary sector through support and development of child executives of voluntary organisations and promotion of higher standards of executive leadership through mutual support, sharing of expertise, training and publications.”

Membership of ACEVO was reported by informants from small, medium and large patients’ organisations. Informants emphasised the value of being able to call someone for advice on how to handle a difficult issue or to obtain example policy documents, (such as an equal opportunity policy which is required for eligibility for some funding programs.)

The Association publications cover practical issues such as recruitment, disciplining staff, appraising the chief executive, the operation of the Disability Discrimination Act. The publications also include model documents such as a job description for the chief executive, chair, treasurer and trustee, and a code of conduct for chief executives and trustees.

(It was not possible to visit this organisation during the study tour.)

5.1.3 Chronic illness

A key UK group undertaking and supporting advocacy work for health consumers was the Long Term Medical Conditions Alliance.

People with a long term medical condition (chronic illness) are a recognised group of health consumers and were the subject of significant policy focus. In the months preceding the election, the Minister for Health announced that a National Service Framework would be developed on long term medical conditions. As this National Service Framework had originally been intended to deal exclusively with neurological conditions, the decision to broaden its scope was widely viewed as a political decision to gain support in the lead up to an election – an approach which indicates the priority assigned to this category of health consumers.

Discussions with a number of LMCA member organisations indicated that this body was seen as effective in its advocacy role. It was particularly valued by smaller organisations which felt that it gave them a voice.

An important issue in the development of the LMCA is that its systemic advocacy role coexisted with its projects to develop its members organisational capacity.

See the case studies for a more detailed discussion of the work of LMCA.

5.1.4 Informal and emerging networks

An important network of health consumer advocates was “Patients in NICE”, a network of health consumer representatives involved in the development of national service frameworks through the National Institute for Clinical Excellence (NICE). It was interesting to note that this network was not hosted by a central patients body, but by large specific illness organisations which took turns in acting as secretariat.

In the UK, a number of informants commented on the development of alliances between organisations at a regional level. The most commonly noted examples were of alliances of organisations working on similar specific illnesses, such as neurological conditions or genetic conditions.

These alliances appeared to have been established to enable groups to advocate more effectively with regional health authorities and local authorities. Many decisions about service delivery are made at this level, and there are also issues of implementation of national policies.

5.2 Infrastructure – European Union

There was very little infrastructure for health consumer organisations at a European level. The European Public Health Alliance was a key network for NGOs, and there were a series of European networks/peaks for specific illness groups, such as diabetes and breast cancer.

There was evidence of major involvement by pharmaceutical bodies in the establishment and ongoing operation of some peak and network bodies for patients, such as the EFPIA Patients Platform and the International Association of Patients Organisations (which is discussed below in the section on relationships with the pharmaceutical industry). This was a matter of concern.

The gaps in infrastructure reflect the development of participatory mechanisms in the EU health competence more generally. At the time of the study...
tour, the Commission was engage in consultations around the development of a European Health Forum to facilitate stakeholder participation in EU health decisions.

**Recommendation:** That Government agencies invest in the development of an effective infrastructure of peak and network agencies. There are a range of functions to be performed, but these include:

- Resourcing organisations to be effective advocates
- Improving the management capacity of organisations, and particularly small and medium sized groups
- Supporting the development of organisations which bring together particular groups of health consumer bodies with similar broad interests, such as chronic illness, or similar conditions, such as neurological conditions.

6. Relationships with the pharmaceutical industry

6.1 Managing the relationship with pharmaceutical industry funders

In the UK, the Long Term Medical Conditions Alliance (LMCA) published a useful document to assist organisations to develop policies on their relationship with pharmaceutical companies: *Working with the pharmaceutical industry: guidelines for voluntary health organisation on developing a policy.*

The complexity of relationships with the pharmaceutical industry was evident in the experience of the Terrence Higgins Trust, a HIV/AIDS charity based in London. Following the success of the South African campaign to reduce patent protections for HIV/AIDS drugs, the Terrence Higgins Trust lost funding from one pharmaceutical industry sponsor, but was offered increased funding from another.

One strategy for managing relationships with pharmaceutical industry funders is to limit the proportion of total income which comes from industry sources. This was the approach recommended by the European Public Health Alliance, amongst others. Some organisations commented that a problem with this approach is that there is not always an alternative funder available to provide the majority of resources.

The following are two examples of organisations in the UK and at European level which received the bulk of their funds from industry sources, but gave every appearance of effectively managing their relationships in such a way as to ensure that health consumer interests rather than industry interests drove the organisation.

**European AIDS Treatment Group:** The European AIDS Treatment Group (EATG) is a German-based organisation working on a European level. It employs four permanent staff and has a contract with a consultant to assist with lobbying the complex European Community structures. A small amount of funding is received from membership fees with the bulk of resources flowing from the pharmaceutical industry. Individual pharmaceutical companies pay for meetings where they get feedback about treatments, but most funds are obtained by direct sponsorship. The companies are provided with the proposed work plan for the year, but they have no opportunity to discuss it or suggest alternative activities or approaches. Funding is only accepted on an unconditional basis. There is no formal policy document governing relationships with the pharmaceutical industry. The informant commented that they just used their ‘common sense’.

The informants reported a history of major conflicts with pharmaceutical companies, including one occasion where the company brought a security guard to a meeting to protect its staff. It is worth noting that this company has remained a funder.

**UK Breast Cancer Coalition:** The UK Breast Cancer Coalition (UKBCC) is a London based organisation which employs two full time and two part time staff and contracts with two agencies for communication and policy. It is an exclusively advocacy organisation and supports its members’ lobbying through training, information (generally via seminars), internet (Advocacy Online campaign – see section below on mobilising individuals), and direct support. The UKBCC relies on funding from grant making bodies, such as the Baring Foundation, and from the pharmaceutical industry. The UKBCC has a strict policy paper on accepting industry funding and this was based on the document prepared by LMCA (discussed above). The UKBCC did not, for example, accept pharmaceutical industry funding for a workshop on the gold standard of care as they did not want suspicions that they were supporting a treatment because of the funding received.

