

RESPONSE FROM BLACK HEALTH AGENCY TO THE CONSULTATION ON THE FUTURE OF SUPPORT TO PPI FORUMS

Introduction

Black Health Agency has been providing support to 22 Forums since September 2003. These range from PCTs in inner city areas of Manchester, Preston and West Yorkshire to mixed urban/rural areas in central Lancashire, Calderdale, the Holme Valley and Western Wakefield; we also support a number of Forums for mental health services covering large geographical areas; two ambulance services Trusts and a specialist cancer hospital trust.

BHA's staff come from a range of backgrounds including former CHC staff, others with experience in the voluntary sector in Britain and overseas, some with experience in CABx and some staff new to public involvement work. Our staff have been involved in policy development around PPI through membership of the Transition Advisory Board on CHC abolition, joint work with a network of voluntary sector organisations that prepared successful bids for Forum support, and with Forum members and others as the new system has developed.

Our general experience has been that the development of Forums has been slower than initially hoped and that the experience is patchy.

BHA supports some Forums that have developed very quickly as outgoing groups linked in to their local communities and local decision-makers who have made a real difference. In some areas Forums have held very large and successful meetings that have influenced local PCTs and acute hospital Trusts – producing major changes in plans for future provision, or encouraging NHS bodies to consult far more widely about plans. Other Forums have got 'bogged down' with issues about process, find it difficult to focus on out-going work and act as 'formal committees' whose main role is seen as attending meetings with the Trust they are linked to.

A common view from many of our staff who were with CHCs is that "Forums haven't moved away enough from the CHC model – the members see it as *our* job to go out and engage with people, not

theirs". On the other hand staff who have no experience of CHCs do not share such concerns.

- **This response is based on practical experience of supporting a large number of varied Forums and past work in developing policy on PPI.**

The consultation:

This response covers some of the questions set out in the Opinion Leader Research questionnaire but, because it is extremely limited in its scope, goes beyond them in a variety of ways.

We have a fundamental concern that the 'consultation' is not asking the right questions – it does not look at many of the wider development issues around the overall approach to patient and public involvement and does not take the opportunity, created by the need for primary legislation, to consider how Forums as a whole might operate better with new arrangements.

The key issues for Forum development that the consultation does not address are:

- **The basic remit of Forums:** The basic role of Forums is often unclear to many Forum members – particularly on their role on looking at and making proposals on wider public health and health inequalities issues.
- **The powers of Forums:** Forums have few powers that, in theory, go beyond those of individual citizens to request information from public bodies. Forum members are often unclear about how to use those powers they do have effectively.
- **The responsibilities of Forums:** The central role of Forums in engaging with diverse local communities is unclear to many Forum members. Too many act as 'formal committees' rather than outgoing bodies.
- **The configuration of Forums:** There are too many Forums. This creates problems in recruitment, support and effective functioning.

- **The formal links between Forums and NHS bodies:** The relationships between Forums and the NHS bodies they relate to are extremely varied. Forum members have little guidance on what they are entitled to expect in those relationships and are torn between adopting an antagonistic role or being 'co-opted'.

A further commentary on these issues follows on page 12.

Comments on the questions raised in the questionnaire:

LOCAL SUPPORT

Staff support: Forum members see their independence as the most important single issue and the suggestion that the NHS should provide Forum support is likely to be advocated by very few members. The perception of independence is key.

Although we endorse the general statement 'staff support for PPI Forums can only be provided by an independent organisation outside the NHS' there are issues within this approach that need to be explored further.

The original rationale for CPPIH contracting with the not-for-profit sector to provide Forum support went further than just having independent organisations. The role envisaged for 'local network providers' was that they would use the networks and knowledge within local voluntary sector and community groups to be able to 'add value' to the work of Forums.

Unfortunately, CPPIH has tended to see organisations providing Forum support as contractors engaged to provide administrative support, rather than as partners, along with the Forums themselves, in developing patient and public involvement. There has been too much burdensome insistence on producing and responding to paperwork, and too little discussion on what information flows are needed

- **Any new arrangements should involve partnership working with the voluntary and community sector at a national, regional and local level.**

Appointing support organisations: Members of Forums will, naturally, want a say in the support they receive. Although a significant number of members will want either full control of the process or active involvement in the appointment process there are practical and policy difficulties with this.

