

Draft discussion paper

Setting up a national organisation of patient and public involvement forums

With the abolition of the CPPIH, there is strong support for setting up an independent national organisation of patients' forums, funded by the Department of Health. There is also support for setting this up as soon as possible to help ease the transition following the abolition of CPPIH.

This paper explores how this might be done. It assumes that there will also be a Centre for PPI Excellence and that the NHS Appointments Commission will undertake appointments to Forums.

Why a national organisation is needed

Forums need to have their own organisation to speak for them and raise health related issues at national level. The national organisation would represent Forums and enable them to work together, feel part of wider patient and public involvement movement, and contribute to key national policy debates on health. These functions can only be done effectively by an organisation owned by Forums.

Good practice also requires that standards are owned by those who are expected to implement them as well as involving them in appraisal and performance review. A national association would enable Forum members and staff to be involved systematically in these activities, whether they are undertaken by the national organisation or the PPI Centre of Excellence or as a collaboration of both.

Aims

The aims of the national organisation would be to:

- Promote the development of standards, training and appraisal for Forums
- Enable Forums to work effectively with the NHS at national level to change policy and practice in order to meet the needs and expectation of users.
- Enable concerns from local Forums to feed into national policy and practice.
- Promote and assist Forums to work with the NHS and the public to reduce health inequalities and promote the needs of disadvantaged and marginalized communities to the NHS

What sort of organisation?

There are three options identified. The Arms Length Review suggested that some functions of existing arms length bodies might be taken over by Community Interest Company that is currently being considered in legislation. Further information is needed on this to include this as an option.

Figure 1 What sort of organisation?		
	Advantages	Disadvantages
A voluntary organisation	More flexibility in fundraising, if registered as a charity	Lack of status and easier to marginalise
		Less stability in funding
An organisation recognised in statute	Recognises the importance of Forums to Government policy	Loss of independence and freedom to act independently if money is direct form the Department of Health
	More stability in funding	

Functions

The main functions of the national organisation would be to:

- Assist in the development of standards, training and appraisal for Forums
- Support each other and share experiences
- Initiate research and surveys based on the work of Forums
- Enable concerns from local Forums to feed into national policy and practice.

Many of these functions might duplicate or overlap with the Centre for PPI.

Standards, training and appraisal for Forums

There is agreement that forums must be involved in these processes but there is less agreement about whether a national organisation could take the lead in carrying out these functions or assist the Centre for PPI to do them. Without knowing yet how the PPI Centre will work it is difficult to decide what is the best way to provide this. If, for example there is a Consortium acting as the Centre, the national Forum organisation could be a member of this Consortium. There are three options:

- By the national Forum organisation
- By the PPI Centre
- By a separately managed unit within the PPI Centre.

There are advantages and disadvantages to both of these options.

Figure 2 Who should set standards?		
	Advantages	Disadvantages
PPI Centre	'Performance management' is clearly separate from sharing and support	Standards and processes might to be seen to be imposed and threaten Forum independence
	In touch with the wider PPI world and can bring in expertise	Adds an additional 'tier' and more likely to be seen as remote from, the experiences of Forums
National Forum organisation	Standards and process would be owned and supported by Forums	There may be problems in both supporting/sharing experiences with appraisal and governance.

Whichever model is chosen, some points are clear:

- This function should be managed by representatives from Forums, staff and members, appointed through the national association
- All Forum members need to be consulted on draft standards and training programmes and arrangements for review. Where Forums' views are not followed, there needs to be a clear explanation for this.
- There need to be close links at all levels between the national organisation and the PPI Centre to ensure that all activities are co-ordinated.
- Many different organisations need to be involved in developing and delivering training, NPSA, the Healthcare Commission, NICE, INVOLVE, MIND, MENCAP and the Democratic Health Network.

Mutual support and sharing information

The boundaries between support and sharing information between Forums and role of the PPI Centre in identifying what is an effective Forum are not clear-cut. But there is a difference. Members and staff will need their own place to discuss issues of interest and concern. This will mainly need to be done on a SHA or regional basis and depending on how staff are organised to support forums might be better done by them rather than the national association.

However, there will be a need for at least an annual meeting to discuss issues that are facing Forums as a movement and concerns rising from local level that are affecting patients' experiences. There were also suggestions as to how this might link with the voluntary sector with an interest in health.

Information from discussions will need to be shared with the PPI Centre to help them build up their understanding of what works and where further help is needed and contribute to the information on good practice.

The CPPIH have developed a Knowledge Management System that enables members to learn from each other and exchange ideas. Consideration will need to be given to whether this should be taken over by the Forum national organisation or the PPI Centre.

Policy, research and surveys

Forums need to be able to take their concerns up to regional and national level. However, if the national organisation gets feedback about a problem it will need a mechanism to find out if this is confined to one or two areas or is a wider problems. To find this out they may wish to commission or co-ordinate surveys of Forums views or experiences. It might, for example, commission to the PPI Centre to carry out this work for it.

There also may be a need for briefings on policy issues or consultations undertaken by the Department of Health. The national organisation would have more credibility in communicating with Forums and collating their responses than the PPI Centre.

It is not appropriate for this to be undertaken by the PPI Centre, which will focus on the 'how' of user involvement rather than policy issues and content.

National voice

It is considered very important that Forums can feed into national policy and practice and the work of the Healthcare Commission. This cannot be done by the PPI Centre who will not have the independence or credibility to speak for Forums.

