

The Patients Forum

Options for the future

Discussion paper for review meeting to be held on 11 May 2006

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Key points

This discussion paper arose from a review of the work and future role of the Patients Forum in consultation with members and stakeholders. Everyone recognised that the Forum had lost some focus in recent years and that it was timely to review its future.

- *How useful are current activities and are there new directions for the Forum?*

There is wide and strong support, among both members and stakeholders, for an organisation that can provide a space to debate health policy issues that affect the voluntary health sector and enable statutory and professional bodies to consult on plans to get a range of patients' views at an early stage.

New directions were suggested, including high level seminars, support services for smaller patient groups, co-ordinating views of patient groups, research, briefings and projects on particular topics of shared interest and being more proactive in putting forward views from a patient's perspective.

- *Is there a need for a national umbrella group to advocate for the voluntary health sector?*

Many members and external stakeholders were concerned that the voice of health service users was weak and unco-ordinated at national level. They felt that it was important that the voluntary health sector work more closely together and co-ordinate their views on national policies to Government and other statutory agencies. This could be spearheaded by a revitalised Forum.

Most agreed that the Forum should be more proactive in setting the agenda, monitoring the effects on patients and particular patient groups of the implementation of policies and raising issues at national level both with Government and other stakeholders.

- *What is necessary for the Forum take on a more proactive role as the umbrella organisation for the voluntary sector?*

It was recognised that the Forum would need to improve its accountability to members and develop its organisational and management capacity if it is to continue and develop a new role.

In deciding its future role and focus, it is essential that the Forum has active support and investment at a senior level of the major voluntary health organisations.

1 Introduction

The Patients Forum was set up in 1989 as an umbrella group for national voluntary organisations to share and coordinate their views. This was a time of major change in the NHS with the introduction of the internal market. National organisations realised they needed to look at the wider picture of health policy changes and co-ordinate their views.

The Patients Association invited 21 national organisations representing a wide range of patients' interests to an inaugural meeting in April 1989. There was involvement at senior levels in these organisations and participants travelled from Scotland and Northern Ireland to attend.

The Forum was initially funded by subscriptions and grants - with the Patients Association and later the organisation to which the Chair belonged, (the National Consumer Council and Carers UK respectively) providing administrative support and a base. This changed when core funding was received from the Department of Health in 1999 and it employed staff and set up a separate office.

The Management Committee commissioned this review of the work of the Forum and any options for the future, taking into account changes in health and social care, the voluntary sector and the needs of members.

The review was undertaken from January to March 2006 by consulting members and stakeholders and reviewing documentation. All members and past members were invited to give their views through an e-mail questionnaire, and interviews were held with former and current members, the management committee and external agencies (appendix).

This report summarises the issues raised in the review, presents options for consideration and identifies barriers that may need to be tackled to secure a long-term future.

2 The Forum and its activities

In general most informants agreed that the Forum's core activities remained valuable. The role required a clearer focus that was complementary and did not overlap other networks

- There is still a role for a space to debate policy issues, but the format and participants need to be reviewed.
- There may be a role for conferences but these should be clearly linked to the Forum's work plan, with an outcome and full costs recovered or used to generate income.
- The Forum is an important resource for statutory bodies to consult and get a range of patients' views, but might be more proactive in setting the agenda with these bodies.
- There is a need for timely policy briefings on the implications for patient groups of current initiatives and 'horizon scanning'.
- Information exchange is useful, but different ways of doing this need to be explored, such as through the website or email groups or separate events for member organisations with similar interests.
- A range of new directions were suggested, including high level seminars, support services for smaller patient groups, co-ordinating views of patient groups, research and projects on particular topics of shared interest, and being more proactive in putting forward views from a patient's perspective.

3 The Forum and its members

When the Forum was set up 21 national organisations were invited to join. Membership was limited, because it was felt that this number was sufficient to enable debate and widening the membership might diffuse this. Later when core funding was obtained from the Department of Health, the membership was expanded. Though this broadened the base, it also weakened the organisation in that members represented more varied interests. It was therefore harder to construct an alliance that could have influence at a high level with both major and minor players.

The Patients Forum has an impressive range of influential organisations in membership. There were 59 members from patient and public interest groups in 2004-2005. There has been a small decline in membership that is probably due to the loss of momentum. Members are also struggling with their own organisations and have other priorities. However, it is likely that membership will decline further with the reduced participation in Forum events that has taken place unless this issue is addressed. The future focus of Forum activities will to some extent determine recruitment and involvement of members.