Forums are, at present, too small and too new to be able to manage contractual issues – there would be significant risks in their attempting to do so. The risks are around financial accountability, breaches of employment law and equal opportunities legislation.

The wider issues that need to be addressed are ones of ensuring consistent levels of support across Forums; issues of consistency were key to the original proposals to change the system of patient and public involvement that led to the abolition of CHCs. Similar comments about the consistency of support and Forum activities could be made quite reasonably today.

Because of the type of contracting model used by CPPIH the only 'consistency' in the process has been that Forum Support Organisations have been contracted to provide support at a standard 'unit price' per Forum that takes little account of the nature of either the patient population or NHS body involved. A very different contracting process that involves both local responsiveness and longer-term planning is needed.

The instability created by short-termism and the appointment of support organisations for only two years in the first instance does not allow for the necessary longer-term development of the capacity and infrastructure needed if Forums are to grow and develop as a central element of citizens' engagement in improving health and health services. Longer-term contracting arrangements backed up by consistent standards and collaborative development are needed if the quality and consistency of support is to improve.

Part of the remit of a PPI Centre of Excellence should include establishing a standard base-line for Forum support, through discussion with a range of stakeholders, including CPPIH, the Healthcare Commission, the Health Development Agency, academic institutions, Forums, Forum Support Organisations and the wider voluntary and community sector. Forums should be able to determine the nature and quality of support at a local level within set parameters.

- **There should be a long-term approach to providing consistent support to Forums through long-term contracting with the voluntary and community sector**
- **Base line standards of support should be developed through a collaborative approach involving partner organisations and Forum members**

Financial control: The same issues about the level of Forum development and risk are associated with moving too quickly to Forums taking full control of their finances. Many Forum members are aware of these problems and will not want to assume the personal responsibility for taking direct financial control.

Forum members will, however, want an influence in how money is spent and a clear separation between set 'core expenditure' (necessary to meet base-line standards) and 'discretionary expenditure' under the control of the Forums to achieve their own work-plan targets should be set out.

- **There should be clarity about 'core expenditure' which is fixed in order to meet consistent support standards and that 'discretionary expenditure' under the control of Forum members to meet work-plan objectives**

Other support: There will continue to be a need for some degree of regional and national co-ordination between Forums to enable joint initiatives, exchange of information and support. Although this is likely to be on a far smaller scale than CPPIH, such functions will need staffing and other resources, for example to continue the KMS. With the abolition of CPPIH some system will be needed to ensure that Forums themselves have an opportunity to meet together to determine regional and national priorities and guide this work.

JOINT WORKING:

With other Forums: The revised Forum Members' Reference guide sets out ways in which Forums can use powers to establish joint committees to carry out joint work.

These provisions should be heavily promoted to enable a smooth transition from the current arrangement of separate Forums linked to each NHS Trust and PCT to a clearer and simpler arrangement of area Forums with sub-committees dealing with issues relating to NHS Trusts covering wider areas.

- **Forums should be positively encouraged to work together to improve their effectiveness and to reduce the emphasis on separate 'meetings for meetings sake'.**

NHS Bodies: The wide variety of local arrangements has created a situation where the relationships Forums have with NHS bodies are very variable and lack consistency. Although there will inevitably be local variations clearer formal arrangements need to be established to create a base-line.

There is a strong tendency for NHS bodies to seek to 'co-opt' Forums to help carry through their own PPI agendas rather than genuinely work as partners with Forums. A clearer remit for Forums and a stronger emphasis on the wider public health is needed to help overcome this tendency.

Important changes in relationships could also be supported through regulatory changes such as: establishing a formal right for a Forum to have an observer with speaking rights attending NHS Trust/PCT Board Meetings; the ability for Forums to place an item on the agenda of Board meetings would help create more consistent links.

- **NHS bodies should more clearly understand the vital need for Forums to be independent and discouraged from trying to 'co-opt' Forums to carry out PPI activities that are a Trust or PCT's responsibility**
- **Forums should have rights to attend NHS Trust and PCT Board meetings as observers with speaking rights and the power to place items on a Board's agenda**

Healthcare Commission: There are important links which can be developed with the Healthcare Commission by giving Forums a formal role in contributing to the Healthcare Commission's performance assessment of NHS bodies. The incorporation of formal reports by relevant Forums as part of the Commission's annual

reviews or improvement reviews and a formal place for Forums on local reference groups will add coherence to the system.

