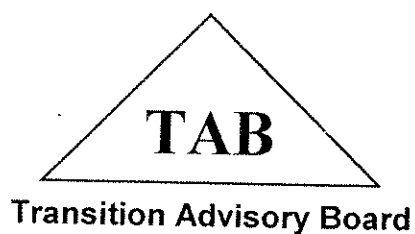


# **PATIENT AND PUBLIC INVOLVMENT IN HEALTH**

## **Interim report on the work of the Transition Advisory Board to the Department of Health**

**August 2002**





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## Foreword

The Transitional Advisory Board (TAB) was appointed to advise the Department of Health on the implementation of the legislation. We began work in February and will complete our work in December at which point we will hand over to the new Commission for Patient and Public Involvement in Health.

We have met monthly since February with considerable work being done in sub groups, involving, where necessary, people with relevant experience and skills outside the TAB. In spite of the short time scale to which we are working, we have attempted to work in an open and transparent fashion so that other stake holders have been able to comment on draft reports and understand the thinking behind our preliminary conclusions. We have done this through the Department of Health Website and e-mail networks of TAB members and others who have been in touch with us.

In July we held the first of two reference group meetings where we presented our interim conclusions. This enabled us to test some ideas and get useful feedback that has informed our interim report. A second meeting is planned for November event with the same participants that will therefore focus on advice to both the Department of Health and the Commission.

This report outlines our conclusions so far. Section 2 outlines further work that needs to be done to work out the details of how the arrangements may work. The Board looks forward to working closely with the Chair designate of the Commission and hope that she will use both the TAB and the reference group meeting as a valuable pool of expertise to help inform initial thinking on the shape of the Commission and its work.

Paul Streets

Chair of the Transitional Advisory Board

Chief Executive of Diabetes UK



## **Summary of preliminary recommendations**

### **The Commission for Patient and Public Involvement in Health**

- 1) The Commission should be an example to the NHS in the transparent and inclusive way it works, in particular with people involved at local level and from disadvantaged groups.
- 2) As a national body, mainly working at local level there will need to be arrangements to enable members of patients' forums, voluntary organisations, and others to communicate with the Commissioners at national level. There may need to be arrangements, based on the nine regional government offices or the four NHS Directorates of Health and Social Care, to bring forum members together regularly in order to:
  - i) Share experiences and good practice, and possibly training
  - ii) Advise CPPIH on how it is performing its own functions and report on patients' experiences of services
  - iii) Contribute to decision-making in public health strategies, managed clinical networks, specialised commissioning and regional scrutiny.
- 3) Selection and appointment of members and performance management of patients' forums as well as some human resource functions will need to be carried out by staff who are accountable to CPPIH centrally. There may need to be an intermediate level, linking staff working centrally and those with PCT forums.
- 4) The Commission will be a significant national player and at an early stage should consult stakeholders on how it will liaise with them. One option would be an advisory council, reference group or college for consultation.
- 5) Commissioners need to have the skills to contribute to the strategy of the Commission but also be credible with people working at local level. Innovative ways of selecting Commissioners should be considered for the second term, including the election of a proportion of Commissioners. Individuals could be screened before election to ensure that they had the necessary skills and experience to contribute to the Commission.
- 6) It will be important that people who would not normally be appointed to national bodies have the opportunity to develop the skills to become Commissioners in the future. Training programmes may need to be developed to assist applicants to gain the relevant skills.

### **Patients' forums**

- 1) The name, PCT patients' forum, does not reflect the role it will have or its independence. A different national 'branding' should be considered.
- 2) Patients' forums need to be involved with advising trusts on their arrangements for providing information and advice rather than providing this themselves.
- 3) The number of members for patients' forums might be determined locally based on national guidelines and in agreement with CPPIH, but may be expected to be between 9 and 15. Patients' forums will need to have a majority of users and carers of that service as members.
- 4) PCT patients' forums may need additional members as membership will include people nominated by forums in NHS trusts in each locality.



- 5) PCT forums have an additional and separate remit to monitor primary care and PCT commissioning. They will need to consider separating arrangements for:
  - a) Strategic decisions about the work programme and the deployment of CPPIH staff between trust forums that must involve all PCT forum members
  - b) Monitoring primary care and the PCT that involves members who are not nominated by trust forums.
- 6) There are some concerns about the election of a non-executive Director to the trust Board from the patients' forums. In the first instance, Regulations should require that each forum can elect a member to have observer status with speaking rights on the Board. Once patients' forums are established locally, the Commission should consider the best ways of enabling patients' forum members to take part in decisions of the trust.
- 7) Forums need to develop new ways of working to enable people who find committees and formal structures off-putting, though they will need to work in a transparent way, record actions and decisions and provide access to the public to reports and papers.
- 8) Forums should work with other community development agencies responsible for area-based or other initiatives who are working with different communities to raise their awareness and interest in health, rather than setting up their own arrangements.
- 9) The CPPIH should consider inclusive ways of selecting forum members in future, including elections.
- 10) Regulations will need to recommend what expenses can be claimed by patients' forum members (and others co-opted or working with members on forum business). These should include:
  - Payment of travelling expenses
  - Dependant care allowances (including child care)
- 11) Recognition for volunteer work is important and incentives will be needed in order to involve people from disadvantaged communities.
  - It is essential that voluntary work does not affect benefits that people receive
  - Granting members statutory time off from employment to carry out voluntary work should be considered.
  - Training for members to help develop skills that may be transferable.
- 12) It will be essential that PCT forums work closely together, where appropriate sharing facilities and exercising functions jointly. PCT forums need to decide the best ways of working together within an OSC or strategic health authority area, to deliver their functions in consultation with all local stakeholders
- 13) Staff may need to work with a number of PCT forums to enable specialisation and co-ordination across forums. The level at which the office is based will depend on local circumstances.
- 14) PCT patients' forums will need, in conjunction with CPPIH nationally and regionally, to develop explicit working arrangements with staff. These should be monitored by the Commission centrally to ensure accountability to each forum is delivered.



### **Independent complaints advocacy**

- 1) Consideration might be given to changing the name to reflect that the service will provide independent support for NHS complaints rather than an advocacy service.
- 2) ICAS needs to be clearly seen as separate from the other activities of the PCT patients' forums and resources should be protected
- 3) ICAS needs to be accessible and widely publicised nationally and locally, using a national logo. A website providing interactive information and a national phone number might be provided as a first point of contact for complainants and phone calls routed to the local ICAS.
- 4) The standards provided by the Community Legal Service should be used as the framework for ICAS.
- 5) The decision about how ICAS is organised in each area should be made by PCT forums in consultation with other local stakeholders to meet the needs of that locality. The decision at which level to provide the service will need to take account of the following:
  - The needs of the local area and its communities
  - The volume of complaints is sufficient to enable staff to develop the necessary expertise, provide relevant cover for sickness and develop specialist representation
  - The service is sufficiently distanced from NHS and Primary Care Trusts that clients will see it as independent.
  - Any likely future reconfiguration of PCT boundaries or mergers
- 6) ICAS needs to support the development of specialist independent advocacy services and, where appropriate, commission services to supplement the generic ICAS.
- 7) Where PCT forums decide to commission ICAS, a business case should be submitted to the CPPIH to enable it to allocate the resources and hold the contract.
- 8) There needs to be a robust and independent evaluation of ICAS pathfinders funded 2002-2003.
- 9) An audit of the skills and competencies required from staff to deliver different levels of advice and representation should be undertaken by the Department of Health and training should be developed to assist the development of ICAS.

### **The transition**

- 1) Regulations governing patients' forums should be flexible to allow people to build on existing developments, local variations and learning within a national framework to ensure consistency.
- 2) In each area local stakeholders, including CHCs, trusts, strategic health authorities, local authorities, OSCs, local strategic partnerships and councils for voluntary service should meet to identify:
  - The functions that PCT patients' forums may wish to perform jointly and in which geographic areas
  - How forums can be co-ordinated,
  - The most appropriate local base for staff teams that will support all patients' forums

- A lead agency to facilitate the transition
- 3) While all stakeholders need to be involved in preparation, there needs to be a lead agency to facilitate the transition. While it is not appropriate that the implementation is seen to be lead by the NHS, strategic health authorities may be in the best position to facilitate these discussions and report to the CPPIH.
  - 4) The new arrangements might be phased by prioritising the most important parts of their role. Initially PCT forums might be set up, followed by forums in trusts. The PCT forum once established might then take over the duties of CHCs.
  - 5) There are concerns about the continued uncertainty for CHC staff and members. A realistic date for the hand over from CHCs should be set to enable timetables for implementation to be drawn up.
  - 6) Further work is urgently needed nationally to identify the skills needed at a local level and to develop, in advance, the training required:
    - to allow CHC staff who transfer or are recruited to these functions to fulfil them effectively
    - For CHC members and others who may wish to offer their services to the new system.
  - 7) It will be important to use the skills and experience of ACHCEW and the regional associations in helping with the transition and ensure that the experience, skills and resources within ACHCEW and the regional associations are available to the Commission.



## 1. The Commission for Patient and Public Involvement in Health

### The legal framework

1. The Commission for Patient and Public Involvement in Health (CPPIH) will be established from January 2003, with a head office in Birmingham. The NHS Appointment Commission will appoint the Chair and Commissioners. The Chair has now been advertised.
2. CPPIH will be an executive non-departmental public body (NDPB). This means that it will have its own money, make its own decisions about how it spends its money, employ its own staff and own its own premises. The Secretary of State will fund the Commission from funds from Parliament. Additionally, the Secretary of State can also make loans to the Commission. Regulations will outline in detail the rights and obligations of the Commission, its relationships with other bodies and how it will conduct its business.
3. The Commission must keep accounts in accordance with the terms specified by the Secretary of State; additionally the Commission must prepare annual accounts. The accounts will be audited and laid before Parliament annually. The detailed arrangements will be determined by Regulations.
4. Non-departmental public bodies (NDPBs) have sponsoring departments and in the case of CPPIH, this will be the Department of Health. As with other NDPBs this will mean that the workplan needs to be agreed with the Department of Health each year.
5. Formal accountability is to the Secretary of State. CPPIH is required to give an annual report to the Secretary of State, which will be laid before Parliament. The response to the listening document stated that the annual report '*will be used by the Health Select Committee and Parliament nationally to hold the Department of Health to account*'.

### Functions

6. The Commission has five main functions:
  - (a) Promoting patient and public involvement
  - (b) Recruitment and appointment of members of patients' forums
  - (c) Providing support for patients' forums, including employment of staff, setting standards and performance management
  - (d) Setting standards and performance managing independent complaints advocacy (ICAS)
  - (e) Putting forward the views of patients and the public, including undertaking reviews on policies and services

### Promoting patient and public involvement

7. CPPIH is responsible for:
  - Promoting the involvement of patients and members of the public in public health issues and debates and decisions that affect their health.

- Advising the Secretary of State, and such bodies as may be prescribed on arrangements for public involvement in, and consultation on, matters relating to the health service in England.

### ***Patients' forums and ICAS***

8. CPPIH will be responsible for:
  - Recruiting and training members of patients' forums.
  - Providing support and assistance to patients' forums, facilitating the co-ordination of patients' forum activities: briefing, support, information and research, administration and secretariat, training and general capacity building. Staff will be based in PCT patients' forums and accountable to them.
  - Setting standards for and performance managing patients' forums and Independent Complaints Advocacy (ICAS)

### ***Representing views of patients and public***

9. CPPIH will represent views at national level the views of patients' forums arising from their annual report and other bodies appearing to the Commission to represent the interests of patients of the health service in England and their carers. This will include undertaking national reviews of services.
10. CPPIH has a duty to report any matters that concern the safety or welfare of patients and the public to whichever person or body it considers most appropriate, where it is not satisfied is being dealt with are not being dealt with or is not satisfied with the way it is being dealt with.

### ***Delivering these functions***

11. The Commission is a national body but it will mainly function at local level with PCT patients' forums (see section 2 on patients' forums). Some functions cannot be carried out at by CPPIH staff working with forums and national level would be too remote. These functions include the appointment of patients' forum members and performance management of patients' forums and ICAS. The suggested levels for delivery of the main functions are outlined below.

<b>Table 1 Suggested levels for delivery of the main functions</b>	
<b><i>Function</i></b>	<b><i>Recommended level for delivery</i></b>
<b>Promoting patient and public involvement</b>	All levels
<b>Representing views of patients and public</b>	All levels
<b>Patients' forums</b>	
• Recruitment of members	Local and intermediate levels
• Selection and appointment of members	Overseen at intermediate level within national framework
• Training	Organised nationally, delivered at local or intermediate levels
• Assistance to patients' forums	Local
• Setting standards for patients'	National



forums	
• Monitoring patients' forums	Intermediate level within national framework
• Allocation of resources (general)	National
ICAS	
• Providing or commissioning ICAS	To be determined locally
• Setting quality standards for ICAS	National
• Monitoring ICAS	Intermediate level within a national framework
Human resources, IT, finance, estates	To Shared Services within national framework

## Intermediate level

### What we want to achieve at intermediate level

- Quality' involvement is happening regionally and locally
- Patients and the public inform:
  - (a) Reconfiguration of services
  - (b) Public health priority setting and strategies
  - (c) Regional specialised commissioning and in developing managed clinical networks
- Patient and public at local level inform CPPIH at national level on policy

12. Some functions cannot be provided at local level and the national level may be too distant. At an intermediate level the Commission will need to ensure that:
  - Involvement of forums at strategic health authority (StHA) or regional levels is coordinated.
  - Forum members are selected and appointed
  - There is human resources management
  - Monitoring and performance management of forums and ICAS
  - Policy collation to advise CPPIH nationally

### **Regional strategies, public health and specialised commissioning**

13. Patient and public involvement is important at a strategic level, including regional specialties and public health strategies. The boundaries for specialised commissioning and managed clinical networks will depend on the nature of the service. Appropriate arrangements for the input of patients and public will vary according to the way services are organised.

