

# ***Involving Patients and the Public in Healthcare: a discussion document***

**Response from the Association of Community Health Councils for England and Wales  
October 2001**

---

## **Introduction**

1. ACHCEW welcomes the Government's intention to redesign the care and treatment of patients around their needs. We welcome the improvements on the *NHS Plan* as a result of work on the Health and Social Care Bill, and the passing of the Health and Social Care Act 2001. These include the duty on health authorities and Trusts to involve and consult the public and proposals to establish a national body for patient and public involvement in the NHS. We welcome any steps that will encourage and support hard to reach and excluded groups in involvement in the planning and delivery of NHS services. The provision of independent advocacy services for individuals who find it necessary to complain about NHS services is also to be welcomed although we have a few reservations about how this will work in practice. We will detail our reservations later in this response. We are disappointed that the Government has not taken the opportunity to address the wider issue of advocacy and access to the NHS in general. Many people need and would benefit from the support of advocates to enable them to access even basic NHS services. It is not just complainants who need advocates.
2. The comments in this response are based on the views of Community Health Councils (CHCs) many of whom have submitted individual responses to the discussion document. They are made in the spirit of achieving the best for patients and the public not in the interests of preserving CHCs. However, that said, we strongly believe that reformed CHCs would allow the Government to deliver its proposals. Reforming CHCs would also allow the Government to build on the vast experience and knowledge of CHC members and staff, it would allow for a smooth transition from the current system to the new, and it is likely to be a more cost effective option than that proposed. We hope that in the interests of patients and the public you will be able to address the concerns raised in this response during the development of the proposals and in subsequent legislation.
3. We would be interested to learn what plans the Department has to evaluate any new systems following their implementation.

## The 'Consultation' Process

1. We are extremely disappointed that patients, the public, their representatives, and NHS and local authority representatives have not been given sufficient time to consider and respond to the proposals in the discussion document. Given that what has been proposed will have far reaching effects on patient and public involvement in the NHS it is a shame that a period of only 6 weeks has been allowed for comment. In some areas this short period of time was further reduced because hard copies of the document were not available at the beginning of the discussion period. It should have been appreciated that it is difficult for CHCs and voluntary organisations to arrange public meetings at short notice and that for this reason their comments are not as widely informed as they would have wished.
2. The 'consultation' process fails to conform to the Cabinet Office's *Code of Practice on Written Consultation* which states that twelve weeks should be "standard minimum period" for a consultation exercise. It also states that: "Timing of consultation should be built into the planning process for a policy (including legislation) or service from the start so that it has the best prospect of improving the proposals concerned, and so that sufficient time is left for it at each stage." It is a pity that the Government's commitment to placing patients and the public at the centre of the NHS has not been supported by allowing a reasonable time for comment on the proposals.
3. We are also concerned that the starting point for the proposals is the abolition of Community Health Councils and ACHCEW, their national body. At 1.5 the discussion document clearly states that "*The immediate focus of this document is the Government's intention to legislate at the earliest opportunity to replace Community Health Councils...*" The discussion paper does not present a range of real options but asks for comment on the detail of the Government's preferred structures. Other options for patient and public involvement that during the passage of the Health and Social Care Bill through Parliament enjoyed widespread and prominent support have been excluded from further consideration and development. For example, the option to establish Patients' Councils as proposed by David Hinchliffe MP. This proposal won All-Party support and was agreed in the House of Commons, as did the option to reform CHCs into Patients' Councils agreed in the House of Lords.
4. The Kennedy Report states that "*Public 'consultation', whereby the public are presented with a 'fait accompli', or their views are ignored, leads to disengagement and cynicism. The net effect is frustration, loss of trust and an increasing lack of interest amongst the public in bodies and structures that are supposed to promote their interest.*" (p 401) We wholeheartedly support this view.
5. The call for the abolition of CHCs, the basis of the proposals, has not been shown to be evidence-based. It has not been possible to find out from the Government how many people or organisations, if any, suggested the abolition of CHCs during consultation on the National Plan. On the contrary, there is evidence to suggest that people value CHCs and would like to see

their retention or the development of similar bodies. In Wales, after extensive public consultation the Assembly for Wales has decided to retain, reorganise and strengthen CHCs. In Scotland Health Councils are also being retained. CHCs and ACHCEW have received numerous statements of support since abolition was proposed. Statements of support continue to be received as more people find out about the proposals. An independent survey of mental health users, by the UK Advocacy Network found that of those who had approached CHCs regarding complaints 90% had found them helpful and the clear majority considered that the abolition of CHCs "was not a good idea". The survey identified the area that would be missed most as "the independent status that CHCs currently hold". A survey of Councils for Voluntary Service (CVS) in England found that 73% of respondents thought that CHCs should be "reformed and strengthened to play a pivotal role in the new arrangements". Undoubtedly, there is a need for local health 'watchdogs'.