It is important to also recognise that there are other potential links, for example with the Health Development Agency and its role in looking at what works to improve people's health and to reduce health inequalities. Although the HDA's functions will be incorporated into the expanded structure of NICE establishing a clear link between Forums and work on reducing health inequalities will be vital if Forums are to be able to address their wider remit.

- **Forum reports should be a formal part of the Healthcare Commission's annual reviews or improvement reviews of NHS Trusts and PCTs**
- **Forums should have a formal link to work carried out to reduce health inequalities**

Health Overview and Scrutiny Committees: Local Authorities enjoy considerable freedom to decide how they will undertake their scrutiny functions. It is neither possible, nor desirable to try to impose a single structure on local democratic bodies that prescribes how they relate to Forums.

However, developing links between Forums and The Centre for Public Scrutiny would help develop best practice.

- **There should be further discussion on best practice in working between Forums and OSCs**
- **The Centre for Public Scrutiny should be involved in a 'Centre of Excellence'**

Strategic Health Authorities: There are currently no formal links between Forums and Strategic Health Authorities, despite the key role of SHAs in performance managing the activities of NHS Trusts and PCTs – including their patient and public involvement functions. Although it would be inappropriate for SHAs to take on a performance management role for Forums (as it would undermine their independence) a responsibility on SHAs to involve Forums in wider initiatives to enhance patient and public involvement would be valuable.

- **Arrangements should be put in place to develop consistent links between Forums and Strategic Health Authorities**

CENTRAL SUPPORT

The central and regional structures of CPPIH are too large and draw resources away from providing effective support to Forums at 'the front line'. Having decided through the Arm's Length Body Review to abolish CPPIH it would be a retrograde step to create a similar set of structures.

In the primary legislation to abolish CPPIH there will be a need to locate some formal powers with an appropriate non-departmental public body (for example the Healthcare Commission). We feel that this formal element of 'central support' should be on a small scale and that the emphasis should be on the development of best practice.

Centre of Excellence

A 'Centre of Excellence' should reflect both the experience and partnerships that are vital to making PPI work effectively and should be established as a collaborative drawing together staff from organisations with the knowledge and experience needed to develop best practice.

Although there is no single 'model' that can be simply adopted for work around patient and public involvement there are examples, such as the Cochrane Collaboration which has succeeded in involving researchers, practitioners and lay people in clinical research, that provide examples of how this work could be undertaken.

- **We believe there should be a wide and open discussion, involving all potential stakeholders, on how a Centre of Excellence should be developed**

A collaborative approach

A collaborative could be managed by stakeholders, including the Healthcare Commission, the Health Development Agency, academic institutions, Forum Support Organisations and the wider voluntary and community sector and – in its initial stages – CPPIH.

Such a collaborative should also involve working with a reference group drawn from Forums themselves who can advise on the priorities and key issues for development and research that Forum members want.

Within such an approach it would be possible to build on and develop the work already undertaken by the voluntary and community sector. This approach, developing capacity within the voluntary and community sector to help engage citizens, ties together with government's plans to develop voluntary and community sector capacity in service delivery.

It should also provide a clear lead to Forums and support staff on the need to focus on reducing health inequalities, ensure diversity and inclusion of marginalised and excluded groups – and should involve organisations from within those groups as stakeholders.

- **A Centre of Excellence should not be a smaller-scale replacement for CPPIH. It should be a collaborative body involving all stakeholders**
- **Forum Support Organisations and the wider voluntary and community sector should be involved in its development and operation at a national, regional and sub-regional level**
- **A reference group of Forum members should be involved in the work of a Centre of Excellence**
- **Organisations from minority and excluded groups and communities should be involved as stakeholders**

Black Health Agency, as a significant organisation working to challenge health inequalities faced by black and ethnic minority communities, and other marginalised and disadvantaged communities, would welcome the opportunity to become involved in the work of a Centre of Excellence.

The functions of a Centre of Excellence

The practical work of the collaborative should involve:

- **developing basic standards for support to forums**
- **establishing transparent systems for monitoring the work of Forums**
- **ensuring the provision of training and development courses and materials to Forum members and support staff**
- **providing information and guidance to forum members and support staff**
- **drawing together examples of best practice and promoting these to Forums and the NHS.**

The separation of these functions from those of appointing and removing Forum members, and 'managing' Forum Support Organisations and Forums themselves is likely to be welcomed by Forum members.