There were 10 associate members from statutory or professional organisations in 2004-2005. Associate members tend to be staff responsible for policy or for patient and public involvement in regulatory bodies or professional associations or are involved in Patient Liaison Groups. Those members who attended meetings found the Forum a useful way in meeting voluntary groups and hearing their views, though declining attendances made this less productive.

There was a perception that the Forum is increasingly reliant on its associate members both at meetings and in the management committee. This has been helpful and supportive to the Forum. Associate membership might be built on to develop joint activities in the future with more formal alliances being formed and undertaking collaborative work.

4 Future role of the Forum

There is support for the Forum to continue and adapt its role to meet the changes in the health world. All those interviewed closely involved with the Forum recognised that changes were needed for the Forum to be able to continue to have a useful role.

The changing environment

The Patients Forum was set up when major changes were occurring in the NHS. Restructuring arising from the introduction of the internal market and the separating of the functions of purchasing and providing health care had significant implications for patient groups. The implications of this are still continuing.

Health and social care

- The lack of stability and coherence in policy on patient and public involvement has made it difficult to create a climate of constructive dialogue with the Government and Department of Health on patient/carer issues. The range of regulatory bodies and next steps agencies have contributed to a hugely complex environment for health policy.
- It is increasingly difficult to influence national policy as more decisions are devolved and it becomes harder to know how to influence change. It is no longer a single official who needs to be targeted and so the Forum needs to be far more sophisticated in its approach as health policy is being developed in a more fragmented way by many different stakeholders. Radical policies emerge and by the time the implications are understood to it is too late to influence them.
- With the internal market also came the need to strengthen 'consumers'. The Patient's Charter in 1990 provided a framework for patients' rights. In 2005 the Choose and Book initiative is a continuation of this agenda.

There are concerns that such initiatives tend to lead to better services for articulate people who are able to act as consumers, but increase health inequalities for the rest of the population.

- In 2004 Community Health Councils were abolished and with them the national association (ACHCEW). ACHCEW had a well-established information service that carried out surveys and produced briefing papers on policy initiatives. The Greater London Association of CHCs, also disbanded, undertook research and provided information to the voluntary sector.
- PPI Forums and the Commission for Patient and Public Involvement in Health (CPPIH), have not become involved in commenting on national issues. The CPPIH will be abolished in 2007, and it is intended to set up a national association for Patients Forums, but the future of PPI Forums themselves is being reviewed.
- A PPI Resource Centre is being set up with funding from the Department of Health. This is likely to focus on the technical and 'how to' aspects of patient and public involvement as a resource to the NHS, its regulatory agencies and PPI Forums.
- Government policy for health is now officially termed to be "patient led". Patient and user involvement are a mainstream activity with varying degrees of implementation.
- The establishment and effectiveness of Oversight and Scrutiny Committees (OSC) has been extremely patchy with poor links to the local voluntary health sector and virtually no links to national patient organisations.
- Following the White Paper on out of hospital care there will be more integrated health and social care services at local level with different degrees of transparency and accountability to patients/carers.
- With the growing complexity of 'health economies', there are concerns that the voluntary sector will find it more difficult to influence what happens at local and national levels, because of fragmentation and the lack of capacity to take part in consultations and implementation programmes, particularly smaller groups.

The voluntary sector

There have also been major changes in the voluntary sector.

- The voluntary sector increasingly relies on contracts for services for funding, and other income is harder to raise. This particularly affects the funding of generic umbrella organisations, such as the Patients Forum.
- There are now new opportunities for the voluntary sector to compete for contracts to provide services in health and social care. While this gives the potential for longer term funding for some activities, other activities may be jeopardised, in particular advocacy, especially where it may involve criticising or questioning national or local policies and

their implementation. The Compact between the voluntary sector and the Government safeguards the independence of voluntary organisations to speak out of behalf of their members and users. An NCVO report indicates that many organisations do not have confidence in this¹.