6. We hope that this discussion process will be open and transparent and that the responses to the discussion paper will be made available for public inspection.
7. Not only are there no real options for consideration the discussion paper also lacks sufficient detail to enable the public and others to make informed comments on the proposals. We are being asked to take a 'leap of faith' and hope that the new bodies will be independent, effective, work together etc without being shown how this will be facilitated. The paper is asking people to sanction the replacement of CHCs an effective known quantity, albeit in need of reform, with a totally unknown quantity. During debate of the Health and Social Care Bill a number of MPs and Peers urged the Government not to abolish CHCs but to reform them so that they, as established bodies, could be the basis for the delivery of the new systems of patient and public involvement.

### **Involvement and Representation**

1. We are pleased that the proposals have been changed to include the involvement of the public in the running and planning of the NHS and not just patients. However the proposals do not distinguish between the two very different functions of involvement and representation. They focus on patient and public involvement in the NHS and fail to recognise that some people are unable to represent themselves. It is essential that patients and the public be involved in the planning and running of the NHS. It is also essential that the views of people who are, for a variety of reasons, unable to represent themselves are represented by bodies and individuals that are truly independent of the NHS. It is currently the duty of CHCs to represent the interests of the public in the NHS. If CHCs are abolished that function will be lost.

## **Patients 'on the Inside'**

1. As stated earlier ACHCEW welcomes steps that will allow patients to have a greater voice in the NHS and welcomes attempts to make that voice an integral part of the NHS. However, the emphasis on the move away from the 'outdated system of patients being on the outside' (1.1) ignores to a degree the reality of the NHS and must not be a substitute for effective scrutiny and support. Things do go wrong and poor decisions will be made so patients and the public will not want to see themselves as being on the 'inside'. What they will want to know is that there will be a strong independent and effective voice to challenge and obtain redress in such circumstances.

## **The Kennedy Report**

1. The Kennedy Report is cited as being in support of the proposals yet it argued strongly for greater and broader lay involvement at Patients' Council and Patients' Forum level. The current proposals do not deliver this. In addition, the Report cites a number of examples of poor practice in consultation and patient involvement. The Government's discussion document and ideas contained within it are themselves examples of the same poor practice. For example, the lack of adequate consultation with involvement of the public at the early stages of development and the lack of power that the proposed bodies will have. Without real power, the Report states that the bodies set up within the NHS to give the public their voice "swiftly become 'talking shops', attractive to those who like to talk but ineffective in terms of translating talk into action." (p 401)

## **Resources**

1. The discussion paper does not give any indication of how the proposals for patient and public involvement will be resourced either in terms of finance nor the number of personnel, including volunteers that will be required to facilitate the development of the new systems. The development of meaningful public involvement is costly in terms of the time and effort that is required, so it is unlikely that the proposals will be without cost to the NHS. The unnecessary duplication of services, for example support to Patients' Forums will prevent the possibility of taking advantage of economies of scale. The reform of CHCs may be a more cost-effective means of attaining similar ends to those envisaged by the Government. The discussion paper does not consider this as an option. Ministers have said that they will be putting in a bid to the Comprehensive Spending Review. If this is successful some of the money will be used to fund the proposals. What will happen if the bid is unsuccessful?

## **Social care**

1. At a time when there is greater and increasing joint working between health and local authorities, we feel it is a pity that the proposals are based on promoting patient and public involvement in the NHS only, and that more importantly they are based on structures within the NHS. It is not at all clear how the proposals will relate to the interface between health and social care.