(The work of the UKBCC in mobilising individuals is discussed in the section on undertaking advocacy.)
6.2 Pharmaceutical industry involvement in peak and network bodies

At European level, there was evidence of major involvement by pharmaceutical bodies in the establishment and ongoing operation of some peak and network bodies for patients. This is occurring at the same time as the pharmaceutical industry is pressing for European Community interventions to remove barriers to a free-market for pharmaceuticals.

As the national policy ‘barriers’ are generally a mixture of cost containment and quality of care strategies, their removal poses significant dangers to consumers. Ordinarily, it would be these peak and network bodies which would be expected to take a critical approach to these issues, however there is little evidence of this occurring.

The European Commission has a small and poorly developed funding program for health NGOs. As health care is technically a competence of member States rather than the EC, there is little sign of investment in developing more independent advocacy organisations.

Groups such as the European Public Health Alliance do advocate on these issues, but are manifestly under-resourced to take a very active role.

There are a number of very vocal patients’ organisations which are supporting elements of this ‘free market’ approach and these are generally arguing for access to the latest (and very expensive) drug developed for treatment of the specific illness they represent.

Examples of pharmaceutical industry in peak and network bodies included the following:

- **International Association of Patients Organisations (IAPO):** IAPO is a London-based organisation, which, at the time of the study tour, employed one staff member. IAPO was established with funding from Pharmaceutical Partners for Better Healthcare, a NGO established by the pharmaceutical industry. While PPBH no longer exists, the pharmaceutical industry remains IAPO’s primary funder. IAPO is not a membership body but has established ‘networker’ arrangements to involve patients’ organisations internationally. Pharmaceutical companies are eligible for membership of the IAPO board but at the time of the study tour there was no industry representative on the board.

- **European Federation of Pharmaceutical Industry Associations (EFPIA) Patients’ Platform:** The EFPIA Patients’ Platform is a meeting of patients’ organisations at European level. EFPIA provides one full time staff person to support the Patients’ Platform and this person is an EFPIA employee. Information about the Patients’ Platform is available through the EFPIA website. A request for a discussion with the relevant staff member was refused. Information was obtained by emailing a list of questions and receiving brief responses from the EFPIA Government Affairs Department.

- **Partners for Better Healthcare (PPBH):** This is an NGO run by the pharmaceutical industry. One example which several informants provided was of a demonstration in the European Parliament during debate about expanding patenting laws. It was claimed that the many people with a chronic illness and with disabilities who took part in the demonstration had been flown there at the expense of the pharmaceutical industry.

6.3 Public relations strategies and health consumer organisations

At European level, there were consistent reports of close links between pharmaceutical companies and individual patients’ organisations in the pursuit of specific policy objectives of benefit to the pharmaceutical industry. One example which several informants provided was of a demonstration in the European Parliament during debate about expanding patenting laws. It was claimed that the many people with a chronic illness and with disabilities who took part in the demonstration had been flown there at the expense of the pharmaceutical industry.

In the UK, Advocacy Online, a private campaign management company, is promoting a product ‘Campaigning for Care’. This is an internet-based campaign in which the content of the site (and therefore the campaign material) is determined in discussions with the funding pharmaceutical companies, and patients’ organisations are asked to put their logo on the sections that relate to their condition. The content was expected to address access to treatment services and drugs, but not waiting time. The patients’ organisations do not have control over the content, but can decide that the link to further information about the condition can be provided by their own homepage or some other source, such as NetDoctor. It was anticipated that sponsors would not be listed on the main pages, but that individuals could identify sponsors by clicking to another page.

**Recommendation:** That health consumer organisations continue to engage in active debate about the appropriate relationships which should exist between health consumer organisations and the pharmaceutical industry.
7. Representing disadvantaged people

In Australia, there are challenges in ensuring that health consumer organisations advocate for the needs of disadvantaged people as well as those on middle or higher incomes. One factor is that disadvantaged people have lower rates of participation in a range of institutions (including community organisations) than people with middle or higher incomes.

7.1 United Kingdom

In the UK, a number of informants confirmed that health consumer organisations were in a similar position. Two informants commented on this issue without prompting and was interesting to note that both were present or former employees of Community Health Councils, which have a statutory duty to address issues of disadvantage.

This problem was re-affirmed in early reports of the outcomes of the research by Allsop and others at De Montford University. Some groups in this study indicated their organisation had an underlying ethos of social inclusion, others commented that they were aware of the needs of disadvantaged communities but felt that they lacked the resources to tackle these issues effectively. Some organisations operating at local level had been established specifically to address the needs of minority ethnic groups.

Suggestions about strategies to deal with this issue were limited. One informant, a former Chair of The Patients Forum, emphasised the value of organisations which provide services to disadvantaged people playing an advocacy role.

A number of informants commented that many community organisations were managing as best they could in a difficult environment, and it was unsurprising that organisations were focussing on the needs of those people who were most actively participating in their organisations.

It is worth noting that one of the identified functions for the proposed national patients body included a specific reference to promoting participation amongst people who are often excluded at national and local level.

7.2 European Union

At European level, the survey undertaken through EPHA showed little evidence of patients’ organisations working on issues of disadvantage.

The organisations which appeared to be most active in advocating on issues of health and disadvantage appeared to be citizen organisations, such as EPHA.

Commentary:

While many health consumer organisations are effective in representing the needs of middle and higher income earners, they are generally less effective in representing the needs of disadvantaged people. Addressing this is a mix of ensuring separate representation of disadvantaged communities in participatory processes and promoting good practice amongst health consumer organisations.

Recommendation: That Government policy makers support the separate representation of disadvantaged people in policy development processes.

Recommendation: That health consumer organisations identify strategies to promote good practice in involving disadvantaged people in their organisations.

8. Criteria for recognising a health consumer (patients) organisation

In Australia, the definition of a health consumer organisation is highly contested

Issues in debate include:

- Whether the criteria should be restrictive or inclusive
- The extent to which emphasis should be placed on formal structure of membership and governance or on organisational practice
- The extent to which economic rationalist distinctions between consumers and providers can and should be applied to community organisations.