### **Recruitment and appointment of patients' forum members**

14. There will need to be a national framework for the recruitment of patients' forum members that follows Nolan guidance and that can be implemented or overseen at intermediate level. Staff will have an important role in capacity building and the recruitment of applicants to join the patients' forums, but not in formally selecting the members with whom they will be working.



15. There will need to be training and support for patients' forum members. There will need to be a nationally accredited programme that can be delivered at local or regional levels as appropriate.

### ***Performance management of patients' forums***

16. There is a need for a national framework to be developed covering monitoring and performance management of patient and public involvement to avoid duplication and excessive monitoring. CPPIH is responsible for performance managing patients' forums, strategic health authorities are responsible for performance managing how trusts work with patients' forums and consult the public. The Commission for Health Improvement (CHI) is also responsible for monitoring trusts and how they work with patients' forums and involve patients and the public.
17. CPPIH staff working with patients' forums will have a development role with members so it is not appropriate for them to be involved in monitoring them. This function therefore needs to be undertaken at an intermediate level by staff accountable to CPPIH at national level. There will need to be procedures for dealing with complaints about patients' forums and CPPIH will need the power to take special measures where there are serious difficulties.

### ***Policy and input to CPPIH nationally***

18. The experiences of patients' forums, ICAS and OSCs need to inform the advice that the Commission provides to ministers at national level. At this level, staff will need to collate and analyse the experiences of patients' forums and work closely with members of forums and other involved in patient and public involvement.

### ***Forms and structures***

19. There will need to be arrangements to bridge the gap between:
- The national office and staff working with forums
  - Between forums members and others working in patient and public involvement and the Commission.

The TAB considers that these need to be based on geographic areas. There would be advantages if the areas with which staff work and in which lay people are brought together, but this is not essential and different arrangements may fit different areas.

### ***Staffing at intermediate level***

20. Staff at an intermediate level might be based in the nine regional development areas, the four NHS directorates of Health and Social Care or strategic health authorities. This will need to be reconsidered when details of how forums will work together are clearer and the resources available to CPPIH are known.

### ***Links between national and local levels***

21. There is a need to bring people involved in patient and public involvement together strategic health authority areas and above to:
- Advise on regional issues and how patients and public can be involved
  - Feed experiences from patients' forums and ICAS to CPPIH at national level
  - Report on issues of concern about policy and
  - Review how arrangements for patient and public involvement are working
22. There were some concerns expressed in the reference group meeting in July that regional arrangements might become bureaucratic and increase rather than reduce the gap between CPPIH at national and local level. However, The TAB

feels that there will need to be some arrangements and that there might be 'regional assemblies' of people involved in patient and public involvement that could meet regularly. This can be reviewed and adapted in order to ensure that it is achieving its objectives.

23. The 9 regional government offices could provide a base for these arrangements and provide an important link in with local government structures. While basing arrangements on regional government areas, might help to take public /patient involvement out of NHS politics, there may also be a danger that it would be marginalised within the NHS. Another option is to base the intermediate level at the 4 Directorates of Health and Social Care. However, it may be too far removed from other structures to which people relate. In the reference group it was suggested that there may not need to be a single national formula and that arrangements might vary in different areas to suit local needs.

## National level

### What we want to achieve at national level

CPPIH will aim to

- Amplify the patient voice at national level
- Actions are taken to improve services as a result of increased patient/public involvement
- Patients and public are involved locally, regionally and nationally, in particular people from disadvantaged communities
- Ensure that ICAS provides a quality service to clients, helps to improve services and provides access to redress.

### Functions and activities

24. At national level CPPIH will need to:
- Set the overall strategy and framework for patient and public involvement at local and regional levels
  - Ensure that people involved at local and regional levels inform the Commission at national level

25. The functions will include:

#### Support for patient forums and ICAS:

- Setting national standards and framework for monitoring ICAS and patients' forums
- Appointment of forum members,
- Training of lay members
- Resource allocation

Policy research – undertaking national reviews, co-ordinating views and experiences of forums.



Promotion of patient and public involvement at national level – including promoting innovative and creative approaches to patient and public involvement and making links with other national agencies (CHI, NPSA, Modernisation Agency, GMC etc)

Communications and publicity: CPPIH will need a high profile nationally and locally in order to encourage people to come forward and become involved.

Human Resources and finance: CPPIH will be responsible for employment of staff and financial management of forums. CPPIH will employ staff working with forums and be responsible for the finances of patients' forums. It is recommended that these functions are provided by shared services now being developed in the NHS on behalf of CPPIH.

Legal advice: for CPPIH and forums on queries regarding their legal rights and duties as well enquiries from patients' and from members of the public, including human rights issues, legal rights to treatment, rights under mental health legislation, issues around charges for NHS services, or operation of section 11 of the Health And Social Care Act 2001. This service would be directed towards prompt dispute resolution, rather than litigation.

### **Forms and structures**

26. CPPIH needs to have a high profile at national level and this requires good links and relationships with other bodies at national level. However, it must also have strong links to its grass roots. This feeling of 'ownership' will be very important in ensuring that those who get involved at local level feel part of a wider and important movement and that they are valued and have something to contribute.

#### *Who should be Commissioners*

27. Commissioners will need a range of experience and skills if the Commission is to be a major player at national level. There is potential for tension in that those people who may be seen at national level to have the credibility to relate to other national players may not be seen as credible by those working in communities. There was a strong feeling among the TAB and the reference group meeting held in July that the Commission should:
- Be an example to the NHS on transparent and inclusive ways of working, including in the selection of Commissioners.
  - Have Commissioners appointed for their skills,
  - Ensure that there is a balance of skills and experience covering regions and interests among Commissioners
  - Include Commissioners who have come from and have contact with hard to reach groups.
28. The qualities required of Commissioners needs to be formulated to enable people who have the skills and relevant experience that they may have gained through different routes. All Commissioners will be expected to be able to take a broader view of health and health care issues and be able to make contributions at national level. Most of all they need a commitment to equity and involving people from hard to reach groups. Some Commissioners will also need specific skills or experience, such as finance and probity. It will also be important to have a balance of experience of the user, movement and an awareness of the implications of regional variations. Qualities identified for commissioners are attached at Annex 1.
29. The TAB asked the reference group meeting whether they felt Commissioners should all be lay people or anyone with the qualities identified should be eligible to



apply. Since it is no longer acceptable to set up bodies with only professionals involved and so to set up a body that excludes professionals needs to be justified. The TAB concluded that no one who can demonstrate that they meet the criteria and has skills to contribute, should be excluded from becoming a Commissioner. This would have the advantages of:

- Helping ensure that patient and public involvement is not marginalised and seen as separate from the main aims of the NHS
- Bringing in wider perspectives and experiences that will make CPPIH more effective at national level.

30. However, there are understandable concerns expressed in the reference group that, if professionals were appointed as Commissioners, they might dominate the Commission. It would be essential that at least two thirds of Commissioners are people who do not work in health care or the NHS.

#### *How should Commissioners be selected*

31. In the first term of two years the NHS Appointments Commission will appoint Commissioners. This will enable Commissioners with the relevant skills to be in place quickly. However, there could be different methods of appointment for Commissioners for the second term. There is an exciting opportunity to develop new forms of governance that are more inclusive and ensure that people involved at local level feel that they have a stake at national level.
32. A proportion of Commissioners might be elected in future. An electoral college might be based on the regional groups. Concerns have been expressed that elected commissioners might not have the necessary experience of operating at national level and this would weaken the effectiveness of the Commission
33. However, there are ways of ensuring a more open process of selection while ensuring that people with the appropriate skills are appointed to the Commission. Positions as commissioners could be openly advertised and candidates pre-screened against specific skills criteria. All those who meet the criteria could be put forward to the Electoral College for election. This way the bottom up council would determine the Board of Commissioners but would guarantee that the Commission had the right skills by involving the NHS Appointments Commission.
34. A certain number of Commissioner posts might be available for appointment at the end of the process, based on an analysis of skills and experiences of the elected Board. The NHS Appointments Commission could then select these in an open process.
35. In the longer term a national training and development programme could be put in place to assist the forum members to acquire the skills needed by Commissioners. Assessment centres could advise people on how they might develop the skills to be eligible to become a Commissioner.

#### *Relationships with other partners*

36. CPPIH will promote patient and public involvement at national level. The links that CPPIH has with other stakeholders will help them incorporate patient experiences into their work and also to inform the work of the Commission. The functions of the Commission and the links with other NHS bodies are outlined below. In many cases there will also be direct links between national bodies and local patients' forums, for example, where there are patient safety issues.
37. CPPIH will also have the role of representing the views of the patients and the public at national level. It will obtain views from patients' forums and the work of its own staff and undertake reviews on particular policy issues. However, its role at



national level needs to be similar to the role of patients' forums – enabling people to put forward their views rather than speaking as the voice for patients. It is important that it encourages and facilitates patient and public interest groups to put forward their views. National voluntary organisations need to be involved in the work of the Commission in its policy development role and in advising on how to involve hard to reach groups.

38. Patient and public involvement needs to be embedded throughout all levels of the NHS. At national level there will need to be arrangements to involve the different stakeholders. CPPIH will need to consult stakeholders about how they wish to be involved. Options considered by the TAB included:
  - a. Stakeholder groups to advise on particular areas – such as OSCs or ICAS
  - b. Reference groups or college for consultation on general strategy.
  - c. Observer status on the Commission for organisations such as the Commission for Healthcare Audit and Inspection.
39. One option that might be considered is to set up a reference group or college for consultation to advise on overall strategy involving all the stakeholders in patient and public involvement at national and local levels, not just people from patients' forums. Regional assemblies as proposed would bring people involved in patients' forums and others involved in patient and public involvement together and could put forward representatives to the advisory council. The group would have two main functions.
  - A sounding board/reference group for CPPIH on key policy issues,
  - A forum to enable people working in patients' forums to put forward their views on policy and on how patient and public involvement is working.
40. The group might comprise of about 100 people drawn from regional groups of patients' forums, NHS staff and professionals working in patient and public involvement, voluntary organisations, national bodies, such as the Commission for Health Improvement and the NHS Confederation. It should have at least two thirds of members for patient or consumer groups and patients' forums.

Table 2 Relationships with bodies at national level		
Function	Activities	Bodies
Promoting patient and public involvement	<p>Advise on good practice in patient and public involvement</p> <p>Monitor how government bodies involve the public</p> <p>Facilitate access for patient and public interest groups to national decision makers</p> <p>Advice on involving people from hard to reach groups</p>	<p>NHS, regulatory and statutory bodies (Commission for Healthcare Audit and Inspection, Social Care Inspectorate, National Patient Safety Agency, NICE, Modernisation Agency)</p> <p>Local Government Association</p> <p>Voluntary sector</p>
Representing views of patients and public	<p>Undertake reviews of policy areas arising from local experiences or in agreed workplan</p> <p>Ensure that CPPIH facilitates involvement but does not speak for all patients or groups representing them</p>	<p>Department of Health, NHS, regulatory and statutory bodies, Local Government Association</p> <p>Voluntary sector patient and public interest groups</p>
Standards and performance management of patients' forums and ICAS	<p>Ensure that patient /public safety issues that arise are forwarded to responsible body and followed up</p> <p>Guidance to forums on working with disadvantaged communities</p>	<p>Department of Health, NHS, regulatory and statutory bodies, NPSA</p> <p>Voluntary sector</p>



## **2. Patients' forums**

1. Under the NHS Reform and Health Care Professions Act the Secretary of State will establish patients' forums for each NHS Trust and PCT in England. The detailed arrangements for recruitment and working arrangements will be outlined in Regulations. Draft Regulations will be published for consultation in the autumn. This paper suggests a framework for these Regulations.
2. There is an exciting opportunity to develop new way of involving patients and the public and so it is essential that Regulations allow for flexibility and learning. For the first time there will be a national body, the Commission for Patient and Public Involvement in Health, which will be able to support and develop forums and ensure that learning and good practice is disseminated.

### **All patients' forums**

3. The Act outlines five functions for all patients' forums. PCT patients' forums have additional functions and there is provision for all patients' forums to carry out any other functions as may be prescribed by Regulations. The functions of all patients forums are to:
  - (a) monitor and review the range and operation of services provided by, or under arrangements made by, the trust for which it is established,
  - (b) obtain the views of patients and their carers about those services and report on those views to the trust,
  - (c) provide advice, and make reports and recommendations about matters relating to the range and operation of those services to the trust,
  - (d) make available to patients and their carers advice and information about those services,
  - (e) in prescribed circumstances, perform any prescribed function of the trust with respect to the provision of a service affording assistance to patients and their families and carers.
4. All patients' forums must, in prescribed circumstances, co-operate with each other in the exercise of their functions and exercise functions jointly.