## **Transition**

1. Although the document talks about building on the best of CHCs, it does not demonstrate how this will happen, nor does it give any indication as to how the transition from the current systems to the new systems will be managed.
2. In a letter to the Chair of the Association (September 2001), Hazel Blears MP stated that the Government "would ensure that CHCs are not abolished before the new structures requiring legislation were set up". We believe that this commitment does not go far enough. If Community Health Councils are to be abolished this must not happen until the new bodies have been evaluated and shown to be operating effectively. Patients and the public must not be left without an effective watchdog or effective means of involvement and representation.

## **Criteria for effective patient and public involvement**

1. We believe that if the proposed new systems and bodies are to enjoy the confidence and support of patients and the wider public, and thereby achieve their aim of greater patient and public involvement in healthcare they must at the very least fulfil the following criteria. They must be and must be seen to be independent. They must be accessible, effective, integrated and accountable and they must be an improvement on the current methods of patient and public involvement. Unfortunately, as this response will illustrate, the proposals as they stand do not meet these essential criteria.

## **An integrated system of patient and public involvement?**

1. The proposed system is complex and fragmented. The public will be confused by the bewildering array of new bodies and may be deterred from approaching any of them. There is little evidence in the discussion paper about how the different bodies will work together to provide an integrated system of informed patient and public involvement. CHCs currently provide accessible one-stop-shops for their communities. A number of CHCs have shop-front premises where members of the public are able drop in for general and specific information and advice. It is not clear from the discussion paper which body, if any, will carry out this simple, yet vital function.

## **Overview and Scrutiny Committees (OSCs)**

1. The provisions in the Health and Social Care Act 2001 allowing overview and scrutiny committees to review and scrutinise matters relating to the health service locally will introduce an element of democracy to the scrutiny process. However, we have a number of concerns about how effective the Committees will be in practice.
2. Given that OSCs have the power, not a duty, to question chief executives and other senior NHS staff at twice yearly meetings it is essential that they are encouraged to exercise this power. They must be encouraged to set aside sufficient time and resources to ensure that scrutiny of the NHS is effective. We are concerned that OSCs will be forced, through a lack of resources, capacity, experience and expertise, to focus on 'cherry-picking' one off issues for investigation rather than continuously scrutinising the NHS. The prospect of continuous scrutiny can be a powerful tool for maintaining and improving standards. OSCs must develop strong links with Patients' Forums, voluntary organisations and other patient and public involvement mechanisms so that their work may be informed by actual experience. This is particularly the case because they will not have the benefit of knowledge through visiting NHS premises or handling individual complaints to inform their scrutiny. Where OSCs have already started to carry out the scrutiny of health they should be encouraged to work with CHCs. The scrutiny work of CHCs is informed by the ability to identify trends that emerge from complaints and visits and the ability to have an overview of the local health economy. Co-option of members should be considered as a way of increasing the capacity and effectiveness of OSCs, particularly in terms of knowledge and expertise.

## **Duty to involve patients and the public**

1. We welcome the introduction of the duty on the NHS to involve and consult with the public in decision-making. Contrary to the proposals we believe that a degree of prescription will be necessary if the NHS is to fulfil this duty and involvement is to be effective and consultation meaningful. The general lack of success over the years in this area, through no lack of trying, clearly demonstrates this point. Provision must be made to facilitate the sharing of information. The results of consultations should be widely disseminated, but failing this they should as a minimum be shared with OSCs and Patients' Forums to inform their work. If NHS organisations fail to fulfil this duty what sanctions will there be?