In addition to the desire to clarify conceptual issues, the debate about criteria is driven by turf wars between organisations seeking recognition as legitimate representatives (or the sole legitimate representative) of health consumer interests. It is also driven by the development of policy frameworks and funding programs for consumer participation, which has high political sensitivity for Governments.

8.1 Organisations of consumers and organisations for consumers

One UK informant side-stepped many of the debates about recognition as a health consumer organisation
by describing different organisations as either ‘organisations of health consumers’ or ‘organisations for health consumers’. This distinction appeared to be in common usage in the disability sector.

8.2 Restrictive or inclusive criteria

The key English network of patients’ organisation, The Patients Forum, had not developed criteria for recognition as a patients’ organisation. Informants indicated that this question had been discussed, but was not seen as urgent. One informant identified the issues of concern as professional domination of supposedly patients’ organisation and the level of pharmaceutical funding of an organisation.

Full (i.e. voting) membership of The Patients Forum is open to [community] organisations representing the interests of users of health services and their families and carers.

No criteria for recognition as a patients’ organisation had been developed at European level. The European Public Health Alliance was keen to see criteria developed. Of concern was the emergence of a number of groups which had close ties to the pharmaceutical industry, and groups which claimed broad representation by had few members and non-transparent processes.

The issue gained momentum from the process of developing participation structures at European Commission level. A consultation document on a European Health Forum had been released in early 2001.

8.3 Organisational structure and organisational practice

In Australia, some criteria for recognition of health consumer organisations focus primarily on issues of organisational structure, such as membership criteria and governance arrangements, rather than the way in which organisations actually involve their community.

In the UK, informants placed little importance on issues of organisational structure when discussing patients’ organisations. An indicator of the low importance attached to these issues was the widespread recognition of non-membership bodies as patients organisations, e.g. The College of Health.

Instead, UK informants discussed issues of good processes in the development of policy positions and commented on the quality of information on which policy positions were based.

At European level, the EPHA informants emphasised transparency about membership and organisational structure, as well as processes which effectively involved members in policy development.

8.4 Organisations which provide services

In Australia, some health consumer organisations have argued that an organisation which provides services has no claim, or a lesser claim, to recognition as a health consumer organisation. This is problematic as health consumer organisations, like other community organisations, generally provide services to their community and advocate on issues affecting their community. Some community organisations have also criticised this approach as it applies an economic rationalist model of market relationships to organisations based on a social capital or community development model.

There was no evidence amongst informants in the UK or at European level of any connection drawn between an organisation’s involvement in service delivery and its recognition as a legitimate health consumer organisation. Informants treated questions on this issue with some surprise. Several questioned the application of market models to organisations based on social capital.

In the UK, a number of informants emphasised the contribution to patient advocacy of organisation able to draw on information about patient experience obtained through their service delivery role. An informant from The Patients’ Forum commented that organisations with a service delivery role attracted sympathy rather than criticism because of the challenge of maintaining good relations with their funder while still acting as an advocate for their community.

One informant from a chronic illness/disability organisation reported that some organisations had been criticised for advocacy work which appeared to support their service delivery role. This informant considered that a satisfactory approach for an organisation undertaking both advocacy and service delivery work was to ‘erect walls’ between their service delivery and advocacy arms.

Commentary

There was evidence of strong antipathy to market models and to the use of economic rationalist language and concepts to analyse and characterise community organisations.

There was also evidence of a strong interest in clarifying the various concepts which underpin the participation of community organisations in the policy debate – engagement as consumers (based on the narrow market model), as citizens (with a broad interest in the development of an effective health service), or patients/health consumers (with a specific interest in the development of an effective health service which meets their needs).

Recommendation: That health consumer organisations and Government policy makers adopt a cautious approach to the incorporation of economic
rationalist analysis into thinking about consumer participation and consumer organisations.

9. Developing policy positions

In Australia, health consumer organisations used a range of processes to develop the policy position on which they advocate. These vary amongst small, medium and large organisations; those which can draw on data from service delivery or solely from their membership of individual consumers; those which have a strong ethos of grass roots involvement and those which centralise decision making power; those which are peak or network bodies and those which work directly with individual consumers; and a range of other factors.

Some Australia health consumer organisations are extremely rigorous in their policy development processes and demonstrate innovative practice in data collection, consumer consultation, and participatory decision making. There are also some examples of poor practice.

9.1 The organisation’s policy document

All but one specific illness organisation visited in the UK provided a copy of a document which outlined the issues facing their constituency. These documents were substantial in length, and most organisations had invested resources in presentation. In several cases, the document had been printed with the assistance of a corporate sponsor.

The informants cited these documents as their primary reference point for their advocacy work on the issues facing their community. The documents were updated regularly, and in some cases this was undertaken annually. Some organisations undertook ‘updates’ which were targeted at a specific issue or sub-group in their constituency, however organisations were consistently able to point to a general document as a reference at any given time.

The development of these documents appeared to be the primary policy development process for these organisations, although there were numerous examples of policy development on specific issues occurring outside this framework. Policy development outside this framework appeared to relate to specific issues requiring more detailed analysis or when issues emerged unexpectedly.

In discussing their documents, informants emphasised the quality of the information on which it was based and the process in which it was developed. It was clear that these were issues for scrutiny and debate.

The quality of the information appeared to relate to how close to the consumer it was obtained. Information from an organisation’s own services was considered to be quality information as it had been obtained directly from the consumer.

There were two examples of interesting approaches to the development of the reference document:

**Neurological Alliance:** The Neurological Alliance is a formally constituted umbrella (peak) organisation for neurological conditions. It employs one part time staff member (0.8 FTE). It developed its policy document through consultation with its member organisations, which are commonly both service provider and advocacy organisations. The consultation commenced with a survey on a number of issues. In addition to completing the survey, member organisations were asked to distribute a shortened version of the survey to individuals attending their services. These were returned directly to the Neurological Alliance and were used as a reference against which to verify the input from member organisations.