### **Monitoring and review**

5. The first three functions relate to the role of the patients' forum in monitoring and reviewing services provided by, or under arrangements made by, the trust (i.e. with other providers) as well as health related functions of the local authority (i.e. arrangements between NHS bodies and local authorities). Patients' forums in PCTs will be expected to monitor primary care services as well as services commissioned from other Trusts by the PCT (which may cover a wide geographical area).
6. Patients' forum members will be independent but working more closely with trusts, including the right to elect one of their members to sit on the trust board. This will require negotiating skills and clarity about their 'insider-outside' role.

### **Taking account of patient and carers' views**

7. Patients' forum members must take account of the views of patients and their carers, in particular the views of people from disadvantaged communities. This



outward looking role will need to be reflected in the role specifications and recruitment of members and their working arrangements.

8. Forums will also advise and monitor trusts' arrangements for patient and public involvement. Forums will not be expected to conduct patient and public involvement on behalf of trusts.

#### ***Report to trusts and OSCs***

9. Patients' forums will provide advice, and make reports and recommendations to trusts and overview and scrutiny committees (OSCs). Forums also can refer to CPPIH and make any other representations and referrals to whomever they think fit about issues arising from their work. Each forum must produce an annual report as soon after 31 March as possible and send it to the Secretary of State, CPPIH, strategic health authorities (StHAs) and relevant trusts and OSCs.

#### ***Advice and information to patients and carers about services***

10. It is the view of the TAB that forums should not provide general information and advice on services:
  - It duplicates the work of Patient Advice and Liaison Services (PALS). In areas where PALS have not been set up, there may be a gap for patients and the public in the short term. However, if the patients' forum takes this on, PALS might be undermined and there would be little incentive for trusts to set them up.
  - Providing information and advice requires an accessible independent office with trained staff available for much of the week. Forums in trusts may not have dedicated staff and members will not have indemnity cover for giving advice.

#### ***Primary care trust forums***

11. In addition to the above functions, PCT patients' forums will have additional functions:
  - (a) To promote the involvement of the public in decisions and consultations on matters affecting their health
  - (b) Put forward views of the public to key local decision makers
  - (c) To advise health authorities, trusts, other public bodies and other providing services to the public on how to encourage such involvement
  - (d) To monitor how well the NHS is meeting its duty to involve and consult the public.
  - (e) To provide independent complaints advocacy
  - (f) To make available information and advice to:
    - patients and carers advice and information about making complaints in relation to services provided by or under arrangements with the trust
    - the public about how they can be involved
12. PCT forums will provide a broad public perspective on issues affecting health. This function enables PCT patients' forums to promote the involvement of the public in decisions and consultation on matters affecting public health directly or indirectly, working with the NHS and other decision makers (such as education or transport). Where there is more than one PCT covering a local authority and OSC



area, patients' forums will need to work together and with local strategic partnerships.

13. In addition to their role in co-ordination, PCT forums will monitor primary care and commissioning decisions. PCT patients' forums will need to consider separate arrangements for:
  - a. Strategic decisions about the work programme and the deployment of CPPIH staff between trust forums that must involve all PCT forum members
  - b. Monitoring primary care and the PCT that involves members who are not nominated by trust forums
14. PCT patients' forums will be responsible for providing ICAS. This is another area where PCT patients' forums may wish to work together. The best way of providing ICAS will depend on local circumstances. This may be at PCT, OSC, local authority or strategic health authority level.
15. There are some concerns that the name, PCT patients' forum, does not reflect the wide role it will have or its independence and a different national 'branding' should be considered. Community health councils in Wales are currently being reformed and a new name is being discussed, if possible the same name should be used in England and Wales. At the reference group meeting in July participants were asked to 'vote for a name. The most popular name was Health Watch (that had 29 votes out of 60). Other suggestions included Community or Citizen's Health Forums, (Place) Health Voice or (Place) Patients.

### **Delivering the functions**

16. A concern about community health councils was that the wide remit and functions were not reflected in the resources they had – leading to variations and inconsistencies. How patients' forums are able to perform their functions will be determined to a large extent by the resources available to support members and for staff to carry out outreach work and provide ICAS. It is important that patients' forums from the start have clear terms of remit and priorities.

### **Communications**

17. It is critical that there are close working links, lines of communication and demarcations between agencies involved in monitoring and review of health and social care. Relationships between patients' forums and these bodies will need to be clarified. Regulations will need to outline arrangements for the provision of information by a patients' forum to other bodies (including another Forum). Agencies include:
  - ICAS – patients' forums and OSCs will need some general feedback on problems and trends, as long as individual complainant's anonymity is preserved
  - OSCs - Patients' forums are required to refer relevant matters to the Overview and Scrutiny Committee. Patients' forums may be able to nominate a member to sit on the OSC. However, some OSCs will cover many trusts and PCTs and their forums.
  - PALS – Patients' forums will monitor PALS and will need a good working relationship in order to share information. If the forum has power to recommend the replacement of PALS, there may be tensions.
  - Private and non-for-profit services funded by the NHS



- Local authority services that impact on health,
- Local strategic partnerships

### **Forums working together**

18. Forums will have a legal obligation to co-operate and work together. There will need to be co-ordination of PCT patients' forums at either OSC or strategic health authority level in order to:
  - a. Coordinate activities across and PCT area
  - b. Share services and facilities, including the deployment of staff
  - c. Monitor services that cover more than one PCT or trust area
19. While trust forum members are responsible for monitoring the services the trust provides, the PCT patients' forums members are responsible for monitoring the services that the PCT commissions that are provided by that trust. There will need to be clarification about the respective roles of forums to avoid duplication and tensions.
20. Staff that will support forums in acute trusts will be based at PCT patients' forums. Forums will need to agree on work priorities and work programmes: There is a potential for tension in this process and guidance will be needed on how to resolve any disputes.
21. PCT forums will need to co-ordinate arrangements for services that cover more than one PCT. Service provision is moving towards clinical networks, a focus on the patient's journey and joining up provision across organisational boundaries. Users with specific long-term conditions have interests that span wider than the locality and also across boundaries of individual trusts, health and social care. The success of patients' forums may be judged on how far they are able to involve and address these concerns.
  - One PCT forum in the area might take the lead, for example on ambulance services, mental health services or learning difficulties or particular clinical services.
  - A joint committee of PCT forums to work jointly in some areas and agree the work plan and deployment of staff with other forums.
22. The numbers of patients receiving some services, which are specially commissioned, may be small and their views and experiences may not be a priority area of work for single forums. For services such as bone marrow transplantation, neonatal intensive care or burns, a regional strategy is crucial to the delivery of a quality service. The boundaries for specialist commissioning will depend on the nature of the service. Arrangements for patients and public input will need to be flexible.
23. Within an OSC or strategic health authority area, all local stakeholders will need to consider together the best ways of working together between forums looking at each function to avoid duplication and ensure the best use of resources. How forums agree to share functions and services will depend on local circumstances, but there will need to be arrangements that bring forum members together regularly to monitor those functions and discuss issues that need to be addressed at this level. The suggested levels at which forums will need to work together to undertake their functions are summarised in Table 1.

<b>Table 1 – How forums will need to work together to undertake their functions</b>			
Function	Individual trust level	Pan trusts/ OSC level	Pan OSC/ StHA level
<b>All patients' forums</b>			
Monitoring and reviewing services	√	√	√ (specialist services)
Taking account of patient and carers' views	√	√	√ (specialist services)
Reporting to Trusts and OSCs	√	√	√ (specialist services)
Advice and information to patients and carers about services	?	?	
<b>PCT patient forums</b>			
Providing a broad public perspective	√	√	√
Providing ICAS		√	√
Working with other patients' forums		√	√
Information and advice on complaints and involvement	√	√	√

### How forums will work

24. The establishment of patients' forums provides an opportunity to develop new ways of working, in particular in involving people from disadvantaged communities. This requires a vision that sees the forum and its members as the core of much wider networks. In this (fried egg) model members are the yolk or core, and will wish to consult and involve patients, carers, outside reference groups or communities in putting forward their views. This model would have implications of the time and skills required of members and staff. Implementing and maintaining it effectively has major resource implications.

### *Involving the wider community*

25. Members are not expected to 'represent' other members of the community served by the trust but will be expected to engage with their views and ensure that they are heard, either through their own networks or by networks set up by the forum or trust. 'The public' is made up of different communities of interest, identity and location, whose interests may not coincide. They will need to work with key local partners to ensure that patients and the public are involved in public health issues and addressing social inclusion.
26. Forum members will be expected to act as a conduit for local views rather than have views as a body, requiring listening and communication skills as well as contact with and the confidence of local communities. People might be involved through:
- Reference groups of people who are interested in particular areas– for example for children's services or those for older people



- Short term working groups
  - Visiting or monitoring teams
27. Patients' forums might maintain a database of people with an interest in a particular area who would like to be involved in specific areas for a limited period of time. This database could form a reference group that can assist in involving communities in trusts that cover a large geographic area, or diverse client groups.<sup>1</sup> It would:
- Allow those who only wanted to contribute in a limited way on a specific service area to do so,
  - Give an opportunity for those who want to contribute more fully access to patients' forum membership.
  - Ensure that members have a constituency to report back to that strengthens their contribution strength.
  - Provide a training ground for potential forum members.
  - Allow disadvantaged communities to come together in their own communities, with the relevant support, making sure their concerns are put forward.
28. There are also opportunities to use the internet to engage more people and set up local chat rooms and bulletin boards so that people can find out about what is going on and comment at a time and place that suits them.

### ***Community empowerment***

29. There are many agencies already working with communities trying to develop and enhance the life experience of individuals. These include:
- Local authorities, through community development workers, Social Services, Environmental Health, Education and Youth Services;
  - Voluntary agencies, often working with specific client groups; Housing Associations and
  - Other projects funded by regeneration grants employing community development workers.
30. The aim of government policy is to make sure that citizens and patients are fully involved in the existing structures. For health this means making sure that health issues are on the agenda of all agencies that make decisions that impact on the health of the local community. An important role for staff at local level may be to work with other agencies and facilitate the inclusion of health in their work. CPPIH staff could focus or specialise in working with groups and agencies from particular disadvantaged communities, such as people from ethnic minority communities, people living in disadvantaged communities or younger people.

### ***Forum work programmes***

31. Each forum will need to set priorities and decide their work programmes. Forums will need to collaborate with OSCs in identifying priorities and how they carry out their activities. Forums will be able to assist CHI in its audits as well as be involved in action planning and monitoring recommendations from CHI visits. Work programmes will need to include:

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<sup>1</sup> Bedfordshire and Hertfordshire Pathfinder Project, Patients' forum Tool kit



- Issues specific to the individual trust, either raised by patients and carers or the trust
- Issues that all trusts in an area consider that will enable them to make comparisons and identify good practice.
- Issues identified as national priorities by CPPIH where forums might be encouraged to look at a particular area or theme (such as on the implementation of a National Service Framework.)

### ***Proceedings of the forum***

32. Most forum activities can be carried out in working groups and other ways rather than in formal committee meetings. Committees, agenda and minutes can be very off putting to many people who might otherwise wish to contribute. However, forums are statutory bodies which will make decisions and will need a committee structure, subject to the regulations as other public committees and government access to information provisions. There may be advantages in not being too prescriptive at this stage. Once CPPIH is established it will be able to identify new ways of working that are effective once it is established and take on the performance management of forums.
33. Patients' forum meetings will need to be held in public, in accessible places and for PCT forums, where appropriate, held in different locations. In general only issues concerning staff or individual members should be held in private meetings. Regulations will need to cover:
  - How forums publicise their activities and meetings,
  - The system for recording decisions and actions agreed and ensuring that these decisions are made in an appropriate way.
  - Making available reports of activities and visits of the forum to the public, including performance information on trusts.

### ***Visiting and inspecting premises***

34. Patients' forums will have the right to visit and inspect premises. Regulations will advise on how patients' forums can exercise their right to visit premises, and limitations or conditions to access. There are established codes developed by CHCs that can be adapted that ensure that visits do not interfere with clinical care, but also do not become like 'royal' visits or inspections.
35. These rights should include any premises where services are provided or funded by the NHS, including GP practices. PCT patients' forums should be able to visit NHS trust services from which their PCT commissions services alongside forum members of that trust, but not by themselves. There will also need to be good liaison with OSCs who may also inspect services.

### ***Access to information***

36. Regulations and guidance will need to outline the provision of information (including descriptions of information which are or are not to be provided) to a patients' forum by an NHS trust, a primary care trust, a strategic health authority, and the Commission for Patient and Public Involvement in Health or providers of independent advocacy services. Such regulations will also need to specify whether the Patient Forum can pass information on to the relevant OSCs.
37. Patients' forum should have the right to any information (other than about individual patients or staff) to which a health authority or trust has access. Where



the trust is not willing to supply this information, they should be required to justify this refusal.

### ***Annual reports***

38. Patients' forums will be required to publish an annual report. The annual report must include details of the arrangements maintained by the forum for obtaining the views of patients and the public. Regulations or guidance will need to cover when it should be sent, to whom it should be sent, and require health authorities, trusts, PCTs and OSCs to respond directly to any recommendations in the report.
39. There may be benefits in a co-ordinated annual report for patients' forums in a PCT or OSC area. There could, for example, be a single annual report with subsections for each patients' forum in the area.