## **Patient Advocacy and Liaison Services (PALS)**

1. We welcome the customer service role envisaged for PALS. However, we believe that their name should be changed since they will not be advocates in the widely accepted definition. PALS could be the Patient Advice and Liaison Service. It is important that their name accurately reflects their roles and does not mislead. We have a number of concerns relating to the independence of PALS and the potential for them to act as 'gatekeepers' to the complaints advocacy services.
2. PALS must not be allowed to act as gatekeepers. At the outset of contacts with potential complainants PALS must make it clear that they have a right to seek help from the Independent Complaints Advocacy Service and must provide information about how the service can be accessed.
3. In their role of supporting and assisting complainants PALS will not be and will not be perceived to be independent. Their status as employees of the Trusts and their role of assisting complainants are bound to come into conflict. This problem might be overcome if PALS were to be employed by an independent body.
4. PALS must be given a status that will allow them to have influence with senior staff and chief executives in particular. We believe that their status would be enhanced if they reported directly to chief executives.
5. Already we have seen the development of PALS in numerous directions with differing remits, resources, terms of engagement etc. In the absence of national standards and guidelines PALS will only be as effective as their Trusts allow them to be which will compromise the services they are able to provide. We believe that there should be common minimum standards covering the operation of PALS to ensure consistency between Trusts. The national body for patient and public involvement could be responsible for developing these standards (see below). Common standards would also facilitate cross boundary working between PALS and would prevent the situation from arising whereby patients would receive different services from bodies with the same name. The document recognises that PALS must not work in isolation but does not say how the proposed systems will prevent this from happening.
6. The relationship between PALS and Patients' Forums is an important one especially given that Patients' Forums will be able to remove poorly performing PALS. Forums will also be reliant on information from PALS to inform their work. This relationship must be clearly defined.
7. We are pleased to see that the annual Patients' Prospectus will include information about changes that have been made as a result of PALS' work. There should also be an obligation for the Prospectus to include information about changes that have not been made as a result of PALS' work or recommendations, with reasons.

## Independent Complaints Advocacy Service

1. We welcome the provisions in the Health and Social Care Act 2012 that place a duty on the Secretary of State to make arrangements for independent support to be available for people wishing to make a complaint against the NHS. However, as stated earlier we do have a number of concerns about how this will work in practice. Neither the discussion document nor the listening document on reforming the NHS complaints procedure gives any detail about how the services will be run. How is the service to be provided? Is there sufficient capacity to ensure that, as the document states, support will be "provided in a way that delivers a consistent and high quality service across the country and between organisations"(4.9). We believe that this is an essential requirement.
2. The ICAS must be truly independent of the organisations and individuals it may have cause to investigate and must be fully accountable for its work. The performance of the complaints advocacy services must be monitored and evaluated with input from users of the services. It has been suggested that *Voices* may be responsible for commissioning this service. We would not be able to support this suggestion if as has also been suggested *Voices* are to be employed by local authorities. The ICAS may also have cause to be involved with complaints that involve the interface between health and social care.
3. It is not clear how the work of the ICAS will be fed into the work of the other patient and public involvement bodies, or how complaints work will be used to influence quality improvements.
4. Although it is not one of their statutory duties, each year CHCs assist and support tens of thousands of people with their complaints about the NHS. The Health Select Committee recommended an expansion in the role of CHCs including a clearer remit for giving support and advice to patients and relatives with complaints. The Public Law Project, following an evaluation of the effectiveness of the NHS complaints procedure, recommended that the Department of Health should formally recognise the role of health councils in assisting complainants by including it in their statutory remit and by specifically allocating resources to support this work. Given their experience of supporting complainants the possibility of reforming CHCs to enable them to provide the independent complaints advocacy service should be considered.
5. It is essential that however the service is provided it should be widely publicised so that people know that they can access it directly. If this does not happen, PALS will fall into the 'gatekeeping' role discussed earlier. Also, it has to be recognised that many people will not want to return to Trusts to complain about them, they would rather seek support from an independent source away from the Trusts.

## **Patient Surveys**

1. The opportunity to complete patient surveys must be open to all patients. That is, within a sample patients must not be excluded from participation because they cannot read, or because English is not their first language or for any other reason. Patients must be able to remain anonymous if they wish, particularly if they are at any time asked to complete surveys when they are still inpatients. People are likely to be more candid about their experiences once they have left hospital. At least some of the questions should focus on issues that matter to patients. There may be scope here for input from Patients' Forums and other patient and public involvement bodies. This would give them the opportunity to inform particular pieces of work. Trusts should also be required to report on instances where they have not acted when the results of surveys indicate that action would be appropriate. It is good practice to give feedback to survey participants and Trusts should develop methods of doing this. Reports in local newspapers could be a suitable method.