**Terrence Higgins Trust Lighthouse:** The Terrence Higgins Trust Lighthouse is a large HIV/AIDS charity with offices in London and nine other locations. The development of its policy document drew on information from services provided by the Trust and from individuals and organisations connected with the Trust. The document was validated through review by the Trust’s expert reference group, which is a group of people with HIV/AIDS, handpicked by the Trust to provide critical feedback.

**Commentary:**

The UK experience is of a sector which has a strong focus on good practice in policy development and a wide expectation that internal policy development processes would be the subject of scrutiny by external organisations. There was also an emphasis on the quality of the information base, and on effectively encapsulating both this information and the emerging policy positions in a formal document.

This approach has a number of advantages:

- It shifts the focus away from characterising an organisation as a legitimate representative of a
specific group of health consumers (or not) to the effectiveness of the organisation in identifying the needs and concerns of the group it claims to represent. While this may mean that turf wars shift focus rather than cease to exist, the debates are at least focussed on an area which would benefit from more creative approaches.

- It provides evidence to rebut criticisms that a policy position put by an organisation’s representative reflects their own personal experience rather than that of the constituency which they claim to represent. It also reduces the likelihood of this occurring.
- It promotes better practice in consultation and participation processes within health consumer organisations, including the sharing of innovative practices by particularly effective organisations.
- It assists in promoting better practice in consultation and participation processes in Government.
- It improves the information available to Government to inform policy development. By producing a printed document, this information is also more accessible for policy makers.

This approach does have dangers. Developing a reference document requires resources and there is no necessity that a formal document will achieve more than a less formal, and less resource intensive approach. Developing such a document also requires writing skills and expertise in policy analysis and smaller organisations may not be able to call upon these.

**Recommendation:** That health consumer organisations promote examples of good practice in policy development processes by health consumer organisations.

### 10. Undertaking advocacy

The UK and Europe offered numerous examples of advocacy strategies. Of particular interest were the following two examples of approaches to mobilising individuals to act as advocates for systemic change.

**UK Breast Cancer Coalition:** The UKBCC is a charity which works exclusively on advocacy in relation to breast cancer. It employs two full time and two part time staff and contracts with two agencies for communication and policy.

UKBCC has 500 members. It is working towards at least one active member in each of the 104 health authority areas and, apart from this objective, is not overly concerned about increasing total membership.

The systemic advocacy work is undertaken almost exclusively by individual members. UKBCC provides its members with an extremely high level of support to undertake this work. This support consists of training, information, internet (through Advocacy Online, discussed below), and direct support (such as attending meetings with members). The informant stated that UKBCC will do anything required to assist them to be more effective.

At the time of the study tour, the focus of work was the implementation of the National Cancer Plan. The Plan, a Government policy document, is to be implemented in each health authority area. The UKBCC developed a user friendly audit kit for each health authority to use to assess implementation. This was developed with the involvement of ‘friendly’ health authorities and so is highly credible. Health authorities will be sent the kit by UKBCC, and members will follow it up. Individual members will send letters asking if the audit has been undertaken, and follow up any failure to do so with their local MP.

Once the audit has been undertaken, individual members will continue their advocacy work by asking the regional health authority to take action on any identified gaps in compliance.

UKBCC does not engage in ‘naming and shaming’ exercises in relation to local health authorities as they do not consider it good for the relationship and, more importantly, it is not helpful to local women who do not have the choice to go elsewhere.

**Advocacy Online:** Advocacy Online is a private company which undertakes campaign management. It has two products, ‘Advocacy Online’, which is discussed in this section, and ‘Campaigning for Care’, which is discussed above in the section on relationships with the pharmaceutical industry.

In a campaign supported by the ‘Advocacy Online’ product, there is a campaign website. An individual enters their postcode on entry to the site, and then selects from a range of campaign options, which can include a letter to the local MP, letter requesting a meeting with the local MP, letter to the local media, letter to the health authority, letter to candidates in the upcoming election, and posters which can be downloaded and printed out for the individual to display.

Based on their postcode, each letter appears on the screen automatically addressed to the correct MP, candidate, health authority, or local media. The form letters can be changed by the individual to emphasise or delete information. Where the individual is writing to request a meeting with a MP, and another person in that area has already done so, the second and subsequent person will be asked if they wish to be linked to the first person. This is aimed at minimising the number of individual visits.

The site automatically generates an email to the individual who has used the site, requesting information on the result of their activities. For example, did they get a meeting with their MP?

The campaign literature in the ‘Advocacy Online’ product is developed by the organisation. The website provides the campaigning organisation with
detailed information on activities including the number of letters printed out and the results of the follow up emails to individuals.

The cost of this service is significant. It costs £UK25,000 (A$67,500) for the first year, £UK20,000 (A$54,000) for the second year, and £UK15,000 (A$44,500) for the third and subsequent years. Some organisations have corporate sponsors and Advocacy Online is promoting its products to the pharmaceutical industry to encourage them to sponsor these campaigns.

11. Case studies

11.1 Long Term Medication Conditions Alliance (LMCA)

The Long Term Medication Conditions Alliance (LMCA) is a London based organisation which acts as the umbrella (peak/network) body for national community organisations working to meet the needs of people with long-term health conditions (chronic illness) in England.

LMCA employs approximately three full time and three part time staff. LMCA is funded by the Department of Health, the National Lotteries Charities Board (now the Community Fund), the Association of the British Pharmaceutical Industry, the Kings Fund (a philanthropic trust), and membership fees. Other funding sources are grants from trusts, support from companies and income generated from fees and publications.

LMCA members are national (English, not UK) community organisations concerned to meet the needs of people with a long-term health conditions. There are 95 members, including such groups as Arthritis Care, Breakthrough Breast Cancer, Caring Matters, Diabetes UK, Fibromyalgia Association UK, and Headway – the Brain Injury Association.