### ***The members***

40. As a statutory body each forum will need to have a core number of members appointed by the Commission for Patient and Public Involvement in Health, meeting the same standards as for other public appointments. The Act requires that forums include:
  - At least one person who is a member or representative of a voluntary organisation that represents patients or carers.
  - At least one person for whom services are being or have been provided by the Trust for which the patients' forum is established.
  - On PCT forums any body that represents the public locally on their health may have a member on the PCT forum - which means that members of local strategic partnership might be members of the PCT forum.
41. The NHS Appointments Commission has suggested that forums should have between 8 and 12 members. Regulations and guidance may need to allow for flexibility in the number of members of each forum. Forums will vary according to the services provided by the trust, the different communities it serves and the geographical area covered. Trusts, for example providing mental health services or learning disability services may cover a wide geographical area. Specialist hospitals, such as Great Ormond Street or the Royal Brompton, have a wide, even national catchment area.
42. PCT patients' forums may need a larger membership, as each patients' forums situated in the area will have at least one member on the PCT patients' forum covering the area. Membership will need to ensure that there are sufficient members to lead on the general duties of PCT forums — monitoring primary care and commissioning, ICAS and public health issues.

### ***Criteria for appointment***

43. The criteria for selection will need to be clearly defined and transparent and based on a role specification for forum members (see appendix 1). People appointed will need to demonstrate a wide interest and commitment to the NHS. People concerned with a single issues may be very useful members as long as they can demonstrate that they can draw on their own experiences and have the ability and willingness to listen to the views of others.
44. There will need to be a range of skills within the forum, but not all members will need to have all the skills. For example, reading and reviewing trust papers is a necessary skill within the forum, but not for all members to have. Forums are looking for people who are not part of traditional networks and who are willing and



able to have their potential and skills developed. People will need to be selected to cover:

- The mix of the local population,
  - Geographical areas in particular in rural areas where the costs of travel for staff and members can be great
  - People with an understanding of a range of conditions /client groups covered by the trust – different interests and identities should be reflected through this criterion
  - Both patients and carer interests are involved.
45. Some of the criteria for membership may vary according to the services provided by the trust and the geographical area covered. PCT forums members will also need to include people with a broader objective view that goes beyond their individual personal preferences and experiences. Forum members in NHS trusts, particularly where there are many long term users, should be patients or carers of that service or people working with that client group. Many mental health trusts have an established advocacy service and processes for user involvement that can be built on.
46. Consideration needs to be given to whether some people should not be eligible to join a forum:
- Someone who is already a member of another PCT patients' forum
  - Someone who is a non-executive directors of a trust or a private provider with whom the trust has contracts
  - Employees of the host trust
  - Staff of a local authority supporting OSCs, working in Social Services or with the health services.
  - Staff of a significant private or voluntary sector providers with whom the host trust has contracts.
47. It has been questioned whether local authority councillors should be eligible to be members of forums. The link will be important with OSCs, but there may be conflicts of interest and councillors might not have the time to contribute to forums.
48. Members will need to agree a code of conduct to ensure that they do not misuse their position as a forum member and ensure they declare any conflicts of interest. The Department of Health has produced a Code for CHC members, which can be adapted.
49. In addition to involving people in reference groups and other ways, an arrangement for forums to appoint associate members to fill any gaps in the core membership. There will need to be criteria for the appointment of associate members and appointments agreed by the core members. Associate membership should normally be time limited and relate to a specific area of work.



**Criteria For Patient Forum Membership and Selection  
(Bedfordshire and Hertfordshire Pathfinder Project)**

**Patient Forum Members...**

- Must be either
  - A patient or carer of a patient using services provided by the Trust or
  - A member of a voluntary organisation associated with services provided by trust
- In the case of a primary care trust forum, must be registered with a GP of that PCT, or be eligible to be registered with a GP of that PCT
- Must be able to demonstrate an interest in health issues and in representing the public's interests in the local health service
- Must agree to being able to devote enough time to be an active patients forum member
- Must have knowledge and/or experience which will enable the patients forum to be more effective in its work
- Must be associated with a group of people or a geographical area not sufficiently represented in the existing membership
- Must have an understanding of what the Equal Opportunities Policy means in relation to patients forums
- Must live or work within the patients forum district
- Must agree to and abide by the forum Code of Conduct
- Must be free from conflicts of interest (a current/unresolved complaint against the Trust represents a conflict of interest)
- Will be appointed in accordance with the forum's Equal Opportunities Policy

***Terms of appointment,***

50. CHC members are appointed for a term of four years and can serve two consecutive terms. This gives people time to gain an understanding of the NHS and local issues and develop contacts in the NHS and local communities, but two or three years might be more attractive for some potential recruits who wanted to limit their commitment, but would require more resources in recruitment and appointment. It is important to be flexible so that people can choose the length of their commitment. A two-year term (to a maximum of say 6 years) might be adopted with the expectation that people would be able to continue if they wanted to.

***Chairs of the forum***

51. Committees normally have a Chair. A chair provides a focus for the forum and leadership, but can sometimes reduce the involvement of other members. An alternative model has been suggested to have an external facilitator for forum meetings, with an agreement to undertake and rotate tasks amongst the membership. This would encourage a sense of 'ownership' by forum members. However, a Chair elected by forum members provides a stable point of contact for staff and between patients' forums. The TAB recommends that each forum should have a chair elected by the members annually. The term of office might be restricted to two years to enable the position to rotate among members.



### ***Non executive directors***

52. Ministers are committed to enabling each patients' forum to elect one of its members as a non-executive director (NED) of the trust. This is seen as an important way of ensuring that patients' forums take part in decisions that affect the community as insiders rather than influencing them from the outside. However, there are practical difficulties in this proposal that have caused concern among managers as well as patient and public representatives.
53. The NHS Appointments Commission holds the views that NEDs elected by patients' forums must have equal status to other NEDs and meet the same criteria and standards as other appointments. This would involve an interview panel run by the NHS Appointments Commission to approve the nomination. The member elected by the patients' forums could be refused appointment by the NHS Appointments Commission, which would cause tensions and undermine the credibility of the process. As the NED would be paid £5000 there is likely to be competition within the patients' forum and this could be divisive.
54. NEDs have corporate responsibility for the management of the trust and this may lead to divided loyalties if the NED remains a member of the patients' forum. If forum chairs are elected this divided loyalty might be particularly difficult. If the chair is not elected this might undermine the position of the (unpaid) chair of the patients' forum.
55. There are some practical difficulties since NEDs are restricted to people who live in the area, which would exclude some people who work or volunteer for voluntary organisations in the area. There may also be difficulties where the terms of office are different. Would the forum's NED resign as an NED when their term on the forum ended? Could the forum demand the right to re-elect the NED or remove them when their term of appointment to the Forum came to an end or they were dissatisfied with their performance.
56. The principle that forums should be able to directly influence decisions is an important one. There may need to be flexibility to enable forums and trusts to work together to identify the best ways of enabling forums to have this role. The TAB recommends that this commitment should not be implemented until forums are fully established. Some options include:
  - (a) Patients' forums should be able to choose whether they wish to elect a NED
  - (b) Patients' forums should be able to nominate an observer with speaking rights to the trust board
  - (c) If a forum decides to elect someone to the Board, the forum might ask the person to resign as a member of the patients' forum but maintain the communication and links with the forum.
  - (d) The criteria and skills required of NEDs elected by forums might be adapted to reflect the person's special role.
  - (e) The NHS Appointment Commission might screen those members who wanted to put themselves forward as the NED before the election. The election would then be among people who have put themselves forward and have already been screened as acceptable by the NHS Appointments Board.
  - (f) The interview panel should include members with credibility in the local community and the trust chair should not participate in the interview.
57. It is recommended that for the first year all forums are given the right to an observer with speaking rights on the trust board. The Commission can then



consider the best way to ensure that patients' forums can take part in decisions affecting their communities.

### ***Accountability of members***

58. Accountability is multi-faceted. Members will need to be accountable:
- Collectively and individually for the views they express on behalf of patients, carers and the public (outcomes)
  - Collectively and individually about how they involve and engage with patients, carers and the public (processes)
  - Individually for their personal conduct
59. For processes and personal conduct, members can be held accountable to CPPIH as part of performance management. For views they express on behalf of patients and the public, they need to be accountable to patients and public. Arrangements might include:
- The annual report
  - Local arrangements, which are explicitly defined to members when they join the forum.
  - Reference groups, that can provide a form of accountability, especially if the reference group elects some forum members.

### ***Performance management***

60. CPPIH is responsible for the performance management of forums. There will need to be a national framework for performance management based on an understanding that members are unpaid volunteers and so the process must be seen as constructive and helpful for forums rather than punitive. The national framework will need to have:
- A requirement to undertake an annual review that all members attend to look back on the past year and plan the work and priorities for the following year. An external facilitator might be used to provide a wider overview.
  - Regular independent evaluations
  - A complaints procedures and the power to take special measures where there are serious difficulties.

### ***Expenses and recognition***

61. Regulations will need to recommend what expenses can be claimed by patients' forum members (and others co-opted or working with members on forum business). These include:
- Payment of travelling expenses
  - Dependant care allowances (including child care)
  - Other allowances such as loss of earnings or for attendance.
62. While the Act enables allowances for attendance to be set down in Regulations, the Department of Health has made it clear that attendance allowances or compensation for loss of remunerative time will not be available to forum members. This is an issue that CPPIH may wish to look at later.

63. However, recognition for volunteer work is important and incentives in particular in order to involve people from disadvantaged communities. It is essential that voluntary work does not affect benefits that people receive.
64. Granting members statutory time off from employment to carry out voluntary work should be considered.

### **Recruitment and selection**

65. CPPIH will appoint patients' forum members, within a national framework agreed with the NHS Appointments Commission. Appointing members to approximately 640 patients' forums is an enormous task. The amount of necessary paperwork involved in sending out information packs to applicants, ensuring criteria for selection/rejection were followed and were fair; and dealing with successful and unsuccessful applicants should not be underestimated. If forums have 12 members each, this would be over 7,500 members. There will need to be:
- Clear nationally agreed processes and criteria for appointment of forum members
  - a strategy to recruit people from disadvantaged communities.

### **Nationally agreed processes**

66. There are three approaches to appointing and selecting patients' forum members: open elections, top down or bottom up.
- Elections based on an electorate that includes all of the electoral roll
  - Elections among voluntary organisations and or a wider panel of patients and citizens. Individuals could be approached by direct mailing and advertisements to create a pool of people who will form the reference groups could elect members to patients' forums.
  - Applications from individual patients and carers that undergo a selection process against agreed criteria and with an agreed process.
67. Whether applicants are elected or selected they will need to meet certain standards as required by public appointments.<sup>2</sup> People applying to join a patients' forum may be asked:
- Why they want to join the forum
  - What they can bring to the role in terms of expertise or knowledge of client groups
  - How they meet the requirements for the role specification
  - What time they can make available
  - What contacts they have with the voluntary sector, local communities or other users and whether they demonstrate a willingness to build contacts with networks of other users/ communities.
68. In some areas, CHCs have worked with trusts and others to build databases of local people who are interested in being involved in local health services. These might be used as a basis for electing all or a proportion of the first forum members, in these areas. There are opportunities now to try new ways of working and it would be a mistake to be over prescriptive about the mechanisms- as long as

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<sup>2</sup> HSC 2002/008 Pre and post appointment checks for all persons working in the NHS in England (also applies to volunteers)



systems fit in within the national standards and framework agreed between the Commission and the NHS Appointments Commission.

69. In other areas, selection may be the preferred option. There will need to be clear criteria for selection so that whoever selects can justify their choices and avoid 'cherry picking'.
- Applicants could be asked to provide references. Guidance would be needed as to what constitutes an adequate and appropriate 'reference'.
  - Interviews could be a useful tool for facilitating selection, but the composition of the panel must be carefully considered and criteria set down for its establishment.

### ***Strategy for recruiting members from disadvantaged communities***

70. CPPIH is expected to ensure that some forum members will be people who are not part of traditional networks or are from disadvantaged communities. Formal selection processes can be off-putting and discourage people who are not part of traditional networks. Recruitment will need to be proactive and advertising carefully focused and designed for the target market based on local knowledge. There will need to be adequate resources locally to facilitate effective publicity.
71. Once established, CPPIH staff will have the task of capacity building and building links between hard to reach group and the patients' forums. In the meantime community health councils may be able to assist in identifying people who may be interested in being involved in the forums. In the long-term indicators or quotas might be adopted for black and ethnic minorities, disabled people, age and gender. The indicators could be a performance measure for CPPIH (or the local arrangements for recruitment and selection).

### ***Recruitment of the first patient forums members***

72. There will need to be a national framework for the recruitment and selection of patients' forum members that follows Nolan guidance. In a separate TAB report on the work of the Commission it is suggested that CPPIH staff based at an intermediate level between national and local levels might do this.
73. Recruitment for the first patients' forums needs to begin before the Commission is formally established. Trusts and PALS have an important role in encouraging users to become involved in the forum, but it is not appropriate for them to be directly involved in the selection. The forum would not be seen as sufficiently independent.
74. While members will need to be appointed by CPPIH, the recruitment and selection could be undertaken on behalf of CPPIH based on national guidelines, either by a local agency, such as a council for voluntary service or local consultancy for which they would need to be reimbursed; or CPPIH staff or CHC staff working with local stakeholders and the host Trust. Whatever route in each area is decided this should be endorsed by the main stakeholders in each area.
75. In recruiting the first forum members, it may not be possible to recruit a sufficient number or range of people from disadvantaged communities. It may not be necessary to fill all the places at the start, as long as there is a core that can begin its work and then turn to setting up reference groups and recruiting new members to fill the gaps identified.
76. Some CHC members may wish to become involved in forums, though how many is not known. Automatic transfer of CHC members regardless of skills and approach would be inappropriate. However, experienced CHC members will have a very important role in supporting and mentoring new members and ensuring that



relevant experiences from CHCs are not lost. Some CHCs have been working with CHC members offering training in the skills that will be needed to work in new ways. The Association of CHCs for England and Wales proposes to undertake a survey of members to identify their interest and their skills. Some members might be prepared to stay on for a limited term (say one year) to assist in the transition.