## **Patients' Forums**

1. We welcome provisions for Patients' Forums to inspect every service that NHS patients use including primary care and the private sector. CHCs had been calling for an extension of their remit to include these areas in order to enhance their overall effectiveness. Will these rights be on a statutory basis or will they be by arrangement and will they include Care Trusts?
2. Tying the statutory representation of patients to NHS structures could cause problems in the future. Over the years there have been several structural changes in the NHS leading to the current position. PCTs are in their infancy and it is possible that they may need to undergo structural adaptation. For that reason it may be better to base Patients' Forums on localities rather than structures. The discussion paper recognises that the 'patient journey' means that bodies will have to work across boundaries. However, it is not inconceivable that a single 'patient journey' could include the following contacts and problems with different parts of the NHS. A GP could refuse to visit a patient at home; the ambulance service could be called to attend the patient – there could be a delay in the arrival of the ambulance; when at hospital the patient could face long delays in the A&E department; and upon admission the patient could be dissatisfied with the care and treatment received. If the patient wished to complain about this sequence of events they would have to approach the PALS for the PCT, the NHS Trust and the ambulance Trust or the independent complaints advocacy service. In addition, the complaints may highlight the need for the Patients' Forums from each of these bodies and/or the OSC to become involved. It is not at all clear how the current proposals, which are firmly based on structures, will make it easy for staff to work across organisational boundaries.

3. We are not convinced that the structure proposed for Patients' Forums will be the most effective way of making the local NHS more responsive to what local patients want. We are disappointed that the proposals in the House of Lords, concerning Patients' Councils, which would have seen them as bases for Patients' Forums have been rejected. Such a structure would have provided accountability mechanisms and independence.
4. If patients are to have confidence in Patients' Forums and their ability to act on their behalf it is essential that they are independent of the Trusts to which they are attached and are able to function as autonomous bodies. To facilitate this they must have sufficient statutory powers, status and a voice equal to health service planners and decision-makers. As envisaged, Patients' Forums will have a lot of duties but there is no indication of whether they will have commensurate powers. How in reality will they 'manage' PALS? They must also have access to sources of independent information in addition to information made available to them by the Trusts.
5. The accountability of and within Patients' Forums needs clarification. Who will they be accountable to? If Patients' Forums were required to hold their meetings in public this would provide a degree of accountability, and it would also give the wider public the opportunity to feed into their work. This latter point has not been addressed by the proposals. CHCs are required to hold their meetings in public at least once in every three months. Many CHCs go further than this and hold additional meetings in public.
6. It is not clear how the agenda for the work of Patients' Forums will be drawn up. Will it be the Patients' Forums themselves or will their work be guided by supporting staff?
7. We have a number of concerns about the membership of Patients' Forums mainly because there is very little detail in this area. We believe that if as suggested members of the Forums will be appointed by the NHS Appointments Commission the very people that the Government wishes to attract into membership, those that are hard to reach, will be excluded, rather than included. People from these groups are unlikely to put themselves forward for consideration by the Appointments Commission. The NHS Appointments Commission must work with local communities and voluntary organisations to develop ways of encouraging people from all walks of life to put themselves forward for membership of the Patients' Forums, thereby allowing them to reflect the diversity of the local population. The criteria for appointment of members must be open and transparent and must be applied with consistency across the country.
8. If membership of Forums is to be drawn from the wider community, the Government must address the issue of statutory time off work where this is appropriate. Over the years CHCs have been limited in their choice of members and some members in turn have been limited in the time they were able to commit to CHC work because they could not take advantage of statutory time off work.