Links with the PPI Centre of Excellence

There is a potential overlap, as proposals now stand, between the national organisation of Forums and the Centre for PPI Excellence. The Centre is likely to be made up of a Consortium of organisations bringing different skills and experience. Perhaps the biggest risk will be a competition between the national organisation of Forums and the PPI Centre. There is also a risk of duplication in activities. For example, who will review annual reports for Forums? The PPI Centre may want to look at them as a part of performance review and the national organisation as part of identifying issues being raised at local level.

The possibilities of competition and duplication must be addressed from the start- with particular emphasis on joint activities, clear boundaries and communication.

The national organisation could be a member of any Consortium that receives the contract to be the Centre of Excellence.

Links with wider user health movement

During the discussions with voluntary organisations, there was interest in how the national Forum organisation might link in with the wider user health movement.

One suggestion was that there might also be a national congress or assembly for health made up of both Forums and national voluntary organisations in

order to provide a stronger voice for patients and public on health issues. Issues raised by Forums and other voluntary organisations could bring together other national patient/public interest groups to give a coherent message to government and set directions. This Council or Assembly might hold meeting once or twice a year to explore themes and experiences, similar to the annual consumer congress that was run by the National Consumer Council.

This might be co-ordinated by an organisation that is a member of the Consortium.

Staffing

An important principle will be to ensure funds from local level without clear benefits to Forums at local level. The organisation must first be able to establish itself and demonstrate the value it can give.

The functions that it might have from the start are:

- Policy and research
- Information and networking
- Standards, training and appraisal – perhaps jointly with the PPI Centre or undertaking consultations on their behalf and monitoring the performance of the Centre for PPI.

Consideration should be given to rotation and secondment of staff between Forums and the national organisation and perhaps the NHS and voluntary sector.

Management

The national organisation needs to democratically represent Forums and their staff. The Association of CHCs was set up as a member organisation and there was sometimes an unhelpful distinction between staff and members. The new organisation needs to learn from this and ensure that the organisation is able to represent all those involved in Forums.

There need to be elections for the Governing body made up of members and staff from the nine regions.

There will also need to be observer status for example, the Centre for PPI Excellence and possibly the Department of Health and the Healthcare Commission.

Funding

The organisation will need to receive core funding from the Department of Health for the core functions, with additional funding available according to an agreed work plan or raised through other sources.

This funding could either be from direct grant or through subscriptions from Forums. Membership would need to be compulsory for all Forums.

This would have the advantages of:

- Safeguarding the independence of the organisation from the Department of Health
- Making the organisation more directly accountable to Forums for how it spends the funds

Next steps

At some point a national organisation for Forum members will be set up. This can either be developed with the sponsorship of the Department of Health or independently by members. If the Department of Health agrees that a national organisation is needed as part of the new arrangements for patient and public involvement, there is a case to be made for considering how this might be set up as a matter of urgency. This would demonstrate the commitment of the Department during what is likely to be a difficult transition.

There is a difficult dilemma in balancing the need to set up an organisation that is owned by Forum members and also ensuring that it is fit for the purpose. Options include:

- Set up by the Department of Health
- Set up with the sponsorship of the Department of Health
- Set up by the sponsorship of the CPPIH
- Set up by members

If the national body is set up directly by the Department of Health, this may be seen to be imposed on Forum members. It would also be difficult for CPPIH to be directly involved in setting it up. At this difficult time for the CPPIH it may be seen as an interested party that would undermine the credibility of any recommendations. However, it would have an important role as a member of the steering group and in nominating members of Forums to the group and in undertaking a consultation on the options identified.

However, it is important to demonstrate the commitment of the Department of Health to members and bring in wider expertise from the PPI world. The Department of Health could set up an independent steering group with the terms of reference and ask an external voluntary organisation or group of voluntary organisations to co-ordinate the group and produce the report. The advantage of this would be that it would be seen as more arms length than if controlled directly by the Department of Health. This model was adopted with success in the research on the options for setting up a national body in January 2002, where the Patients Forum, LMCA and Consumers Association commissioned work on behalf of the Department of Health.

Membership should include a majority of people from Forums, as well as people from the voluntary sector who have experience of running national representative organisations. The group might need to meet two or three times.

The group would look at:

- Different models for a national representational organisation
- How it might be set up

- How it should be managed
- Staffing and budget
- How it should work with the PPI Centre for Excellence, the voluntary sector and the Department of Health
- Recommendations on the setting up of the organisation

The group should meet in public with open access to agenda and minutes so that people have the opportunity to comment as the deliberations proceed. The report that is produced should be circulated for comment to Forums and final proposal based on these views. Where Forum members' views are not followed, clear justifications should be given for the reasons.

Figure 3 How should the national organisation be set up?		
	Advantages	Disadvantages
By the Department of Health	May have statutory recognition and secure funding	May not be owned by members
	Can be done relatively quickly	
By independent group with the sponsorship of the Department of Health	May have statutory recognition and secure funding	
	Could bring in expertise from wider PPI world	
	Independent of the Department of Health	
By the CPPIH	Could be done reasonably quickly during the transition	May be seen to be conflicts in an organisation due for abolition planning a successor organisation
	May have statutory recognition and secure funding	CPPIH has been criticised for its top-down working methods
By members	Owned by members	Will not have statutory recognition and secure funding
	Clearly independent	Will take longer to set up
		May not be integral part of the PPI arrangements

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