More than half of LMCA members are small organisations with no paid staff or 1-1.5 paid staff. Other community organisations and public bodies can become associate members and companies can become corporate supporters.

LMCA’s purpose is:

We work for better lives for people with long-term health conditions, aiming to:

- Gain recognition of their needs and ensure adequate resources are available to meet them
- Campaign to achieve change in areas where LMCA member organisations have common concerns
- Find and promote solutions to shared problems
- Develop effective partnerships between those who plan and provide services and people who use them

- Promote participation by individuals in their own care and treatment and greater control over their lives
- Support member organisations to help them develop strong voices and effective services

What LMCA does is:

- Provide support to members, through meetings and conferences, publications, a network for smaller organisations, linking members, providing information and signposting to other sources of help
- Develop self-management programmes, through supporting and developing new self-management programmes, co-ordinating a national network of organisations in this field and helping to develop policy
- Campaign for change and influence policy, through undertaking research, publications, events, meetings, the media, as members of consultative committees and through working with other organisations.

The Membership Project, which is funded by a National Lotteries grant, provides communication and support to member organisations, including developing joint projects between organisations, signposting organisations to available resources (such as NCVO training), partnering organisations with other groups which have experienced similar problems, training and establishing a small group network.

The small group network was set up for support between small groups but also plays a key role in bringing these groups into the LMCA policy development process.

The needs of small groups is the subject of a recent research/policy development project within LMCA.

The Policy Project is funded by the Department of Health. It organises representatives for committees, develops policy responses on key areas and ensures that that member organisations are kept abreast of policy issues.
The Self-Management Project followed from the LMCA’s Living with long term illness (LILL) Project. It focuses on developing consumer-led self-management courses. LMCA is seeking funding to act as a central coordinating body for self-management courses.

LMCA is very well-regarded and is attracting substantial amounts of departmental and other funding. The Chief Executive was recently awarded a OBE for services to health care.

11.2 European Public Health Alliance (EPHA)

The European Public Health Alliance (EPHA) is a Brussels based organisation which acts as an umbrella organisation (peak/network) for NGOs working on health issues in Europe.

EPHA has three full time and two part time staff. It is funded primarily by the European Commission and also obtains income from membership fees.

The membership consists of non-governmental and other not-for-profit organisations working in support of health in Europe. There are more than 80 members. These include specific illness organisations, however the membership of the EPHA Executive indicates the type of groups which are most active in the organisations:

- International Union Against Cancer/European Cancer Leagues, Belgium
- Royal Society for the prevention of Accidents, UK
- Blue Cross European Community Group, Denmark
- Greek Network of Health Promoting Schools Association, Greece
- International Planned Parenthood Federation, European Network
- Chartered Institute of Environmental Health, United Kingdom
- National Association of Alcohol Prevention, France.

EPHA’s aims are:

To promote and protect the health interests of all people living in Europe and to strengthen the dialogue between the EU institutions, citizens and NGOs in support of health public policies by:

- Monitoring the policy making process within the EU institutions and maximising the flow of information concerning health promotion and public health policy developments amongst all interested players including: Commission officials, MEPs, member state and candidate country ministries, NGOs and citizens.
- Promoting greater awareness amongst European citizens and non-governmental organisations about policy developments and programme initiatives that effect the health of EU citizens so that they can contribute to the policy making process and take practical action to take part in appropriate programmes
- Supporting collaboration at European level between non-governmental organisations and other not for profit organisations active in the member state and candidate countries in health promotion and public health.

The decision making structures of the organisation consist of a general assembly held once a year to discuss the broad policy of the organisation and an executive committee which determines priorities and targets, sets out the annual work programme and provide expert advice on the work of the organisation on an ongoing basis.

The process of policy development is for an issue to be researched by the secretariat, a draft policy document distributed to the membership for comment, and then a revised policy document presented to the executive committee for further discussion and adoption.

EPHA activities include:

- Publication of a bi-monthly magazine on health policy in the EU and Europe, European Public Health Update
- Secretariat assistance to the European Parliamentary Health Intergroup, which is an informal working group of Parliamentarians interested in health issues. The working group provides a forum for discussion between health NGOs and Members of the European Parliament with an interest in health issues. Officials from the European Commission and other EU institutions also take part in the working group.
- Maintaining a website with detailed information on current health issues at European level. This appeared to be extremely well utilised by members.
- Providing background information and advice to members seeking to lobby the EU. EPHA also has desk space available for groups seeking a short-term base close to the European Parliament. There is a lucrative market for consultancy services to assist organisations to lobby the EU institutions, however EPHA has decided that this is not an appropriate role for it to play.

EPHA work is largely focussed on the institutions of the EU. The office is located near the European Parliament in Brussels. The organisation receives funding from the European Commission.

The EU competence on health is largely limited to public health. Health services remain the exclusive competence of member States. The EU has competence in relation to a many of the social determinants of health.

The EU competence frames the scope of lobbying work of EPHA. Issues of health services, for
example, are difficult to pursue through EU structures. The EU competence also facilitates the active consideration of health issues in areas, such as transport and agricultural subsidies, which are commonly developed without any serious integration of health concerns.

The priorities for EPHA work are partly driven by issues identified by its membership (such as patient participation) and partly by opportunities to participate in European Commission policy development processes (such as the development of a new public health program).

The development of the EU internal market in relation to health is creating new challenges for EPHA. Principles and processes of trade regulation are being used to create new policies in relation to health services, health workforce and health products, such as pharmaceuticals. EPHA, and other interested NGOs, lack the resources and the expertise to tackle the complex issues of trade regulation, and the EU structures of trade regulation are not designed to promote NGO participation. (This is discussed in the EPHA draft policy on patient participation, which is attached.)

11.3 The Patients Forum

The Patients Forum is a London-based organisation working across the UK. It is a network of national and regional organisations with a concern for the healthcare interests of patients [health consumers] and their supporters.

The Patients Forum employs one staff member on a three year project funded by the Ministry of Health. Prior to this funding, the organisation was run on a purely voluntary basis.