- Since the Patients Forum was set up new umbrella groups, such as the LMCA and the Genetic Interest Group have emerged. The LMCA has a membership of condition based organisations and about 1/3 of members of the Patients Forum are also members of the LMCA.
- The patient world is bigger now and less benevolent. Whether it is intentional or not there is a perception that the Government is creating a 'divide and rule' climate among the voluntary sector by funding different organisations for the same purpose. Some organisations are perceived to have a special relationship with Government – shown in being represented on strategic working groups with civil servants - and the Government may use them to the exclusion of other patient voices. This weakens the patients' voice.
- Pharmaceutical funding of patient groups has become widespread -, which can potentially affect the credibility and impartiality of groups that they fund.
- Recently there has been a reduction of the generic health and public interest organisations' activities around NHS policy and general advocacy. The College of Health and Women's Health have wound up and the National Consumer Council has not recently undertaken activities around health policy. Other established organisations such as the Maternity Alliance and the National Centre for Independent Living are ceasing to operate due to financial difficulties.

Does the voluntary health sector need an umbrella organisation?

The Patients Forum was set up in 1989 at a time of change when voluntary organisations felt the need to come together to share intelligence and influence policy making at national level. This situation still remains though the world in which they operate is more complex and more competitive.

While there are increased opportunities for voluntary groups to work on specific conditions, such as cancer, particularly around the national service frameworks, there are few opportunities around generic health policy issues that underpin services for specific conditions. There are no other organisations taking a wider view of health.

The LMCA is the main organisation that has a membership overlapping with the Patients Forum. The potential overlap with other organisations depends on the focus that the Forum has in future. For example many conditions or

¹ Blackmore, A (2004) Standing apart, working together: a study of the myths and realities of voluntary and community sector independence. NCVO.

diseases are covered by organisations such as LMCA, Specialist Health Care Alliance or mental health umbrella groups.

Gaps that are identified include:

- The lack of independent early information for the voluntary sector on policy changes in health and social care, so that groups can be involved in policy development.
- A lack of a co-ordinated voice for the generic interests of patients and the public. By working together through an umbrella group the voluntary health sector can put forward their views without threatening their future potential sources of funding.
- The lack of monitoring of the impact of health policies on particular groups of patients.

Do we need the Patients Forum?

To consider:

- Whether there is a role for a national umbrella group for the voluntary health sector, working more closely with other organisations, in particular the LMCA, to improve the use of resources and avoid duplication and fragmentation.

Are there shared concerns among members?

The Forum's broad based membership is its strength and its weakness. The Forum has a very varied and diverse membership and this may make shared views difficult to achieve. It encompasses interest in older people, learning disability, sensory impairment, mental health and child health amongst its members' concerns, as well as specific long-term medical conditions.

At the moment the 'mission' of the Forum is concerned with processes rather than values and this needs to be reviewed when the direction of the Forum is considered. If the Forum adopted a clear set of values that most organisations could sign up to, this might help focus on its aims and assist in assessing policies and initiatives as well as determining priorities and work plans. The values might be based on consumer principles such as: access, choice, information, redress, safety, equity, transparency, quality and representation. These are shared concerns that override the interests of any one client group, disease or condition.

All voluntary health sector groups are concerned that current policies may increase inequalities that will result in better services for some and poorer services for others. It will be the most vulnerable and inarticulate groups of patients, whose needs will present the most challenges and who will not automatically benefit from increased choice and increased localism. Several informants felt that the Forum needs to find a theme or an angle that is a unique perspective. Social inclusion and inequalities and the public health agenda, looking more at the social aspects of health, including urban and civic renewal is one possibility suggested.

The Forum has traditionally focussed on the NHS and health care; increasingly the boundaries between health and social care are getting blurred. The Forum might therefore consider extending its remit to look more at issues around the interface of health and social care.

Identifying shared concerns

To consider:

- The Forum might consider adopting a set of principles that members would accept and which assist in assessing new policies and initiatives.
- The Forum might consider a theme or area around which to develop the work plan and focus recruitment, e.g. inequalities in health or social care/health interface issues

Should current activities continue?

There was a general agreement that Forum needs to be clear about what it is aiming to do and be more proactive than it had been in the past. In this section we look at current activities that members value and how they might be developed.

Providing a space for discussions on policy

The Forum has been successful in providing a safe space to discuss policy through meetings, seminars and conferences - where patient group representatives can debate policy concerns, influence policy makers and share information across the sectors. Providing an independent policy space is something that is of continued value to most stakeholders. However, new ways of doing this need to be considered – attendance at regular meetings has declined to a stage where they are less valuable to members and policy makers.

With its wide membership, the Forum has access to a range of views and experiences. Choice, integration of health and social care, inequalities and public health are areas where work is urgently needed to understand better the detailed implications and impact on access for different patient groups. It would be useful to monitor through the network of patient groups what was happening in particular areas.