77. In many areas CHCs are working with trusts to set up forms or panels, often with the expectation that these can transfer into the new arrangements when established. As far as possible the guidance needs to build on the good practices rather than impose totally new processes and set up forums from scratch.

### ***Training for members***

78. Induction training should be mandatory on all members. The skills members will need and what induction training should cover needs to reflect the skills they will need to work effectively within trusts. There will also need to be training, support and mentoring available based on the individual's needs, starting from where people are at.
79. If patients' forums are to attract people who are not part of traditional networks:
- Some may be recruited for their potential that can be developed and will require individualised support
  - Some will have needs and enable them to participate, such as translation, signing or Braille. All training materials will need to be available in different formats.
80. A training strategy needs to be developed for the induction of the first forum members as soon as possible. This could involve accrediting and commissioning a range of providers and its own staff. ACHCEW staff have been working many of these training issues, and consideration should be given as to how their skills and experience can be retained. Urgent discussions are needed between the Department of Health, ACHCEW, and other bodies who may have experience or an interest of developing a training and development strategy (such as the National Consumer Council, College of Health, the Modernisation Agency; NHS University; the London Change Management Board and others).
81. In the long term training may provide an incentive for recruitment. One way is to develop the accredited training for lay people so that they can obtain qualifications from the work they do.<sup>3</sup> Forum membership could be a basis for obtaining qualifications that can help the volunteer's personal and professional development. This may encourage some people to be involved as patient forum members or associates. ACHCEW and others have done some work on training and GNVQs for members. This might be an incentive for some people.

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<sup>3</sup> Department of Health (2001) Involving Patients and the Public in Healthcare: Response to the Listening Exercise. (Para 3.62).

## **What needs to be developed for the first forum members**

### *Recruitment*

- Recruitment pack for applicants
- Role specification for forum members
- Person specification for forum members
- Application form

### *Appointments*

- Member agreement/contract
- Code of conduct
- Local information packs

### *Training*

- Induction – standardised induction that system that can be rolled out nationally.
- Handbook for members
- National training strategy for continuing professional development and modules that can be delivered locally

## **Resources and staffing**

### *Funding*

82. The funding for patients' forums will be channelled through CPPIH and included in its accounts. Who manages payments and accounts for each patients' forums will need to be addressed. These could be provided on an agency basis by trusts, StHAs, or by CPPIH nationally or locally. This may depend on the level of the CPPIH networks and resources available to the Commission
83. The formula for the allocation of funding to PCT forums will need to be considered. Allocations will need to take into account:
  - Population, numbers, health needs and levels of deprivation
  - The number of trusts, their size and activities
  - Proportion of disadvantaged communities. Engaging effectively with a multi-ethnic population will demand a significantly higher level of resourcing (staffing and budgets) at all levels of the new structures.
  - Any special needs of members (Braille, signing, translation)
84. There will also need to be a separate national fund held to support people with special needs and enable them to participate. Language translation, signing and Braille can be expensive for individual forums and needs to be provided to forums as necessary.

### *Staffing*

85. The staff support available will affect how forums carry out their functions. The level of support required by PCT and trust forums to perform their functions needs to be identified to prevent tensions between PCT forums and trust forums.



86. An analysis of the skills required of staff will be needed in order to draw up job descriptions and person specifications. This needs to be done urgently so that CHC staff whose jobs are now at risk will be able to consider the options available to them and training they might require for the new jobs. There are at present about 700 CHC staff with a wide range of skills.
87. CPPIH staff will need to:
- Provide support for patients' forums
    - Empower patients' forums to monitor and pursue improvements
    - Logistical and administrative support
    - Coordinate patients' forums in the area to avoid duplication and enable them to set local priorities.
  - Facilitate communication and networking between forums and voluntary sector, Local Strategic Partnerships, Independent Complaints Advocacy Services and Overview and Scrutiny Committees etc
  - Build capacity and outreach to engage people who are not part of traditional networks in the work of patients' forums
  - Support regulation/ audit/ inspection from PPI point of view at local level by being a repository of data about the patient experience (for CHI, clinical governance etc).
88. Further work is urgently needed at national level in identifying the skills that will need to be available among staff supporting PCT forums. These may include:
- Facilitation and training – helping members to work together and develop their skills
  - Community development and empowerment – working with agencies and communities to raise health and health care as an issue with disadvantaged communities
  - Providing complaints advice and advocacy
  - Management and co-ordination – supervision of staff and ensuring that forums work together with and with OSCs and local strategic partnerships
  - Administrative support – running the office, dealing with expenses, supplies etc.
89. In many areas it is likely that the best use of resources will be for staff working with forums to work in teams, sharing facilities and services and developing some specialist area of activities. Teams may need to work with a number of PCT forums. There are benefits in staff working in teams. It will:
- Allow the development of specialist expertise in for example, training, facilitation, research, seeking public views, community development, and complaints advocacy.
  - Enable co-ordination of forum work that can follow the patient journey and managed clinical networks
  - Allow facilities and services to be shared
  - Provide staff support, that is particularly important in dealing with complaints
  - Provide staff cover for sickness and holiday
  - Enable better supervision and line management of staff.



- Provide more stability if there are trust and PCT mergers

### ***Accountability of staff***

90. Staff will be employed by CPPIH but accountable to PCT patients' forums. There are in-built difficulties for organizations where lines of accountability are unclear. There was often confusion with CHCs where staff were employed by the NHS but 'line managed' by the CHC Chair. Views are being sought on managing this dual accountability.
91. The TAB believes that there will be advantages in many areas for staff working with PCT patients' forums to work in teams that will allow for different skills and specialization. This may reduce the problems that may occur where staff are working to a lay committee in relative isolation. There will need to be explicit arrangements agreed between each PCT patients' forums with CPPIH.

### ***Premises***

92. At the moment there are approximately 200 CHC offices, each mainly covering a local authority area. There will now be over 640 patients' forums, including 300 PCT forums. There will need to be an 'office' or an identified point of contact for the forum in each Trust. However, offices where staff are based will need to be independent premises. The office will need to be accessible to disabled people but does not need to be a high street or shop front. Experience of CHCs is that high street offices may attract people from the immediate vicinity, they do not increase the access for people living in other parts of the district.
93. As CPPIH will be required to work as far as possible on PCT level, a network of local offices may need to be retained. However, it will be important to make sure that the offices that are retained are fit for the purpose and enable staff and members to co-ordinate their activities and share services and facilities.

### **3. Independent complaints advocacy (ICAS)**

#### **Background**

1. Most community health councils (CHCs) have hitherto provided information and advice to complainants. This is not a statutory duty; they vary in the help they offer from information on the procedures to intensive casework. In the Health and Social Care Act 2001 the Secretary of State was given the duty of providing an independent complaints advocacy service (ICAS) to replace the service provided by CHCs. In the NHS Reform and Health Professions Act 2002, primary care trust patients' forums are given the responsibility for providing ICAS using their own staff or commissioning from other agencies, where appropriate.
2. The Commission for Patient and Public Involvement in Health is responsible to the Secretary of State for the provision of ICAS and will set standards and performance manage ICAS. The Commission will also allocate resources and may need to hold contracts where advocacy is commissioned from an external provider, as PCT forums are not legal entities.
3. The paper is based on the current situation but there are changes on the horizon that may need to be taken into account at a later stage and will significantly affect ICAS. These are:
  - Changes to the NHS complaints procedure, including a role for the Commission for Healthcare Audit and Inspection.
  - Changes to the way clinical negligence and compensation claims are handled in the NHS
  - Changes to the procedures for social care complaints currently under review. Social care complaints relating to children and mental health are also relevant.
  - The establishment of PALS that may affect the numbers of complaints and how they are dealt with.

#### **What sort of service do complainants need?**

4. Clients, who may be patients, carers or others making a complaint on someone else's behalf, may need:
  - Independent information – on rights and entitlements, and making an effective complaint
  - Independent advice on the best way to resolve or follow up concerns (which may or may not involve clients/patients using the complaints procedure)
  - Independent support or advocacy in making the complaint through all the stages.
5. The service needs to be positive and responsive to clients' needs, helping them identify where they stand and find the best course of action to tackle problems quickly. The extent of help that clients need may depend on the:
  - Nature and complexity of the complaint: some complaints may involve complex clinical issues, many different services or are very complex.



- The client's capacity to make the complaint. People in need of additional help may be people whose first language is not English, people with learning, literacy or communication difficulties, people with mental health problems or frail elderly people. People who are very distressed, such as after bereavement may also need ongoing support in making a complaint.
6. Advocates are on the side of the person they represent which means that they are structurally and psychologically independent of the services. There are different forms of independent advocacy depending on the needs of the client group: legal advocacy, professional or specialist advocacy, unpaid informal or citizen advocacy, peer advocacy or self-advocacy. Complaints advocacy is concerned with time limited assistance for a particular complaint.
  7. This is different from the major part of the work of many specialist advocates, where the relationship with the client may span many years and they provide support rather than advice. The need for advocacy in mental health is unique because of the powers of compulsion in the Mental Health Act. Standards that are developed for ICAS need to be consistent with standards developed by other advice and advocacy services.
  8. Consultations undertaken for the Department of Health indicate that many people confused the term ICAS with ACAS and understood the term advocacy in different ways. Members of the public consulted were enthusiastic about the service but felt that support was a more appropriate term than advocacy. Consideration might be given to calling the service independent health complaints support.

### **Aims of ICAS**

9. The aims of the independent complaints advocacy service are to:
  - Ensure individual clients have access to independent assistance and support in making a complaint about NHS services according to their needs
  - Help clients identify the options for taking forward their complaints or deal with problems that have arisen in services;
  - Help clients make an effective complaint through the NHS procedures; and
  - Provide up to date and timely information to those responsible for scrutinising the NHS.

### **Values of ICAS**

#### **Accessible**

10. ICAS need to be accessible to the public. It will need to:
  - Be free of charge for people with complaints about services they have received from the NHS
  - Have outposts or hold sessions in accessible points in the area it serves
  - Be visible and well publicised as an independent service, separate from patients' forums other activities
  - Have arrangements to assist people who face particular difficulties in making a complaint, whether because of communication, language or literacy difficulties, learning disabilities or mental health problems.

### ***Empowering***

11. The service should seek to empower clients to be self-reliant and retain ownership of the complaint throughout wherever possible. It should encourage self-advocacy, though some people will require support.

### ***Client focussed***

12. ICAS should assist all clients without judging the validity of the complaint. The client's immediate needs are given priority over the pursuit of the complaint, unless the client explicitly indicates otherwise.

### ***Comprehensive and integrated***

13. ICAS need to provide a comprehensive and integrated service to clients receiving care provided or commissioned by the NHS, including in private services. While the complaints procedures for NHS and social services are now separate, ICAS will need to be able to assist clients with social care complaints where these are jointly commissioned or form a part of an NHS complaint (such as where the complaint is about discharge from hospital or care packages). ICAS may also need to help take complaints against NHS professionals through the regulatory bodies (such as the GMC). Where appropriate clients will be signposted or referred to other agencies that can help.
14. ICAS is not designed as a service for people who are seeking legal recourse or compensation. However, where the client has started legal proceedings for compensation, this should not prevent them using ICAS. How ICAS relates to legal services will need to be clarified and this may need to be reviewed when the new arrangements for mediation and compensation are decided.

### ***Confidential***

15. The service must be confidential and no private or personal information passed on to any other agency without the prior consent of the client. Any summaries provided for clinical governance should be anonymised, unless the client gives consent for disclosure to, for example, clinical governance leads, patients' forums, or Overview and Scrutiny Committees (OSCs).

### ***Commitment to quality***

16. Everyone approaching their local ICAS must be sure of getting information or timely help from trained staff. If the first person they see cannot help, they are required to help the client find someone who can.

### ***Co-operative***

17. ICAS will need to work with PALS, NHS staff, advocacy services and other agencies to help with specific clients or enable them to give information and solve problems.

### ***Contributing to improved services***

18. While respecting confidentiality, information from clients' experiences will be available to those responsible for commissioning, providing, and scrutinising services.

### ***What ICAS should provide***

19. Clients need different types and levels of information and advice services. Four levels of services are suggested that follow the levels used by the Community



Legal Service. The first two levels of assistance could be provided by many agencies in the community, as at present. Levels 3 and 4 would be a specialist service provided by ICAS. ICAS may also have a role in co-ordinating and supplying information to agencies and outlets providing levels 1 and 2.

### **Level 1 - Self help information**

20. The public need general information through leaflets, directories, web sites or other computer based systems or other published materials. Information about complaints procedures can be provided in libraries, health centres, advice agencies and community organisations and Patient Advice and Liaison Services (PALS). PALS are based in each trust and will provide information and on the spot help for patients, their families and carers.<sup>4</sup>
21. Publicity for ICAS is important. There should be a national logo for ICAS related to CPPIH and an information pack for clients. Many good examples of self-help packs already exist (including those prepared by CHCs and the Public Law Project).
22. Other ways of enabling people to access the service might be considered, such as a national web site offering information on possible courses of action according to set questions.