Full membership of the organisation is open to community organisations representing the interests of users of health services and their families and carers. Non-voting (subscriber) membership is open to other bodies such as professional and academic organisations and statutory management and regulatory bodies. There are 55 full members and 17 non-voting members.

The remit of The Patients Forum is to:
- Promote wider discussion of health issues among the whole range of organisations representing patients and cares;
- Improve arrangements for communication, time consultation and liaison between the health consumer network and Government and relevant statutory and professional organisations.

The aims of The Patients Forum are to:
- Provide a forum for national and regional organisations representing the interests of people who use health and related services and their supporters to share experiences, information and ideas, to strengthen their work and to participate in informing and influencing decision makers;
- Promote information exchange and discussion amongst members and subscribers and through meetings with colleagues from the statutory sector, the professions and the academic world.

The Patients Forum activities include:
- Holding a meeting of groups working at national level every two months
- Maintaining a website which provides information about current issues, a directory of members, and a web-based discussion forum
- Conferences and seminars
- Putting forward names of individuals to work on taskforces

The Patients Forum considers its key role to be information exchange. Informants emphasised that it does not undertake advocacy. Despite this, the informants indicated that the group had provided input to the debate on participatory structures which was then underway in Parliament. Informants emphasised that this was a residual role.

The organisation appeared to be very well respected in the sector and in Government. The organisation hosted the Patient and Public Involvement Project which developed a proposal for a national patients’ body.
Recommendations

Recommendation: That health consumer organisations and Government policy makers advocate for and support research into health consumer organisations.
(see Discussion – 3. Research into health consumer organisations)

Recommendation: That Government agencies develop funding policies which
• resource core activities, including systemic advocacy, and
• address the policy gap between funding and participation frameworks
(see Discussion – 4. Funding arrangements)

Recommendation: That Government agencies invest in the development of an effective infrastructure of peak and network agencies. There are a range of functions to be performed, but these include:
• Resourcing organisations to be effective advocates
• Improving the management capacity of organisations, and particularly small and medium sized groups
• Supporting the development of organisations which bring together particular groups of health consumer bodies with similar broad interests, such as chronic illness, or similar conditions, such as neurological conditions.
(see Discussion – 5. Infrastructure)

Recommendation: That Government policy makers support the separate representation of disadvantaged people in policy development processes.
(see Discussion – 7. Representing disadvantaged people)

Recommendation: That health consumer organisations promote examples of good practice in policy development processes by health consumer organisations.
(see Discussion – 6. Developing policy positions)

Recommendation: That health consumer organisations and Government policy makers adopt a cautious approach to the incorporation of economic rationalist analysis into thinking about consumer participation and consumer organisations.
(see Discussion – 8. Criteria for recognising and health consumer (patients) organisation)

Recommendation: That each jurisdiction develop formal agreements on key issues in the NGO-Government relationship and develop effective structures to monitor its implementation and further develop it over time.
(see Discussion – 4. Funding arrangements)

Recommendation: That health consumer organisations continue to engage in active debate about the appropriate relationships which should exist between health consumer organisations and the pharmaceutical industry.
(see Discussion – 6. Relationships with the pharmaceutical industry)

Recommendation: That Government agencies fund the establishment of a web-based listing of funding options and associated resources.
(see Discussion – 4. Funding arrangements)
1. Background

EPHA is developing this policy on patient participation in order to:

- Contribute to current debates about European governance
- Address issues of balanced representation in relation to patient and citizen participation
- Examine issues of independence for patients’ organisations and of appropriate relationships between patients’ organisations and other health stakeholders
- Consider how best to support patients organisations to participate in decision making.
- Reflect on barriers to effective patient and citizen participation in decisions about health care which are occurring within the single market

2. Patient participation and citizen participation

Patients and citizens

Patients are users of the health care system. Citizens are the population as a whole (sometimes referred to as ‘the public’ or ‘the broader community’).

Both patients and citizens have a role to play in health decision making. In this document, health decision making includes decisions about health care systems and decisions which affect the health of the population, including issues of public health and the social determinants of health.

All patients have in common an interest in the ready availability of quality health care services and of appropriate information and support services to assist them to return to good health or to live well with their condition. Some patients have an interest in broad public health measures and the social determinants of health, but others do not. Patients are a diverse group and there are different interests between those with a chronic illness and those with acute conditions, and between wealthy patients and those who have low incomes, amongst others. On any given issue, there are likely to be a number of patient perspectives.

There are many ways to describe the citizen interest in the health system. One useful approach is stewardship: citizens are trustees of the national health. That trust is an intergenerational responsibility to use the available resources of the government and the community to improve the health of the community as a whole. The resources available to national governments include regulation and provision of health care services, as well as public health measures and social determinants of health. The scope of the European Community is more limited as there is currently no competence in relation to health care services, however there are a range of decisions made across the European Community competencies which impact on health of the population as a whole.

Rationale for citizen and patient participation in health decision making

Involving citizens in decision making about government policy is a basic democratic principle. There are arguments that formal processes for citizen involvement over and above the election process fill a ‘democratic deficit’ in the current political system.

Participation by citizens and patients in decision making is also about better decision making. It brings the knowledge of various sectors of the community to the decision making process. As patients have expertise in their condition and their treatment, they have important information to contribute to decision making in the health system.

Citizen and patient participation is also about educating the broader population about the many and complex issues which are considered in health decision making.

Citizen and patient participation is also about gaining broad public ownership of the decisions which are made. This is particularly important in the health sector as many of the decisions are controversial, such as those relating to rationing of health services, location of hospitals, regional allocations of funds, and access to and payment for pharmaceuticals.

Organised citizen and patient advocacy is important to ensure that the needs of patients and of the community as a whole are effectively balanced against the interests of business and the health
professions. It is also important to ensure that health managers hear citizen and patient views.

Patients and consumers

Patients are sometimes referred to as consumers. Consumers are purchasers of good or services or are users of goods and services.