If it was agreed to concentrate on a particular issue, the topic might be divided into topic areas with members working together on areas of interest to them. For example, different members would be interested in monitoring the way that 'Choice' is implemented, such as in relation to transport or how support is provided to people with communication needs. However, any working groups would require professional policy support to maximise the time of member organisations.

Liaison with other bodies at national level

Providing a reference point for statutory bodies to consult and try out ideas at an early stage was valued, in particular by the Department of Health. This may be important again with major health legislation likely in 2007.

The only concern was that if this was seen as the main function of the Forum, the Forum lost momentum and accepted the agenda of others. Providing a shared space for the voluntary sector and policy makers to meet should continue – but as a less major part of its work.

Policy briefings and updates

Many members would appreciate horizon scanning, updates and briefings on issues as soon as they arise outlining the possible implications for their constituencies. The Forum might require access to professional policy analysts on a sessional basis and separately funded. Briefings could be sold to non - members and libraries etc.

Sharing information between organisations

Again this role was valued but was not seen as critical in the regular meetings. Also it should enable a matching of organisations with common interests to share information and support each other

Enhancing current activities

To consider:

- Changing the format of seminars, holding them in association with other bodies and aiming to attract non-members and the media, with reports and briefings to inform debate and enable follow up.
- Providing a briefing and update service for members might be considered and separate funding sought.
- Members' database might be developed with interests and concerns so that members can be put in touch with others.
- Develop email groups and the website as an interactive tool for members and to promote the Forum.
- The future of the newsletter might be reviewed as a method of communicating with members and supporters, depending on resources and other priorities.

Are there new directions for the Forum?

Though many members were happy with the Forum in its current role, the status quo is not an option. Two main new directions were raised in the consultation:

- Co-ordinating views of members to influence policy; and
- Providing services to members.

Co-ordinating the views of patient groups to influence policy

While the Forum was seen as providing a useful space to share information, it was criticised for the lack of outputs and the lack of follow up. The Forum has focused on information exchange and being a source of information rather than as a “voice”. Because it does not attempt to reach a consensus view, it can be difficult to act as a conduit for members’ views. There is no such thing a ‘patient view’ but a range of views.

However, it is worth looking at this role again, as there is clearly a gap at national level. It may be appropriate for this to be taken on by an umbrella group such as the Forum because there are difficulties for

- Small organisations to comment on consultations on policy because of their lack of resources and also to get their views heard.
- Organisations dependent on funding from contracts or public funding to openly criticize government policy may be wary of standing out alone.

If the Forum were to be more proactive and be a voice for patient groups, it would need to address issues of:

- Accountability to members
- What sort of consensus can and should be achieved.

If any views or policy statements are made on behalf of the Forum they need to be based on evidence and the Forum could seek funding to commission research or surveys of member organisations on topics of interest and use this as a basis to promote patients’ views to policy makers. Links might be developed with think tanks, universities or very specialist organisations for joint research and policy briefing work.

Services to member organisations

The decline in membership is likely to be arrested and new members recruited if the Forum has a higher profile, as has happened after major national conferences.

The issue is to look at ways of making itself more attractive to small organisations. Three areas were mentioned:

- Helping them to find out about health policy issues and have a voice. This is done through general activities but a more personal service might be provided to new staff.
- Support about governance: helping smaller organisations to learn from each other, by giving practical advice

More investigation would be needed to find out about the demand for such services. People established in the policy world, rather than potential users of these services made these suggestions.

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| New directions |
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To consider

- Whether the Forum should have a more proactive role in collecting and coordinating information about health from the patients' perspective
- Whether the Forum should provide services on policy to members.

Accountability and building the capacity of the Forum

Everyone recognised that the Forum had lost some focus in recent years and had needed to look at its role and how it worked with members' organisations.

In order to take on again a stronger role on the national stage, the Forum will need to:

- Address issues of accountability to members
- Establish support and investment at a senior level in member organisations.
- Widen its funding base to safeguard its independence.

Accountability

To consider

- How the Forum can be more accountable and ensure greater involvement of members
- How the Forum can re-engage support and investment from Chief Executives in national voluntary organisations.

5 Options for the future

The Forum faces four options for the future:

- 1 It can wind up – given that its work is done
- 2 It becomes a more informal forum for policy officers
- 3 It can merge with another organisation
- 4 It can relaunch itself as a separate organisation, though working more closely with other organisations and alliances.