### **Level 2 - Assisted information**

23. Most people who want to make a complaint can benefit from advice to help them clarify what they want and identify the best course of action. Many people need support in order to challenge a large or unknown organisation or professionals on whom they rely for their well being. Assisted information helps clients access information, to identify where a client needs further information or advice and refer on. Sometimes assisted information is all that clients need, though they may wish to refer back from time to time.
24. Assisted information can be provided by organisations such as CABx or other advice services that have an information service, but do not have a specific service level agreement to provide ICAS. Staff are able to help clients access information, to identify where a client needs further information or advice and to help clients select an appropriate service where they will be able to receive this information. The service will not provide advice and would refer on clients who need further help.
25. A national helpline number which complainants could call and calls routed to the local ICAS provider might be considered. People could obtain an information pack this way and also discuss their complaint with ICAS staff.

### **Level 3 - General help**

26. General help involves identifying clients' problems, giving information and explaining options, identifying further action the client can take, giving assistance in filling in forms or contacting third parties to seek information. This will generally be done in one interview although there may be some follow up work. The client then retains responsibility for further action.
27. Initial contact could be by telephone or letter with outreach points to meet clients or conduct interviews. Outreach points will be important to ensure access. These could be in CAB or other advice agencies. In rural areas face-to-face contact is difficult. There are examples of organisations developing video conferencing to

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<sup>4</sup> The DoH published a resource pack in February, *Supporting the implementation of patient advice and liaison services*. This is available on the DoH website.

allow remote access to advice services in areas where travel distances are a barrier to using services.

#### **Level 4 – Casework**

28. Clients may need a caseworker or advocate to help them. This may include negotiation with third parties on the client's behalf by phone or letter. It could also include assistance in preparing for independent reviews (the second stage of the NHS complaints procedure) and representation at any hearing.
29. Research suggests that overall about one third of clients require basic information, a third need further support such as letter writing and understanding the process, and a third need long term support through all stages of the complaints process, including support at meetings.<sup>5</sup> Some will need specialist advocacy because they have communication or learning difficulties, their first language is not English, or they have mental health problems. There may also need to be special arrangements for children and young people.

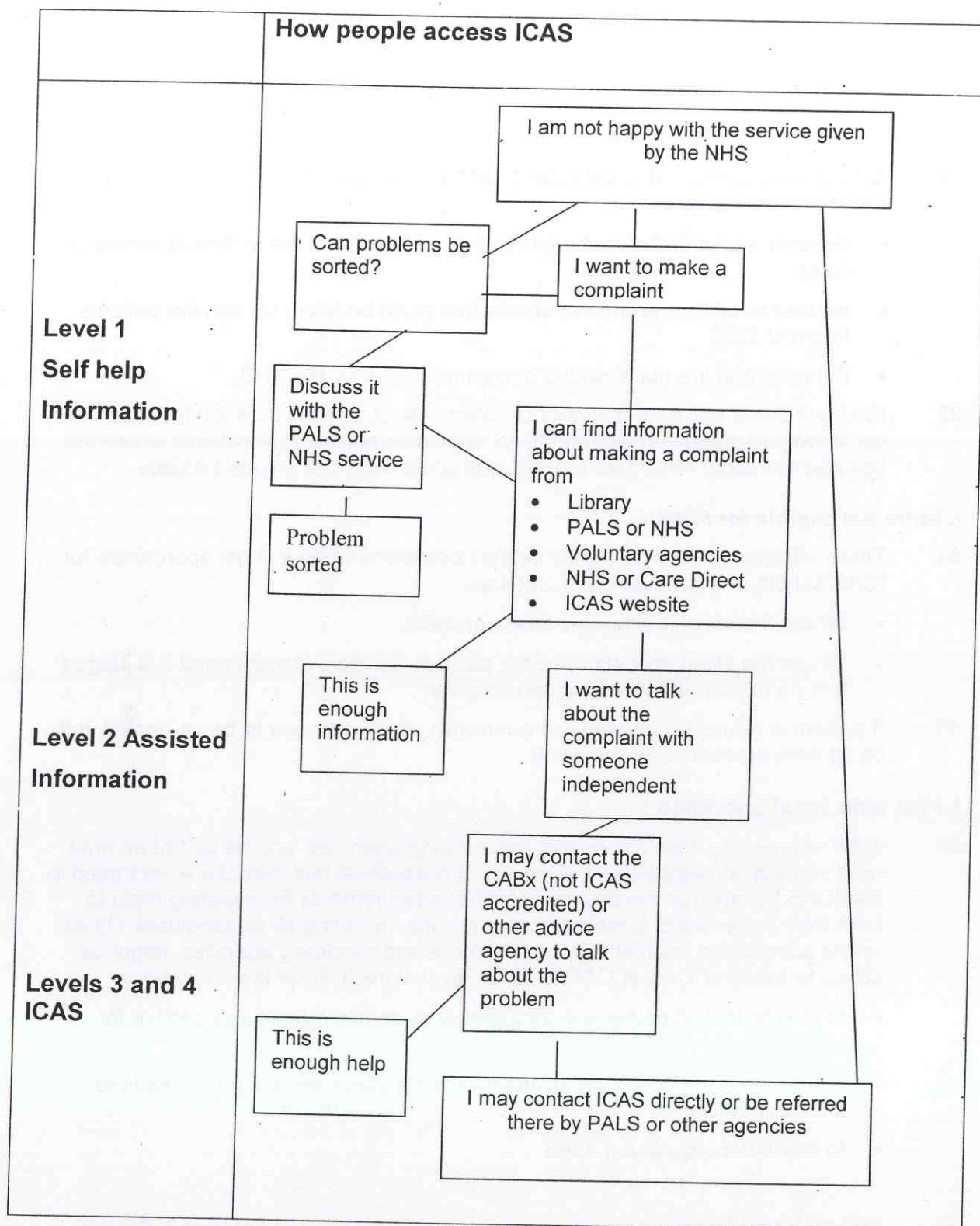
#### **Clinical advice for clients**

30. Some clients may also benefit from independent clinical advice. CHCs estimate that about 80% of the complaints they deal with arise from communication problems and 20% cover clinical issues. Clinical advice from an independent clinician can be important to clients. This will be needed on two levels.
  - For some clients, talking through the complaint with an independent health professional is sufficient to help them understand what has happened and to decide whether they wish to pursue the complaint. To be effective this service needs to be available speedily.
  - Specialist clinical advice for more complex complaints. Consideration might be given to recommending that clients have access to clinical advice through ICAS staff. Action for the Victims of Medical Accidents already provides a direct line for CHCs providing independent clinical advice on complaints and this should be developed to provide advice to all ICAS.

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<sup>5</sup> Opinion Leader Research Mapping Health Advocacy, prepared for the Department of Health February 2002.





### **Who can use ICAS**

31. Everyone should be able to refer him or herself to the service, the extent of the support would depend on the perceived needs or wishes of the client.

### ***Complaints not covered by ICAS***

32. ICAS is a service to individual patients and carers. It is not appropriate to help where complaints cover:
- General issues that do not relate to the experience of the individual patient or carer.
  - Issues raised by a group of patients that could be taken up with the patients' forum or OSC
  - Services that are not provided or commissioned by the NHS.
33. ICAS will assist clients in making complaints about care trusts when they are set up. Views are sought on whether ICAS should be able to assist clients where the complaint is about NHS care but includes social care and private services.

### ***Clients not eligible for ICAS***

34. There will also need to be clearly defined occasions when it is not appropriate for ICAS to help an individual client, such as:
- Where the client is abusive, violent or racist.
  - Where the client persists once the procedures are exhausted and it is judged that no further effective help can be given.
35. If a client is refused or the service withdrawn, there will need to be an appeal and complaints procedure for the client.

### **Links with local agencies**

36. ICAS will need to have close links with existing agencies, and be part of an area wide strategy for support and advocacy. It is essential that clients are not forced to use ICAS because of the absence of other arrangements for assisting them to have their voice heard. Local reference groups, including all stakeholders, linked where appropriate to other forums for advice and advocacy agencies, might be set up to oversee ICAS at OSC or StHA level>it might have three functions:
- to ensure that all partners work together to enable a seamless service for clients
  - to advise on the best local arrangements for ICAS, including the needs for specialist advocacy
  - to monitor the quality of ICAS
37. Protocols and formal referrals arrangements will be needed between ICAS and some of these services, including (subject to the client confidentiality) the transfer of client information between services.

### **Other ICAS**

38. ICAS will need to have agreed arrangements for working together where, for example, a client lives in an area distant from the service subject to the complaint. Clients may prefer to use the ICAS near where they live or work.



### **Health Service staff**

39. ICAS will need to have close working relations with PALS and NHS Trust and PCT complaints staff. The aim of PALS is to resolve issues before they escalate into serious problems. PALS role is to inform and support people to access the complaints procedure when appropriate. Where a client is provided with help by the PALS and then goes to ICAS, there may be potential for sharing information between PALS and ICAS at the request of the client.

### **Local authority complaints procedures**

40. Some complaints involve health and social care. The boundaries and interface with other complaints procedures will need to be clearly outlined. At the moment the NHS and Social Services complaints procedures are different. However, complaints can be jointly investigated during local resolution, though not at independent review or the second stage. ICAS need to work with all agencies to provide a complete service to clients.

### **CABx and advice agencies**

41. CABx have a useful network, which might provide access points for ICAS. There may be CABx, Law Centres or other voluntary agencies capable of offering an ICAS service in their area.

### **Local advocacy projects**

42. Some local advocacy projects provide advocacy services for clients of some health and social care services. ICAS should not duplicate or replace existing provision. Some clients may prefer the advocate they know to assist them in making the complaint, with advice and support from ICAS where necessary.
43. The need for advocacy in mental health is unique because of the powers of compulsion in the Mental Health Act. ICAS need to recognise this and support the development of specialist independent mental health advocacy services, where appropriate commissioning services to supplement the generic ICAS.
44. Informal facilitative advocacy services will be important in helping vulnerable people and people from hard to reach groups access the complaints process. The PCT patients' forum will be able to commission specialist advocacy in support of the generic ICAS service.

### **Community organisations**

45. In general most advice agencies and advocacy services regard NHS complaints as an area for specialist advice and support, because they are often complex and do not arise frequently in their work. They have therefore worked alongside CHCs but most do not feel equipped to provide complaints advocacy. They will have an important role in publicising the service and sign-posting people to ICAS.

### **Bereavement, counselling and support**

46. Many clients may experience distress and ICAS will need links with counselling services and support groups so that they can tell clients about these services where appropriate.

### **Community Legal Service Partnerships**

47. The Community Legal Service (CLS) was set up in April 2000 by the Legal Services Commission, an executive non-departmental public body created under the Access to Justice Act 1999 to replace the Legal Aid Board ([www.legalservices.gov.uk](http://www.legalservices.gov.uk)). It aims to improve access for the public to quality information, advice and legal services through local networks of quality assured services supported by co-ordinated funding, based on an assessment of local



need. Consideration needs to be given to how the provision of ICAS relates to Community Legal Services Partnerships at local level.

### **OSCs/CHCs/ Patients' forums**

48. ICAS will need to have arrangements to ensure that any complaints received by Patients' forums or OSCs are referred where appropriate to the ICAS. Similarly there will also need to be arrangements for the provision of statistical information and anonymised briefings to ensure that experiences of patients are available to OSCs and patients' forums to help them in their monitoring and scrutiny roles.

### **Helping to improve health care**

49. Information from complaints must be used to improve services, otherwise the learning from complaints will be lost. ICAS will need to have regular reporting mechanisms to:
- Clinical governance in PCTs and NHS trusts
  - OSCs and patients' forums
  - Strategic Health Authorities
50. Information from ICAS will supplement the information received by OSCs from trusts, who will have information on all complaints, while ICAS will only deal with a proportion. All reporting will need to be anonymised unless individual clients give ICAS permission to do otherwise. Particular attention will need to be given to returns with a small number of complaints to ensure that individuals are not identifiable. Patients' forums and OSCs will need to advise on the information they require from Trusts and ICAS.
51. However, anonymised statistical information may be specific enough to pick up problems early. Most complainants have a desire to see changes and confidentiality is often more important to professionals and providers than complainants. ICAS will need to have arrangements to ensure that information is followed up, with the complainant's permission, by ICAS, the patients' forum or the OSC.
52. There will need to be mechanisms for local information to be fed to national agencies, such as CPPIH, National Care Standards Commission, National Patient Safety Agency and the Commission for Health Improvement. The local networks of CPPIH might be given responsibility for following up service issues arising from individual complaints. This should be quarterly and computerised, based on common recording templates.