Consumer principles provide a valuable framework to guide improvements in health care services for patients and for the benefit of citizens generally. The European Consumers’ Organisation (BEUC) has identified eight core consumer rights: safety, information, choice, representation, redress, education, satisfaction of basic needs, and a clean environment.

There are arguments that patients should participate in health decision making on grounds of consumer sovereignty, which is an approach drawing on classical market theory. There have also been suggestions that their role as consumers make patients the sole or primary partner in health decision making. The application of classical market theory to patients and health care systems is, however, problematic and a focus on broad patient and citizen participation is more appropriate.

One problem with applying classical market theory to the health care system is that improving the health of an individual is widely regarded as a common good, not merely an individual benefit. The interest in effective services is therefore not limited to the direct recipient of care. It is a broad citizen interest.

A second problem with applying classical market theory to the health care system is that the patient is commonly not the person paying for the services or not the only person paying for the services. In national health care systems, the payer is the state and the source of funds is tax revenue. This gives citizens an immediate financial interest in the transaction. In systems based on contributory insurance, the insurance companies and fellow contributors have a direct financial interest. In both cases, citizens have an interest in the overall cost of health care services to the community.

Participation processes and patients’ rights.

Some member states have focussed efforts on documenting individual rights in the health care system.

Patients’ charters and legislation to protect patients’ rights have an important role to play in describing what constitutes lawful (or prescribed) conduct, and in identifying and providing mechanisms for redress where these are breached.

Codification of individual rights is insufficient to incorporate the public interest into health decision making as the public interest is more than an aggregate of individual rights. Commonly, decisions about the rights of an individual are not processes in which wider issues of resource allocation and accountability can be effectively debated.

Examples of this are the recent decisions of the Court of Justice of the European Communities in the Kohll and Decker cases (1998). These cases overturned existing arrangements for coverage of health care abroad, but did not examine the wide-ranging implications for health care systems in Member States; such as capacity to contain rising health care costs and ensure adequate quality of care.

A focus on individual rights needs to co-exist with participatory processes which involve citizens and patients in decision making.

Involving patients and involving citizens

Citizens have an interest in decisions about health systems, public health and other issues which affect the health of the population as a whole.

Patients have an interest in decisions about health care systems and may have a broader interest in health matters. There are a number of conditions which are affected by issues which commonly fall into the scope of public health, such as food choices (e.g. Coeliac Disease) and air quality (e.g. asthma). There are also some patients’ organisations which have chosen to focus on broad strategies of prevention which are also public health measures.

As decisions about health care systems, public health and other issues affecting the health of the population as a whole may be of concern to citizens and patients, it is appropriate for European Community policy makers to provide both citizens’ organisations and patients’ organisations with opportunities to take part in these debates. Different organisations will have different levels of interest in specific issues, and it should be left to the individual organisation to determine whether or not it is a priority for participation.

3. Patients’ organisations

Criteria for identifying patients’ organisations

The criteria for identifying a patients’ organisation is contentious, however there are growing needs to clearly identify patients’ organisations and to distinguish them from other health stakeholders.

The need to identify patients’ organisations flows from growing interest at national and European level in involving patients’ organisations in health decision making. There is also growing interest at national level to funding patients’ organisations to facilitate their participation, and the European Commission is also being approached to provide similar support.

The primary issue in distinguishing patients’ organisations from other health stakeholders is the extent to which the organisation reflects the views of
patients and their carers, rather than the views of health professionals (including researchers) or the pharmaceutical industry.

Patients’ organisations can also be distinguished from citizens’ organisations by their focus on the needs of health service users rather than on issues of concern to the community as a whole. In practice, the distinction between patients’ organisations and citizens’ organisations is not always clear.

In addition, there are other factors which need to be considered when determining whether or not an organisation should be recognised as a legitimate representative of patient interests. These include:

- Do they have a membership which is consistent with the organisation’s title and the constituency it claims to represent?
- Do they have processes to involve their membership in developing the organisation’s policy positions?
- Are they transparent about their structure and internal processes?
- Are they transparent about sources of funding and relationships to industry and other stakeholders?

In some parts of the patient movement, emphasis is placed upon the extent to which an organisation represents the views of patients over and above the views of their carers and family. This is particularly important in relation to conditions which have historically been viewed as reducing the capacity of the patient to identify and articulate their own interests, such as mental illness.

Participation by under-represented groups

As with many membership organisations, patients’ organisations commonly have very low rates of participation from people with lower socio-economic status, from indigenous communities and other ethnic minorities, and from other marginalised groups. While this does not undermine the value of participation by patients’ organisations, it does mean that additional strategies are required to ensure effective representation of the interests of disadvantaged groups.

There is evidence that some patients’ organisations have recognised this gap in their membership and have implemented strategies to identify the needs of disadvantaged groups and to incorporate this information into their advocacy work.

As heavy users of the health care system have a greater motivation to pursue improvements in care, the majority of patients’ organisations relate to chronic conditions. Patients with acute conditions do not commonly organise as patients’ organisations and alternative processes to identify their needs and advocate their interests are required.

Ensuring the independence of patients’ organisations

The value placed upon the participation of patients’ organisations flows from their ability to reflect, accurately and fairly, the views of the patients they represent. In order to do this, they need to be independent from other health stakeholders.

One area of particular concern is the relationship between patients’ organisations and the pharmaceutical industry.

While the views of patients and pharmaceutical companies can overlap on different issues, they are not identical. While it is important that these commonalities are pursued when they exist, it is also important that patients’ organisations maintain the capacity and independence to express views which are different from industry and which may be critical of industry.

Some patients’ organisations refuse to accept funding from pharmaceutical companies on the grounds that this is a conflict of interest. Many patients’ organisations do accept funding from pharmaceutical companies.

Approaches to minimising conflict of interest for patients’ organisations which receive pharmaceutical funding include:

- establishing limits on industry sponsorship as a proportion of total income; and
- clearly articulating the role of the sponsoring body in relation to sponsored projects and the organisation generally in policy documents.