Option 1 Winding up the Forum

The Forum could be wound up on 31 March 2007 when the Department of Health grant ends. There was little support for this from anyone actively involved with the Forum. However, if capacity and governance issues are not addressed, merger or a winding up may be the only option.

Option 2 – A forum for policy officers in the voluntary health sector

Assuming that membership remains at current levels, it would be possible to fund regular meetings for information exchange and with speakers using a self employed person to organise the meetings and maintain membership communications. In this option the Forum would not seek additional funding or look to having a profile outside the voluntary health sector. It would need to maintain membership levels to maintain the income.

Though a large section of the membership would be content with this outcome, this has limited feasibility since a further decline in membership, income and influence would be inevitable.

Option 3 - Merger

There was little support for a merger. The role of the Forum is distinct and needs to be retained. If the Forum was merged with a condition-based group, it would lose its legitimacy and separate identity.

Option 4 – Alliances and relaunch

The Forum might focus on becoming **the** umbrella organisation for the voluntary health sector, with alliances and with other umbrella groups, filling a gap that is widely identified among members and stakeholders.

However, closer partnerships with other networks and patient organisations would be essential to add to the existing network's strength. There was considerable support for closer working with other agencies and alliances:

- Joint work in policy and information collection with other voluntary organisations, for example with the LMCA.
- Sharing membership and 'cross marketing with LMCA – making activities available to members where relevant.

- Closer links with organisations, such as CEMVO or the Patient Information Network, through reciprocal membership and joint projects
- Joint events with the Royal Colleges and BMA Patient Liaison Groups assuming a coordination and support role.
- Sharing facilities and office accommodation by accommodating staff in a voluntary sector environment to reduce costs and avoid duplication.

If it is decided that the Forum is to be relaunched, it needs to change radically. A new name – maybe whilst retaining the core elements - that reflects its changed direction may indicate its unique focus, and give any relaunch greater impact. The Forum will need to agree a transition plan and strengthen its capacity to move forward.

Appendix - Methods and interviews

E mail questionnaire

An email questionnaire was circulated to current full members and associate members and members whose subscriptions had lapsed in the last year. Email questionnaires were received from:

a) Members (21)

Asthma UK, Breast Cancer Care, Chiropractic Patients Association (2 questionnaires received), Contact a Family, Continence Foundation, Haemophilia Society, Home from Hospital, Nikki Joule, L'Arche UK, Mencap, Mental Health Foundation, Migraine Trust, Mind, Motor Neurone Disease Association, NAPP, Princess Royal Trust for Carers, Rethink, RNID, Which

b) Associate Members (7)

BMA, BMA Liaison Group, INVOLVE, NpfiT, Picker Institute Europe, RPSGB, SW Bristol NHS Trust,

Comments made in the questionnaires are available in a separate file.

Interviews

Interviews were held with

Duleep Allirajah (Macmillan Cancer Relief), Jon Barrick (Stroke Association), Francine Bates (Contact a Family), Diana Basterfeld (Patients Forum staff member), Sally Brearley (HeathLink), Harry Cayton (DH), Anna Coote (Healthcare Commission), Danny Daniels (NAPP), Niall Dixon (King's Fund), Mark Duman (Patient Information Network), Jonathan Ellis (Help the Aged), Ruth Geall (Muscular Dystrophy Campaign), David Gilbert (PPI Resource Centre), Sharon Grant (CPPIH), Carol Herrity (Mencap), Nikki Joule (Patients Forum Management Committee), Marcia Kelson (NICE), Alistair Kent (GIG), Elizabeth Manero (HealthLink), Peter Mansell (NPSA), Kristin McCarthy (DPP), Clara Mackay (Breastcancer Care), Brian McGinnis (L'Arche UK), Gerry McMullen (Islington PPIF) Barbara Meredith (NICE), Eileen Neilson (RPSGB), David Pink (LMCA), Amy Poole (Specialist Healthcare Alliance), Cliff Prior (Rethink), Krishna Sarda (CEMVO), Jenny Singleton (Islington PCT), Bob Ricketts (DH), Meredith Vivian (DH), Peter Walsh (AVMA), Judith Wardle (Continence Foundation), Simon Williams (Patients Association), Toby Williamson (Mental Health Foundation), Jo Webber (NHS Confederation), Marlene Winfield (Connecting for Health), Barbara Wood (BMA Patient Liaison Group)