### **Setting up ICAS**

53. PCT patients' forums will provide ICAS using its own staff or through other local providers, where appropriate. PCT forums have a duty to work together and undertake some activities jointly. Consideration will need to be given in each area as to the size of the area for which ICAS is best provided. ICAS will need to see clients in local areas, and at times make home visits, but they could be based on StHA or PCT, LA or OSC area. There may be advantages of a flexible approach in different areas, according to the needs of clients as well as the skills and services locally available. There will need to be different ways of delivering the services in urban and rural areas. This is an area that may become clearer following the evaluation of the pathfinder ICAS.
54. The decision on the level to provide ICAS must be made based on an assessment of the needs of each area and in consultation with local people and local agencies, including community organisations, advocacy groups, advice agencies,



other patients' forums and NHS providers. The decision on the level to provide ICAS needs to be based on consultation with all the local stakeholders, taking into account:

- The needs of the local population
- The way PCT forum staff are organised in that area
- The volume of complaints enables staff to develop the necessary expertise, and provide relevant cover for sickness or the development of specialist representation
  - The service is sufficiently distanced from NHS and Primary Care Trusts that it will be seen as independent.
  - Any likely future configuration of PCT boundaries or mergers
  - Staff have the support necessary to be an effective independent service.

### **Arrangements for specialist advocacy**

55. PCT forums may decide to commission services from external agencies. Some clients will need a different kind of advocacy. There are two ways that their needs might be met:

- by contracting appropriate advocacy organizations to provide ICAS, whom clients may approach directly. This might include advocacy for clients about mental health services, learning disabilities or where there are communication or language difficulties.
- by ensuring that the main ICAS provider works with advocacy or another agencies to meet the needs of appropriate clients. Where the client already has an advocate, the client may wish him/her to assist them in making their complaint. ICAS would be able to provide the advocate with specialist advice to help them do this. There might be a financial arrangement to support advocates to assist in this way with their clients.

56. All contracts should be awarded following a transparent process and through competitive tenders. Forums are not legal entities and so cannot hold the contract. In the future PCT forums may decide to commission ICAS from other providers or to terminate a contract with a provider in order to set up its own service using its own staff. It will be important that these decisions are made in a transparent way and that the reasons submitted as a business case to CPPIH who will provide the resources and hold the contracts.

## **Standards and performance management – the role of CPPIH**

### **Standards**

57. CPPIH might follow the model adopted by the National Association of CABx, where national standards are achieved through national services and bureau support, a central resource of information; and a national training scheme to defined competences. There will need to be core measurable standards that all designated ICAS must meet. Key quality areas identified include:
- a. Access to services: making others aware of the service and non-discrimination, basing delivery of the services on local needs and priorities.
  - b. Seamless services where clients are referred to the appropriate service that can help them
  - c. Speed: clients need to be handled speedily to agreed time limits.



- d. Meeting clients needs: giving information and advice relevant to clients needs, including confidentiality, privacy and fair treatment
  - e. Trained staff – staff must possess or acquire the skills and knowledge required to meet client's needs based on accredited training.
  - f. Running the service: there must be processes and procedures that ensure an effective and efficient service to their clients
  - g. Running the organisation: there must be structures and procedures that ensure effective and accountable management of the organisation and resources.
  - h. Commitment to quality: including having a complaints procedure, other user feedback and maintaining quality procedures.
58. The framework provided by the Community Legal Service (CLS) can be used. The Quality Mark (QM) is increasingly accepted as the standard for information and advice agencies and can provide the basis for ICAS. There will need to be additional areas specific to ICAS, including audit of the quality of advice given and how information collected from complaints is used to improve services.
59. If CPPIH adopts the Quality Mark of the CLS, it will be important that this is clearly distinct from PALS. It may confuse the public if both ICAS and PALS to use the same CLS logo as they may feel that PALS with the QM may also be in a position to provide independent advice.

#### ***Support and central resources***

60. While the ICAS will operate at the local level, there will be a need to use common data bases, systems for accessing information and resources, as well as format for information collected to inform OSCs and patients' forums. ICAS will need a database, which uses a coding for complaints, which matches the NHS. This service will need to be provided or commissioned by CPPIH at national level. Work could begin on this now.
61. ICAS staff would benefit from access second tier advice as CHCs currently do from Action for Victims of Medical Accidents. It would be appropriate that such services are funded as a national resource.

#### ***Monitoring and accreditation***

62. Each ICAS will need a system for collecting information to monitor their activities. Opinion Leader Research suggested that the type of information that should be collected could include:
- Equalities monitoring of complainants
  - Services complained about (issue and institution)
  - Complaint outcomes
  - Time taken to deal with complaints
  - Client satisfaction/feedback
  - ICAS performance against its own target (e.g. time taken to respond).
63. ICAS will need to be audited nationally according to national standards. There may be advantages in separating commissioning/or providing ICAS and the audit function. The CLS Quality Mark might be used to prevent duplication. The CLS also operates the Quality Mark procedures for all services from Level 1 as outlined above. Organisations are audited annually and can carry the logo and be included



in the CLS Director and website. The Quality Mark award could be taken as the necessary framework for ICAS services. The many organisations now participating in the QM scheme would be reluctant to submit to a different set of standards in order to offer ICAS.

64. The award of the Quality Mark is subject to an annual audit against the standards. NACAB has a system for accreditation and audit of its CABx and is the only organisation whose own audit team has been accredited by the Law Services Commission. This means that the NACAB audit of member bureaux replaces the CLS audit one year in three, and gives the Quality Mark. NACAB's own Membership requirements mirror the CLS standards but in addition includes two more elements, which would be important for ICAS:
- Quality of advice assessment which looks at substance as well as process; and
  - Standards of participation in NACAB's social policy aim, using clients' experience as evidence to influence policy and services.
65. There will need to be a complaints procedure where CPPIH can investigate problems and take special measures if necessary.

### **Funding ICAS**

66. CPPIH will advise on the levels of funding and its allocation. The resources needed to provide a consistently good service will need to cover staffing, including training and continuous professional development, accommodation, supplies, equipment, printing and stationery and communications. Staff will also need regular professional supervision as well as access to support or counselling in cases where the complaint may cause personal distress for a member of staff.
67. It is not possible to estimate the likely demand for ICAS. It is estimated that CHCs handle 30,000 formal complaints a year – an average of 150 complaints a year per CHC, with a caseload of about 50 live cases at any one time. This is about 25% of complaints about the NHS (based on NHS complaints statistics). In addition there are clients receiving assistance from CAB, advocacy services and other voluntary groups. Many variables may affect the demand. PALS and improvements in handling complaints at local level may decrease the demand, while better publicity for the service may increase it. It is generally estimated that only 10% of potential complaints are actually made. The complaints dealt with by ICAS are likely to be more complex and serious.
- Core funding based on an estimated number of cases may be most appropriate based on a national formula that can be reviewed.
  - Where a specialist advocacy agency assists ICAS in helping a client, there might be a financial arrangement on a case-by-case basis.
  - A special fund held by CPPIH for which ICAS can bid where there is a rush of complex cases which need more resources than usual.

### **Managing change and the transition**

68. A major challenge in ensuring a smooth transition is the need for stability and sustainability. Opinion Leader Research noted the very strong desire for a smooth transition to the new structures. It is important to plan to ensure:
- continuity of provision for clients while the transfer takes place; and
  - in filling the gaps in provision that exist or may arise as CHCs wind down services due to loss of staff.



69. Some ICAS pathfinders have been set up and additional funding is available in this financial year for further ICAS. It is important that services developed in this interim period can be merged into the new structure. For agencies providing ICAS, there will need to be some commitment or arrangements to ensure that the service is continued after the abolition of CHCs for at least an interim period. This will allow some stability for the service, until the results of the evaluation of pathfinders are known and PCT patients' forums are in a position to take over arrangements for ICAS.

### ***Developing models***

70. This transition period gives the opportunity to develop and test some ideas for how ICAS should be provided. There are likely to be different ways of providing ICAS that may be suitable for different communities, such as rural and urban communities and in areas with a high proportion of people who are not part of traditional networks or may have particular difficulties in making a complaint. It is important that learning from these pathfinders contributes to the overall framework. Funds for pathfinder ICAS can help to identify the implications of different models and there should be robust and independent evaluation of these pathfinders.
71. All Pathfinder ICAS should work to draft national standards and information systems that will ensure that there is some consistency nationally. This should include a commitment to work towards a Community Legal Service Quality Mark. There is otherwise a danger that ICAS will develop in different ways, and, once established, will be harder to change. (see Annex)
72. Existing services to complainants provided by CHCs and advice agencies may not need substantial funding since staff are already in post. However, they should have the opportunity to apply for designation as a pathfinder or shadow ICAS, with funding if necessary to assist in developing new systems to comply with the standards.

### ***Areas where there is no independent support for complainants***

73. Funding for pathfinder ICAS is unlikely to address the problem in areas where there is no existing service for complainants. These areas need to be mapped and a local strategy developed as to the best way of providing ICAS in each locality. ACHCEW and NACAB may be able to assist in identifying these areas. In each of these areas responsibility will need to be given to the StHA, PCT or other agency to bring together possible partners to develop this service. Capacity building may be necessary.

### ***Occupational audit and training***

74. ICAS staff or volunteers will require skills in administration, advocacy, communication, diplomacy and negotiating. They will need experience in these areas as well as additional training in the NHS, local community networks and NHS complaints.
75. An audit of the skills and competencies required from staff to deliver different levels of advice and representation should be undertaken by the Department of Health and training developed to assist the development of pathfinder ICAS. There will need to be an accredited national training scheme to defined competences. The Department of Health may wish to identify the relevance of training programmes already developed and possible relevant NVQs.



### ***National helpline and website***

76. A national phone number might be provided as a first point of contact for complainants and phone calls routed to the local ICAS. In interim the helpline could be a separate service run by specialist staff. It could be set up as a pilot in an area where there was a low level of support available to complainants and rolled out nationally if successful.

### ***Appraisal and development for ICAS in the transition***

77. Designated ICAS will need support and appraisal during this year.
- Action research and appraisal of projects so that the lessons can contribute to the framework for ICAS
  - Support for ICAS projects and enabling them to exchange information and share experiences.
  - Development and capacity building in those areas where there is no existing service for complainants.

### ***Preparing for ICAS***

78. In order to make the best use of pathfinder ICAS developed this year, preliminary work will be needed on these before the establishment of CPPIH. There will need to be:
- Draft standards for complaints handling and arrangements for referrals and sharing client information need to be agreed between PALS, ICAS and OSCs and patients' forums and community groups.
  - The identification of skills, competencies and appropriate training for people providing ICAS
  - A performance management framework for ICAS
  - Transfer arrangements: Advice will be needed to ensure that ongoing clients are informed of changes and continue to review support during the transfer. There may need to give permission for the transfer of their case files. Guidance will be needed on what happens to CHC complaints archives.

## 4. The transition

1. There is an urgent need to guidance on what can be done at local level to make the transition as smooth as possible. There is confusion in the NHS about who should be leading preparations towards the new arrangements. In many areas CHCs are working with trusts to set up forums or panels, in other areas trusts are working without input from the CHC - often with the expectation that these can transfer into the new arrangements when established. If people set up new structures that do not fit in with the national framework, this will cause frustration and disillusionment locally.
2. In each area local stakeholders, including CHCs, trusts, strategic health authorities, local authorities, OSCs, local strategic partnerships and councils for voluntary service should meet to identify:
  - The functions that PCT patients' forums may wish to perform jointly and in which geographic areas
  - How forums can be co-ordinated,
  - The most appropriate local base for staff teams that will support patients' forums
3. There will need to be an implementation plan in each Directorate of Health and Social Care with an agreed timetable for ensuring that each function can be transferred by the national date. While it is not appropriate that the implementation is seen to be lead by the NHS, however strategic health authorities may be in the best position to facilitate the discussions and report to CPPIH.
4. The Department of Health has suggested that there are two approaches to implementation:
  - The big bang – a national date for the abolition of CHCs and start of the new arrangements
  - A staggered approach where specific elements of the new package are implemented in turn and longer term managed hand over from CHCs.
5. In general people at the reference group meeting in July favoured a single start or end date because it would be clear and avoid confusion, combined with an agreed realistic national abolition date for CHCs. The new arrangements might be phased by prioritising the most important aspects. Initially PCT forums might be set up, followed by setting up forums in trusts. The PCT forum once established might then take over the duties of CHCs. There are some areas where PCT forums can be set up and functions handed over to the new bodies as soon as the Commission is in a position to appoint members.
6. There are concerns about the continued uncertainty for CHC staff and members and a realistic date for the hand over from CHCs should be set to enable timetables for implementation to be drawn up. Many CHCs have indicated that they would find it helpful to have the eventual abolition date set to enable planning for the transition. CHC staff need to know their employment position and the opportunities available as soon as possible in order to avoid experienced staff moving on and to give continuity. Staff issues are not a matter for the TAB, and are being negotiated between the Department of Health and CHC staff representatives.
7. Further work is urgently needed nationally to identify the skills needed at a local level and develop, in advance the training required:



- to allow CHC staff who transfer or are recruited to these functions to fulfil them effectively
  - For CHC members and others who may wish to offer their services to the new system.
8. The functions of ACHCEW and the regional CHC associations will be taken over by CPPIH and its local staff. It is important to use the skills and experience of ACHCEW and the regional associations in helping with the transition and ensure that the experience, skills and resources within ACHCEW and the regional associations are available to the Commission.

## **5. Future work programme of the TAB**

This report outlines in general terms how the new arrangements may work. Some issues that we have addressed can wait for the Commission to take forward when it is established. However, in other areas further planning must start before the Commission is established. These areas have been identified for further work:

### **The Commission**

The Tab looks forward to working with the Chair designate on:

- Person specification and job descriptions for Commissioners and Chief Executive
- Organisation of the Commission.

### **Patients' forums**

There is much to do at national level to pave the way for the new arrangements. There needs to be a framework for setting up forums, recruiting and training of members and staffing arrangements. Some work can start on this.