Funding from pharmaceutical companies is not limited to direct sponsorship. In some cases, a formally constituted not-for-profit agency acts as a conduit between the pharmaceutical company and patients’ organisations.

4. Infrastructure to support participation

Infrastructure

Infrastructure refers to structures which support NGOs to operate more effectively.

In the context of promoting patient and citizen participation in decision making about health, this would include structures to support networking, debate and, where appropriate, the development of common positions. These structures include such things as umbrella organisations (such as EPHA); informal networks; forums and conferences; and newsletters and email lists.

Infrastructure in Member States

Infrastructure in Member States varies greatly. Examples include:

- umbrella body for a specific condition
- umbrella body for a collection of similar conditions (such as neurological conditions)
• umbrella body for all patients or for patients and citizens
• a statutory body to pursue the interests of all patients or of patients and citizens
• informal networks relating to a specific issue

These bodies and networks may be funded by membership fees, public donations, government grants and contracts, grants from charitable foundations, or funding from pharmaceutical companies and other parts of the health industry. There are a number of Member States which have decided to provide public funding for infrastructure bodies. This reflects a commitment to promoting civil society and also reflects a recognition amongst policy makers of the practical assistance of such infrastructure to the process of involving civil society. This practical assistance can include:

• Facilitating wider consultation with patients’ and citizens’ organisations. Infrastructure bodies can provide advice on strategies for effective consultation and on the constituency which various respondent organisations represent. They can also undertake part or all of a consultation process.

• Identifying a suitable representative. Infrastructure bodies can recommend individuals with the appropriate expertise to contribute a patient or citizen perspective to committees working on specific policy issues. They can also develop processes to facilitate exchange of information between these representatives and others with an interest in the specific issue.

• Providing a primary point for negotiation during policy development. This allows the development of compromise positions which have broad acceptance amongst civil society organisations and the broader community.

Another reason for public funding of this infrastructure is the recognition by governments that corporate funding has the potential to undermine the independence of the advice and input provided by the organisation. Infrastructure organisations commonly face particular difficulties in raising sufficient public donations to support their work.

Europe-wide infrastructure

Infrastructure for NGOs working for health at European level consists of:

• Umbrella NGOs funded by the European Commission to promote the involvement of civil society. EPHA is an example.

• European NGOs working on specific conditions or on related conditions. Some of these have a membership of national organisations from across Europe and clear processes for developing the policy positions which are advocated at European level. Many do not. Some are self-funding and some rely heavily on funding from pharmaceutical companies.

• Structures which are attached to the pharmaceutical industry or which are in close partnership with industry. These include the EFPIA Patients’ Platform, a number of conferences, and some umbrella patients’ organisations.

At the time of writing, discussions were underway about the development of a European Health Forum to be established by the European Commission.

There is significant scope for development of infrastructure on health decision making at European level. Trends which support development of this infrastructure include:

• Policy makers seeking civil society input which relates to a broad set of conditions (or all conditions) rather than to a specific illness. Achieving representation of a broad collection of interests requires investment in umbrella organisations, forums and networks that can negotiate common positions and seek broad input on policy questions.

• The need for civil society input into increasingly complex decisions about health. There are decisions about health which are occurring under the trade competence. Effective civil society input on these matters requires sophisticated analysis. Developing the capacity for sophisticated analysis of the intersection of trade, social protection measures and health is an issue of resources.

• Public concern about the role of the pharmaceutical industry in sponsoring patient and citizen debate on issues in which they have a direct economic interest.

• The need to ensure that the interests of disadvantaged patients and citizens are represented in debates about health services. This is particularly important to prevent entrenching inequities.

5. European Community competence for health

Health care services formally remain an exclusive competence of member States. The internal market, in so far as it affects the free movement of goods and services (health care), the free movement of professionals and other workers (health care), and the free movement of citizens (patients), already means that major decisions concerning health care rest with the European Community.

The European Commission’s formal commitment to health resides in Directorate SANCO and relates to public health and not to health care. This is, however, only a small part of the Commission’s work on health.
Adhering to the formal competence in the structure of decision making in the European Commission means that the development of policies on health care services is being driven by principles appropriate to private economic transactions in the single market rather than national social protection mechanisms. An approach to health care services, which is based on trade principles rather than social protection, poses considerable dangers to patients and citizens. It threatens to exacerbate inequities in access to health care service, to undermine strategies of cost-containment and threaten strategies to ensure quality of health care services. It also has the potential to further focus Member State resources on health services rather than on a balanced investment in health services and public health measures.

The structure of the European Commission also provides no site within the Commission services for citizens’ and patients’ organisations to contribute to debate about the development of European Community policies on health care.

6. Conclusions

Both patients and citizens are two distinct interests and both have a role to play in health decision making. Patients are users of the health care system and citizens are trustees of the national health. Both patients and citizens and their respective organisations should have the opportunity to participate in health decision making.

While calling for transparency in European Community decision making, NGOs have a responsibility to be transparent about their own structures and activities. Patients’ organisations and citizen’s organisations need to provide clear information about their membership, processes for involving members in policy development, structure and internal processes, and sources of funding and relationships with industry and other stakeholders, amongst other issues.

Patients’ organisations are well developed in the areas of chronic illness, but there are gaps in representation in relation to acute conditions and disadvantaged communities. Additional strategies are required to ensure effective representation of the interests of these groups.

There is very limited infrastructure in place to support patients’ organisations and citizen’s organisations to effectively participate in health decision making at European level. There are a number of trends which support further development of this infrastructure, including policymakers’ desire for input relating to a broad set of conditions rather than specific conditions; the need for civil society input into increasingly more complex decisions about health, public concerns about the role of the pharmaceutical industry in sponsoring debate on issues in which they have an economic interest, and the need to represent the interests of disadvantaged patients and citizens in debates about health care services.

Adhering to the European Commission’s formal competence in the structure of decision making in the European Commission means that the development of policies on health care services is being driven by principles appropriate to private economic transactions in the single market rather than national social protection mechanisms. It also provides no structure to facilitate the involvement of civil society in European Community decisions about health care.
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