9. Patients' Forums must be able to elect their Trust board member free from interference from the Trusts. It is not inconceivable that some Trusts will try to manipulate the election process in an attempt to get someone who, for example, they know or someone they know to be amenable to their views.
10. We question how much influence, on behalf of patients a lone Forum member will be able to exert on a Trust Board. Consideration should be given to increasing the number of Patients' Forum elected members to Trust boards. The Kennedy Report refers to the involvement of the public and patients being heavily outweighed by professionals as giving "the appearance of public involvement without any real substance."(p 401) Increasing the numbers of Forum members on Trust boards would also counter the potential effects of isolation.
11. Forum members on Trust boards may be faced by conflicting loyalties between the need to be bound by decisions of the board and their duty to represent patients and the public. It is not clear how these members will be accountable to fellow members of the Forum. Will Patients' Forums be able to remove their elected member from a Trust board? The remuneration of Forum members acting as non-executive directors of Trust boards will set them apart from other Patients' Forum members. How will this be reconciled?
12. Observer status rather than Trust board membership has not been considered. CHC observers at health authority and Trust board meetings are able to speak with authority and without being compromised by the notion of being bound by collectively made decisions. Observer status would allow Patients' Forum members to maintain their independence from management.
13. It is not clear how long members of Patients' Forums will serve. We believe that Forum members should be expected to serve for a period of not less than two years in order to give them sufficient time to gain knowledge and experience of the NHS locally and nationally. If the period of membership is too short this will not give members time to become acquainted with their role and be effective in their work. CHC members are appointed for four-year terms and can serve a maximum of two terms without interruption. A high turnover of members will also be costly in terms of the provision of training needed to equip people for effective membership.
14. The document acknowledges that Patients' Forums need to work together and we see joint working as being essential, particularly in the absence of any one body being able to take an overview of what is happening in a local health economy. If Forums work in isolation how they measure the performance of their Trusts will be extremely limited. For example, the results of a Casualty Watch survey for a Trust may appear to be acceptable in isolation, but would not necessarily been seen in the same light when compared with neighbouring or similar Trusts in the locality. It is not clear how joint working will be facilitated, but we believe that Patients' Councils as proposed by David Hinchliffe MP would be a way of supporting joint working and should be reconsidered as an option.
15. With regard to administrative and secretarial support for Patients' Forums there will need to be a degree of prescription if it is to be consistent across Forums. This support must be independent of Trusts and local authorities.

Forum members must also have access to independent legal and policy advice and research. CHCs currently have access to these resources from their paid staff and from the Association of CHCs.

## **Voice**

1. Since groups with this name already exist consideration should be given to changing the name of the proposed bodies to avoid confusion.
2. We are concerned that if *Voices* are based at Strategic Health Authority (StHA) level they will be too remote. Although *Voices* should be linked in some way to StHAs, with only 28 *Voices* they will be responsible for vast geographical areas with large populations and therefore cannot be considered to be a local resource. As a result of their remoteness it will be difficult to make and sustain contact with patient groups and individuals, particularly those traditionally seen as being hard to reach. We believe that *Voices* would be more effective if they were placed at the level of PCTs.
3. The intention of the proposals to "ensure that there are opportunities for patients and the public to be involved at all levels, locally, strategically and nationally." (3.3) will not be supported by the introduction of national and local *Voices*. Rather than building on and developing the current systems of patient and public involvement and representation the proposals remove the possibility of any effective involvement of ordinary members of the public from this and national level. Currently lay members direct and oversee the work of local CHCs, regional associations of CHCs and ACHCEW the national body. This means that the views and priorities of local, lay representatives are articulated at local, regional and national level, thereby ensuring that they have input at almost every level at which decisions are made in the NHS. We suggest that consideration be given to making provisions for lay involvement at the level of *Voices* (at PCT level).
4. One option would be for each Patients' Forum within the boundaries of PCTs to nominate one of their members, as in the David Hinchliffe Patients' Council model. *Voice* staff could then be attached to the 'joint' forums where they would provide support and co-ordination. The joint forums would be able to take an overview of a local health economy including public health issues, and input to policy decisions. This is a key aspect of the work of CHCs that has not been addressed by the proposals. A further option would be for PCT Patients' Forums to take on a co-ordinating role for Forums in their areas and perform the *Voice* functions.
5. It is not clear to whom *Voices* will be accountable although it is clear that they will not be accountable to the public. Including lay people in the make up of *Voices* would introduce a degree of accountability. It is essential that *Voices* reflect rather than 'manage' the voices of local communities.

6. We believe that the independence of *Voices* would be seriously compromised if they are employed by or located in local authorities. They must be independent of both the NHS and local authorities particularly if they will be responsible for commissioning independent complaints advocacy. We believe that the national body would be a more appropriate employer (see comments below).