Organisational issues:

Such a collaborative need not be a large body. Aside from a small central secretariat the main elements of its work could be delivered by engaging support through contracts with the voluntary and community sector, funding specific pieces of work, and by seconding staff from partner organisations.

There should, however, be a long-term approach that uses joint working to develop the capacity of partner organisations to develop their skills and experience in standard-setting, monitoring, training, research and dissemination.

- **There should be a small central organisation that develops long term partnerships with non-departmental public bodies, the voluntary and community sector and others**

RECRUITMENT

Although the NHS Appointments Commission is independent of NHS Trusts and PCTs there is great concern among Forum members that

it is not genuinely independent of the NHS and the Department of Health.

This perception may be unfair, although as a Special Health Authority the NHS Appointments Commission is ultimately accountable to the department. These concerns will not be addressed simply by looking at recruitment methods. The 'status' of Forum membership, the support and training Forum members receive and a guarantee of their independence will be needed too.

An enormous amount of work has been undertaken by the Commission and by FSOs to recruit Forum members by engaging with community and patient groups. Although such work will need to continue it has not been sufficient to ensure sufficient active members.

Neither has recruitment been sufficiently rigorous to ensure that members joining Forums have clear expectations and an understanding of their roles – this has led to many counter-productive conflicts and disputes between Forum members, Forum members and CPPIH, and between Forum members and FSOs. A programme of accredited training, prior to appointment, and continuing training (including approaches such as action learning and mentoring) developed through the Centre of Excellence would help address these issues.

Although the emphasis on ensuring that Forum membership is diverse and reflective of local communities is welcome, and follows regulations and guidance, this approach has not as yet resulted in genuine diversity. Recruitment strategies should be developed at national, regional and local levels, in partnership with relevant community and voluntary organisations. Programmes should target those most under-represented and excluded, such as young people, BME and refugee communities, people with learning disabilities, and lesbian, gay, bisexual and transgender people.

Formal arrangements with local voluntary and community groups to nominate members to Forums – following completion of a training package – would both aid recruitment and enhance public perception of Forums as independent and locally relevant.

Forum membership also needs to be given higher status through both regulatory change – such as legally enforceable paid time off

from work; and through a high-quality consistent and accredited training programme.

- **There needs to be a renewed national membership drive including targeted programmes to recruit a diverse membership at national, regional and sub-regional levels**
- **Formal arrangements for the nomination of members by voluntary and community sector organisations need to be put in place**
- **Forum membership should require completion of an accredited training programme**
- **Continued training for Forum members needs to be in place and other measures enacted, such as paid time off from work for Forum duties**

THE WIDER ISSUES ON FORUM DEVELOPMENT

This section of our response attempts to look at some wider issues which could be addressed when looking at the primary legislation required to abolish CPPIH.

The basic remit of Forums:

The basic role of Forums is often unclear to many Forum members – particularly on their role on looking at and making proposals on wider public health and health inequalities issues.

There is a tension within policy towards Forums – do they have a main focus on improving public health or on monitoring services? These roles are very different and, in practice, many Forums have ‘defaulted’ to being a formal committee looking at what the Trust/PCT is doing with some monitoring of services through visits and undertake little wider activity on public health.

Some of these difficulties are the result of the generally small membership of Forums – they do not have sufficient members to

allow some degree of 'specialisation' between these functions. However, the wider issue is that it is often harder to see how Forums can 'make a real difference' on wider public health issues. This needs to be addressed through the work of a Centre of Excellence and, in the short-term through clearer guidance.

- **Regulations should define improving public health and reducing health inequalities as Forums' main role**

The powers of Forums:

Forums have few powers that, in theory, go beyond those of individual citizens to request information from public bodies. Forum members are often unclear about how to effectively use those powers they do have.

The introduction of provisions of the Freedom of Information Act from January 2005 means that Forums have no more powers in relation to requesting information from NHS bodies than ordinary citizens.

Many Forums have experienced difficulties in obtaining information from NHS bodies in a format that is of use, and reliance on 'exchanges of correspondence' slows their functioning.