- Advice on Regulations and guidance on the conduct and setting up of forums
- Role descriptions for members
- Codes of conduct
- Induction training
- Competencies and qualifications for staff
- Framework for recruiting and selecting the first forum members
- Relationship between overview and scrutiny and patients' forums

### **The transition**

- Advice to the NHS and CHCs on what they can do to prepare the way for the new arrangements
- Transitional issues affecting CHC staff and members



## **Annex 1 – Commissioners – role and qualities**

### **Commissioners – role and duties**

As a Commissioner you will be expected to use your skills together with your personal experience of patient and public involvement

in health to guide the work of the Commission.

- You will contribute to the development of strategic direction and long term plans for improving patient and public involvement in health
- You will contribute to building and maintaining a close relationship between all those concerned with patient and public involvement in health, in particular ensuring good communications are maintained with those involved locally in patient and public involvement.
- You may be required to represent the Commission at meetings and events at local and national level.
- You will help to ensure that the Commission promotes equality of opportunity in the treatment of its staff and those it comes in contact with.
- You will be asked to sit on various committees such as the Audit Committee to ensure proper financial procedures and committees to review professional conduct and staff disciplinary matters.
- You will help ensure the best use of financial resources to fulfil the Commission's objectives.

### **Commissioners – qualities required**

We are looking for a range of experience and skills that will contribute to the work of the Commission and help it promote patient and public involvement at local and national level. Commissioners will be expected to be able to take a broader view of health and health care issues and be able to make contributions at national level

#### *Essential*

All Commissioners will be expected to demonstrate that they have the following qualities

1. Experience or demonstrated commitment to ensuring that patients, the public and in particular socially excluded groups, are able to have their say about, and influence, decisions that would affect their health
1. Are able to take a strategic overview of health policy issues, drawing on their own experiences of working in patient and public involvement
2. Have communication skills, and able to communicate with people from different backgrounds and interests at local and national level
3. Be familiar with committees and able to negotiate with other national stakeholders and articulate the views of patients and the public at national level
4. Be committed to the public service values of accountability, probity, openness and equality of opportunity.

#### *Desirable*

Commissioners appointed will need to demonstrate in addition that they have relevant experience and expertise to contribute to the work of CPPIH. Commissioners will be appointed to have a balance of experience and skills. We will be looking to include an understanding of the needs of different regions of England, in particular urban and rural areas.

Professionals and NHS staff involved in patients and public involvement will be considered on condition that they have the essential qualities. The Board will, however, comprise a majority of members involved in patient and public involvement from a patient or citizen's perspective.

Commissioners may have at least one of the following experience or areas of expertise:

1. Community development, public health and tackling inequalities, in particular in relation to consultation and public involvement

2. Social inclusion – experience of involving people and communities who are excluded or have difficulty accessing services, such as people from minority ethnic communities, rural areas.
3. Experience in helping particular client or patient groups influence services and quality of treatment, such as experience in the expert patient group or specialised clinical services.
4. Advocacy and user led groups that assist people to make their voice heard
5. Corporate experience – such as financial management, probity and organisational management
6. Providing information and advice to people about health services and their rights or in making complaints.



## **Annex 2 Role specifications and training for members**

### **Role specification and training of patients' forum members**

#### *Qualities required of patients' forum members*

Members will need to be:

- Prepared to listen and learn
- Commitment to equality
- Open-minded and tolerant of others ideas and views
- Able to take a patient/public perspective
- Good team player
- Contacts and membership or confidence of disadvantaged communities
- Determination and perseverance
- Self-servicing
- Time commitment?

#### **Knowledge**

Members will need to have:

- Knowledge and understanding of the experiences of services users and carers (trust forums)
- Knowledge of NHS structures or willingness to learn
- Knowledge of local community and networks (PCT forums)
- Understanding of meeting procedures or willingness to undergo training

#### **Skills**

Some members of the forum will need to have specific skills, but not all members will need these. It is important not to be unduly prescriptive, as this will exclude people. Commitment and knowledge is more important.

Skills required among Forum members include:

- Communication, listening and informed questioning
- Information gathering and handling, including IT skills
- Negotiating and influencing skills
- Equal opportunities
- Observational skills
- Facilitation skills
- Working with NHS staff and other organisations
- Self-development and reflective practice

Some skills can be developed and training offered

- Public speaking
- Project management
- IT skills

### *Induction training*

This should be compulsory cover information about the Patients' forum, equal opportunities and enable team building. This should only be half a day. Mentoring of less experienced members might be developed for those who wanted it.

There will need to be an induction training programme rolled out across all the new Patients' forums from the very outset. This will require a body of trainers to be trained together using the same materials. There would need to be a standardised pack / handbook available which would complement the induction training and could be used for reference.

The induction training will also function as a team building exercise, which will be essential under the new system. The training will need to be sensitive to the different needs of the Patient Forum members, which are likely to include new people and those from CHCs. People from CHCs will need to understand their new role and be able to move on with confidence.

There is already a variety of material available which needs to be reviewed and modified for the new system. This will ensure that we do not "reinvent the wheel" but rather draw on resources, which already exist. Consideration will need to be given to producing induction packs in different formats such as languages, Braille or on audiocassettes.

### ***Follow up training***

Induction training is the minimum requirement but members could be required to take other training in order to undertake other tasks. Joint training with staff and members and OSCs should be undertaken. Also there are different approaches that might suit some people, such as shadowing trust staff.

Training could be undertaken at levels that would enable PF members to undertake particular tasks. For example a member would not be able to make a visit until they had attended the training programme on visiting:

1. Knowing the NHS and the voluntary sector
2. Visits, including confidentiality
3. Actions and attending meetings
4. Board meetings

The training offered would need to be accredited either by the Commission or by an already existing accrediting body, which will continue to develop standards that are modern and credible. The provision of accredited training for members of Patients' forums' will also make membership more attractive to a wider range of individual and is in line with the NHS commitment to lifelong learning. As with the CAB movement, the training would develop Kudos and would also be offered as a bonus for being a member. Modules can be devised which could form part of an adult learning package, which is transferable to other areas.

### ***Continuing development programmes***

Individuals will have different needs and so need individualised programmes accordingly. Training also needs to allow for programmes on and 'career development'. Providing training that is recognised externally is a way to motivate some groups, in particular from disadvantaged communities and younger people. Participation may encourage them to join and put them in a better position to get work. Qualifications need to be structured so that they are recognisable to employers. Training can be incorporated into the work that the member does as a forum member. Distance learning and the Internet could be used.



## **Annex 3 Draft Terms Of Reference for Shadow Patients' forums**

### **(Bedfordshire and Hertfordshire pathfinder pilot)**

#### *Bill Requirements*

These are the requirements of the Bill and are not negotiable:

- a) Monitor and review the operation of services provided and commissioned by or is responsible for, [name of Trust].
- b) Obtain the views of patients and their carers about those services and report on those views to the trust.
- c) Provide advice, and make reports and recommendations, about matters relating to those services to the trust.
- d) Make available to patients and their carers advice and information about those services.
- e) Prepare an Annual Report in relation to its activities in each financial year, detailing the arrangements maintained by the Forum in that year for obtaining the views of patients.

#### **Local Implementation and Additional Standards**

The following are important activities that groups need to be doing in considering the development of Patients' forums:

In pursuing a Monitoring Programme the Forum will:

- i) Be proactive in engaging the public, including hard reaching groups, in the health decision-making process.
- ii) Determine the frequency and range of such visits. In pursuance of its statutory duty to visit premises where health care is delivered, a reasonable expectation of Patient Forums is to cover the range of sites and services provided for local people.
- iii) Consider a number of different factors in prioritising the monitoring/visiting programme:
  - Follow up issues arising from consultation proposals for service developments or variations;
  - Follow up on issues identified through the annual negotiations about the PCT's Commissioning Plans;
  - Monitoring service delivery issues raised through complaints via ICAS or other information received from the public via individuals/special interest groups;
  - Patient Forum involvement in service reviews initiated by service providers and the commissioning authority, and establishing a

common analytical framework for reporting the findings of the monitoring/visiting programme.

- iv) Liase with other Patients' forums.
- v) Liase with ICAS and Overview and Scrutiny Committees.
- vi) Monitor issues with regard to provision of services across (out of line) geographical and organisational boundaries and make reports to the relevant bodies as appropriate.
- vii) Monitor the performance of PALS by receiving regular reports and using information about concerns raised within that service as an aid to monitoring the Trust.
- viii) Liase with NHS Staff and those Staff involved with Social Care provision, from Chairs and Chief Executives to front line staff.
- ix) Ensure all parts of the Public Patient Involvement agenda are reflected and integrated in the work of the group.
- x) Report back to host CHC.
- xi) Determine a policy on representation on Trust, Health Authority or other groups/committees and nominate members to be the representatives as appropriate.
- xii) To contribute, as part of the Local Network, to the work of the Patient and Public Involvement Pathfinder Pilot.



## Annex 4 Requirements for Pathfinder ICAS

### *Standards for ICAS*

There are core measurable standards that all designated ICAS must meet.

1. Access to services: adequate arrangements for local publicity; standards for availability and access; making others aware of the service and non-discrimination, basing delivery of the services on local needs and priorities.
2. Seamless services where clients are referred to the appropriate service that can help them
3. Speed: clients need to be handled speedily to agreed time limits.
4. Meeting clients needs: giving information and advice relevant to clients needs, including confidentiality, privacy and fair treatment
5. Trained staff: staff must possess or acquire the skills and knowledge required to meet clients' needs based on accredited training.
6. Running the service: there must be processes and procedures that ensure an effective and efficient service to their clients, procedures for case- recording, supervision and case review; a commitment to, and written policies for confidentiality and privacy; written policies on health and safety, data protection, storage of and access to clients' records, conflict of interest;
7. Running the organisation: there must be structures and procedures that ensure effective and accountable management of the organisation and resources.
8. Commitment to quality: including having a complaints procedure, other user feedback and maintaining quality procedures.
9. Commitment to improving health services: processes to collect and maintain data to meet the needs of relevant bodies and to enable ICAS to raise and follow up issues with the service providers.
10. Quality mark awarded by the Community Legal Service or a commitment to apply for the QM within 12 months.

*ICAS providers will also need to have in place:*

1. Procedures for procedures for case recording, supervision and case review;
2. Referral procedures to enable clients to access:
  - a. Legal advice
  - b. Other services such as counselling
  - c. Other advice and assistance, including informal and specialist advocacy
  - d. An alternative ICAS provider
3. Arrangements to meet special needs arising from language, disability etc
4. Partnerships to work with, or to access personal advocates as required
5. Access to second-tier support, notably independent clinical advice
6. An arrangement to ensure that information on trends and problems in services is brought to the attention of those responsible for providing and monitoring services.

### *The scope of the ICAS service:*

1. A "complaint" is defined as a concern identified by the client for which they want independent information or advice
2. ICAS will provide a service to clients where the patient was treated in the ICAS catchment area or the complainant lives or works in that area. Where appropriate, links will be made with the ICAS local to the service about which the complaint is being made to transfer cases or ensure that information on the quality of services is recorded.
3. ICAS can deal with any complaint that includes in part a complaint about a service provided or funded by the NHS

### *The level of service*

The basic principle is to meet the needs of the client, which will be identified in an initial interview, preferably face-to-face but could be by telephone. The purpose of the interview will be to:

- (i) Identify the nature of the grievance and allow the client to express their feelings fully;
- (ii) Establish what the client wants to do about it;
- (iii) Identify the options available;
- (iv) Give the client all the relevant information;
- (v) Allow the client to identify what option, if any, they wish to pursue;
- (vi) Discuss how it might best be pursued;
- (vii) Determine the respective roles of the ICAS staff and the client in pursuing it.

Formalities will include full details of the client and how to contact them; data protection consent; form of authority if appropriate; details of how the client can contact the ICAS case officer.

ICAS can offer, if the client wishes:

- (i) To speak to others on the client's behalf;
- (ii) To apply for records and other relevant information held by others;
- (iii) To write to others on the client's behalf;
- (iv) To accompany clients to meetings;
- (v) To represent clients at formal hearings [i.e. accompany and present their case];
- (vi) Their capacity to see that concerns arising out of individual complaints are: reported to the relevant bodies; raised at regular meetings with the service providers.
- (vii) Follow up of wider quality issues raised in a complaint and action recommended following a complaint investigation.

ICAS will provide written guidance on:

- (i) The NHS and social services complaints procedures;
- (ii) The service which ICAS can provide for the client; and

The terms and conditions to facilitate the service e.g. on ICAS side: timetables for actioning – on the client's side: timely response to requests/communications



## TAB Members

Paul Streets, Chair and Chief Executive Diabetes UK

Nik Barstow	Chair, UNISON CHCs Staff Forum
Sally Brearley	Vice Chair, Association for Community Health Councils of England and Wales
Cllr Kate Carr	Local Government Association
Rosemary Edwards	Deputy Chair, National Association of Citizens Advice Bureau
Gary Fereday	Policy Manager, NHS Confederation
David Gilbert	Head of Patient and Public Involvement, Commission for Health Improvement
Bill Hamilton	Assistant Chief Executive (Scrutiny) Bedfordshire County Council representing the Local Government Association
Alan Hartley	Chair, Association of Community Health Councils of England and Wales
Robert Johnstone	Trustee, Long term Medical Conditions Alliance
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