### **Voice: the Commission for Patient and Public Involvement in Health (VCPPIH)**

1. Without a clear statement of the purpose of the national body it is not possible to decide its functions. We are disappointed that the Government has not taken the opportunity to develop a national body along the lines of those proposed following a Department sponsored scoping study. The proposals made following this study were based on extensive consultation with Department of Health networks, individuals with experience at national level, professional bodies, CHCs and the voluntary sector. The proposals in the discussion paper limit the functions of VCPPIH to matters concerning patient and public involvement. We believe that the remit of VCPPIH should be increased so that it is able to take a wide view of health matters as they affect patients and the public. VCPPIH must have a scrutiny role, and must also have the ability to apply pressure for change based on patient and public experience.
2. We believe that to maintain the independence of the patient and public involvement support roles, VCPPIH should be responsible for employing *Voices*, the ICAS, PALS and Patients' Forum support staff. As the employer they would be in position to develop, implement and monitor national standards of training and operation for these bodies. The proposals suggest a standard setting role for VCPPIH but do not give it powers of enforcement. VCPPIH support for patient and public involvement bodies must include the provision of independent legal and policy advice.
3. VCPPIH must be given statutory duties and powers and should be accountable to the Secretary of State either directly or through a Select Committee. VCPPIH should also be accountable to its members, although it is not clear who these might be. Whatever the membership of the Commission there must be patient and public representation. It must not simply be a case of appointing people on the recommendation of the Secretary of State or the NHS Appointments Commission. Appointments to VCPPIH must be open and transparent.
4. VCPPIH should be centrally funded and must not rely on member subscriptions for income. Membership must not be on a voluntary subscription basis. Reliance on voluntary subscriptions can have a de-stabilising effect on the central body, as has been the experience of ACHCEW.

## Conclusion

1. In conclusion, whilst recognising that the proposals in *Involving patients and the public in healthcare* represents a step forward from the original proposals in the NHS Plan, this Association remains disappointed by the document. We believe that it represents a lost opportunity to genuinely meet the Government's laudable aim of creating "a patient-centred NHS".
2. We believe that there are issues of both process and content. It is our view that following the passing of the Health and Social Care Act 2012, the Government should have established and evaluated the mechanisms relating to patient and public involvement in the Act before seeking further change. The Act included three key recommendations in this area – the duty on health bodies to involve and consult; the duty on the Secretary of State to provide independent advocacy; and the extension of local authority overview and scrutiny committees to health. At the time of writing, there is no detail about how these will work, and none of these provisions have been given commencement dates. This renders it impossible to judge whether the proposals in the discussion document, if taken in conjunction with the provisions of the Health and Social Care Act, would provide an effective, integrated and independent system of involvement and scrutiny. This is exacerbated by the fact that the "listening exercise" on the NHS complaints process, another crucial part of the jigsaw, is being carried out at the same time. These concerns combined with the short period for discussion and the limited nature of the discussion topics, means that the proposals cannot be properly considered and analysed.
3. We have, however, in our submission, sought to set out ways in which the proposals could be built upon. Our comments are detailed, and are based on the collective experience gained by CHCs over 27 years. There are, however, fundamental flaws in the new structures, which must, at a minimum, be addressed. We see these as being the need for lay involvement at all levels; the need for local mechanisms to be genuinely local; the need for the mechanisms to be integrated; and the need for the national body to have the power and the freedom to act as an effective national voice for patients and the public on the full range of health policy matters. If these points are not addressed, then the new structures will not be effective, and could not enjoy the support of this Association.
4. The press notice accompanying the discussion document states that "The new system will build on the good work being undertaken by many Community Health Councils (CHCs) across the country..." However, there is no evidence that the proposals reflect the experience of the majority of CHCs, or that the skills of CHC staff, and in particular CHC members, will be utilised in the new structures. We continue to believe that the best way to build on the best of CHCs is to use reformed CHCs as the basis for the new structures. The Government's desire to take as the immediate focus of their proposals the abolition of CHCs appears to independent observers to be based on vindictiveness, rather than a desire to ensure a strong public voice in the NHS.

5. We understand that the Government intends to legislate in the autumn. We hope that any Bill that is produced will reflect the concerns that we have raised in our submission. Otherwise, we run a real danger that the events of the past year will be repeated, and that people of goodwill in CHCs will once again find themselves focussing resources on campaigning against the fundamentals of Government policy, in the interests of the communities that we serve. It is possible for the Government to produce a Bill that would reflect our concerns, and would have the support of CHC staff and members. If this can be achieved, then we can all focus over the coming months on delivering robust and representative models of patient and public involvement. That is the cause that unites us, and we hope that the Government will rise to the challenge.