The powers of Forums to visit premises where NHS patients are treated remain in place but, with the revision of CPPIH guidance in the Forum Members' Reference Guide, are more limited than originally appeared.

The ability of Forums to engage with NHS Trusts and PCTs at the highest level is varied and patchy – some are invited to take part in Board meetings, others seen simply as members of the public in attendance. (This issue is discussed in more detail below)

There are some regulatory changes which could be made that would enhance the power and effectiveness of Forums:

- **A right to insist that a relevant NHS body sends a senior member of staff to a meeting of the Forum to respond to issues raised by it – in a similar way that OSCs exercise such powers**

- **A clearer right to make visits to premises where NHS patients are treated without providing notice**

The formal links between Forums and NHS bodies:

The relationships between Forums and the NHS bodies they relate to are extremely varied. Forum members have little guidance on what they are entitled to expect in those relationships and are torn between adopting an antagonistic role or being 'co-opted'.

The proposal that Forums should appoint a member to Trust or PCT Boards has apparently been dropped. It was a poorly thought-through proposal creating potentially insoluble problems around accountability and governance.

However, simple requirements on Trusts and PCTs to have an observer with speaking rights at board meetings could overcome some of the existing problems of patchy and inconsistent relationships by establishing a clear base-line.

This could be addressed by regulatory change:

- **Formal rights for Forums to send an observer with speaking rights to meetings of relevant NHS Trust and PCT Boards, and a right to place items on the agenda of Board meetings.**

The responsibilities of Forums:

The central role of Forums in engaging with diverse local communities is unclear to many Forum members. Too many act as 'formal committees' rather than outgoing bodies.

Although the desire to let Forums develop their own ways of working seems, at first glance, to be a participatory and inclusive approach it has many drawbacks. Faced with a 'blank sheet' many Forums have begun to operate in different ways with little real discussion. Clearer terms of reference and operating procedures for Forums should be established – in discussion with Forums and support organisations.

Many problems around establishing effective functioning Forums result from volunteer members with their 'own agenda' not seeing their responsibility to involve patients and the public more widely in discussion.

Although the approaches that might achieve this are detailed in the Forum Members' Reference Guide there is need for a stronger regulatory emphasis. A duty on Forums equivalent to that on NHS bodies under Section 11 of the Health and Social Care Act should be central to the Regulations.

- **Basic Terms of Reference, Standing Orders and Codes of Conduct for Forums and their members should be set out in regulations**
- **There should be a formal requirement of forums to consult relevant local communities and patient groups on the development of their work-plans and in drawing up reports and recommendations**

The configuration of Forums:

There are too many Forums. This creates problems in recruitment, support and effective functioning.

The creation of at least two 'tiers' of Forums – for PCT and NHS Trusts with different powers and potentially complex arrangements for joint working has been confusing. There are also Forums covering widely geographical areas – for ambulance services, large mental health Trusts, specialist hospitals etc, that face particular difficulties.

Forums should be area-based (on areas co-terminus with PCT boundaries) with a duty to co-operate and establish joint committees to cover geographically dispersed NHS Trusts.

The precise local configurations and whether a Forum covers one, two or more PCT areas could be separately determined – although, with many potential 'mergers' of PCTs, it would be useful to have flexible arrangements capable of mirroring changing structures in the NHS.

- **The number of Forums should be reduced**
- **Forums should be based on areas co-terminus with PCT boundaries, although the precise arrangements should be based on local requirements**
- **There should be a duty on Forums to co-operate and work through joint committees to monitor the services of NHS Trusts which cover areas wider than those of a single Forum**

FUNDING THE SYSTEM

Our view is that resources spent on a large national and regional structure for CPPIH took resources away from the front-line work needed to develop Forums.

We welcome the commitment given, in response to the Arms Length Body Review decisions, that funding released by the abolition of CPPIH would be spent on supporting Forums and their work.

We feel that Forum members will want to know, at the earliest possible stage, what this might mean in practice for them – what additional support will they see on the ground as a result?

We share a view expressed by many Forum members that the resources FSOs have to support individual Forums is inadequate and should be significantly increased.

- **Forums should be given an early indication as to the amount of extra support they can expect as a result of CPPIH abolition**
- **Staffing and other resources for Forums at a local level should be significantly increased**